MEASURING AND VALUING UNPAID CARE WORK: ASSESSING THE GENDERED IMPLICATIONS OF SOUTH AFRICA'S HOME-BASED CARE POLICY

by

NINA HUNTER

Submitted as the thesis
in fulfilment of the academic
requirements for the degree of
Doctor of Development Studies in the
School of Development Studies,
University of KwaZulu-Natal
Howard College Campus
Durban

March 2010

ABSTRACT

The objective of this research is to reveal the implications of the choice of home- and community-based care as opposed to other policy choices and, using a gendered lens, to find a plausible way of assessing the social and economic effects of this care policy for households, families, and centrally for women. Women's paid and unpaid work, the continuum of paid and unpaid health/care work, care work, the care economy and community care are reviewed, as well as household structure, unemployment and the provision of health and welfare services in South Africa. The costs of unpaid care provision, methods for and issues to do with measuring time-use, and approaches to valuing unpaid care work are also considered. Time-use and financial cost information obtained as part of the 2004 KwaZulu-Natal Income Dynamics Study qualitative study from 19 family caregivers of 17 terminally ill people in 16 households, is the central source of data. The qualitative study employed a modified extended case study method. The psychological, emotional, social and physical costs of unpaid care work are not counted. Instead, caregivers' labour time spent in unpaid care work is counted and valued using four methods (average earnings, opportunity cost, generalist, specialist), and financial costs to households of unpaid care provision are also counted. In this way unpaid care work is assigned various costs, a necessary step if this work is to be included in policy making processes. The findings are not representative but make possible some speculation about home-based care in KwaZulu-Natal. Findings on financial costs suggest that the welfare grant to the poorest elderly is subsidising the health services. On average 10 hours are spent by household caregivers in unpaid care work per ill person per day, and women are accounting for the bulk of this time. Moreover, in terms of valuing, most appropriate to the poor in KwaZulu-Natal is the generalist method using the proportionate approach and median earnings rates. If family caregivers were paid for the time spent in unpaid care work and households were reimbursed for their financial costs, for 2004/5 using the low estimate it would cost approximately R585 per month per ill person for unpaid care provision that takes place seven days a week and 10 hours per day (R7,619 per month using the high estimate). When multiplied by the number of AIDS-sick people in KwaZulu-Natal, this spending on costed unpaid care provision exceeds the monthly health and welfare spending on home-based care in KwaZulu-Natal for 2004/5 of approximately R2 million by R104,025,512 million if the low estimate is used. These costs are compared to the costs of a selection of similar public and private interventions in South Africa. Without fail the costs of unpaid care provision do not exceed 26 percent of the costs of alternatives. The findings show that the home- and community-based care guidelines have inequality-creating effects: wealthier families may be able to buy in care if necessary, while poorer families have to provide this care themselves. Moreover, government is saving substantially on the health budget by limiting the provision of public inpatient care. Because of the high costs of operation of both high- and low-cost inpatient centres, as well as home-based care as delivered by NGOs/FBOs/CBOs, the potential for these interventions to deliver to all of those in need of such care, when compared with unpaid care provision, is not great from the perspective of a government seeking to cut costs. The findings show that home-based care is cost-effective for government but not for family caregivers who carry the bulk of care costs. Policy options such as payment for caregiving, the basic income grant and expansion of the expanded public works programme are presented. Since family caregivers are meeting a minimum standard of productive participation, it is argued that a citizen-based model of social protection be adopted. Finally, what worked and did not work with regard to the study is used to inform recommendations for improved future research on unpaid care work in South Africa. [662 words]

Word count: 81,402

PREFACE

The experimental work described in this thesis was carried out in the School of Development Studies, University of KwaZulu-Natal, Howard College Campus, Durban, from May 2004 to October 2009, under the supervision of Professor Francie Lund.

These studies represent original work by the author and have not otherwise been submitted in any form for any degree or diploma to any tertiary institution. Where use has been made of the work of others it is duly acknowledged in the text.

____

Signature

LIST OF CONTENTS

LIST OF BOXES

LIST OF FIGURES

LIST OF TABLES

ACKNOWLEDGEMENTS

My thanks go to Francie Lund for her enthusiastic supervision – her time, energy, wit, insightful thought and for the original idea of this research. I shall miss the many meetings we had which were such important points of contact for me during a relatively isolated time.

To Julian May go my thanks for his support and guidance throughout the project and over the time at the School of Development Studies that I have been both student and colleague. This thesis would not have been possible without his truly gifted ability to raise funds which opened the doors for the research on which this thesis is based and supported my work on it.

Funding from the Department for International Development – Southern Africa and the Ernst and Ethel Eriksen Trust, as well as a National Research Foundation Prestigious/Equity Scholarship for Doctoral Study in South Africa sponsored my work on this thesis, for which I am grateful.

The 2004 KwaZulu-Natal Income Dynamics Study qualitative study was funded by the Department for International Development – Southern Africa as well as the Mellon Foundation Poverty Node. The South African national Department for Social Development lent their support to the study.

The collaborating institutions on the 2004 KwaZulu-Natal Income Dynamics Study included the University of KwaZulu-Natal, the University of Wisconsin-Madison and the International Food Policy Research Institute. In order to accommodate new areas of interest, the number of participating institutions was extended to include the London School of Hygiene and Tropical Medicine and the Norwegian Institute of Urban and Regional Studies. The 2004 wave was formally supported by the South African national Department of Social Development. In addition to the resources provided by each of the collaborating institutions, the study was funded by the Department for International Development, the National Research Foundation, the Norwegian

Research Council, the United States Agency for International Development and the Mellon Foundation.

To Makhosi Dlalisa, Themba Mbhele, Themba Mpanza and Zithobile Mbona go my thanks for their dedicated and often challenging time in the field that enabled the qualitative data to be collected. I hope that the difficult times can be compensated in some small way by the completion of this thesis.

Michelle Adato, Cathy van de Ruit and Myriam Velia were all involved in the qualitative study. It was a wonderful experience to work both in and out of the field with them, which I shall always remember fondly, and I am grateful for their contribution towards the qualitative study.

My thanks also go to Debbie Budlender for constantly answering questions via email and phone and commenting comprehensively on a draft version of the thesis, which has benefited greatly from her generous input.

Many thanks to Dori Posel for giving of her time in calculating regressions and discussing issues related to the study.

A team of staff members from the School of Development Studies – Daniela Casale, Richard Devey, Dori Posel, Caroline Skinner, Imraan Valodia – liberally gave of their time and advice in a workshop. This thesis is better for the suggestions made and guidance given in this forum.

There were a host of individuals at various organizations who provided me with information used in this research, for which I am extremely grateful:

Birgitta Anderson, Nana Bonga, Ishaan Boodram, Ansunet Botha, Colleen Dempers, Priscilla Dlamini, Les Harris, Sheila Hinde, Karen Hinton, Elizabeth Howlett, Eileen Hunt, Liza Johnson, Thembani Khumalo, Gerard Lagleder, Barry McDaniel, Eugene Meyer, Nirvasha Moodley, Ronnie Naidoo, Warren Oxford-Huggett, S.R. Pillay, Kenelma Rieder, Zodwa Sithole, Elizabeth

Thalmeier, Sally Tsipa, Jeremy Upfold, Cecelia van Wyk, Lesley van Zyl and an anonymous individual.

My family have been an unstinting support over the years it has taken to complete this thesis. My thanks to Manfred and Margie Surendorff for their neverending love and support since before I can remember, Garth Hunter for pushing me to do this and for giving me the space to finish it in, and my children Mika and Nasia.

To Gladys Mthethwa, Lydia Kubeka and Princess Zuma go my gratitude for looking after Mika and our home at various times so that I could work on this.

Finally, I thank my Father in Heaven, for all that He has given me.

DEDICATION

This thesis is dedicated to Themba Mpanza:

A courageous soul
A wonderfully warm personality
A sensitive individual
A joy to be with

I am sad that I will not be able to undertake further research with you. I would have immensely enjoyed doing so.

LIST OF ACRONYMS AND ABBREVIATIONS

AIDS	Acquired Immune-deficiency Syndrome
ARV	Anti-retroviral
CBC	Community-based Care
CBO	Community-based Organization
CEO	Chief Executive Officer
CPIX	Consumer Price Index for Metropolitan and Other Urban Areas
FBO	Faith-based Organization
GDP	Gross Domestic Product
GEAR	Growth, Employment and Redistribution
HBC	Home-based Care
HCBC	Home- and Community-based Care
HIV	Human Immune-Deficiency Virus
ICHC	Integrated Community Home-based Care
IMF	International Monetary Fund
KIDS	KwaZulu-Natal Income Dynamics Study
LFS	Labour Force Survey
NGO	Non-governmental Organization
NPO	Non-profit Organization
OPD	Out Patient Department
PSLSD	Project for Statistics on Living Standards and Development
RDP	Reconstruction and Development Programme
SEPPI	Socio-Economic Study of the Persistence of Poverty and Inequality
SNA	System of National Accounts
TUS	Time Use Survey
UKZN	University of KwaZulu-Natal
WHO	World Health Organization

GLOSSARY OF TERMS

This glossary represents the understanding of these terms in this thesis and differs from the South African government's definitions. It is restricted to 'care' terms since this is often where confusion arises.

Care economy	unremunerated work undertaken within the home, which ensures the physical, social and psychological maintenance and development of family members, and 'volunteer' activities in the community (Ogden, Esim, & Grown, 2006)
Community caregiver	community-based health worker cadres who are selected, trained and work in the communities in which they live; their role is to act as agents for health promotion, care and health development (Friedman, 2002, 2005)
Community-(based) care	non-residential and non-hospital care; the shift of balance of care from hospitals to the community in a way that reasserts family responsibility (Evandrou, Falkingham, & Glennester, 1990)
Family caregiver	an unpaid household member who provides care within the home to a fellow household member on a regular basis (Hunter, 2005)
Home-based care	the care given to sick people in their homes, which may include care given by family, friends, neighbours, nurses, midwives, health and social services workers and others, and can be physical, psychosocial, spiritual and palliative (adapted from World Health Organization, 2002, p. 37)

Main caregiver(s)	in the 2004 KwaZulu-Natal Income Dynamics Study qualitative study, the person(s) who lives within the same household as the cared-for and is responsible for their care on a day-to-day basis
Reproductive work/ labour	work that includes activities such as purchasing household goods, preparing and serving food, laundering and repairing clothing, maintaining furnishings and appliances, socializing children, providing care and emotional support for adults, and maintaining kin and community ties (Glenn, 1992)
Sexual division of labour	the pattern of work allocation between women and men, and the social practices that constitute some sorts of work as suitable for women but unsuitable for men, and other sorts of work as unsuitable for women but suitable for men (Elson, 1991b)
Unpaid care work	“the term ‘unpaid’ differentiates this care from paid care provided by employees in the public and NGO sectors and employees and self-employed persons in the private sector. The word ‘care’ indicates that the services provided nurture other people. The word ‘work’ indicates that these activities are costly in time and energy and are undertaken as obligations (contractual or social, such as reproductive labour)” (Elson, 2000, p. 24).

1 INTRODUCTION

1.1 OUTLINE OF TOPIC AREA

Provision of health and welfare services as undertaken by the state, the not-for-profit and the private sectors is only a portion of the overall health and welfare resources provided in a society. Unpaid care work constitutes an important part thereof, and is defined as follows:

> the term ‘unpaid’ differentiates this care from paid care provided by employees in the public and NGO sectors and employees and self-employed persons in the private sector. The word ‘care’ indicates that the services provided nurture other people. The word ‘work’ indicates that these activities are costly in time and energy and are undertaken as obligations (contractual or social) (Elson, 2000, p. 24).

In all countries of the world and across all societies, most unpaid care work is undertaken by women within their own homes. While women are undertaking this work they are prevented from doing other things, and they are restricted in where they can go. The benefit from unpaid care work is derived by society more generally, yet this work is largely taken for granted by policy makers and planners, and is relatively uncounted, unmeasured and uncosted (Budlender, 2002).

Little is also known about the value of this work. Chen et al. (2005) explain that in official statistics the measurement of work and production hinges on the boundary set by the System of National Accounts (SNA). National accounts are the basis for calculations of Gross Domestic Product (GDP). Growth in GDP is used as the main indicator of how well or how poorly an economy is performing. The 1993 SNA was developed to ensure that statistics are comparable and internationally consistent. According to the 1993 SNA, work that falls within the boundary is considered ‘economic’ while work that falls outside the boundary is considered ‘non-economic’. As part of the 1993 revision of the SNA, the production boundary was extended to include the production of all goods for household consumption, whether or not the goods were marketed. While subsistence production of goods was recognized as an 'economic' activity, the provision of domestic and personal services by household members for consumption within the household – such as cooking, cleaning, child-care – was left out of the production boundary. The 1993 SNA recommended that the valuation of activities outside the SNA boundary be undertaken outside the national accounts in satellite accounts.

Not counting domestic and personal services by household members for consumption within the household seems all the more problematic in the light of the increased time women are having to spend on this work with decreased social spending and the privatization of former state social and health services (Chen et al., 2005) which is the case in many countries. This has meant that many of the costs of providing services have had to be picked up by women with their own time, energy and resources (Ogden et al., 2004).

1.2 RESEARCH PROBLEM

In some developing countries the Human Immune-Deficiency Virus (HIV)/Acquired Immune-Deficiency Syndrome (AIDS) epidemic is resulting in increasing numbers of people in need of care, and the burden of care is falling primarily on women within households (Ogden et al., 2004). Research in sub-Saharan Africa has documented the gendered nature of care provision for those infected and affected, the difficulties that home-based care (HBC) presents for caregivers and the limited support by HBC organizations (Chimwaza & Watkins, 2004; Jackson & Kerkhoven, 1995; Seeley & Kajura, 1993).[1] This has also been shown to be the case in South Africa (Hunter, 2005, 2007; Orner 2006).

In 2001 South Africa adopted an explicit home- and community-based care (HCBC) policy as part of its approach to meeting care needs. The fact that ill people require care in the home increases costs for households, but this policy does not alleviate these costs, and is instead cost-

---

[1] The term 'caregiver' shall be used interchangeably with the term 'carer'.

effective for the state. A central hypothesis of this thesis is that the costs of this unpaid care work, in the form of labour costs to caregivers and financial costs to households, are likely to be high.

The objective of this research is to reveal the implications of the choice of HCBC as opposed to other policy choices and, using a gendered lens, to find a plausible way of assessing the social and economic effects of this care policy for households, families, and centrally for women.

The intellectual and conceptual work of this thesis consists of applying methods developed elsewhere and elaborating new techniques to count the time spent in care activities by family caregivers, to place a cost on these activities, and to count the financial costs of care provision by households. Time-use and financial cost information obtained from family caregivers of terminally ill people as part of the 2004 KwaZulu-Natal Income Dynamics Study (KIDS) qualitative study is the central source of data. This data was collected as part of the modified extended case study method. The labour time of caregivers and the financial costs to households of unpaid care work for ill people in the home are counted, a value is placed on the labour time, and these costs are then compared to the costs of similar public and private interventions in South Africa. It is not suggested that care "can be remunerated by wages in exact compensation" (Joshi, 1992, p. 111). Caring has a value to the caregiver and to the care receiver that cannot be priced, and only some aspects of caregiving can be measured (Arno, Levine & Memmott, 1999). Yet such costing has been described as "a necessary first step to recognizing, valuing and including unpaid HIV/AIDS care work in public health and other policy-making processes" (Ogden et al., 2006, p. 340).

In developed countries, models have been developed to cost various aspects of care. In England the Personal Social Services Research Unit at the University of Kent undertakes research which brings together information to estimate national unit costs for a range of paid health and social care services (Netten & Curtis, 2003). Other research has estimated the costs of unpaid care work using various approaches (Arno et al., 1999; Jönsson et al., 2006; Rice et al., 1993; Wilson et al., 2005). This work makes assumptions about family structure, the labour market and provision of health services, for example, which might not apply to a developing country context. This study explores such assumptions.

The key research questions are as follows:

- What caring activities are being undertaken by family caregivers for ill people in households in KwaZulu-Natal?
- What is the daily time spent in these caring activities?
- If this labour time is ascribed as various types of work, what are the costs associated with undertaking this care work?
- What financial costs result from the provision of unpaid care to ill people within households?
- How do these total cost figures compare with the costs of similar public and private sector interventions in South Africa?
- In what ways does a typology of care activities developed for a 'northern' context apply to a 'southern' setting?

1.3 STRUCTURE OF THESIS

The onset of the HIV/AIDS epidemic has meant that substantially more unpaid care work falls on women within the home. It is this unpaid care work and its attendant costs that are the focus of this thesis. As such, chapter 2 comprises a review of theoretical approaches to do with gender and the economy of paid and unpaid work, with a focus on care work. These issues are then concentrated on South Africa, with its disrupted household structures, extremely high rates of unemployment and the related problem of poverty. As will be seen, in post-Apartheid South Africa there has been an increase in welfare spending but a decrease in spending on health and education. Health care provision within the home is the government's central 'care' solution presented in the face of a ravaging HIV/AIDS epidemic, yet the bulk of this work is undertaken by women on an unpaid basis, with little external support. Understanding the costs of this care work is therefore highly relevant.

Chapter 3 documents issues that are pertinent to the task of measuring and valuing the unpaid care work of family caregivers. The chapter begins with an account of some of the costs of unpaid care provision recorded in international studies, and then moves on to issues relevant to measuring unpaid care work, that is, the collection of time-use data. Since some unpaid care work has already been counted in the South African context using the Time Use Survey (TUS), these findings are also described. The review ends with a focus on valuing the costs of unpaid care work – the various methods that can be employed for this purpose, and how these methods have been applied to South African data.

The focus then shifts to the study itself. Chapter 4 describes the research methodology of the 2004 KIDS qualitative study which provides the data that enables a particular type of care work, to be counted, namely care for people in late-stage HIV/AIDS, over intensive illness episodes. The fieldwork for the care component of the qualitative study which took place in six study sites is detailed. In 16 households 19 'main' family caregivers were caring for 17 terminally ill people. In this chapter the benefits of using the extended case study method are evident.

Chapter 5 is the first chapter of results. The care situations and gendered care provision in the study households are detailed in order to provide a context for the time-use and financial cost findings that will follow. However, before this some findings from the 2004 KIDS are delineated. These findings provide a useful description of the care situation in KwaZulu-Natal, and a strength of this section is that unlike the findings from the qualitative study, it is possible to generalize to some extent from these KIDS findings. The results on the cared-for do not differ much from a KIDS cohort that are likely to have died of AIDS, as analysed by Sienaert (2008), leading to the conclusion that a large portion are likely to have been ill with HIV/AIDS.

Chapter 6 is the second chapter of results and is central to the thesis, which is really about finding a way to count the time spent in unpaid care work for those terminally ill with HIV/AIDS. Because of this much detail is provided on how the time that was spent providing unpaid care was counted. This time is then counted and found to be substantial and undertaken almost solely by women. Values are attached to this time using various methodologies. Next the method and earnings rate most appropriate for the African poor in KwaZulu-Natal is selected. The methodology for counting financial costs is also described, and these costs are then counted. Finally, the labour costs and the financial costs are added together in order to arrive at various estimates of the cost of unpaid care provision within the home for those in late-stage HIV/AIDS in KwaZulu-Natal. In this way, this unpaid care work, usually taken for granted, has been made visible.

In the following chapter, the third results chapter, it is possible to see something of the value of this work through various comparisons. In Chapter 7 one of the costs of unpaid care provision calculated in chapter 6 – the 'best fit' for the province – is compared to the costs of alternative policy interventions. These other interventions are private home care, public inpatient care, NPO inpatient care and NPO home-based care, and they are costed in a comprehensive manner that includes 'unseen' costs such as unpaid care work. Not surprisingly unpaid care provision costs very little when compared with these other interventions. It does not exceed 26 percent of the costs of these interventions. However, it exceeds spending on HBC by over R100 million.

Chapter 8 centres on the extent to which the reviewed literature was found to be true through a reflection on the findings from the 2004 KIDS qualitative study. The UK's typology of care activities is also applied to KwaZulu-Natal and some conclusions drawn. A key focus of the chapter is on the methodology of counting unpaid care work time in this study and how to improve this type of data collection for the future. Also reflected on is the process of valuing unpaid care work and the various methodologies employed in the study.

Chapter 9 concludes by reflecting on various policy options for South Africa that emanate from the study findings. First, however, these options are contextualized through a discussion of recent relevant social policy developments and the social policy role of the state with regard to care. The policy options include improving the service of HCBC, making some kind of payment for caregiving, introducing a basic income grant and, finally, the option of mass-based employment under the expanded public works programme. It is argued that since family caregivers carry the bulk of the costs of care provision in the home they should be treated equitably when compared with paid workers who are also productive, and that the government should find an appropriate means of support that acknowledges their contribution.

2 LITERATURE REVIEW – GENDER AND THE ECONOMY OF PAID AND UNPAID WORK

The focus in this chapter is on the unpaid care work that women do within the home. This chapter defines care work and the care economy, reviews the types of work women do, the continuum of care provision, the impact of the labour market on women, and issues relating to community care, and ends with a reflection on these issues in the South African context.

2.1 WOMEN'S PAID AND UNPAID WORK IN AN ERA OF RETRENCHMENT

There are five distinct types of work that people may undertake: formal market work, informal market work, subsistence production, unpaid care work and volunteer work (Beneria, 1992; UNIFEM, 2000, as cited by Chen et al., 2005, p. 23).[2] Evidence from a number of time use surveys show that there are marked differences in how men and women allocate their time between market and non-market work (Kes & Swaminathan, 2006). Such studies show that women spend more time in work overall, spend fewer hours in paid work and have less discretionary time than men do (United Nations Development Programme, 2007, p. 342).

There is a gender dimension to the social relations structuring the lives of individual men and women. Social practices constitute some sorts of work as suitable for women but unsuitable for men, and other sorts of work as unsuitable for women but suitable for men. The access to and control over resources is also gendered (Elson, 1991a, 1991b). Social and cultural norms play an

---

[2] Chen et al. (2005) separate informal employment into two categories. Informal self-employment includes employers in informal enterprises; own account workers in informal enterprises; unpaid family workers (in informal and formal enterprises); members of informal producers' cooperatives. Informal wage employment comprises employees without formal contracts, worker benefits or social protection employed by formal or informal enterprises or as paid domestic workers by households. Formal employment comprises employment at formal economic enterprises.

important role in defining and sustaining rigidity in the sexual division of labour, and this is most evident in the division of responsibilities between productive (market) and reproductive (household) work, with women taking chief responsibility for the latter (Blackden & Wodon, 2006).

On the whole women spend more time than men doing unpaid care work and housework, with multiple and overlapping activities. At the same time many also engage in paid and unpaid market activities. In developed countries, a high percentage of part-time workers are women, who combine paid market work and unpaid care work, while in developing countries, women tend to spend time in unpaid food production and processing, and fuel and water collection, which limits their time for both paid market work and unpaid care work (Chen et al., 2005).

Unpaid care work is heavily gendered. Most people who are providing unpaid care are doing so for family members: generally, the closer the kin relationship the greater the sense of responsibility for looking after the person, and the greater the public expectation that this will take place (Heron, 1998). However, within families it is on women that this expectation focuses and it is women who principally undertake care activities, in both developed (Pascall & Lewis, 2004) and developing countries (Chen et al., 2005; Ogden et al., 2004).

The 1985 General Household Survey (GHS) in the United Kingdom was a benchmark in making care work more visible as a specific component was added to the survey. More men than expected were involved in providing care within the home, but this was usually spousal care, and where spousal care was not taking place, men were less likely than women to be providing personal care (Parker, 1992). Intimate personal care is still “heavily gendered” (Twigg & Atkin, 1994, p. 4). Caring is a central component in the sexual division of labour. This form of patriarchy is universal – most care (both paid and unpaid) is undertaken by women, and it is women who bear the main costs of unpaid caring – “in terms of performing the actual care and in terms of foregone income and emotional strain” (Bubeck, 1995, p. 167). This highlights the importance of looking within the household in any analysis of unpaid care provision, since the household as a unit conceals gendered patterns and the associated costs to individuals.

However, the sexual division of labour in the household is highly resistant to change, and an unequal burden is placed on women (Bakker, 1994). Blackden and Wodon (2006, p. 3) note that

> the disproportionate cost borne by women of reproductive work in the household economy not only limits the time women can spend in economic activities but restricts them (spatially and culturally) to activities compatible with their domestic obligations.

Women’s ability to participate in the labour market, their decisions about work more generally, their position in the labour market and their ability to get ahead in the labour market are all constrained by their unpaid care work in the household and community. Women’s unpaid care work and the need to balance this with earning also channels them into certain types of employment that are more precarious in terms of earnings and benefits, such as part-time work or informal wage work, that fail to enable them to escape from poverty (Chen et al., 2005).

Many women are confronted at some stage of their lives with having to balance paid work and child or elder care. Better-off women can afford to pay others to look after their children or elderly relatives (Chen et al., 2005). For poorer women, either reproductive work has to be transferred to other women or it becomes extra work as paid work is added to unpaid work (Elson, 1991a). Where women have no other adult women to fulfil household production or domestic roles, they are faced with time and mobility constraints that lead to lower paying jobs which tend to be more compatible with child care (Blackden & Wodon, 2006).

In developing countries, the challenges of unpaid care work are compounded for many women. HIV/AIDS with its increasing care demands has meant that the amount of unpaid care work has increased within households (Chen et al., 2005). The amount of time and energy required to carry out unpaid care work increases exponentially when there is an illness and is “layered on top of the existing care” (Ogden et al., 2004, p. 6).

Women’s role in unpaid care work tends to direct them into similar occupations and sectors in the paid economy, notably the clothing and textile industries, teaching, childcare, health care and domestic services (Chen et al., 2005). Folbre and Nelson (2000, p. 126) describe “a persistent pattern of occupational gender segregation” for those women who are in the labour market.

Over the last three decades, women have entered the labour force in striking numbers in both the developed and developing world (International Labour Organization, 2004), partly due to the inability of households to survive on a single worker income (Chen et al., 2005). In developing countries this increase has largely been accounted for by the increased numbers of women entering the informal economy (ibid).[3] In South Africa employment rates for men are consistently higher than those for women; however Casale (2004) describes a continued and dramatic feminization of the labour market over the second half of the 1990s. This has translated predominantly into a rise in unemployment among women and has been associated with women being pushed into the labour market out of economic need. The increase in employment among women over this period has been largely due to the increase in self-employment in the informal economy, which is associated with lower earnings than in the formal economy and insecure working conditions.

Neo-liberal policies involve shifts in the forms and role of the state, away from class solidarity and social concerns (May, 2003). Under free market economic policies the state, in both developed and developing countries, has extended the power and security of capital variously through trade liberalization, market deregulation, reductions in government employment and privatization of services (such as health, education, welfare, housing) formerly paid for by the state (Chen et al., 2005). Programmes of economic stabilization aim to curb inflation, promoting the rate of growth of output and exports and increasing productivity and efficiency (Elson, 1991a).

---

[3] The term informal economy refers to all economic activities by workers and economic units that are – in law or in practice – not covered or insufficiently covered by formal arrangements (Flodman Becker, 2004). By deduction, the formal economy is covered by formal arrangements.

However, as Elson argues, macro-economics considers only the monetary aspects of the productive economy, and it ignores the human resource aspects of the reproductive economy, which disproportionately involves women's work. There is an assumption that the reproductive economy can continue to function without regard to its relation to the productive economy. Yet there is an interdependence between the two (Elson, 1994). Caring is vital for the maintenance of the physical and mental health of the workforce, and it is central to the reproduction of society itself (Graham, 1983).

Global neo-liberalism has consequences for increasing women's unpaid care work. Beneria (1999) provides a useful summary of the gender biases of neo-liberal programmes of economic stabilization that empirical research has shown. Firstly, the sexual division of labour means that these programmes and reduced household budgets increase women's domestic and reproductive work. One such study undertaken by Moser (1992) in Guayaquil, Ecuador, shows that the increasing demands on women's time, in addition to higher prices and lower incomes, results in more time being spent by women on domestic and community duties. Secondly, cuts in essential services such as health and education increase women's responsibility in family care. Thirdly, household members who previously did not are now forced to participate in the paid labour force as a result of lower real incomes. In particular, there has been a noteworthy increase in the participation of women in the informal economy (Cağatay, Elson, & Grown, 1995). Fourthly, low wages in the export sector, that is, women's wages in labour-intensive industries, is used as a way to keep exports competitive. Cağatay et al. (1995, p. 1828) add to these factors "[a] deterioration of physical and mental health and, in extreme cases, disintegration of families and communities". Therefore, in contexts where policies of economic stabilization are occurring, there is pressure on women to increase both their paid work and their unpaid work.

The increasing participation of women in the labour market means that many women are being faced with the double burden of market and non-market production (Chen et al., 2005). Yet while there has been an increased participation of women in the labour market, there is no evidence of any change in the amount of unpaid work that women do (Lewis, 2001). The policies that combine to increase the demands on women's paid and unpaid time simultaneously limit women's ability to gain economic and social security (Chen et al., 2005), but there is generally little or no support by governments for women's contribution to the production of labour.

2.2 THE CONTINUUM OF PAID AND UNPAID HEALTH/CARE WORK

Care work may be paid or unpaid. Care needs are also variable and different policies and institutions are needed for different types of care (Standing, 2001). Types of care provider across formal (registered) and informal (non-registered) settings include the following: public and private health services, state-regulated or paid social workers, public or private care provider agencies, voluntary and community organizations, paid domestic workers and relatives.

Figure 1: Continuum of Care Provision

<=>	**Tertiary Health Care**	**<=>**	**Secondary Health Care**	**<=>**	**Primary Health Care**	**<=>**	**Community-Based Care**	**<=>**	**Home-Based Care**	**<=>**

<==>

Source: World Health Organization (2000, as cited in Ogden et al., 2004, p. 24)

With regard to caring for people living with HIV/AIDS, Ogden et al. (2004) refer to the World Health Organization's (WHO's) continuum of care provision, developed to "promote, create and sustain a holistic approach to 'care and support' for people living with HIV/AIDS" (Ogden et al., 2004, p. 23). The care continuum provides a framework for governments to follow to put into place "some of the key components enabling those individuals who obtain an HIV diagnosis to receive clinical and non-clinical care" (Ogden et al., 2006, p. 337).

The person living with HIV/AIDS is located at the centre of a range of role players who are linked. From this perspective the provision of care extends from the home to the hospital, through various levels of care, and back to the home. The entry point to the continuum is voluntary counselling and testing for HIV. Discharge planning and referral networks are part of the continuum, and various forms of care can be accessed at different points along the continuum (see Figure 1). Tertiary health care is made up of specialists and specialised care facilities; secondary health care is comprised of district hospitals, HIV clinics, social/legal support and hospice; primary health care consists of health posts, dispensaries and traditional care; community-based care (CBC) is provided by non-governmental organizations (NGOs), churches, youth groups and volunteers; it is not stated who HBC is provided by, which is problematic.

Ogden et al. (2004) attempt to fill this gap, describing how the vast bulk of illness care is provided in the home by the unlinked system of home care, that is unpaid and untrained family members – nearly always female – and friends and neighbours of those living with HIV/AIDS, who are not linked to any formal care and support service.

According to Chen et al. (2005), through the lens of the continuum of care provision the links between formal and informal work, and between paid and unpaid work, and the changing spatial boundaries of caregiving – between the health facility and the home – become more evident. In South Africa typically, tertiary and secondary health care are paid, while for primary health care there are a cadre of paid workers, often with some assistance from unpaid workers. While in some developed countries HCBC is paid for, in part or in full, there is no assured compensation for CBC and HBC in South Africa – apart from stipends for some community caregivers – despite the fact that unpaid care work requires some nursing skills.

2.3 DEFINING CARE WORK AND THE CARE ECONOMY[4]

The concept of care is a mixed notion that draws on a number of elements (Twigg & Atkin, 1994), is both ambiguous and contested (Daly & Lewis, 1998), but is a central concept for social policy (Graham, 1983). Twigg (1992) defines informal care as normally occurring “in the context

---

[4] Many of the references in this section are from the 1980s and 1990s, which although some time ago was a formative time in the United Kingdom with regard to policy-making and research on the issue of care.

of family or marital relationships, and … provided on an unpaid basis that draws on feelings of love, obligation and duty". It can be distinguished from similar care provided in the formal sector on an organised and paid basis. As section 2.2 shows, caring is an activity which extends across public/private boundaries, between care in formal and informal settings, and is both paid and unpaid caring (Daly & Lewis, 1998).

Self-care is one of the three basic types of caring. The second type is kinship or friendship care: care for those who are similarly capable. The third type is care for dependants, including young children, the frail elderly, the sick and some of the disabled, all of whom cannot survive or function without regular caring personal assistance.[5] The three types of caring may combine or co-exist in caring situations. Caring for dependants constitutes the vast proportion of human caring interactions (Jochimsen, 2003), and is the focus of this thesis.

In this thesis the attention falls explicitly on unpaid care work in private homes along the lines suggested by Elson (2000), as outlined in section 1.1. Folbre (2006) suggests moving beyond the term 'unpaid care' to a more disaggregated analysis that distinguishes between different forms of care work according to their relationship to the market, characteristics of the labour process, and types of beneficiaries. Here the focus is on the care of a particular type of beneficiary, namely dependent people who are likely to have HIV/AIDS.

What are some of 'care work's' descriptive elements and how does it unfold in practice? A useful starting point is Bubeck's (1995) reference to four aspects of care which make up women's part in the sexual division of labour, namely: the gendered nature of care, care as an activity, the psychology of care and the ethic of care. The gendered nature of care has been discussed in section 2.1. The remaining concepts are explored one by one through the work of various authors.

The second dimension of care is care as an activity. Bubeck (1995) indicates that a key component of care as an activity is that it involves face-to-face interaction between carer and cared-for. Parker and Lawton (1990, as cited in Parker, 1992, p. 10) have developed a 'typology'

---

[5] There are many people with disabilities who require no care and live independently.

of caring activities, based on the eight tasks defined in the United Kingdom's 1985 GHS. This typology has been used to develop the questions relating to caring activities for this study and is referred to in Chapter 6. While such a typology focuses on tasks rather than purpose, and in this way may "restrict rather than extend our conceptual horizons" (Nolan, 1994, p. 647), it is nevertheless sufficient for the purposes of this analysis. The typology is as follows:

- Help with personal care, eg. dressing, toileting;
- Physical help, eg. with walking, getting in and out of bed;
- Help with paperwork or financial matters;
- Other practical help, eg. preparing meals, doing shopping;
- Keeping the person company;
- Taking the person out;
- Giving medicine, including giving injections, changing dressings;
- Keeping an eye on the person to see that s/he is all right.

Caring has its own sequence and the tasks of care change over time (Lewis, 2001). Type of care is tied to the different groups in need of care and an equally variable list of care requirements (for example, constant versus periodic caring) within these groups (Means & Smith, 1998).

Jochimsen (2003) refers to three components that make up a caring situation. A resource component is constituted of time and of material and/or financial resources. The latter is necessary to respond to the cared-for's needs and to sustain the caregiver so that he/she can perform the caring service. Regarding time, the performance of a single caring activity requires more time than is usually allotted for instrumental aspects of the work only, and includes the communicative aspect of care. Moreover, the caring relationship must continue over time in order for the caring activities to be fully effective and to achieve their goal (Jochimsen, 2003).

Parker (1981) defines care work as "tending" and suggests that it has four parts, as outlined in the following equation, figuratively speaking:

Tending = duration + intensity + complexity + prognosis

Parker notes that, firstly, it is necessary to have an idea of the duration of a caring episode, as care of different durations will require different resources. The notion of duration is a key difference between paid care and unpaid care: for a paid caregiver there are ‘hours of work’ that specify a given period, and someone will replace the caregiver should the need arise; for an unpaid caregiver there are no such assumptions or prescriptions. Secondly, the intensity of caring varies according to the dependency of the person receiving care – cared-for’s who are highly dependent may require constant attention, while those who are not very dependent may require help with specific tasks only.

Thirdly, the notion of complexity refers to the extent to which special skill is required in the provision of care. Parker emphasizes that care and treatment have for a long time been regarded as separate activities. Those who offer treatment do not often tend as well, and different professional and occupational groupings reflect this division. Similarly, Twigg (2003) highlights the boundary that exists between social and medical care. Parker (1981, p. 29) maintains that everyday experience and research findings show that “no sharp line of demarcation can be convincingly maintained”. Instead “good tending is a vital part of successful treatment” and “under some circumstances tending itself may be the treatment”. Finally, the fourth component of tending is prognosis: “whether more or less care is expected to be required as time passes” (Parker, 1981, p. 29). By highlighting the labour involved in caring it is possible to quantify the economic contribution of caring (Graham, 1983).

The third dimension of care provision is the psychology of care. Care cannot be understood only as an activity. Rather, the love and duty involved in care are powerful components of care work (Lewis, 2001). Various authors (for instance Folbre & Nelson, 2000; Parker, 1981) refer to a dual meaning of the term ‘care’: the actual work of looking after someone who cannot do so for themselves (‘caring for’), and an affection or concern for the person (‘caring about’). According to Daly and Lewis (1998), care is not like other labour because it is often initiated and provided under conditions of social and/or familial responsibility. Dalley (1988) also notes that in public discourse the two are not separated, and hence the economic value of ‘caring’ is lost.

Importantly, Bubeck (1995) maintains that care does not require the existence of an emotional bond between carer and cared-for, and that the term ‘care’ does not mean that the work is always done willingly, or with love. In fact the ‘love’ aspect of caring may not always be present. Whether the work is done willingly depends on the relationship between the caregiver and cared-for and possibly other people in the family or society. In some cases the care is given unwillingly, because the woman feels forced by psychological, social or even physical pressures (Budlender, 2002). In a similar vein, caring can also be an empowering activity because of its other-directed and other-beneficial nature (Bubeck, 1995). Fast, Williamson and Keating (1999) mention the following benefits of caregiving: satisfaction, a greater sense of mastery and self-confidence, and increased knowledge about self. However, this is the ‘best case scenario’, while the opposite may also be true, with care experienced as a burden (Bubeck, 1995). Caring may also give rise to dependency, powerlessness and even poverty (Graham, 1983). The emotional significance of caring has been studied within the field of psychology (Graham, 1983), and the literature on burden and stress in particular has been dominated by psychological methodology (Twigg & Atkin, 1994).

The fourth dimension of care, the ethic of care, refers to a moral outlook – caring as an attitude – which is part of the activity of care. The attitude of caring involves “a close attention to the feelings, needs, wants, or ideas of others” (Bubeck, 1995, p. 153) but may not always be present in the caring relationship.

Finally it is essential to point to the differentiation that can be made between carers. Caring takes place within relationships of obligation – marriage, parenthood, kinship – in which people feel responsible for and obliged to give care to spouses, children or parents (Twigg & Atkin, 1994). Co-residence is also a significant marker of who will care, playing an important part in “defining who within a family ends up as the carer, overriding factors such as gender and relationship” (Twigg & Atkin, 1994, p. 9). There is also differentiation in terms of the circumstances and expectations of carers. As Twigg (1992) points out, caring for a spouse is different to caring for an elderly parent, and caring for a person involved in a car accident is different to caring for someone with dementia. Furthermore, whether the carer and the cared-for are the same sex or not, and whether the two are kin or not, has implications for the type of support provided (Parker, 1992).

Carers can also be differentiated according to whether the caring task is shared or not, and the extent of involvement in care provision. Sole carers are the only people who have responsibility for the care of a person; main carers may be involved with someone else in the provision of care for the person but they are more involved than others; joint carers are two or more people who are equally involved in providing care to the person; 'not main carers' are involved in care provision but others have a greater degree of responsibility than them. A useful way to differentiate between carers who are more or less heavily involved is to distinguish between carers on the basis of the tasks they carry out. Personal and/or physical care may be used as a proxy measure of heavy involvement (Parker, 1992).

Changing focus, importantly a significant aspect of economic life takes place in the household production of non-marketed goods and services (Floro, 1995). The care economy refers to the activities and relationships that are involved in maintaining and developing people, unpaid, within the home and in the community (Glenn, 1992; Ogden et al., 2006). Lund (2006, p. 161) indicates that this work, undertaken almost entirely by women – as family members or as volunteers – makes up the bulk of caring work undertaken in society, while that provided by the state or the formal private system constitutes a tiny part thereof. The concept of the care economy focuses on the economic costs and benefits of care, the sexual division of labour involved in providing different types of care and the contribution of care to economic growth and development (Ogden et al., 2004). The care economy lens is useful in helping to distinguish the care provided in the home by family members from care provided by trained individuals – paid or volunteer – who are linked to care and support programmes (Ogden et al., 2006, p. 334).

Bakker (1994) points to the need for the resources in reproduction to be ascribed a proper value. Indeed, the value of the time, energy and resources in the care economy is generally unrecognized and remains almost entirely unaccounted for in most systems of national accounts (Ogden et al., 2004). Caring activities were and are mainly considered "pre- or post-economic activities", and "standard economic theory is unable to represent the context of reproduction … which is so essential to human beings" (Jochimsen, 2003, p. 5). While market rationality assumes that individuals are independent and competitive, the rationality of care assumes connection, relationship and interdependence. In this way neo-classical economic explanatory models face difficulties (Lewis, 2001).

2.4 CRITIQUE OF COMMUNITY CARE

Evandrou et al. (1990) define community care as non-residential and non-hospital care. Community care policies were introduced in most developed countries many decades ago. In the United Kingdom community care was introduced within social services by the Thatcher government which emphasized cost cutting and conservative family values. These policies were targeted at various groups whose dependency was defined in medical terms, namely the elderly, mentally ill, handicapped, physically dependent and chronically sick (Dalley, 1988). A basic tenet of the approach is that the community must accept and participate in the rehabilitation of the individual, if the individual is to lead as full a life possible in the wider community (McGovern, 1989).

The meaning attributed to community care has changed in the United Kingdom over the last two decades: "initially it meant shifting the balance of care from hospitals to the community, but more recently, it has been used in a way which reasserts family responsibility" (Evandrou et al., 1990, p. 268). There has been a shift in the role of the state from the direct provision of services for dependent people, to supporting those who become increasingly responsible for providing most of the care, namely relatives, friends and neighbours (Glendinning, 1992; Parker, 1992).

Community care is justified in terms of its low-cost to government and in terms of the quality of life it lends when compared to institutional provision (Rimmer, 1983). However, it is argued that not enough resources have been made available for its implementation (Dalley, 1988). In the United Kingdom, long-stay hospital provision was reduced at a significant rate but local authority community-based services were not expanded sufficiently rapidly to offset this reduction (Ungerson, 1987). The professional services which were defined as comprising community care (such as home nursing, day care, respite care, group homes etc.) have in practice been found to be insufficient (Dalley, 1988). Community care in this sense is understood as "essentially cost-cutting rather than liberalizing and liberating" (Ungerson, 1987, p. 53).

According to Dalley (1988, p. 18), community care is "a form of care that is largely uncosted and unmeasured, which can be invoked by planners and politicians without its cost being borne by official resources". In community care the tasks that were performed by residential workers are performed unpaid by family members or friends. The cost effectiveness of community care depends on "not putting a financial value on the contribution of informal carers, who may in fact shoulder considerable financial, social and emotional burdens" (DHSS, 1981, as cited in Rimmer, 1983, p. 135). The main reason that the cost of community care has been considered to be lower than other alternatives is that in public expenditure terms community care policies are lower cost than their institutional alternatives. It is only the public expenditure costs of community care that are considered – the costs to caregivers within the home are ignored (Fast & Frederick, 1999; Rimmer, 1983). Fast and Frederick (1999, p. 4) explain that "any redistribution of responsibility for care from the formal to the informal sector also represents a redistribution of costs such that reductions in public expenditures are off-set by increases in costs to informal caregivers." Community care is not a cheap option if the unpaid labour of caregivers is included in the financial calculations (Glendinning, 1992, p. 162).

Therefore while the effect for those concerned with public spending will be reduced costs and improved efficiency, costs will in effect be shifted from the paid economy to the unpaid economy of the household, or rather, of women (Bakker, 1994; Chen et al., 2005; Elson, 1991b). This is linked to a second set of criticisms of community care. Although voluntary organizations, friends and neighbours may play a role in community care, this help tends to be sporadic and irregular (Dalley, 1988), and community care is “in most cases family care, and within the family it is women who bear the main brunt of caring” (Rimmer, 1983, p. 135). Most often care provision falls onto wives, mothers and daughters, who tend to be women of middle age, middle generation, between children and their own parents (Dalley, 1988). Parker (1981) argues that the availability of a community care system and the position of women has been taken for granted. Some (for instance Ungerson, 1987) maintain that policies for community care are, within a context of public expenditure cuts, incompatible with policies for equal opportunity for women. Cuts in social spending have been met by pressure from the feminist movement to recognize unpaid care work, and this has in turn resulted in more attention being focused on this work, and on legitimizing such work (Standing, 2001).

Other criticisms of community care also relate to “the substance of the policies themselves and the principles upon which they are based” (Dalley, 1988, p. 5). The third broad criticism concerns the belief that the family is the appropriate location for care, the dependent person can best achieve privacy and independence in their own home, and that the family has a moral duty to care. Linked to this, the fourth set of criticisms relate to the fact that community care policies are based on premises which do not always correspond to the needs or wishes of all dependent people. That is, the assumption is that community care is “appropriate to all categories of dependency. Just as all forms of institutional and residential care are perceived as unacceptable, so all forms and conditions of dependency are regarded as being amenable to care in the community” (Dalley, 1988, p. 6).

Ogden et al. (2004) also point to problems arising from the general terminology used to describe care that takes place in the home. The terms ‘home-based care’, ‘homecare’ and ‘community home-based care’ are usually used interchangeably to refer to “both that universe of care (clinical and non-clinical) that is provided by lay, volunteer or professional providers who are linked to programmes and care (generally non-clinical) that is provided by family members who are not linked to programmes”. Yet by using these terms to refer to what is actually a variety of types of care means that the specific benefits and costs of unlinked care – where caregivers are not linked to or supported by any formal HIV/AIDS care programmes – are missed.

In both developed and developing countries, governments are concerned with different groups in need of care. In developed countries the concern of social policy makers is with the growing number of elderly people requiring care. Many of these governments have therefore attempted to "strengthen the family's capacity to care" (Daly & Standing, 2001, p. 8). In some developing countries, chiefly those in sub-Saharan Africa, the concern of governments has been with the increasing numbers of people with HIV/AIDS who require care, and community care policies have been placed centre-stage to this end. Almost all AIDS care in sub-Saharan Africa is home-based, and women are disproportionately responsible for this care (Urdang, 2006, p. 173). Yet, as noted in section 2.2, for the vast majority of AIDS-affected families care is 'unlinked' (Ogden et al., 2004). Urdang (2006, p. 177) argues for the valuation of the unpaid care work which underpins the HIV/AIDS epidemic, and notes that if this is not done "governments will simply continue to allow this work to subsidise the national economy", which is able to limit expenditure on care provision more generally as a result.

2.5 HOUSEHOLD STRUCTURE AND UNEMPLOYMENT IN SOUTH AFRICA

Not explicitly stated in the literature from the developed world, reviewed in the previous sections, is the assumption of functional, nuclear families and relatively high rates of employment, both of which are not the case in South Africa.

In South Africa nuclear families are not the norm and most families could be best described as disrupted. This is distinct from the nuclear and lone families commonly found in developed countries, which informs the theoretical approaches developed in these countries and outlined thus far. There is no single dominant family system in South African society. Amoateng, Heaton and Kalule-Sabiti (2007, p. 48) analyse the 2001 population census and find that two-fifths of households are nuclear and just over a third are extended. The population groups show differences in living arrangements with Africans and coloureds most likely to live in extended family households (even more common among the least educated and poor), and whites and Indians most likely to live in nuclear family households. Extended households are more common in rural areas, while nuclear households are more common in urban areas. Eight out of ten households were occupied by family groups in 2001, indicating that the majority in South Africa live with family, while less than one of four households were occupied by non-relatives or a single person (Amoateng et al., 2007, p. 47).

Budlender and Lund (2008, p. 17) analyse the 2005 South African GHS and find that about a third of South African households consist of children and a middle generation (18-49 years), about a quarter are middle generation only, while about a fifth have three or more generations. Moreover, only 35 percent of under 18 children are resident with both their biological parents, 39 percent are living with their mother but not father, and 22 percent are not living with either biological parent (Budlender & Lund, 2008, p. 16). For African children the pattern deviates most strikingly from a nuclear family norm. In fact a higher percentage of African children live with grandparents compared with other race groups, and African children are also more likely to live with a sibling or other relative (Amoateng et al., 2007). There is also a very high rate of childbirth out of marriage, and many fathers have limited involvement with their offspring (Budlender & Lund, 2008).

Overall Amoateng et al. (2007) describe an increasing tendency towards complexity of households especially among Africans. They note that families and households in South Africa are becoming more diverse, in line with rapid social, economic and political changes in broader society.

The (un)employment regime in South Africa is also quite distinct from that in many other countries. In all, the population that are not economically active totalled 32 percent of the working age population in 2005 (own calculations using Statistics South Africa, 2005, p. xvii). The official unemployment rate, which classifies someone as unemployed only if they have taken active steps in recent weeks to find work, was 26 percent in September 2004, but the expanded unemployment rate, which includes those who would prefer to work but are not actively seeking work because they have given up hope of finding it, was 40 percent. Both rates of unemployment have decreased slightly since 2003 to the present (Budlender & Lund, 2008; The Presidency, Republic of South Africa, 2008, p. 21). However, Bhorat and Oosthuizen (2006) point to the worrying development of a rapid rise in unemployment rates for those with completed secondary and tertiary education. These authors also show that for 1995 and 2002, and for those who had completed secondary and tertiary education, Africans were more often unemployed than any other race group (ibid, p. 168).

Sienaert (2008) describes labour market outcomes as the central determinant of poverty in South Africa. About one-third of the population lived on less than $2/day (or R174 per month) in 2000, according to Hoogeveen and Özler (2006, p. 64), and this figure is higher for Africans at 40 percent than for other race groups. These authors show that the sheer number of people that fall below this poverty line has increased – albeit marginally – for the country as a whole and for Africans (ibid, p. 65). Leibbrandt et al. (2006, p. 106) corroborate this finding: they document an increase in the population falling below the same poverty line, from 26 percent in 1996 to 28 percent in 2001. The persistent problem of inequality in South Africa must also not be forgotten. Inequality has grown even wider in recent years to a Gini coefficient of 0.73 in 2001 (Leibbrandt et al., 2006, p. 101). Added to this are very high rates of HIV/AIDS, more of which shall be described in the following section, and it is evident that this is a quite particular context. All of this should be borne in mind when applying knowledge on care provision from a developed world context to a developing country setting, but especially when applying this knowledge to a context as specific as South Africa.

2.6 PROVISION OF HEALTH AND WELFARE SERVICES IN SOUTH AFRICA

South Africa is a middle-income developing country whose constitution emphasises non-sexism alongside non-racism and whose policy pronouncements emphasize gender equality. The Reconstruction and Development Programme (RDP) was penned before the new democratic South Africa came into being in 1994. According to Lund (2008a, p. 1) it "had a strongly redistributive intent, committing itself to the delivery of basic infrastructure to previously excluded groups as an intrinsic part of economic policy in post-apartheid South Africa".

In 1996 the Growth, Employment and Redistribution policy (GEAR) – was introduced as the new macro-economic policy. This was critiqued as being a new neo-liberal framework, but Stephen Gelb, one of the authors, argues that it did not introduce any fundamentally new policies into the macroeconomic policy regime. Rather, he notes that before GEAR was implemented, and in some cases before the RDP was the overarching policy, a harsh interest rate policy was adopted, as well as trade liberalization and financial liberalization policies which reintegrated South Africa's capital markets with those of the global economy. Re-packaging then-existing macroeconomic policy was part of the ANC's reaffirming their commitment to these policies for foreign and domestic investors (Gelb, 2006b).

Writing in 2006, May notes that GEAR has had some success in achieving stability in terms of inflation and the long-term exchange rate (May, 2006). However, Gelb (2006b) argues that the reductions in the fiscal deficit and the inflation rate over the past decade should not be taken to represent macroeconomic success. He believes that any success has come at too high a price in the form of low growth of output and employment (Gelb, 2006a, p. 1).

Interestingly, GEAR has differed from programmes of economic stabilization in some fundamental respects. For instance, no user fees were introduced, initially no attempt was made to cut the size of the civil service and social spending was not substantially cut (Lund, 2008a). In fact there has been a rise in the absolute amounts allocated for social spending since the end of apartheid, with a decline in the proportion spent on health and education and a rise in welfare spending (Budlender & Lund, 2008). Despite this, better quality living conditions for the poor have not necessarily been a reality in the decade following the implementation of GEAR (Patel, 2005).

In South Africa formal provision for the care needs of dependent people is offered by health and welfare departments. Prior to the 1994 elections there was an emphasis on curative and hospital-based care, but this changed to a focus on preventive and promotive primary health care with the introduction of the new democratic government, which emphasized the role of community health centres, local clinics and the training of para-professional health workers (Van Rensburg & Harrison, 1995). A district health system was introduced as the new vehicle for the delivery of health care services (McCoy & Engelbrecht, 1999, p. 132). However, in the words of Tollman and Pick (2002, p. 1725), since the new government came to power it has

> struggled to realize the promise contained within the decentralized, PHC (primary health care)-centred policy framework … Community-based health practice in many parts of South Africa remains poorly developed, and this lack of development has seriously constrained local health development…

These authors cite a lack of managerial capacity and limited community-based experience as some of the obstacles to achieving successful community-based health practice. Moreover, although efforts have been made over time to link district health system development to local government development, the health districts and the municipal boundaries are still not fully aligned.

At the same time, developmental social welfare – as introduced in the White Paper on Social Welfare – was adopted by the new government as its approach to welfare. The underlying aim was that policies for economic growth be closely integrated with social welfare policies. Similar to primary health care, this approach is seen as promoting ‘prevention’ as opposed to ‘cure’

(Mullagee, Nyman, Budlender, & Newman, 2001). This approach is rights-based, it emphasizes participation in development, as well as partnerships between the state, private, non-profit sectors and families and communities. Developmental social welfare tackles the issue of human agency in development and active citizenship. It also attempts to come to terms with financial and human resource constraints that present in a context of mass poverty and HIV/AIDS (Patel, 2005). According to Lund (2008a), in South Africa's welfare sector a distinction was traditionally made between direct welfare services and state social assistance in the form of cash transfers. Developmental social welfare aims to provide people with pathways out of poverty with cash transfers remaining "as support of last resort" (Lund, 2008a, p. 1). Yet through embracing a neo-liberal paradigm in the form of GEAR, some believe that the government has shifted its focus away from social goals. Although social spending may have increased in absolute terms, Patel (2005) points to the individualization of care that has occurred, with responsibility for social welfare having moved from the state to individuals, families and the private sector.

In line with the primary health care and developmental social welfare approaches, HCBC has been adopted by government as the preferred policy approach to meeting the need for care for all groups. The Department of Health (2001b, p. 1) introduced guidelines on HCBC in 2001, defining HCBC as "the provision of health services by formal and informal caregivers in the home, in order to promote, restore and maintain a person's maximum level of comfort, function and health including care towards a dignified death". No clear definition is given of CBC, but HBC is defined as an integral part thereof. HBC is described by the Department of Health (2001a) as a cheap, cost-effective and flexible means of providing basic symptomatic and palliative care for people with HIV/AIDS.[6]

According to the Department of Health, HBC programmes may be targeted at a range of beneficiaries including those with HIV/AIDS. The goals and objectives include ensuring access to care and follow-up through a functional referral system, and empowering the client, the caregiver(s) and the community through appropriate targeted education and training (Department

---

[6] In practice the reality of how HBC, CBC and HCBC are implemented differs from the official government definition of these terms.

of Health, 2001). HBC is described as requiring little or no medical input, with nurses as lead actors and most activity undertaken by nursing assistants or community workers with basic training (Department of Health, 2001a). The scope for primary health care management of HIV-infected individuals and their families is proposed in the form of psychosocial support to families, supervision of palliative care and follow-up of patients discharged from hospital (Department of Health, 2000a, 2000b). The role players are to come from the formal system (doctors, nurses, psychologists, rehabilitation therapists, social workers), the non-formal system (NGOs, CBOs and faith-based organizations (FBOs), traditional healers and traditional leaders), the private sector, the informal system (caregivers, families, community health workers, volunteers), and finally the client/consumer (Department of Health, 2001b).

The Department of Health states that most of the conditions affecting adults with HIV infection can be effectively managed at home. Cost-effectiveness is frequently underlined: HBC is described as a means by which increased demand for care can be diverted away from hospitals and into a lower-cost environment (Department of Health, 2000b). Another frequent theme is that this approach is better for the person receiving care.

However the guidelines make no reference to gender and there is no focus on family caregivers within the home (Hunter, 2005). Moreover “it is the informal carers who are going to be the ‘case managers’ chiefly responsible for the organization and procurement of the appropriate care ‘package’ for the person they are caring for” (Ungerson, 1987, p. 144). Yet this is not acknowledged and no guidelines are given on how this ‘case management’ is to unfold practically.

How is HBC defined by the Department of Social Development? There is no policy document similar to that of the Department of Health on the Department of Social Development’s website, so it would appear that this department does not have a separate policy on HCBC. Both departments are, however, mandated to work together on this programme. The Department of Health’s definition of HCBC is a relatively narrow definition which focuses on the cared-for similar to that adopted in this thesis. The expanded public works programme, for which the

Department of Social Development is the lead department, defines HCBC as “the provision of comprehensive services including health and social services, by formal and informal caregivers in the home” (Department of Public Works, 2006). For the Department of Social Development and for the expanded public works programme the term HCBC has a broader definition that also includes services to child-headed households, orphans and vulnerable children. (Department of Public Works, 2006; Department of Social Development, 2002). A wide array of services offered by various HCBC organizations falls outside of the ambit of actual HBC (Community Agency for Social Enquiry, 2005).

HCBC programmes are run by NGOs/FBOs/CBOs, some of which are subsidized by the Department of Health or Department of Social Development to do so. Much of the research on caregiving in the home has tended to focus on community caregivers who are part of HCBC programmes, but who do not live within the home of the cared-for and who do not provide care on an everyday basis, as family caregivers do. In many cases the distinction is not clearly made between these non-resident caregivers and family caregivers. While some of the tasks undertaken by community caregivers are the same as those undertaken by family caregivers, this service cannot be said to be the same.

As Lund (2008b) notes, the employment regime of community caregivers is very varied. The most informal are unpaid volunteer carers who are not ‘employed’ although they are working and may be attached to small and informal NGOs/FBOs/CBOs. On the other extreme are trained community health workers, paid by the Department of Health and attached to a health team at a clinic. Their work is monitored and supervized, they receive a stipend, and are ‘employed’, though most do not receive any work-related benefits. Recently a policy framework for community care workers has been drafted which aims to improve the management of community caregivers, lay out a structure for compliance with relevant legislation such as the Basic Conditions of Employment Act and set up requirements for the various departments and programmes involved in this service delivery (Department of Health and Department of Social Development, 2009).

In 2005 HIV prevalence for the total population was 11.0 percent for South Africa using the ASSA 2003 model, and 15.6 percent for KwaZulu-Natal (Actuarial Society of South Africa AIDS Committee, 2009). This means that in South Africa there are and will be a substantial number of people in need of care. Much social research in South Africa has been on those infected and their care provision. Research has looked at the experience of morbidity and mortality within households (Johnson et al., 2002), the CBC programmes in place (Russell & Schneider, 2000), and the means by which these programmes can be extended (Goudge, Gilson, & Msimango, 2003; Johnson, Modiba, Monnakgotla, Muirhead & Schneider, 2001).

Booysen, Bachmann, Matebesi and Meyer (2003) conducted a longitudinal study of HIV/AIDS affected and non-affected households, where affected households were those in which the person being cared for were HIV/AIDS affected and non-affected households did not include persons suffering from tuberculosis or pneumonia. They found that being cared for at home was slightly more likely among those care recipients from affected households than those from non-affected households. Moreover, ill members in affected households required significantly more care at home, than those in non-affected households, with care provided mainly by family members. There were fewer economically active persons in affected households, and these households were more dependent on non-employment sources of income.

Steinberg et al. (2002) undertook a study of 771 AIDS-affected households that had contact with NGOs. They found that over two-thirds of caregivers within households were female, and more than 40 percent of households reported that the primary caregiver had taken time off from formal or informal work or schooling to care for the AIDS sick person. The households worst affected by HIV/AIDS were also most underserved by basic public services such as sanitation and piped water.

Only a few studies provide detail on the experience of family caregivers. Akintola (2006) undertook research with unpaid caregivers of people living with HIV in two semi-rural communities in the greater Marianhill area, outside of Durban: that is, 21 primary (family) caregivers and 20 volunteer (non-family) caregivers. Ten key informants were also interviewed.

Almost all caregivers were women. Akintola found a general lack of male participation in HBC even when men were present in study households, and a gendered division of caring roles.

Most family caregivers were sisters or mothers of those in their care, and none was a spouse. Caregivers undertook a wide array of caring activities and experienced noteworthy physical health effects associated with caregiving due to the physically taxing nature of the caregiving tasks they carried out. Work overload was found to be a direct result of the lack of support from other family members. These caregivers had multiple-caring commitments, which transcended the care of the person in their care. Emotional and psychological problems were experienced by caregivers, in particular, constant worry about the pain and suffering of those in their care was recorded, as well as a concern over their inability to provide a cure for the person's illness. Some caregivers were themselves living with HIV or AIDS which added to their distress.

Akintola notes that HBC policies and programmes work on the assumption that family members are available, willing and capable of caring for ill people in their homes. Yet these findings show that HBC as currently practised constitutes the transfer of the responsibility to care to women who are already burdened by poverty and other caregiving responsibilities.

In one of the few studies in South Africa that has focused solely on the impact of caregiving on family caregivers, Orner (2006) investigated the psychosocial impacts on caregivers of caring for people living with AIDS in the home. This qualitative study was based on in-depth interviews with 45 primary caregivers, 43 of whom are female, in Khayelitsha, Gugulethu and Delft, in the Western Cape. Caregiving was found to place considerable practical and emotional demands on caregivers. This negatively impacted on their mental health, made worse by insufficient support, dire poverty and the added responsibilities of caring for other household members. Caring took place in a context of lack of basic resources, and this exacerbated the intensity of the caregiving process. Caregiving also impacted negatively on normal working and social patterns. Stigma and prejudice towards caregivers was common and worsened levels of stress. While the support received ranged widely, a lack of support was debilitating and not knowing how to access support structures was another source of stress for some caregivers.

Finally, Wallwork (2006) compared four different models of HBC in Durban and also found a disconnect between carers and the health system. Wallwork argued for HBC to become a formalized health service within the Department of Health, in order to reduce the burden on households.

3 LITERATURE REVIEW – MEASURING AND VALUING UNPAID CARE WORK TIME

The previous literature review highlighted the unpaid care work that women undertake within the home. Ogden, Esim and Grown (2006, p. 334) argue that making this unpaid work and the unpaid workers visible is of value to governments and policy makers "in order to … capture the benefits of these activities, but also to … enumerate their costs – so that the unpaid contributions of women to the productive economy can be acknowledged and compensated". The most obvious way to make this work more visible is to measure the time spent undertaking it so that a monetary value can be placed on it. This chapter reviews the literature on methods used to measure and value time-use.

3.1 COSTS OF UNPAID CARE PROVISION

The bulk of the cost of unpaid care is in terms of a commitment of time (Netten, 1996). Labour time, the most important input into care, is usually combined with raw materials, physical, environmental, social and human capital to provide care services (Folbre, 2006). These inputs can be labelled as costs. The costs attached to providing care within the home are incurred not only by the caregiver but also by recipients of care, families, employers of care providers, and by society at large (Fast et al., 1999). These costs are both financial and non-financial, and financial costs are incurred both in the present and in the future. The focus of this section is on present and future costs of unpaid care provision in order to provide the rationale for measuring the time spent in unpaid care work and for assigning a value to it. Not all of the possible costs will be incurred by every caregiver in every situation but all need to be taken into consideration (Netten, 1996).

Care provision for a dependent person is associated with lower rates of labour market participation among women (Glendinning, 1992). A caregiver who is an employee may give up waged time, move from full-time to part-time work, or give up their entire job (Netten, 1996). This applies similarly to caregivers involved in other types of income earning. Some women have to leave the labour market to care, while others' employment is curtailed (by taking up part-time employment, for example), and these women will experience reduced earnings, but also reduced benefits (Rimmer, 1983). In a United States study, Robinson (1997) found that uncompensated care to the frail elderly resulted in nine percent of home-based caregivers who left the labour force to provide care, 29 percent who adjusted their work schedules, and 18 percent who took time off without pay. It is not only current, but also future earnings and benefits, such as occupational pensions, which are affected (Glendinning, 1992; Graham, 1983).

Giving up work may also mean an early retirement if the carer is older, since re-employment is often difficult at older ages, and this may in turn increase the risk of poverty in old age (Rimmer, 1983). According to Joshi (1992) the degree to which caring work interferes with a woman's capacity to earn depends on the helplessness of those she cares for, on the extent to which the care is shared by other people, and on expenditures on commodities which make multiple roles easier – such as domestic machinery. Moreover, opportunity costs will differ depending on the stage of the individual in the life cycle, and on other determinants of their potential earnings (such as their occupation or education level) (Rimmer, 1983). All aspects of costs increase with disease severity and problem behaviour (Moore, Zhu, & Clipp, 2001).

Further costs include giving up non-waged time. Care for others can be displaced, also opportunities for leisure and self-fulfilment (Netten, 1996), other unpaid work, domestic and subsistence work (Chen et al., 2005). A caregiver may also give up accommodation – the loss of a room used for the cared-for could mean the lost opportunity to earn a market rent (Netten, 1996).

The value of the unpaid work of carers is often a major component of the total cost of care provision within the home. Ancona-Berk and Chalmers (1986, as cited in Fast & Frederick, 1999, p. 2) argue that: "community based care is less costly than hospital care only when kin care is assigned no value". Rice et al. (1993), for instance, find the costs of care for a patient with

Alzheimer’s disease in northern California to be about the same whether the patient lives at home or in a nursing home. Yet the break down of costs varies. For patients at home, three-quarters of the total cost is the imputed value of the labour of unpaid carers compared with 12 percent of the cost for institutionalized patients. Similarly Stommel, Given and Given (1994) in the United States calculate the costs of cancer home care to families. Monetary costs assigned to family labour are either equated with income losses to the carer or are based on a putative market value of the expended labour time. The authors find that when family labour is included in the cost calculations, average cancer home care costs are not much lower than the costs of nursing home care.

Direct financial expenditure on goods and services as a result of caregiving also constitutes noteworthy costs. Netten (1993) defines the financial costs of care to include those goods and services which would not have been purchased in the absence of disability. She gives the following examples: higher costs of heating, laundry, special foods and travel. Netten goes on to distinguish between two principal types of good: consumption goods, which are consumed or used in the process of production (e.g. actual expenditure on food, heating and laundry which is directly attributable to disability), and capital goods, which are manufactured goods that are used to produce commodities (e.g. adaptations such as ramps for a disabled person). Further out-of-pocket expenditures include buying time to care by purchasing other services (such as child care services or garden services) and purchasing respite care (Fast et al., 1999), and the direct costs of unreimbursed health care expenses (Arno et al., 1999). McDaid (2001) reminds us of the importance of identifying whether income is being received by the person being cared for as this may be used for these direct costs, which then cannot be considered a household expense on care provision. However, in developing countries where money tends not to be received for caregiving, this would not be a concern.

Other consequences for caregivers of shifting the responsibility for care from paid to unpaid caregivers include stress, burden, guilt and deteriorating health (Fast & Frederick, 1999, p. 4). A literature on the caregiver’s burden (see for instance Pakenham, Dadds, & Terry, 1995) focuses on the social, physical and emotional problems associated with providing care. Emotional wellbeing costs include psychological stress, poorer morale and loss of control and independence, while social wellbeing costs relate to interpersonal relationships and social activities (Fast et al., 1999).

Many of the factors stated thus far lead to lowered standards of living among households in which care is being given, which are closely linked to lowered standards of living in old age (Graham, 1983). Evandron (1990, as cited in Glendinning, 1992, p. 171) finds that carers are consistently worse off than non-carers. Especially disadvantaged are carers living in the same household as the cared-for, female carers, carers who have sole responsibility for providing care and carers who are not economically active.

Some of the costs described above are easier to count than others. Direct financial costs as well as accommodation have a monetary value attached to them, which makes it easier to cost these. The same applies to accommodation if it is being rented, but not if it is owned or has been built.

In order to understand more about the costs borne by family caregivers, this thesis estimates the costs of the unpaid care provision undertaken for ill people within the home. This is done by estimating the labour costs of family caregivers and the financial costs of households.

3.2 MEASURING UNPAID CARE WORK TIME

There is general agreement that the best way to measure unpaid work is through the measurement of time spent on these activities (Goldschmidt-Clermont, 1982). However difficulties arise in measuring time-use, and unpaid care work time in particular (McDaid, 2001). This section focuses on aspects relevant to collecting time-use information.

3.2.1 *The System of National Accounts*

Unpaid care work produces something without which the rest of the economy and society would not exist (Budlender et al., 2001). Throughout the world women are more likely than men to do unpaid care work. As Heintz (2007, p. 7) notes, “workers do not spring into existence, fully formed and ready to toil. Real economic resources go into producing human beings”. The economic inputs include both marketed and non-marketed goods and services. There are equivalents for many of these services in the market economy. For example, one can pay for a domestic worker to clean, for a nursemaid to look after a child (Budlender et al., 2001). These activities amount to production, since they can be delegated to a paid worker (Goldschmidt-Clermont, 1982), but they are not included in the calculation of GDP.

The SNA encompasses the rules that govern how countries should calculate figures in their national accounts so as to produce internationally comparable estimates. The SNA states that GDP should be based on the value of activities that fall within a certain ‘production boundary’ (Budlender, 2006). The 1993 SNA provides a comprehensive framework of accounts with common definitions and concepts to describe the economy of a country (Budlender et al., 2001).

The United Nations Statistical Division has developed an activity classification system for time use surveys as a response to the perception that existing classification systems were biased towards a first world situation. The United Nations classification system is organised according to ten broad categories that can be grouped according to how they are treated in the SNA, and therefore in the calculation of GDP. The categories are as follows:

SNA production activities

1. Work in establishments – for example, domestic work, looking for employment.
2. Primary production not for establishments – for example, growing vegetables on a household plot, collecting fuel and water.

3. Other production of goods and services not for establishments – for example, informal street trading, informal provision of hairdressing at home (Budlender et al., 2001).

Activity categories one to three fall inside the SNA production boundary, and would therefore be included in the national accounts and the GDP calculation. The only exceptions are the codes for looking for work and time spent on travelling related to SNA type activity. Collecting fuel and water are included under primary production not for establishments as these activities are officially part of the SNA – although probably not included in most countries (Budlender et al., 2001).

Non-SNA production activities
4. Household maintenance – for example, housework, household shopping.
5. Care of persons in the household – for example, looking after children or the elderly.
6. Community service to non-household members – for example, caring for non-household members, cooking for collective occasions (Budlender et al., 2001).

Activity categories four to six, which include unpaid care work, fall outside the SNA production boundary, although they are widely recognised as 'productive' activities, and correspond for the most part to unpaid labour. Activities in categories four to six are also referred to as 'extended SNA work' and as being part of the 'extended' production boundary (Budlender et al., 2001). In other words, unpaid care work is recognised as work that produces value, but it is not included within the SNA production boundary and is therefore excluded from the national accounts that underlie the GDP. According to Budlender (2006, p. 6), reasons given for this are that it "would be too complicated technically, would upset existing time series, and would produce estimates that are difficult to interpret". However, while the SNA excludes the production of domestic and personal services by household members for consumption within the same household (Charmes, 2006), such activities are widely considered to be "the largest single item missing in national accounting" (Goldschmidt-Clermont, 1982, p. 3).

Budlender (2006) cautions that estimates and descriptions of production in a particular country could result in problematic policies if they do not take account of unpaid care work and its interactions with SNA production and with the general well-being of the population. The 1993 SNA makes provision for the investigation of concepts not specifically highlighted in the 1993 SNA through the notion of satellite accounts (Budlender et al., 2001). Time-use data are the building block for the information contained in such satellite accounts.

Goldschmidt-Clermont (1982) measured productive activities carried out by household members for consumption by their own household. In this thesis one such productive activity not accounted for in the national accounts will be measured, namely unpaid care work by household members for ill people within the household.

Non-productive activities

7. Learning – for example, attending school, attending work-related courses.
8. Social and cultural – for example, socializing with family or friends, participating in cultural and religious activities.
9. Mass media use – for example, watching television, visiting the library.
0. Personal care – for example, sleeping, washing and dressing oneself (Budlender et al., 2001).

The activity categories seven to 0 do not fall within the SNA production boundary, even when the extended boundary is considered. According to the United Nations (2005), an activity is said to be productive if its performance can be delegated to another person and yield the same results. The SNA defines work and production as all activities that fulfil this third person criterion. For example, it is possible to hire someone else to clean the house, but it is not possible to hire someone else to learn for you. This activity fails the third person test and is not regarded as work or production (Budlender, 2006; Budlender et al., 2001).

3.2.2 Methods for measuring time-use

Time-use statistics are quantitative summaries of how individuals allocate their time over a specified period (for instance, 24 hours of a day). Such statistics provide information on activities that the reference population engage in and the time spent doing these activities. The most common focus of time-use data collection has been the measurement of domestic activities and of the care economy, and the distinction between male and female has been a key part of this research (Charmes, 2006). Since it is women who chiefly undertake non-market work within the household, national time-use research methods are an essential statistical tool for "improving measurement and valuation of paid and unpaid work and for increasing the visibility of women's work both at home and in the labor market" (United Nations Secretariat, Statistics Division, 1999, p. 2).

Time-use data can be selective, where time spent is recorded only for a selected activity or activities within a specified period, or exhaustive, where all activities engaged in during a specified block of time are measured (United Nations, 2005). Three principal methods for measuring the allocation of time are cited by Juster (1985) and the United Nations Secretariat, Statistics Division (1999): observation, stylized questions and time-use diaries. In this thesis aspects of all three of the main time-use methods are used.

The observation method involves the researcher observing what the person is doing at particular times and recording the activities, with no direct involvement by the person being observed. One of the advantages of the observation method is that it does not require that people whose activities are recorded can read and write, or that they have a western concept of time (Budlender, 2002). This method is also useful for collecting information on unstructured activities or simultaneous activities (Kes & Swaminathan, 2006) which are frequently among the activities that constitute care work. Time spent on simultaneous activities refers to time that is spent undertaking more than one activity at the same time. For instance, one activity such as feeding a person, and another activity such as talking to the person. A problem with the observation approach is that through observation the activities themselves are likely to be altered (Juster, 1985). This method is also very researcher-intensive and costly because the researcher can only follow and observe one person at a time (Budlender, 2002). A further problem is that an observer could make inferences about the purpose or motivation of the activity which would be better made by the person or persons being observed (Juster, 1985). For these reasons observation is not widely used to gather time-use information.

Time allocation may also be measured through a series of stylized questions, which inquire about the frequency with which a certain activity is undertaken, and the duration of the activity (Juster, 1985; United Nations, 2005). For example, ‘how often is the person given food in a day?’, and then, ‘how long does feeding the person take at each of these times?’ This method is normally used in a questionnaire, among a series of other questions (Budlender, 2002). There are a number of variants of the stylized method which Budlender (2002, citing INSTRAW, 1995) describes.

There are two central approaches that fall within the stylized method. The first involves targeting only specific activities (the approach adopted in this study). The second attempts to provide for all possible activities and the total time is constrained to 24 hours in a day (Budlender, 2006; United Nations, 2005). The stylized method is generally only able to provide information on one of two or more activities undertaken at one time, as well as the duration of activities. It does not provide information on simultaneous activities, the chronological order of activities, the number of episodes per activity nor contextual information (United Nations, 2005).

The third method is the use of time diaries. A time diary collects time allocation data in a structured way and usually involves a short recall period (Van den Berg & Spauwen, 2006). The respondent describes each activity for a specified period of time. Budlender (2006) notes that in some cases a pre-defined set of activities is provided from which the respondent must choose for every time slot in the day, and in other instances the respondent describes what he/she did for each part of the day and codes are assigned afterwards. In some cases, the diary will have time slots along the side or top of the page against which the activities must be recorded. In other cases, the respondent just names each activity, with a beginning and ending time. Time diaries may be filled out by the respondent or he/she may report activities to an interviewer who then records the information. There are two main types of time diaries. In the ‘yesterday’ diary, the respondent is asked what he/she did for each period of the previous day. In the ‘today’ diary, the respondent is given a diary to fill during a specified day in the future (Budlender, 2002; Juster, 1985).

Juster (1985) and Kan (2006) broadly outline the advantages of the time diary method: all activities are covered for a defined span of time and therefore it is comprehensive; the time diary has a built-in control check in that an external control variable is available (that is, 24 hours for recording activities over a day); if there is no list of activities built in, respondents report activities in self-descriptive terms which can then be coded according to uniform coding decisions.

The ‘yesterday’ diary can be filled in through an interview, which is helpful if respondents are illiterate or find writing and reading difficult. However, it is problematic if the person does not remember well what they did on the previous day. In this way the ‘today’ diary is advantageous, although in practice most respondents do not record activities as they do them. Further disadvantages are that the ‘today’ diary requires literacy skills and commitment from the respondent to carry the diary with them during the prescribed day and remember to write things down (Budlender, 2002).

Disadvantages to the time diary method in general include the fact that seasonal activity patterns vary and daily time-uses vary vastly depending on whether the day is a week day, a weekend day, a day spent away from home, etc. This is relevant to care work to the extent that the carer or other household members are employed, in which case it would tend to differ by day of the week. Another disadvantage is that if the data collection period does not include the proper proportion of the various types of days, the estimates are likely to be biased. Also, if activities are measured over long periods of time difficulties are experienced. It is far preferable to ask people to record activities using a short and recent time span such as the last 24 hours (Juster, 1985). Moreover, the time diary is time consuming for respondents – and thereby places an additional burden on them which is not desirable when the burden of care work is already high. Low participation rates are also common with this method, partly because it is time consuming. In general it is a costly method to use in financial terms.

According to Budlender (2006), the attraction of stylized approaches is that they involve far fewer questions and require less time than a time diary, and the data produced are easier to analyse. In addition, obtaining information using stylized questions costs less than the time diary.

With regard to the stylized method, in principle it may be possible to construct a lengthy list of activities that would comprise all the activities of households and thereby create a set of estimates that is fully comprehensive. However this may be somewhat arduous for respondents to complete (Juster, 1985). As Budlender (2006, p. 52) notes: “there must inevitably come a point where the number of activities for which the respondent is prompted results in fatigue on the part of respondent and fieldworker, and thus poor quality data”. As it is, stylized estimates require more effort in calculating on the part of respondents than do time diaries (Kan, 2006). Moreover, where unpaid care work activities are done intermittently throughout the day it may be difficult for respondents to estimate these separate times and arrive at a total time that is accurate (Budlender, 2006; Van den Berg & Spauwen, 2006). Therefore, the reliability of the estimate will depend on the type of activity undertaken. Making meals may be easy to estimate time for because there are standard times for meals, but keeping an eye on an ill person may be more difficult (Budlender, 2002). Budlender (2006) and the United Nations (2005) note that respondents tend to under-report activities that are considered less desirable (for instance, relaxing) and over-report activities that are regarded as desirable (for instance, tending to the person in need of care).

Stylized approaches are also preferable for specific, short time periods (such as yesterday), rather than asking about usual activities over a day or week, for instance (United Nations, 2005), although the latter tends to be how they are generally used. In this respect, Juster and Stafford (1985) conclude that the main bias of stylized questions when asking about ‘usual’ activities is that respondents tend to recall days when the activity asked about was particularly prominent, and treat that as an average day, thereby resulting in overestimation. In fact, Kan (2006) notes that stylized estimates tend to produce total time greater than 168 hours (24 X 7) a week. One disadvantage of stylized questions is that there is no way of checking whether the answers ‘make sense’, in terms of whether they add up to 24 hours (Budlender, 2002), since this is (usually) not a prerequisite (Van den Berg & Spauwen, 2006).

Juster (1985) believes that time allocation data obtained using the stylized activity mode is only satisfactory for sets of activities that are performed with high frequency – such as on a daily basis – and that do not vary greatly in the amounts of time involved. In contrast, Fast and Frederick (1999) and the United Nations (2005) argue that stylized methods provide better estimates of time spent on irregular, infrequent and episodic activities than the time diary. According to Kan (2006) the gap in estimates from the time diary and from stylized questions should be larger when the respondent has irregular patterns of participation in an activity. Hence, women should report hours spent in caregiving more accurately than men because they undertake caregiving more than men. Therefore the discrepancy in estimates could vary across different groups depending on the levels of their usual participation in an activity.

A problem specific to the measurement of unpaid care work is the separation between ‘normal’ housework that somebody does anyway and additional housework that is due to the care demands of the cared-for. Van den Berg and Spauwen (2006) mention that respondents find it difficult to make a distinction between ‘normal’ housework and ‘informal care’ housework when completing the stylized method. Similarly, Netten (1993) indicates that caregivers find it impossible to estimate what is typical. She cites a study of ten local authorities in England in which a number of caregivers were able to identify tasks but not the amount of time spent on these tasks. The United Nations (2005) notes that for activities that take place daily it will probably be easier to estimate what is ‘typical’, than activities that occur infrequently.

A further shortcoming of stylized approaches is that they do not provide information on the time of the day that different activities take place (Budlender, 2006; United Nations, 2005). This makes it difficult to analyse the interaction between economic activities and unpaid care work, and it also prevents the use of contextual variables, such as location, and travel. The stylized method is likely not to count, or to undercount, travel time when reporting time spent on care, and here explicit attention needs to be paid to recording travel information (Budlender, 2006).

Similarly, another limitation of stylized approaches relates to the definition and boundaries of care work. Where respondents are asked in the stylized approach how much time they spent on a particular activity, their responses will depend on what they understand the activity to include (Budlender, 2006). If, for example, they are asked how much time they spent looking after an ill person, some might include the time spent travelling to and from a health facility with the person while others might not. Simultaneous activities add a further complication in that some respondents might include them in their estimates while others may reflect only one of two activities undertaken at one time. It is therefore important that questions be stated in such a way that respondents understand the boundaries of the activities that they must report on (United Nations, 2005).

With the diary approach undertaken as an interview the person describes the activities in their own words, and the coder can then decide whether activity time should be counted as care work or not (Budlender, 2006). According to Folbre (2006), however, the stylized method may be superior to a diary-based method in one important aspect. She argues that activity-based surveys should be supplemented by more stylized questions regarding care responsibilities in order to get at the non-activity-based caregiving that occurs, and which is usually understated in measurements of unpaid caregiving time-use.

As with Juster and Stafford (1985), van den Berg and Spauwen (2006) also point to the problem of overestimation with stylized questions, where respondents report time-use that adds up to more than 168 hours per week. However, they note that activities that are usually performed in combination with other activities tend to contribute to this outcome. If simultaneous activities are taken into account when stylized questions are asked, these authors consider this method to be a valid tool to measure time spent on unpaid care work. According to the United Nations (2005), while stylized methods typically overestimate time-use an exception occurs if the length of the retrospective time horizon is long (for instance, six months or a year). Juster and Stafford (1991) add to this if events take place relatively rarely and if activities lack salience (for instance, buying a bucket for the person to use to go to the toilet, that occurs only once). Similarly, Folbre (2006) describes how time devoted to the care of sick and disabled people is seriously understated by activity-based measures – she cites Australian time-use data and research on the impact of HIV/AIDS on time-use as evidence for this claim.

Kan (2006) describes research that shows that the size of the gap between diary and stylized estimates depends on the gender of respondents, the total household work hours, education and other socio-economic variables. Kan compares stylized estimates and time diary estimates of housework time collected from the same respondents and using comparable time frames. She finds that the gap between estimates is generally smaller with regard to women – although some other authors have found the opposite to be true (see Kan, 2006, p. 3). Kan notes that women generally report their housework hours more accurately than men, and that the difference between the two types of estimates is less than five percent for women. Moreover, for women the gap in estimates is associated with the amount of housework undertaken as a simultaneous activity, and the level of irregularity in housework hours. Kan finds that if dependent children are present the gap in estimates is inflated for men and women. By deduction the same may well be true for dependent adults who are ill. However, overall Kan finds systematic errors in stylized housework time estimates.

In terms of ‘output’ some of the drawbacks of the stylized method are that both validity and reliability are relatively low. Kan (2006) observes simply that inaccuracy in respondents’ estimations also points to the limitations of the human memory. Kan and van den Berg and Spauwen (2006) highlight the problem of validity that is presented by the retrospective way of questioning and that may lead to recall bias, a drawback that also applies to time diaries that are retrospective. Van den Berg and Spauwen tested the stylized method for test-retest reliability and found that it was unstable over time, but emphasize that this could be due to learning effects from completing a time diary, which was also part of their study.

Nevertheless, there seems to be consensus among some authors that the time diary is the method of choice. Both Juster (1985) and Juster and Stafford (1991) expound the virtues of the time diary and INSTRAW (1995, p. 69, as cited in Budlender, 2002) describes this method as the "tool of preference" because it avoids some of the problems associated with the other methods. Juster and Stafford (1991, p. 473) recommend time diaries be "administered to a sample of individuals in a population and organized in such a way as to provide a probability sample of all types of days and of the different seasons of the year". However, if literacy levels are low, as is the case in many developing countries, despite being the method of choice the time diary may not be the best method to use. In fact decisions as to which method to apply for time use surveys in various developing countries have been centrally based on data quality concerns that relate to the literacy level of respondents, and in these contexts Kes and Swaminarathan (2006) propose the use of illustrated survey materials or interviewer-administered surveys, and the United Nations (2005) suggest the stylized method as being preferable to a leave-behind time diary.

Ultimately though, in their guide to producing time-use statistics, the United Nations (2005) point out that arriving at an appropriate design for producing statistics on time-use requires the balancing of objectives and resources. Similarly, Kan (2006) notes that in collecting time-use estimates there is usually a trade off between minimizing the burden on respondents and achieving a high response rate. Stylized estimates are cheaper to collect than diary estimates and less demanding on respondents, and there is therefore usually a higher response rate with this method compared with the more demanding time diary method, which results in a lower response rate. In fact, Kan (2006) and van den Berg and Spauwen (2006) argue that data from stylized questions should not be abandoned but made better use of by applying cautiousness in the interpretation of results. As something of a 'mid-way' solution, Kan suggests combining the diary and the survey type approaches, and having a sub-sample of the survey type respondents record time diaries.

In the South African context there are particular advantages and disadvantages that apply to each time-use method. While observation does not require literacy or having a western concept of time, and it can pick up on simultaneous activities, activities can be altered through the observation process, and it is costly. The time-use diary that is filled in through an interview is advantageous if the respondent is illiterate or has low literacy, and it records simultaneous activities, but this method is costly, time consuming (which results in low participation rates), if there is no interview it require literacy skills and commitment from participants, and the information obtained can be biased if the proper proportion and variety of days is not included. While stylized questions are less costly, take less time because there are less questions (and relatedly a higher response rate), there are additional disadvantages. It is difficult to obtain information on simultaneous activities, order of activities, contextual information and number of episodes, and recall of a 'usual' day may result in overestimation. Moreover the stylized method requires more effort in terms of calculation on the part of respondents, and if a lot of activities are asked about respondent and interviewer fatigue may result.

Finally, Kes and Swaminathan (2006) and Blackden and Wodon (2006) highlight the need for research on the impact of serious illness such as HIV/AIDS on women's time allocation patterns. One study of 100 households in Ethiopia (see Baryoh, 1994, as cited in Bollinger, Stover, & Seyoum, 1999, p. 5) found that the workload of women who either had HIV/AIDS or lived in a household that was affected by HIV/AIDS or both, was significantly different from the workload of women who lived in households that were neither afflicted nor affected. The most time-consuming activity for women in HIV/AIDS affected households was nursing at home (50.2 hours per week on average). Moreover, women in HIV/AIDS affected households spent substantially less time on child care when compared with women in non-HIV/AIDS affected households, and much less time on agricultural activities when compared with women in non-HIV/AIDS affected households.

3.2.3 Accounting for simultaneous activities

Simultaneous activities is a persistent problem in the measurement of time in general and in the measurement of unpaid caregiving (Van den Berg & Spauwen, 2006). The issue of simultaneous activities was mentioned in the previous section and refers to two or more types of activities undertaken at the same time by one individual. For instance, this could involve cooking a meal while at the same time looking after a child. Pollak (1999, as cited in Budlender et al. 2001) notes an interesting distinction between types of simultaneous activities. 'Parallel activities' include, for instance, driving a car and listening to the radio. The second type of simultaneous activity involves bearing responsibility for the care of another person at the same time as doing something else ('on-call activities'). A person doing one of these on-call activities can do something else at the same time "but the range of activities that are compatible with being on call is constrained in terms of location and is limited to activities that must be interrupted" (Pollak, 1999, p.8, as cited in Budlender et al., 2001, p. 22).

According to Budlender (2006) simultaneous activities must be recorded and analysed if unpaid care work and especially care work more narrowly defined is to be accurately recorded. Ironmonger (2003) shows that counting one activity time only is a gross underestimate of the time spent by adults on child care. Since more simultaneous work is carried out by women than men, an undercounting of women's work will result if simultaneous activities are not counted (Beneria, 1992; Budlender, 2002).

Some time use surveys do not attempt to capture simultaneous activities, while others attempt to do so but often experience difficulties in obtaining accurate and comprehensive measures (Budlender, 2006). Even where methods allow for multiple activities, these activities may not be remembered by respondents. According to Budlender (2002) research has shown that women do not remember to mention all the child care work they do. Another difficulty with recording simultaneous activities is that some respondents might include them in their estimates while others will think only of one of two or more activities they were doing at one time, in trying to add together the different bits of their day (Budlender, 2006).

There are various options in measuring simultaneous time-use. When two activities are reported for the same period, one option is to allocate the same amount of time to each activity as the time taken for the simultaneous activity. If, for example, a person spends one hour cleaning and, at the same time, one hour caring for children, it could be counted as one hour spent cleaning and one hour spent in child care. The drawback to this approach is that it would result in double-counting of the time and would not satisfy the constraint that a day has only 24 hours (Ironmonger, 2003; United Nations, 2005). A second option, suggested by Ironmonger (2003), is to ascribe 30 minutes to cleaning and 30 minutes to child care. But this also does not seem to be a satisfactory way to account for the time spent, since 30 minutes was not solely spent cleaning and 30 minutes was not solely spent caring for children. While the United Nations (2005) suggests as a third option counting only one of the simultaneous activities, this means that no simultaneous time is counted.

An alternative entails regarding the activities not as two separate activities but as joint activities. For example, instead of ‘cleaning’ (one activity) and ‘caring for children’ (another activity), ‘cleaning and caring for children’ is seen as an activity on its own. This approach does not entail double-counting and all activities that are counted sum to 24 hours in a day or 168 hours in a week (Ironmonger, 2003). However, while this approach may be conceptually appealing, the United Nations (2005) point out that it may lead to an enormous number of activity categories, which may be difficult to deal with. As alternatives they propose two options. With the first option the time spent on solo activities is allocated as a proportion of time for joint activities. With the second option – which involves valuing time – the time spent in joint activities is divided by the value of the outputs produced by the time. For example, if a person is both cooking and looking after a child at the same time, and the value of cooking is R15 per hour and the value of looking after a child is R5 per hour, then an hour of simultaneously cooking and looking after a child would be allocated as 45 minutes of cooking and 15 minutes of looking after a child.

Despite these approaches, Budlender concludes that “current methods, even where provision is made for simultaneous activities, almost certainly produce less than comprehensive results”, and that more research and experimentation is required in this area (Budlender, 2006, p. 52).

3.2.4 Collecting time-use data

Time use surveys undertaken at the national level have until recently been the preserve of industrialised countries. In developing countries, time-use information was previously collected as part of small and non-representative samples, often case-studies of a single or few localities. Some of these studies did not cover 24 hours in a day, and participant observation tended to be the main method of data collection. These approaches have recently been replaced with nation-wide surveys in many developing countries (Charmes, 2006; United Nations Secretariat, Statistics Division, 1999).

The limited scope and methods of time-use data collection in developing countries has been attributed to “difficulties in measuring time in a population not accustomed to being regulated by ‘clock time’ nor experienced with filling in a questionnaire” (United Nations Secretariat, Statistics Division, 1999, p. 2). It is essential to understand how respondents and the community in which they live identify the hours of the day and how they calculate the amount of time it takes them to perform an activity. They may relate their activities to traditional cultural practices, productive activities, schedules of daily radio and television programmes, or routine activities included in their daily schedules (United Nations, 2005). Another data quality concern is the ‘hassle factor’ involved in providing time-use information, which is usually a time consuming process and requires effort on the part of respondents. Respondents may therefore not always be willing to spend time in providing time-use information. Respondent and enumerator burden due to the volume of information being collected is also a concern (United Nations Secretariat, Statistics Division, 1999).

There are various factors which need to be taken into account with regard to time-use data collection. As highlighted in section 3.2.2, the period of time over which the study is conducted will have an effect on time-use findings. Time-use data collected at different times of the year will give different results, especially in rural areas where agriculture is a dominant activity, and there are likely to be seasonal differentials in working hours. Linked to this are the type of days covered. In developed countries, Fridays, Saturdays and Sundays have been found to have activity patterns which are different to those for other weekdays. Further factors are the number of days covered per person and the time lapse between the days and when the activity is recorded. Fewer days covered is likely to be more specific, whereas more days will result in a better idea of an average day for the person. However, obtaining information on many days is likely to result in respondent fatigue. Memory lapse is also likely to be a problem if the time between the activity and the recording is too great. If diary-based methods are used a further issue is the length of the timeslots in which activities are recorded. If timeslots are shorter respondent fatigue may result and it is unlikely that respondents will be able to recall this level of detail after a day has lapsed (Budlender, 2006). As Haraldsen (1999) notes, it is easier to remember *what* happened than *when* it happened (emphasis added).

Budlender (2006) notes that many classification systems tend to neglect care work which is more narrowly defined, that is ‘person care’. In some cases it is not explicitly stated, and may be presumed to fall under housework in general, yet if this is not made clear to respondents, it is unlikely to be reported. According to Budlender, the ideal is for care work to be disaggregated into active and passive, and by the type of person receiving care, although the extent to which this can be done is dictated by the method used and the purpose of the particular survey. Moreover, if the focus is on care, not only one but all caregivers must complete the instrument that measures time-use (Van den Berg & Spauwen, 2006). Finally, Charmes (2006) states what appears to be the obvious, but is nevertheless useful as a reminder when collecting time-use data: when obtaining time-use data on care provision, the more detailed and contextualised the activities that are specified, the longer will be the time recorded for these activities.

3.2.5 The South African Time Use Survey and the care economy

In South Africa the central source of data on time-use is the 2000 TUS conducted by Statistics South Africa. The TUS utilised the same activity classification system as that outlined in section 3.2.1 (Budlender, 2008). Apart from this, little research has been undertaken on time spent in unpaid work, and few quantitative South African studies contain any questions on care provision.

The child labour component of the 2006 Labour Force Survey (LFS) contains a few questions on time spent on housework and care of others.

The 2000 TUS consists of a 24-hour open-ended diary with half-hour slots as the main instrument used to record activities. The diary was administered through face-to-face interviews with two people from each of the sampled households, aged ten or over, who had undertaken the activities. The realised sample was 8,564 households and 14,553 respondents (Budlender, 2006; Budlender et al., 2001). One of the focuses of the TUS was on unpaid care work and the survey therefore provides a number of findings on care provision in South Africa.

Results show that men tend to spend longer than women on SNA work, while women spend considerably longer than men on extended SNA work. Men are also more likely than women to do SNA work, while women are more likely than men to do extended SNA work (Budlender, 2008. On average women spend a larger proportion of their day (23 percent) on productive activities than men (19 percent), although they are likely to be paid for less of this time (Budlender et al., 2001, p. 5). Women do eight times as much care work as men, on average, and most of this is undertaken in respondents' own homes (Budlender et al., 2001, p. 44). With regard to non-SNA production activities, Budlender (2008) finds that the majority of men and women undertake some housework, the level of community care is very low for both men and women, and person care is very low for men, but not for women.

Women account for over three-quarters of the volume of unpaid care work. Males do a fairly consistently low amount of unpaid care work, while there is high variability in the amount of this work that women undertake. Moreover, 30 percent of males compared to less than 10 percent of females spent no time on unpaid care work on the previous day. However, two percent of women and a negligible number of males spent longer than 12 hours on unpaid care work (Budlender, 2008, p. 30). Among women, African women spend more time on unpaid care work than women in the other population groups, and among women and men the unemployed spend more time on unpaid care work than other groups. Unpaid care work activities are more likely than SNA work activities to be done simultaneously (Budlender, 2008).

Sienaert (2008), analysing the 2000 TUS, finds that the time costs of looking after children (defined as household residents aged 0 to 14) are substantial. They tend to reduce total household market work and are carried almost entirely by women. Children reduce the market labour supply and increase the non-market labour supply of women such that women's total work time rises with children, on average.

Less than half a percent of males and one percent of females participate in at least one of three adult care activities: physical care of non-child household members, physical care of accompanying adults, care for non-household adults. Yet the average time spent on adult care by these individuals is substantial at 79 minutes per day. However, because of the low participation rates and the low overall averages it is not useful to calculate the average minutes for sub-groups of the population. Of those who provide care for adults, a third are aged 50 and over; half are single; those with children living with them are over-represented by six percentage points when compared with the survey population, suggesting that these carers have a number of care responsibilities; the unemployed represent 13 percent of adult carers but only seven percent of the total survey population; 46 percent are found in rural areas versus only 36 percent of the sampled population. Budlender believes this latter finding could be attributable to the over-representation of older people in rural areas and thus a greater need for care, and also adult children returning 'home' to rural areas to be cared for (Budlender, 2008, p. 26). Only eight percent of adult carers are from the poorest households and 46 percent personally report no cash income (Budlender, 2008, p. 27).

Overall the results show that most people do not report direct care. Almost a third of females but only six percent of males spent some time on person care in the previous 24 hours (Budlender, 2008, p. 18). However, there are some individuals who spend a lot of their time providing care for persons: four percent of females and negligible numbers of males spent six hours or longer on person care in the previous day (Budlender, 2008, p. 31). The amount of time spent on person care is relatively even across the population groups. Unemployed women spend more time caring for persons than other groups but the same is not true for unemployed men. Moreover, across all population groups, females were found to be more likely than males to do some person care and less likely to do paid work. These gender differences relating to person care are more noteworthy for Africans and coloureds than for whites. Further, African women were found to be six times more likely than African men to combine person care and paid work in the same day (Budlender, 2008, p. 19). With regard to person care across settlement types, there are only small differences among women, but among men, levels of this type of work are strikingly lower in deep rural areas than in other areas, signifying that care provision by males is seen as socially unacceptable in these areas.

With regard to income levels, among women it is those in the poorest group who are more likely to report person care than in the other income groups. This could signify that these women are less likely to be able to buy in care provision than those in higher income groups. Women in the poorest households spend longer on person care than those in better-off households. Coloured women spend more time than other women on person care, while African men spend less time than other men. Women in the middle age group bear the main burden of person care. Women in child-plus-adult households spend much longer on person care than those in other types of household, while women living in three-generation households have the next highest expenditure of time (Budlender, 2008).

Budlender (2008) ran a Tobit estimation to establish the key determinants of time spent providing care for persons. She finds that being male, being employed, having one's child under the age of seven living in the household, years of schooling, age and 'age multiplied by the same age' are all significant determinants of time spent on person care. Among the dummy factors, having one's young child co-residing has the strongest effect, and gender has the next strongest effect. Being male and being employed reduces the time spent on person care, while all the other factors increase the time spent.

Apart from providing useful indications of the distribution of unpaid care work, the TUS provides data that "lay the basis for an elaboration of GDP through parallel national accounts" (Budlender et al., 2001, p. 3). However, these findings only give a broad picture of the situation with regard to care provision in South Africa. The TUS is not able to provide information on the activities of a small proportion of the population, or activities whose entire duration is relatively short – such as time periods over which care is provided for dependent people (Budlender, 2008). The survey does not provide enough detailed time-use information on care provision and specific care activities undertaken within the home. The research obtained for this thesis provides this type of information, and contributes towards filling this research gap. It provides detailed information on care activities and in this way sheds light on care provision within the home for a person in need of much care.

3.3 VALUING UNPAID CARE WORK TIME

Jochimsen (2003) describes the 'love' dimension of care as non-commodifiable, non-transactable, and difficult to operationalize and quantify, unlike the 'labour' aspect of caring. Therefore the greater the role of emotional care in non-market work, the less likely it is that market-based estimates will account for its value (Folbre & Nelson, 2000). Likewise, Netten (1996, p. 141) reminds us that it is society's valuation, and not the caregiver's valuation of care time that is applied: "the value that each person puts on his or her time (or money) will be individually determined". It is important to identify levels of satisfaction from time spent caring as this directly impacts upon caregivers' valuation of time spent caring and their motivation to provide care (McDaid, 2001). McDaid (2001) indicates that many approaches to valuing unpaid care work assume that each unit of time has the same value to an individual, yet the value of time spent caring will depend partly on the caregiver's relationship with the person they are caring for prior to the onset of the need for care, their perceptions of the person's needs, and the level of satisfaction from caring. Moreover, within each type of activity each additional unit of time given up will be more costly from the caregiver's perspective (Netten, 1993).

Many caregivers may be retired or not in paid employment prior to caregiving, and they would lose time that they may otherwise have spent on leisure activities and on activities that contribute towards household production, yet the time of these individuals is often overlooked in estimates of costs (McDaid, 2001). The process of imputing market values to 'homemaker output' is based on the presumption of perfect substitutability between home-produced goods and commodities. However, purchased services are "only partial substitutes for personal services in which the identity of the care provider and the continuity of the care relationship matter" (Folbre & Nelson, 2000, p. 129), and that "markets on their own are unlikely to provide the particular volume and quality of 'real' care that society desires for children, the sick, and the elderly" (Folbre & Nelson, 2000, p. 138). Folbre (2006, p. 195) argues that the development of satellite accounts "must emphasize that the market metric can provide only a lower bound estimate of the value of family care – what it would cost society to provide an acceptable substitute".

Clearly it is not possible to fully and adequately value the time spent in unpaid care work. McDaid (2001) calls for a standardization of the methodology for valuing both formal care and unpaid care costs, before any firm conclusions can be drawn from study estimates. Yet the absence of such a standardized methodology does not mean that attempts at valuing unpaid care work should not be made. In this thesis a value is only being placed on some of the labour time spent in unpaid care work by caregivers. No attempt is made to put a value on the psychological, emotional, social and physical cost of unpaid care work.

3.3.1 Approaches to valuing unpaid care work

The unit of measurement in the market is monetary, while for unpaid household activities it is non-market time. Time spent undertaking household activities needs to be given a monetary value in order to have a common unit of measurement between the market and the household, and to make analysis of the interactions between the two possible (Goldschmidt-Clermont, 1982). This is the process of valuing unpaid work. Despite the imperfections of applying value to unpaid work, different methods have been developed to assign a monetary value to this type of work.

A distinction can be made between input- and output-related methods. Output-related methods calculate the value of what is produced. Input-related methods calculate what goes into producing it by imputing value to labour time spent on unpaid care work. An hourly ‘wage’ is assigned to the time spent (Beneria, 1992). Output-related methods are generally believed to be superior to input-related methods because they focus on what is actually produced and not on the means by which a good or service is produced. However, most studies and standard national accounts use the costs of the inputs to production to value household production (Budlender & Brathaug, 2002), mainly because it is easier to impute value to labour time spent in unpaid care work (Beneria, 1992).

According to Beneria, the two methods differ in terms of their usefulness. For example, if a person has to walk longer to fetch water, input-related accounting will show an increase in time input while there is no increase in output. From the perspective of accounting for women’s work, it is important to illustrate that the effort required to fetch the same amount of water has been intensified, even if output has not. In this way an input-related method can be regarded as superior. This could be why Folbre (2006) suggests that “we need better measures of the *inputs* into care, rather than merely capturing some of the *outputs* of care in terms of improved health and education in the Human Development Index” (author’s emphasis). Since an explicit aim of this study is to make visible all aspects of women’s work, particularly those that are frequently invisible, input-related rather than output-related methods are adopted.

Beneria (1992) and Budlender (2002) together define four input-related methods by which the time measurement of unpaid care work can be converted into money measures, and, apart from where otherwise stated, the information cited below is taken from this work. The four methods are presented here in terms of a range of values likely to fluctuate from low to high. Part of the work of this thesis is to choose the most appropriate of the methods for the South African context.

The average earnings method: The average earnings in the economy *as a whole* is estimated and assigned to each hour of unpaid work. The mean is estimated separately for males and females. The average earnings method lowers the overall estimated value of unpaid work, since women generally perform more unpaid work than men, and the average female wage is usually lower than the average male wage.

The opportunity cost method: The normal wage or income from paid work that the person would be doing *if they were employed* is taken as the value of the opportunity cost. Joshi (1992, p. 110) describes how unpaid work caring for others "competes for the time and energy a person might otherwise devote to earning their own cash in paid work". The opportunity cost method generally gives the highest values of all the methods, and gives the widest range of estimates for a particular amount of time spent on care, depending on the skills and the opportunity wage of the individual performing it. This method is based on questionable logic, since a meal produced by a doctor, for example, will be imputed a higher value than an identical meal prepared by an unskilled worker, even though the unskilled worker may be a better cook.

The generalist method: *The mean wage of workers performing similar work to the unpaid work is used*. For instance, for housework the wage of a paid domestic worker could be used, and for care of an ill person, the wage of a nursing assistant could be used. The generalist method usually gives the lowest values of all the methods, since domestic workers are generally at the low end of the wage hierarchy.

The specialist method: This method focuses on *the activity* and not on the person who undertakes the activity. For each activity the wage earned by paid workers, whose functions and circumstances match the unpaid care work undertaken, is used. For instance, time spent on cooking activities could be valued at the wage of a paid chef, while time spent on cleaning activities could be valued at the wage of a paid cleaner. The specialist method generates estimates that are relatively high, and is more indicative of the market value of household production.

Crucially, Jönsson et al. (2006) note that the method chosen to value unpaid work can have a considerable impact on the results, with the results varying widely depending on the method used. Overall, Budlender (2002) notes that the differences between the values from the various approaches will be large where there are substantial inequalities in wages and salaries in the economy, as is the case in South Africa. Moreover, estimating the different values will provide upper and lower bounds on the true market replacement cost of unpaid care provision (Fast & Frederick, 1999, p. 2).

Budlender (2008) points to a helpful distinction between the four input-related methods. The average earnings and opportunity cost methods are useful if the aim is to work out what the caregiver would have earned if she/he were working instead of providing unpaid care. It therefore makes sense to sex disaggregate when using this approach. However, if the aim is to estimate the value of care provision for the cared-for, the focus will be on estimating what the cared-for would have paid to purchase in such care services. In this case the generalist and specialist approaches would be useful and sex disaggregation does not make sense.

Zick and Bryant (1983) referring to a developed country context, note that most of the work on valuing unpaid work has been done using the equivalent of the generalist and the specialist methods. Both methods estimate the price a household would hypothetically pay for services that are usually performed by its members, but there are problems with this approach. Firstly, it excludes the management component of unpaid work. If the household were to hire a market substitute to do the work, someone would have to supervise the person doing the work. Secondly, the fact that households are not observed to be purchasing these services suggests that families perceive that they can peform the task at a lower cost and that market substitutes are not perfect substitutes for this work. Thirdly, most individuals do not work at any one household activity full-time. If higher full-time rather than lower part-time wage rates are used the approach will overstate the value of unpaid work time to the household.

The opportunity cost method is an appropriate method to use if the concern is with the personal financial sacrifices which women make when caring. Moreover in a full employment economy, there is an obvious trade-off for a working aged adult between wage employment and providing unpaid care work, and here costing the value of unpaid care work in terms of the wage foregone is appropriate. However in the South African context this method is problematic since, as highlighted in section 2.5, a large percentage of individuals who are doing unpaid care work are unemployed or not economically active. It could therefore be argued that a person who was previously and is now unemployed should have an opportunity cost of zero. Yet there are unlikely to be no opportunity costs to providing unpaid care work, and instead it is likely that there are opportunity costs to other activities – such as household chores or leisure – rather than to actual employment. Alternately it could be put forward that where there is a high probability of not getting a job, the wage must be discounted appropriately – that is, the wage the person would have earned in a full employment economy should be discounted by the percentage chance of getting work.

There are further challenges involved with applying the opportunity cost method. Firstly, the approach uses the wage that the person would earn if they were working in their paid job, and therefore uses different wages for the same activity when the work is performed by different people. Secondly, for people who are unemployed and therefore do not have a usual wage, and for those working in subsistence agriculture where there is no wage, there is the problem of what wage to use for these groups. A possible solution is as follows: for the unemployed, estimates could be based on level of education and skill level, and for those working in subsistence agriculture an unskilled manual labourer or a farm labourer wage could be used.

Ultimately, all of the input-related methods apply a market wage in their calculations. Zick and Bryant (1983) recommend that only the gross wage should be used in these calculations, and not a wage from which the wage earner’s costs or expenses have been subtracted. However, while this applies to the generalist and specialist methods, where the cost of buying in the care worker’s time is important, it is not relevant to the average earnings and opportunity cost methods, which focus on the wage that is foregone by the family caregiver. Therefore, for the first two methods the gross wage is used, while for the second two methods the net wage is applied.

3.3.2 Valuations of unpaid care work in South Africa

Budlender and Brathaug (2002) and Budlender (2008) using the 2000 TUS take the following steps to arrive at the value of unpaid labour:

- Calculate the number of hours spent by individuals doing unpaid labour in a year;
- Multiply the amounts for individuals by the total relevant population (people aged 10 and older for the TUS);
- Calculate the appropriate wage for certain groups and particular non-SNA productive activities;
- Multiply the number of hours by the appropriate earnings rate calculated;
- Calculate the resultant value of unpaid care work as a percentage of South Africa's GDP for the year 2000 (R887,797 million) (Budlender & Brathaug, 2002, p. 15).

Budlender and Brathaug's (2002) results are shown in Table 3.1 using the four input-related methods for valuation.

Table 3.1: Comparison of results of different valuation approaches estimated by Budlender and Brathaug (2002)

Data	Approach	Time measure	Value (Rm)	% of GDP
LFS	Average earnings	24-hour	440,132	50
LFS	Average earnings	Full minutes	489,617	55
Census	Average earnings	24-hour	285,679	32
LFS	Opportunity cost	24-hour	334,779	38
LFS	Generalist	24-hour	159,705	18
LFS	Generalist	Full minutes	178,372	20
Census	Generalist	24-hour	94,943	11
LFS	Specialist	24-hour	216,467	24

Source: Budlender and Brathaug (2002, p. 21) using 2000 TUS. Time measure refers to methods for calculating time spent on simultaneous activities. The ‘full minutes’ method refers to 30 minutes assigned to each of the two activities that the respondent stated took place per half hour; the ‘24-hour’ method refers to time taken for simultaneous activities per half hour that sum to 24 hours per day (Budlender et al., 2001).

A wide variety of estimates of value added in household production can be seen. Budlender and Brathaug (2002, p. 21) note that “at the most conservative, using Census data, the domestic and care wage and the 24-hour measure, household production would be equal in value to 11 percent of GDP”. This is, however, an underestimate of true value added. On the other hand using the LFS data, economy-wide average earnings and the full minutes measure, household production is equal to 55 percent of GDP.

Budlender (2008) estimates the value of unpaid care work and person care in particular, introducing refinements and using only the average wage and the generalist approach. Budlender (2008, p. 36) finds that, in absolute terms, the value of unpaid care work is estimated at between R97 billion and R270 billion. This comes to between 10.9 percent of GDP when using the median wage of domestic workers, and 30.4 percent of GDP when using the median wage for all employees. The value of person care is estimated at between R12 billion and R33 billion. That is, between 1.4 percent of GDP when using the median wage of domestic workers, and 3.7 percent of GDP when using the median wage for all employees.

Table 3.2: Lowest and highest percentages of the value of related interventions that unpaid care work and person care constitutes

	Lowest – unpaid care work	Highest – unpaid care work	Lowest – person care	Highest – person care
Paid work	19	53	2	7
Formal sector employee earnings	33	91	4	11
Earnings of care workers in paid economy	115	321	15	39
Community & related services	87	242	11	30
Social services expenditure	171	476	22	59

Source: based on Budlender (2008) using 2000 TUS

Similar ranges are cited in table 3.2 with regard to other earnings and other comparable services. For instance, unpaid care work is equivalent to between 19 and 53 percent of the value of paid work, depending on the valuation approach used. Clearly the value of person care and unpaid care work is relatively high when considered as a percentage of these other earnings and services. This is particularly the case for unpaid care work and the earnings of care workers in the paid economy and the two services. Budlender notes that for men, unpaid care work is equivalent to less than a quarter of the value of paid work, while for women the value of unpaid care work is about the same as the value of paid work. She concludes that the amount of unpaid care work and unpaid person care undertaken in the South African economy is substantial.

Finally, Sienaert (2008) places a value on child costs using the Income and Expenditure Survey, the September LFS and the TUS all from 2000. He estimates that child consumption costs about half of an adult's on average, based on children's impact on adult goods spending. As already noted, the time costs of children are substantial and are carried almost entirely by women. Sienaert finds that the adult equivalence of children rises to about one on average, when time costs are taken into account.

4 RESEARCH METHODOLOGY

This chapter details how the 2004 KIDS qualitative study took place, and specifically the care component on which the time-use and financial cost analyses in Chapter 6 are based. Through this description the role of the researcher becomes clear. To begin, the qualitative study undertaken in some of the KIDS research sites is introduced and contextualised through a description of the larger quantitative KIDS.

4.1 THE 2004 KWAZULU-NATAL INCOME DYNAMICS STUDY

In 1993, 1,558 households of all races in 73 sampling points or clusters in KwaZulu-Natal were surveyed as part of the national Project for Statistics on Living Standards and Development (PSLSD), the first nationally representative household survey in South Africa to investigate poverty, inequality and socio-economic dynamics[7] (May, Agüero, Carter, & Timæus, 2007). Although the PSLSD was not designed to be a panel study, a large proportion of these households were resurveyed from March to June 1998 as part of the KIDS. A third survey in these same households was undertaken in the first half of 2004.

Some changes were made to the sample after the 1993 PSLSD. In the 1998 KIDS the 165 white and coloured households were excluded from the sampling frame, mainly because of the low percentages of households from these race groups, and therefore only African and Indian households were interviewed as part of the ongoing panel. In addition, changes had occurred with some of the households: 63 interviewed in 1998 were tracked to new locations, four had disappeared as a result of death and 218 could not be located (May et al., 2007).

---

[7] Three non-white racial categories were used under Apartheid for classifying the population – African, coloured and Indian. Clusters refer to census units, equivalent to a small locality. It is important to note that clusters are not communities *per se*, and that there is differentiation within clusters.

Ninety percent of the interviews for the 2004 KIDS were conducted between March and July 2004 and data collection ended officially in January 2005. Individuals in households who were likely to be key decision makers were termed ‘core’ persons. This concept determines who or what was followed in each of the waves of the study, and as such it is an important feature of the 1998 and the 2004 waves of KIDS. In all, 865 households with core adult members from 760 of the 1,354 eligible households interviewed in 1993 were interviewed as part of the third wave of KIDS (May et al., 2007).

The 2004 study – as the 1998 study – was based on the 1993 household socio-economic questionnaire with some new modules added, including questions on caring. Some modules were expanded or amended, and these included the modules on deaths in the household and on health.

In 2004, as in 1998, the households of the core members of the original panel of households were identified and surveyed. Where core household members now lived apart, the households they had joined or established were followed up as far as this was feasible. The panel was also refreshed by designating the adult children of core household members who had established their own households and now had children of their own ‘next generation’ cores and these households were also surveyed. Core members’ children aged less than 18 who were being cared for by other households were also tracked to increase the longitudinal information on children.

Ethics committees of the three universities involved in the study approved the 2004 fieldwork with regard to issues such as confidentiality, anonymity, the right of refusal and signed informed consent (see Appendix A for ethical approval from the University of KwaZulu-Natal (UKZN)). The relevant local administrative authorities (municipal offices and/or traditional leaders) were approached in advance for permission to work in the survey areas.

The questionnaire and an informed consent form were translated into isiZulu and back-translated into English, to ensure consistency of interpretation, and were administered in the language of the respondent, either in English or in isiZulu.

4.2 THE 2004 KIDS QUALITATIVE STUDY

In 2004 an additional qualitative component was added to the KIDS panel study.

4.2.1 Selection of study sites and households

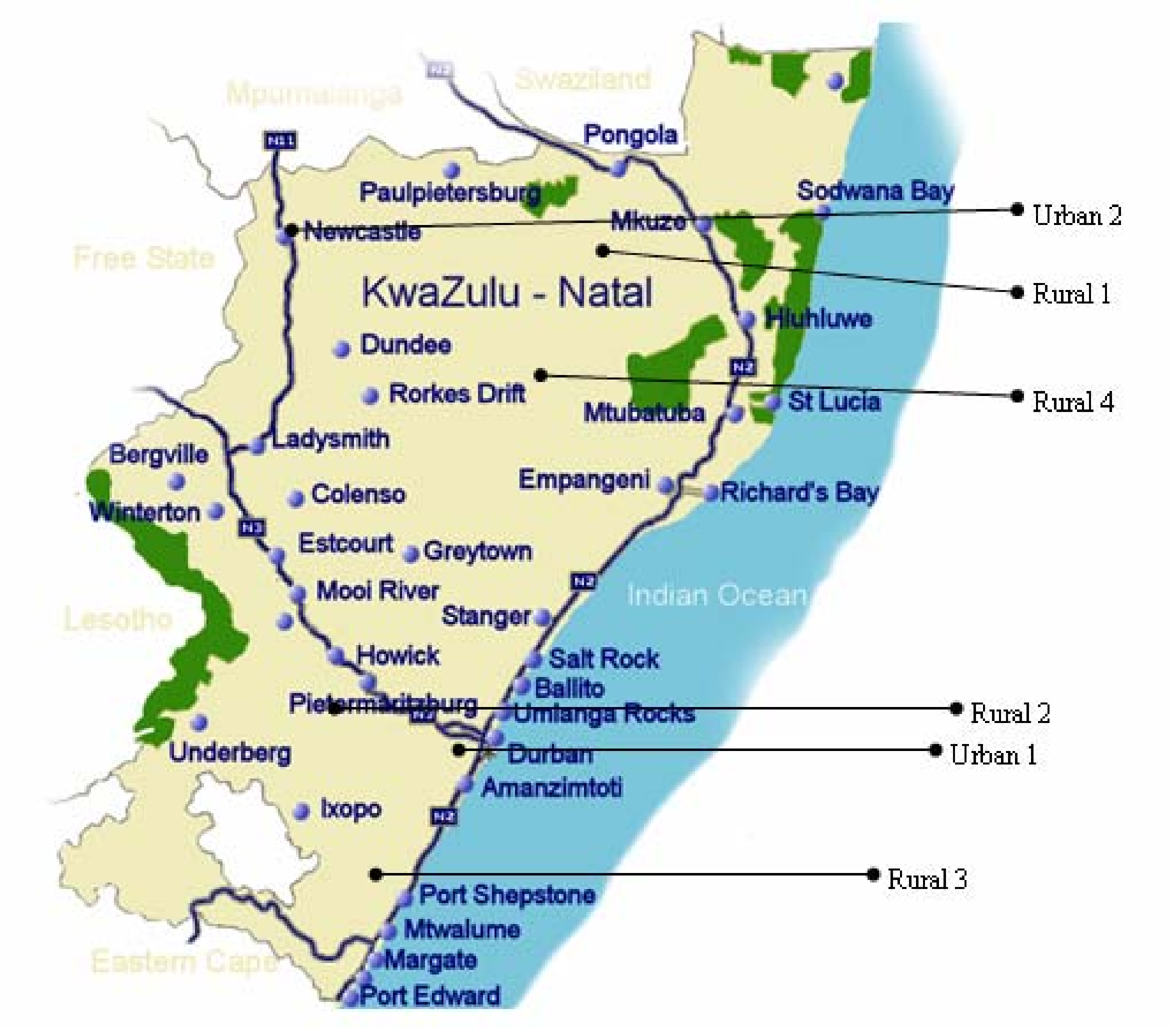
Five research themes formed a part of the 2004 KIDS qualitative study: care, orphans, livelihoods, child support grant and changing household structure.[8]

Thirty-six households across six research sites in KwaZulu-Natal province in South Africa were extensively visited by three field researchers as part of the qualitative component of the 2004 KIDS between June 2004 and March 2005 (see Figure 2). Two urban and four rural KIDS clusters were selected. Rural 1 lies south of Pongola in northern Zululand. Rural 2 is close to Richmond, south of Pietermaritzburg in the midlands region. Rural 3 lies north of Port Shepstone on the south coast. Rural 4 is located close to Ulundi (not shown on the map) in Zululand. Urban 1 lies south of Durban, KwaZulu-Natal's metropolitan area, and Urban 2 lies outside of Newcastle in the battlefields region.

---

[8] The researcher co-managed the qualitative study with Cathy van de Ruit, a PhD student from the University of Pennsylvania, and Dr Michelle Adato from the International Food Policy Research Institute was the research methods advisor on the study. Ms van de Ruit collected data on the changing household structure and livelihoods themes. Dr Adato collected data on the orphans and child support grant themes. The researcher collected data on the child support grant and care themes.

Figure 2: Map of KwaZulu-Natal



Source: http://www.findandstay.co.za/images/Maps/MapKwaZuluNatal.png

Information collected in preparation for the 2004 KIDS was used to select the study sites. The clusters selected were stratified on the following variables: rural/urban; geographical spread within the province; degree and types of activities (mainly presence but also absence) pertaining to the four research themes (described below); if they had been part of another qualitative study linked to KIDS in 2001 (the Socio-Economic Study of the Persistence of Poverty and Inequality (SEPPI)); if they were a part of the Political Economy of Social Capital study, another qualitative study linked to the 2004 KIDS; if the field researchers would be safe from a security standpoint.

Telephone interview information obtained from local leaders in the KIDS clusters was used to provide information on the activities relating to the research themes and field researcher safety. Information could only be obtained on 46 of the 58 African KIDS research sites (Indian KIDS research sites were not included).

Permission to conduct the research was obtained from various local leaders, for the six clusters chosen for the study.

Within each cluster six households were selected in the following way. A mini-survey that collected information on the study themes was conducted in all KIDS households in each cluster (see Appendix B for the mini-survey sections for the care theme). The first criterion was that households be part of the 2004 KIDS, as an aim was to compare qualitative and quantitative data. The second criterion was that households contain a pair of conditions to enable data collection on two of the themes, apart from the 'changing household structure' theme, which was covered in all households.

An attempt was made to select combinations of themes so that in each cluster there were the following household combinations across the six case study households: care and child support grant; care and orphan; care and livelihoods; child support grant and orphan; child support grant and livelihoods; livelihoods and orphan.

After explaining the background and purpose of the study and assuring confidentiality, consent was obtained from the six case study households in each cluster. The 2004 KIDS pre-test found that participants were unwilling to sign the consent form as they feared some type of fraud. Instead, they were willing to give verbal consent after an explanation and after receiving a written information sheet. Both the field manager and the UKZN staff randomly checked that consent had been given. In the 2004 KIDS qualitative study the same approach was adopted with informed consent obtained verbally from participants.

4.2.2 Field researchers[9]

The first field researcher was a male in his fifties, who had had extensive research experience spanning over 25 years. The second was a female in her late twenties. Her previous research experience included in-depth interviewing and focus group discussions. The third field researcher was a female in her forties who undertook the first month of fieldwork in Urban 1, and was then replaced by a male in his forties. He had undertaken qualitative research, mainly interviewing, on various research projects.

The field researchers were all first language isiZulu speakers. All undertook training in ethnographic methodology, on HIV/AIDS and HBC prior to the commencement of the fieldwork.

The initial three field researchers visited all six study sites, sometimes with the researcher, once these had been selected in order to familiarize themselves with the study areas, locate the KIDS households, get to know the community leaders and other key contact people in these locations, and ask permission to conduct the study in these areas, as well as to obtain further information on the research themes in these study sites, and to find a place for the field researcher for that area to live. The field researchers and the researcher also piloted the structured guides for the various themes in early May 2004 in a rural KIDS research site south of Durban. After this time these three field researchers also spent two weeks in each of their two study sites undertaking mini-surveys in each of the KIDS study households.

---

[9] The term 'field researcher' and not 'fieldworker' was chosen to refer to the individuals who undertook the research work in the field. This raises questions about who the researcher was. In this study the writer of this thesis was the researcher but the field researchers undertook more than simply research assistance. They employed the research methodology in the research sites for extended periods of time, with continual guidance from the researcher who was not usually located in the research sites.

4.2.3 Fieldwork

Yin (1984) defines the case study research method as an empirical inquiry that investigates a contemporary phenomenon within its real-life context, using multiple sources of evidence. A modified extended case study method was chosen for the 2004 KIDS qualitative study. The term ‘modified’ was used because the period in the field and the period with each case study household was shorter than is most often the case using an ‘extended case method’. This approach is useful as it embraces engagement as the road to knowledge, and it engages using multiple dialogues which enable it to reach various explanations of empirical phenomena (Burawoy, 1998). The extended case study method was appropriate for this study because it enabled trust to be established between the field researchers and study participants, what field researchers believed to be truthful information to be obtained, and information to be verified, as described in section 4.3.4.

The household was the case study unit, with contextual/relational analysis undertaken with respect to each household. Fairly structured interview guides were used for each research theme. Field researchers were trained in the use of the structured guides prior to the commencement of fieldwork.

Each field researcher lived in two research sites for two one-month periods, and travelled between the two sites at intervals. Field researchers took a few days off in the middle of each month of fieldwork, and returned to their homes. The field researchers found this to be essential time as the fieldwork itself was intense and continuous.

Over the two months in the field, field researchers conducted numerous and repeated visits to the three ‘care’ study households in each research site. Visits were structured around the activities of household members and the information that the field researchers had to collect. Field researchers spent whole days with some households, or undertook a number of shorter visits over many days.

In all, the field researchers were exposed to the study households a great deal over the two months that they lived in each study site.

During these visits, formal and informal interviews and discussions were conducted with different household members. Ethnographic techniques were used, including interviewing and observing and participating in activities related to the topics of the research, both at the household and community level. Specific methods used as part of the study were household trees, household events maps and mini-events maps of illness periods. The purpose of these methods was to build trust and rapport with households, and to observe and learn in a way that is not possible with more rapid research methods.

Household members were identified through a household tree, a method developed by Adato, Lund and Mhlongo (2007) as part of the SEPPI conducted in some KIDS households in 2001. This approach, which took place at the beginning of fieldwork periods, involved drawings of households. The definition of households took into account everyone who contributed to or drew resources away from the household. Household events mapping, a method developed in the same study by the same researchers, involved a combination of interviewing and participatory, visual methods. The aim was to trace events over time, and these methods were intended to stimulate recall and involve different household members in this process. Events mapping of illness periods involved identifying key events in the illness periods, with a specific focus on access to institutional support (Adato, Hunter, & van de Ruit, 2004; Adato, Kadiyala, Roopnaraine, Biermayr-Jenzano, & Norman, 2005).

In addition, the case studies included a time-use component. According to Budlender (2006, p. 52), in a successful time-use study training of fieldworkers is crucial, as well as good backup materials, and “a solid fieldwork supervision and support structure that allows fieldworkers who encounter difficulties or have queries to get rapid responses”. Backup materials refer to detailed instructional and training materials that should be developed for supervisors and interviewers (United Nations, 2005). Every attempt was made to see that the above was in place. In particular, because the stylized questions were administered by field researchers, they needed to have a good understanding of the scope of the prescribed activities, and to be able to communicate this to informants (Budlender, 2006) and answer any questions raised by respondents (United Nations, 2005). As a result, field researcher training received a lot of attention, the structured guides were designed to be inclusive in terms of detail and the researcher was in frequent contact with field researchers to answer any queries posed by respondents and any uncertainties the field researchers had.

Note-taking during interviews and elaboration on fieldnotes after household visits occurred in the field. While the information was obtained in isiZulu, this material was recorded in English. After every month in the field, field researchers spent two weeks in Durban typing up field notes. The researcher read through the study information once it was typed up and asked the field researchers to find additional information that would fill in any gaps when they returned to the study site for the second month. No tape recording was used, therefore quotations included in this thesis are not word-for-word quotes but are based on interview notes. The quotations are as close an approximation of quotes as possible. Quotations or narratives are of the field researchers' account of the statement, and are usually made in the third person.

To the extent that it was possible to meet with key informants in each cluster, key informant interviews were also completed. These were undertaken with two heads of clinics that served two of the rural study areas and with community caregivers in five of the six research sites. In one research site there were no community caregivers.

The interview material has been edited for clarity of reading, but without changing the meaning. All names have been changed for the sake of confidentiality, and all material relating to identity has been placed in secure storage.

As already noted, ethical clearance for the 2004 KIDS was obtained from the UKZN's Research Ethics Committee, and this covered the 2004 KIDS qualitative study as well. Field researchers were given instructions to ask no questions about HIV status because of ethical reasons and because of the stigma associated with HIV/AIDS.

Field researchers were given the option of attending counselling sessions because of the challenging nature of the fieldwork. Specifically, the fact that they were working in relatively poor areas meant that high expectations were placed on field researchers by those living in the study areas. Across study sites the field researchers tended to be regarded as being able to assist local residents. This is illustrated in one of the field researcher's observations:

> ... I am trying to say that even [though] they knew that I am a researcher … they did not want to accept that. I was perceived as a saviour, a social worker, a caregiver … somebody who was there to solve all the people's problems. Unfortunately, I was not that somebody but a data collector and that's all. This was stressful sometimes. It's not that I didn't explain my role but things changed when I lived with them. I think a stranger is more approachable to people with problems. A stranger also brings a sense of hope to the community. (Field researcher, Rural 2 & Rural 4)

Another difficulty for field researchers related to the care component. Here the emotionally taxing nature of the work itself was difficult, and this was also a reason for field researchers to attend counselling sessions.

Finally, a number of grocery packs were given to each study household as an acknowledgement of their time and effort spent participating in the study. Items were chosen with the ill people's nutrition in mind and after a discussion with the field researchers on suitable groceries for these study households.

4.2.4 The issue of dying

There are a number of issues relating to the collection of data for the 2004 KIDS qualitative study that need to be raised. One of these is the issue of dying, which was central to the study because of the focus on caregiving for terminally ill people. Five of the ill people did not get better and died over the fieldwork period. Two ill people died shortly after fieldwork was completed. Adato et al. (2007) also found death to be a permeating theme in their study in KIDS research sites.

The death of ill people over the fieldwork period, and particularly when field researchers were living in these research sites, was especially difficult for field researchers to experience. It was also difficult for field researchers to collect further information from these study households about the care of the person after they had died. Ill people were also interviewed for the study, and two of them died before being interviewed. In some of the cases the 24-hour diary information had not yet been obtained before the ill people died, and it was therefore not possible to obtain this information. Care survey questions seem to have been relatively unaffected by the death of ill people since many of the caregivers had to reflect back in time to remember this information anyway. The difficulty lay in actually obtaining this information from caregivers after the person's death, something that was delayed until some time had passed in order for it to be appropriate to do so.

One of the field researchers died some months after fieldwork had been completed. Post-fieldwork interviews were undertaken with two of the field researchers who undertook research in the rural areas, and additional insight would have been gained into the six urban case studies, and the issue of urban care, if it had been possible to interview this field researcher. In addition, it was not possible to obtain some missing information (including time-use information) because the field researcher died. Had the field researcher not died, this would have meant that there was a comprehensive picture of the study households for the researcher, with no unanswered questions.

4.3 THE 'CARE' COMPONENT OF THE 2004 KIDS QUALITATIVE STUDY

As noted, 'care' was one of the themes adopted in the 2004 KIDS qualitative study. In this section detail specific to this theme will be elaborated upon.

4.3.1 Household selection

As already noted, all KIDS households in each study site were visited before fieldwork commenced and a mini-survey was undertaken in these households. Following Booysen et al. (2003), in the mini-survey the following questions were asked in order to identify care for ill people (see Appendix B):

- During the last 30 days has anyone been frequently or continuously ill?
- Has anyone in this household been bedridden over the last month?
- Is anyone in this household being treated for TB at present?
- Has anyone in this household been admitted to hospital for pneumonia in the past month?

If any of these questions was answered in the affirmative, the following was obtained: the age and sex of the person, whether they were ill because of an injury, and the age, sex and relationship to the ill person of any caregivers who provided care on a regular basis. Only households in which care within the home was taking place and in which the ill person was over 10 and under 60, were eligible for selection. This is because the aim was to increase the likelihood of people with HIV/AIDS being selected, and those with HIV/AIDS tend to fall within this age range. In some cases the field researcher was told why care was required, and therefore what the ill person's condition was. Households in which care was being received for those with chronic, non-HIV related conditions – such as diabetes, arthritis, high blood pressure – were not included. It was not possible to select all care study households through use of the mini-survey and Appendix C details how the remaining care households were selected. This means that only four of the 18 care study households were KIDS households.

It seems likely that a number of the ill people may have been ill with HIV/AIDS since shortly after fieldwork was completed in all clusters, seven of the 17 ill people included in the study had died non-accidentally. Subsequent to this one of the field researchers was told by some of those she knew in the Rural 4 study area that another ill person had died, and that he had made public the fact that he was HIV-positive. It is however also likely that at least some of the people being cared for were not HIV-positive.

4.3.2 Representivity

It should be emphasized that the information collected as part of the care component of the study is not representative of the situation in KwaZulu-Natal. However, the study areas were scattered around the province. Also, where there is consistency across households, there is no reason to believe that care situations would be substantially different in other parts of the province.

While there were only 17 ill people in the study, they cover a range of situations across the 17 cases. There was a mix of rural and urban households and caregivers spanned different ages. There were also a range of problems across the households. For instance, in one household a caregiver looked after two ill people. In another household the caregiver told the field researcher that she was HIV positive and unwell, and she was caring for her AIDS-sick son. However, there was also some consistency across cases. Most caregivers were mothers, and most caregivers did not share the care task with another caregiver. Finally, the study focused on the ill who were chronically ill. This is a stage that people with HIV/AIDS will go through. While it is not possible to get a confident sense of the extent to which an occurrence is widely experienced, the strength of this qualitative information is that it provides in-depth insight into lived experience. This research will aim to suggest ways of generalizing from this lived experience.

4.3.3 Information collected

The structured guide for the care component of the study (see Appendix D) provided a guideline on the information to be collected in each care study household over the two months in each study site.

The main caregiver(s) were identified in each household. As noted, these were the people who lived within the same household as the ill person and who were responsible for the care of the ill person on a day-to-day basis. The main caregivers' biographical information, as well as location and time information relating to the care of the ill person were obtained.

Not all of the information obtained using the care structured guide was used in this thesis. The following information asked of main caregivers was set aside for use in this thesis and is reflected in detail in Chapter 6:

- Education and work history of the main caregiver;
- Survey type questions to obtain time-use information on different types of care and related financial costs associated with care provision;
- Information on financial costs associated with care, as well as further probing and verification of financial cost information.

A mini-events map of the illness period was also completed with the main caregiver(s) in order to obtain information on the ill person's condition and on visits to health facilities over the illness period.

Additional information was collected in order to complete reports for the funders of the study: one report assesses how the government's care policy is working in practice (Hunter, 2005) and another focuses on the perspectives of caregivers on their task of care provision (Hunter, 2007). Some of this information was included in this thesis for descriptive purposes, while the yesterday time diaries were analysed regarding the issue of simultaneous time-use (see section 6.3.6):

- The main caregivers' experience of providing care;
- Caring and how it fits in with the main caregivers' other productive, reproductive and leisure activities;
- Additional support to the ill person/main caregiver(s);
- Training received by the main caregiver(s);

- Yesterday time diary of caring activities for the ill person over the previous 24 hours undertaken as an interview.

Questions were also asked of the ill person and these answers were used to get a sense of care provision from their perspective, which in turn enabled the information provided by main caregivers to be validated to an extent.

In addition, verbal information from interviewees was supplemented by observation. Field researchers were tasked with observing activities and items relating to care provision in a structured fashion. The same observation sheet was filled out in each care household. This observation information was also used to verify some of the information obtained from main caregivers and the ill people.

After completion of the fieldwork in each research site, field researchers were requested to reflect on their time in each study area and type answers to questions relating to the methodology and to their time in each study site.

Finally, once the fieldwork had been completed, and once the researcher had read through all of the typed-up fieldnotes, the researcher interviewed the field researchers on aspects relating to the study. The interviews included any queries that arose from a reading of the study material, requests for missing information that the field researchers may have known the answers to, as well as specific questions relating to the collection of time-use and financial cost information.

4.3.4 The extended case study method

The three field researchers were well placed to give an informed opinion of the extended case study method, each having undertaken a minimum of four months of actual fieldwork in two study areas.

Field researchers were asked specifically how they were able to tell if study participants were telling the truth. All field researchers noted that living in the study areas meant that those living there, and particularly those in the case study households began to trust them through continued interaction. This enabled them to obtain information that they otherwise may not have obtained. This is not to say that the information provided by respondents is not to be otherwise trusted but that it is more likely that this information can be regarded with more certainty if it is collected as part of the extended case study method than with a quicker visit.

> I sometimes think it's good to bring a stranger in the community. A stranger is neutral, and it's somebody that you can trust that they are telling the truth [rather] than getting information from the community people. The community learnt to trust me and then they gave me a true reflection of their life stories. (Field researcher, Rural 2 & Rural 4)

While it cannot be known if it was a 'true reflection' of their lives, living in the study areas represented an improvement – in research terms – over quicker, transitory visits.

> The people tried their best to give the accurate information since they knew that you were living amongst them. If they had lied I am sure they were aware that you [could] go to them to ask about what they must have said that was not true. (Field researcher, Urban 1 & Urban 2)

This narrative points to the fact that it is more likely that truthful information is obtained through an ethnographic method because the interviewees know that this information can be verified by the field researcher who lives in the same area. This is not to say that truthful information would not be obtained through other research methods but that this method brings with it relative certainty on this score. Constant visits to the study households over time opened up the way to verify the information provided by respondents:

> I think the 'time factor' tells that it was not easy for the people to lie. Even though some families [did try] to give wrong information but the fact that I was going to live there for

> about a month, it made things difficult for these people to lie to me. I was able to establish trust with them. I could observe some of the things and be able to tell that they were telling the truth. (Field researcher, Rural 2 & Rural 4)
>
> With ethnography you can't hide issues. You see people day after day. Eventually they start to open up. (Field researcher, Rural 1 & Rural 3)

This research could be regarded by some as extractive. Yet there is a trade-off of obtaining information that may be considered to be private but which may have positive benefits in policy terms. The fact that this information would be used for policy purposes was explained to study participants.

Care information is often personal, and therefore may not be easily shared. A methodology such as the extended case study method – where trust is established through continual interaction – plays an important role in the collection of time-use and financial cost information. One field researcher in particular spoke of the contribution of this method to the collection of care information:

> Getting the information about the ill person is not an easy task. People do not want to talk about it with the [family] they are living with so how can they tell everything to a person who will be there for a day? They can lie on the first day because they might think that you are there for a day. Once they are aware that a person is living (in the community in which they live) they will change their attitude. (Field researcher, Urban 1 & Urban 2)
>
> Since we [had] to deal with people who were sick, especially those who were related to HIV/AIDS, if I was not living in the area we were not going to get the information. It is not easy for a person to open up to a stranger about (their) status. There are [ill people] that could not tell their members about their status but because of the time I spent with them it was easy for them to tell me without [my] asking them. (ibid)

Frequent visits to the households over a period of time meant that it was possible to establish trust between field researchers and interviewees. It also meant that the data collection on these issues could be fitted in between collection of information on other themes and reserved for appropriate times.

> Dealing with the care [structured] guide was a very delicate matter so more time was put into that ... it takes time for the [caregiver] to open up and for the ill to open up … we cannot push them for information. (ibid)

The same field researcher believed that the multiple tools that made up the methodology enabled him to ascertain the truth specifically with regard to the information about care provision:

> [The method enabled me to obtain] the truth about the sick people that I worked with and some honest answers they told me. It was easy for me to go back to the information that I could not believe to confirm it [using] another approach. (ibid)

In all, the fact that the extended case study method brings with it the establishment of trust between field researcher and study participant, and thereby a high likelihood of obtaining honest answers to study questions, is a noteworthy benefit when collecting sensitive and relatively private information on care provision, something which would arguably not be obtained so successfully using another method. Therefore, the extended case study method laid the foundation for the collection of time-use and financial cost information, which are fundamental to this thesis.

4.3.5 Tools used to collect study information

Two different tools were used to count caregivers' time in the study: a care survey and a mini-events map of the illness period. However, the main method of collecting information on time spent caring was stylized questions in the care survey (see 'survey-type questions' in Appendix D). Budlender (2006, p. 10) defines stylized approaches as those "where respondents are given a pre-set list of activities and must state how long they spent (or usually spend) on each over a given period". The care survey consisted of stylized questions on personal care (bathing, dressing, undressing, toileting), preventing wetting/soiling of clothes/linen, giving medication, massaging, applying dressings, helping to drink, helping to eat, buying/preparing special food, helping with movement (e.g. help with getting in/out of bed, walking inside/outside), help with financial matters/paperwork, putting linen on and taking it off the bed, linen and clothes laundry, keeping the person company, keeping an eye on the person, going with/for the person to health or other facilities, obtaining oral/non-oral medication/treatment from health facilities. These questions were based on the 'typology' of care activities developed by Parker and Lawton (1990, as cited in Parker, 1992, p. 10) (see section 2.3). The frequency and duration of these activities was obtained, as well as information on which caregivers helped the ill person with each activity. Reference to a day was to a full 24 hour cycle and reference to a week was a full seven day week, including weekends.

As noted earlier in the thesis, Budlender (2002) indicates that stylized questions do not allow for much flexibility. In order to compensate for the possible exclusion of information through a 'rigidity' in terms of what was asked, field researchers were encouraged to include additional information stated by respondents, and to probe along these lines in order to make up for this methodological weakness. For instance, in the Ngidi care survey the field researcher noted that the estimation of how long it took to give Zinhle medication included time taken to convince her to take the medication. This was not specifically asked for among the stylized questions, and would have been missed if it was not mentioned by the caregiver respondent. In this way such information was recorded, despite the fact that it was not enquired about.

In terms of time measurement, the fact that some care activities occur simultaneously is always of concern. However, most of the activities asked about in this study using stylized questions were activities that tend to occur on their own – such as feeding, bathing or dressing an ill person. A minority of simultaneous activities may in actual fact be simultaneous – for instance, keeping a person company and keeping an eye on the person. However this information was excluded as the information obtained was not reliable (see section 6.2.4). In order to obtain a more detailed understanding of simultaneous activities such as these, the 24-hour diary of caregivers' activities is analysed in section 6.2.5, and this lends insight to the occurrence of simultaneous activities in this study.

The mini-events map of the illness period was the second means of collecting information on the time spent undertaking care activities (see Appendix E). The mini-events map was put together soon after fieldwork had started, since at this point it was considered necessary to collect information on the timeline of illness, in order to be able to understand in context the information collected in the present. The aim was to identify when the following took place and draw this on a large piece of paper with the help of the caregivers: when the person first became ill, any hospital stays, visits to health facilities with and for the ill person, visits from others to the ill person in the home, training received by caregivers, when the person was bedridden and when they were not bedridden.

The central tool used to obtain information about financial costs associated with care provision was a financial costs document which was compiled once the care survey had been completed (see Appendix F). All of the financial costs documented in the care survey and in the mini-events maps (where these had been completed by that time) were listed in the financial costs document by the researcher, and field researchers were then requested to confirm with the caregivers the costs that were stated, and to make any corrections where this was necessary. Respondents were also asked whether there were any additional costs associated with care provision that had not already been stated.

4.3.6 Field researchers' perspectives on the collection of time-use information

Two of the three field researchers reflected on the care survey estimations and on the extent to which they felt certain about these estimations. It was not possible to obtain this information from the third field researcher, as he had died.

The field researcher who worked in Rural 1 spoke of the difficulty respondents experienced in giving answers to questions on the length of time taken for care activities, and the frequency of care activities, as posed in the care survey.

> There was a problem because they didn't record anything. They forgot what they did the previous day … Most can't tell you when they were born. It is a time consuming process. (Field researcher, Rural 1 & Rural 3)
>
> They tried their best but [estimating] the time frames was difficult for almost all [of] these households … It was something that was not in their system. They were not used to it. What they did (caregiving) was part of their duty and they never thought they would have to account for the time they spent. They don't see the relevance of time to illness and care. (ibid)

Respondents did not record or make mental notes on time-related information on an everyday basis. The difficulty was that while they were not focussed on the time taken to undertake their normal day-to-day activities, let alone care-related activities, they were asked to recall this information. The challenge of remembering accurate time-use information comes in addition to the usual trial that recalling information presents to research participants, especially where there is a long time period intervening between an event and the survey (see Eisenhower, Mathiowetz, & Morganstein, 1991). The recall periods in the 2004 KIDS qualitative study ranged from the current time (that is, the period referred to was the current time period) to 390 days (or 13 months) at the most. For five ill people the time period was current, while for four ill people the recall period was 30 days or less. The average recall period for the study was 112 days (or 3.7 months).

The field researcher who worked in Rural 1 also worked in Rural 3. He felt that the estimations made by caregivers in Rural 3 were not exact, rather they were “about speculation”. This field researcher believed that caregivers guessed the answers to questions about time. The field researcher for Rural 2 and Rural 4 also pointed to the difficulty for respondent caregivers in giving time estimations. She hypothesized that this could be because the people who answered the questions were ‘uneducated’ – something that was not stated by the other field researchers, but might well have been thought. With regard to both Rural 2 and Rural 4 the field researcher felt that respondents in all households were exaggerating when they answered the questions, but she emphasized that this was not purposeful, and rather that it was because it was difficult to give time estimates: in other words, because of the nature of the information that was being collected. The problem of overestimation is also referred to in the literature on stylized questions. This field researcher too pointed to the fact that it had something to do with the fact that when the caregivers provided care they did not pay attention to the time it took to do so, and therefore it was not easy to provide these time and frequency estimations:

> I think most of the information is reliable. I think there was a problem with the household when they had to estimate things related to time and the distances. It was difficult for them to estimate. I think they never thought that somebody could ask these kinds of questions. (Field researcher, Rural 2 & Rural 4)

The type of information asked of respondents has to do with numbers, and is not simply descriptive. Most of the respondents do not deal with or reason with information that is numeric, except for money. Therefore it is more difficult for caregivers to answer questions about numbers than descriptive questions. Overall it seems that time-use information – especially time-use that occurred more than 24 hours before – is simply very difficult for respondents to recall, and is therefore referred to as ‘speculation’ and ‘exaggeration’ by field researchers trying to account for respondents’ inability to accurately recall time-use information.

One field researcher felt that sometimes respondents were trying to get across the fact that they were struggling financially. She had the following to say:

> I think the fact that they thought of me as a social worker, it has caused them to make exaggerations on their things related to their lives. I think they wanted … to prove [to me] that they are poor and they need assistance and help urgently. (Field researcher, Rural 2 & Rural 4)

While this field researcher had not introduced herself as a social worker this was a commonly held perception in the areas she worked in. It is not clear to what extent this has impacted upon the financial cost information provided. Neither of the other two field researchers raised this as a concern.

4.3.7 The researcher's role

The researcher worked on both the 2004 KIDS and on the 2004 KIDS qualitative study. The researcher added questions on care provision to the death and health sections of the 2004 KIDS (the analysis of which is presented in section 5.1), and was also responsible for piloting these sections with other members of the KIDS team, and training the KIDS field researchers on these two sections of the questionnaire.

With regard to the 2004 KIDS qualitative study, the researcher planned the care research and devised the care structured guide. She undertook training in ethnographic methodology with the field researchers, trained the field researchers on how to use the care structured guide, was involved in the pilot study, was in telephonic contact with the field researchers for the selection of the care study households and was available to answer questions over the telephone when the field researchers were in the field. The researcher undertook visits to each fieldwork site during the first month of fieldwork to get feedback on the research process thus far and to guide the research, as well as during each field researcher's second month in each study site. The researcher met each of the study households in the four rural study sites between the first and second month in the field. The fieldwork for the urban study sites was undertaken after this time, and the researcher visited these sites to meet with the field researcher, getting feedback from him and guiding him on the research process, and to deliver groceries for the study households.

Detailed time-use information on care activities within the home for ill and dying people has not previously been collected in the South African context. The same is true of the detailed information on the financial costs of HBC provision. Therefore there was an element of the unknown in the research process. A central part of the epistemology of the thesis, and one of the researcher's most important roles, was to find a way to appropriately and accurately collect and then count this time-use and financial cost information.

The researcher drafted the questions used to collect this information and guided the field researchers in how to go about obtaining it. In an earlier section it was noted that field researchers indicated that respondents used 'guesswork' with regard to the time-use information they were asked about. The researcher's role was to moderate the guesswork through her involvement in the data collection. In addition, the researcher's role was to find a way to best count this research information, once obtained. This process was deductive. The guiding principle was to err on the side of caution in terms of what information was counted and what information was not counted. Ultimately, using her mind to 'get on top of' these issues was the researcher's most important role, and this will be reflected throughout this thesis.

5 RESULTS – DESCRIPTIVE ANALYSIS

In order to contextualize the study findings that follow in Chapter 6, basic descriptive findings on caregivers, cared-for and care situations are presented from an analysis of both the 2004 KIDS and the 2004 KIDS qualitative study.

5.1 PROFILE OF UNPAID CARE PROVISION IN AFRICAN HOUSEHOLDS USING THE 2004 KIDS

In this section the ‘health’ and ‘death’ sections of the 2004 KIDS quantitative data are analysed. An assessment of these data provides a broad background on care provision by family caregivers in the context of ill health and death within the home in African households in KwaZulu-Natal. While qualitative data gives insight into lived experience it is not possible to generalize from these findings, something which quantitative data should allow for because of larger sample sizes. In this way an analysis of the 2004 KIDS supplements the findings from the qualitative study in this thesis. As noted in Chapter 2, there is very little research on HBC provided by family caregivers in South Africa, and an analysis of these quantitative data will also serve to add to this body of information. However, these data do not provide information on variation over time in illness and care, nor detailed information about caring activities, something which the qualitative data provide.

Two sections of the 2004 KIDS focussed on the care of members of KIDS households between 1998 and 2004, one on the dying (‘death’), the other on the injured or ill (‘health’) (see Appendix G for the roster and these sections of the questionnaire). In the ‘health’ section respondents were asked if any resident household member had been sick or injured during the last 15 days. It was emphasized that this included both people who had recovered and those with some type of permanent injury, disability or illness. Interviewers were given a list of illnesses to prompt from. This list excludes HIV/AIDS, but people with HIV/AIDS could have one or more of the stated illnesses. There is therefore no information from the 2004 KIDS that indicates whether these dead and ill people were HIV-positive or not.

The combined roster for 1993, 1998 and 2004 was merged with the ‘health’ and ‘death’ sections of the 2004 KIDS dataset and a number of restrictions applied. Firstly, only those ill or dying people who were unwell not as a result of an injury were included. In all, 84.9 percent of the 549 who died between 1998 and 2004 died not because of an injury, and 95.2 percent of the 768 ill household members were unwell for non-injury related reasons. Further, only those cases in which the individual was over 10 and under 60 were selected, as with the ill people selected for the qualitative study. This means that this analysis excludes elderly care provision as well as care for the very young, but instead focuses on the care of those in age groups more likely to be affected by HIV/AIDS. Finally, as with the 2004 KIDS qualitative study, the sample was restricted to African households only, with results for Indian households excluded. These restrictions mean that this analysis will provide some characteristics of ill people and their caregivers that can be generalised to the qualitative study. When the selection specified above is applied the dataset consists of 253 people who died in 203 households, and 422 people in 344 households who were sick in the last 15 days.

Respondents were asked if there was a household member whose usual activities were most limited by caring for the ill person. This is taken to be the first definition of caring and these caregivers are referred to as ‘day-to-day caregivers’. With regard to day-to-day caregiving, valid person codes were given for 122 of the 253 people who died (48.2 percent), and for 218 of the 422 ill people (51.7 percent).

Respondents were also asked if there was a household member who took time off work or school to care for the ill person during the illness. This is taken to be the second definition of caring. These caregivers are referred to as ‘occasional caregivers’. The same person can be a ‘day-to-day caregiver’ as well as an ‘occasional caregiver’, and this was the case in seven of the households, in which the ill people died. A valid person code was given for an occasional caregiver for 39 of the 253 people (15.4 percent) who died, and for 56 of the 422 ill people (13.3 percent).

In some households there was more than one caregiver and in some cases one caregiver cared for more than one ill person in a household.

5.1.1 Care situations

This section highlights the various care situations within the selected KIDS study households. In 108 households 129 dying people received care over the period 1998 to 2004. In half of these households day-to-day care only was provided by one caregiver, while in the other half both day-to-day and occasional care were given. In these households care was received for between one and three people, although all of this care was not necessarily given at the same time within households. In almost all (85 percent) households only one dying person received care, while in a tenth of households two, and in five percent of households three dying people received care.

In 195 households day-to-day care or occasional care or a combination of both was undertaken for 222 ill people. In two-thirds of these households the caregiver provided day-to-day care only. Between one and three people received care in these households over the period 1998 to 2004. In the bulk (85 percent) of households care was provided for one ill person only. In almost all of these households (95 percent) only one caregiver was providing care to the ill person. In 13 percent of households care was provided for two ill people, and in three of the households care was provided for three ill people.

In seven households care was provided in the same household to both ill people who did not die and to those who died. The care provided to different household members did not necessarily happen at the same time: it could be weeks, months or years apart. Nevertheless, in two households only one caregiver provided care to between two and three ill and dying household members over the time period. In five households between two and three caregivers provided care to between two and four ill and dying people. These care situations indicate the magnitude of care provision within some households. Ideally households such as these should be the focus of in-depth case studies in order to understand the specific burdens experienced by caregivers and households in providing care within the home.

5.1.2 Characteristics of cared-for

The datasets on the ill and dying who received care were combined for the analysis of the cared-for and caregivers. Of the 358 ill or dying people receiving care, substantially less were male (40 percent) than female (60 percent), which could be explained by the fact that HIV prevalence is higher among females than males in South Africa (Day & Gray, 2007, p. 252). Sienaert (2008, p. 212) also using the 2004 KIDS describes some characteristics of a cohort of individuals, 79 percent of whom were likely to have died of AIDS. Interestingly 44 percent of these individuals are male, very similar to the sex breakdown of the ill or dying people receiving care profiled here.

While an age limit was imposed which influences the findings on age, Table 5.1 shows that two-thirds of males and three-quarters of females cluster between 11 and 39. The average age is 32 years, with very little difference across the sexes. The average age in Sienaert’s (2008, p. 212) cohort was also 32 years. Less of those aged 40 to 59 are male (25.6 percent) than female (35.6 percent).

Table 5.1: Age distribution of cared-for (percentage, n=224)

Age	Male	Female	Male & female
11-19	21.8	23.3	22.8
20-29	24.4	21.9	22.8
30-39	28.2	19.2	22.3
40-49	14.1	19.2	17.4
50-59	11.5	16.4	14.7
Average	31.3	32.7	32.2

With regard to the relationship of the cared-for to the household head, Table 5.2 shows that over half of those receiving care are the son or daughter or the son- or daughter-in-law of the head. This can be compared to 62 percent of Sienaert's (2008, p. 212) cohort. In a non-HIV/AIDS context more of the cared-for would be elderly. Over a fifth could be assumed to be of the same generation as the head: either the resident or absent head (the person designated by the respondent as the household head who does not meet the residency criteria of a minimum of 15 days in the last year) or the wife/husband/partner of the head or a brother or sister of the head or a brother- or sister-in-law of the head, although this is the case for more males (22 percent) than females (19 percent). A further 16 percent are the grandchild of the head, although more are female than male.

Table 5.2: Relationship to household head of cared-for (percentage, n=358)

Relationship to household head	Male	Female	Male & female
Resident head	12.0	3.2	6.7
Absent head	4.2	0.0	1.7
Wife/husband/partner of head	0.0	11.1	6.7
Brother/sister of head	3.5	2.8	3.1
Brother-/sister-in-law of head	2.1	1.4	1.7
Son/daughter of head	50.7	51.4	51.1
Son-/daughter-in-law of head	4.2	3.2	3.6
Nephew or niece of head	1.4	0.5	0.8
Grandchild of head	9.9	19.4	15.6
Other relative	4.9	4.6	4.7
Other non-relative	7.0	2.3	4.2
	100.0	100.0	100.0

Note: percentages in this and the tables that follow do not always precisely add up to 100 percent due to rounding

Table 5.3 shows that over three-quarters of those receiving care had some primary or secondary education as their highest level of qualification. There are no great sex differences although it is surprising that more males than females have no education or grade 0, and more females than males have a post-school degree or diploma.

Table 5.3: Highest level of education of cared-for (percentage, n=338)

Highest Education	Male	Female	Male & female
No education/grade 0	7.5	4.9	5.9
Primary/secondary/failed matric	76.9	80.5	79.0
Matric with/without exemption	13.4	10.8	11.8
Post-school degree/diploma	1.5	2.5	2.1
Other	0.7	1.5	1.2
	100.0	100.0	100.0

The main activity of those being cared for was not obtained for those who had died, hence the smaller sample size. Table 5.4 illustrates that the unemployed constitute two-fifths of the cared-for across types of care. This compares with 43 percent of those who are likely to have died of AIDS (Sienaert, 2008, p. 212). Surprisingly, slightly more males than females are unemployed. It is likely that a number of those who are receiving care had to leave their work because they were no longer well enough to work. Further, a quarter of those receiving care were in formal education (school, university or college) (10 percent of Sienaert's cohort) while 18 percent were employed in some way (41 percent of Sienaert's cohort) (ibid). More males than females were employed in regular or casual employment, while more females than males were in self-employment. Smaller percentages were retired or receiving a pension or undertaking housework or child rearing.

Table 5.4: Main activity of cared-for (percentage, n=224)

Main activity	Male	Female	Male & female
Attending formal education	24.4	25.3	25.0
Retired/pensioner	6.4	6.8	6.7
Unemployed	44.9	38.4	40.6
Housework/child rearing	0	8.9	5.8
EMPLOYED	21.9	16.4	18.3
Regular	10.3	4.1	6.3
Casual	10.3	7.5	8.5
Self	1.3	4.8	3.6
Other	2.6	4.1	3.6

Illness periods were stated for those who were cared for. Respondents were asked for how long before dying the cared-for person was too sick or injured to do what he or she usually did. This would seem to be the period over which intensity of care provision would have been the greatest. Table 5.5 shows that those who died and received care were ill before dying for almost a year on average – remarkably similar to Steinberg et al.'s (2002) finding. This is a considerable length of time. Almost a third (30 percent) were ill for three months or less, while over half (50 percent) were ill for six months or less. It is not possible to tell which of the ill people were household members before they became ill, and therefore it is not possible to know more about illness-associated migration. All that is known is that only nine of the ill people did not live in the household for 15 or more days in the last year.

Table 5.5: Illness periods of cared-for who died (percentage, n=129)

Illness period (months)	Male	Female	Male & female
One	7.9	9.1	8.5
Two	7.9	10.6	9.3
Three	7.9	16.7	12.4
Four	3.2	4.5	3.9
Five	7.9	6.1	7.0
Six	7.9	13.6	10.9
7 to 12	25.5	24.2	24.8
13 to 24	25.5	6.0	15.5
25 +	6.4	9.0	7.8
Mean	13.0	10.4	11.7

As Table 5.6 shows, the average number of months that the cared-for who did not die were not able to perform their normal activities was 12.5. This high number is surprising, and appears to be attributable to a few outliers on the high end. However, in all, two-thirds of ill people receiving care within homes were ill for a week or under. The remainder were ill for much longer periods of time. Over a tenth were ill for between a month and six months, while a tenth were ill for over six months.

Table 5.6: Illness periods of cared-for who were ill (percentage, n=358)

Illness period	Male	Female	Male & female
0 days	58.5	43.1	49.2
1 – 7 days	17.5	16.2	16.8
8 – 14 days	4.2	7.5	6.1
15 – 30 days	1.4	4.2	3.1
1>6 months	9.8	14.1	12.3
6+ months	8.4	15.2	12.6
Mean (months)	10.1	6.5	12.5

Striking in this section are the similarities between findings from the cohort of individuals likely to have died of AIDS in the KIDS, and the cared-for profiled here, leading to the conclusion that a fair portion of the cared-for were ill were likely to have been ill with HIV/AIDS.

5.1.3 Characteristics of caregivers

Across households and types of care the large majority of caregivers of ill and dying people (85 percent) were female (n=327). That is, in line with experience elsewhere, care is assumed by females over males in the majority of cases.

Table 5.7 details the age distribution of all types of caregivers. The average age of caregivers was 46 years, with male caregivers older than female caregivers on average. A noteworthy portion of caregivers were older, with 44 percent aged 50 and over. A further third were aged between 30 and 49. The youngest caregiver was eight, while the oldest was 85 – respectively extremely young and old to be undertaking caregiving.

Table 5.7: Age distribution of caregivers (percentage, n=314)

Age	Male	Female	Male & female
>20	4.7	9.7	7.6
20-29	11.7	20.4	16.9
30-39	16.4	13.4	14.6
40-49	19.5	14.5	16.6
50-59	22.7	21.0	21.7
60+	25.0	21.0	22.6
Average	48.0	43.7	45.5
Range	15-79	8-85	8-85

With regard to the relationship of the caregiver to the household head (see Table 5.8), what is striking is that over a quarter of caregivers were wives, husbands or partners of the head, although this was the case for more male than female caregivers. If the categories that are roughly the same generation as the household head are combined (namely, resident head; absent head; wife/husband/partner of head; brother/sister of head; brother-/sister-in-law of head), this constitutes half (49 percent) of all caregivers for the ill and dying. Almost a third (31 percent) were sons or daughters or sons- or daughters-in-law of the head, and this was the case for more female than male caregivers.

Table 5.8: Relationship of caregivers to household head (percentage, n=327)

Relationship to household head	Male	Female	Male & female
Father or mother of head	1.5	1.0	1.2
Father- or mother-in-law of head	0.7	0.0	0.3
Resident head	14.2	17.6	16.2
Absent head	0.0	1.6	0.9
Wife/husband/partner of head	37.3	22.8	28.7
Brother/sister of head	2.2	2.6	2.4
Brother-/sister-in-law of head	0.7	1.6	1.2
Son/daughter of head	22.4	26.9	25.1
Son-/daughter-in-law of head	6.7	5.7	6.1
Grandchild of head	6.0	13.0	10.1
Great-grandchild of head	0.0	0.5	0.3
Other relative	3.7	4.1	4.0
Other non-relative	4.5	2.1	3.1
Household help	0.0	0.5	0.3
	100.0	100.0	100.0

Table 5.9 shows that this sample of carers was not very educated – three-quarters have some primary or secondary school education (slightly more females than males), while over a tenth of all types of caregivers had no education. This is not surprising when the high average age of most caregivers is taken into consideration. Only slightly less than a tenth had either a matric or a post-school qualification. Overall there were no noteworthy sex differences with regard to education.

Table 5.9: Highest education level of caregivers (percentage, n=320)

Highest Level of Education	Male	Female	Total
No education/grade 0	14.5	13.2	13.8
Primary/secondary/failed matric	73.3	76.2	75.0
Matric with/without exemption	8.4	7.9	8.1
Post-school degree/diploma	3.8	2.6	3.1
	100.0	100.0	100.0

In terms of their main activity, Table 5.10 indicates that over half of the caregivers were either unemployed or retired/pensioners. Most of the caregivers were therefore neither easily employable (because of low levels of education), nor employed. However, the fact that they were not employed could be the reason for their, and not someone else, taking on the caregiving role for ill people within their homes. These caregivers were defined as either having their usual activities limited by caregiving or they took time off work or school to care for the person. Therefore the paid and/or unpaid activities of caregivers in the study would have been curtailed because of caregiving. About a quarter were employed in some way, while a tenth were in formal education (more females than males) and a further tenth were involved in housework and/or child rearing as their main activity. Interestingly, with regard to the latter, more males than females were undertaking this traditionally female activity.

Table 5.10: Main activity of caregivers (percentage, n=313)

Main activity	Male	Female	Total
Attending formal education	4.8	12.8	9.6
Retired/pensioner	23.0	22.5	22.7
Unemployed	31.0	28.3	29.4
Housework/child rearing	11.9	10.2	10.9
EMPLOYED	**25.4**	**25.1**	**25.2**
Regular	8.7	8.0	8.3
Casual	10.3	10.2	10.2
Self	6.3	7.0	6.7
Other	4.0	1.1	2.2

5.2 PROFILE OF THE 2004 KIDS QUALITATIVE STUDY ‘CARE’ HOUSEHOLDS

As a result of purposive sampling, in the qualitative study three of the households in each of the six research sites contained an adult who was ill and being cared for by at least one household member. Field researchers were asked to identify the main caregivers in each household, and these individuals provided information on care provision. A main caregiver was defined as the person who lived in the same household as the ill person and was responsible for his/her day-to-day care.

Across the study sites, in 18 households 21 main caregivers were undertaking care for 19 people. However, in the Ntini household the caregiver, Sanile, died over the fieldwork period before the time-use and financial cost information had been obtained.[10] In addition, the information relating to the care of Bongiwe in the Xaba household was felt to be unreliable. Therefore these two cases were excluded, and this thesis draws on the cases of 17 ill people in 16 households being cared for by 19 main caregivers. Only three of the 16 households were KIDS households, and therefore panel study analysis of these households did not make sense. Some of the descriptive information that follows in this section is drawn from Hunter (2005) and Hunter (2007).

5.2.1 Care situations

The purpose of this section is to give a sense of the reality of care and to provide a flavour of the care situations, demographics and income among study households, as a backdrop to the estimations in Chapter 6. The 19 main caregivers ranged in age from 16 to 72 and 18 were female. In eight of the households there were additional household members, both male and female, who provided some care to the ill person, and who ranged in age from six to 75. The 17

---

[10] For the sake of confidentiality all names have been changed and all material relating to identity has been placed in secure storage.

cared-for ranged from 23 to 51. Table 5.11 shows the number of caregivers and recipients across age categories.

Table 5.11: Demographic characteristics of caregivers and care recipients

Characteristic	Number of caregivers	Number of care recipients
Male	1	10
Female	18	7
<20	1	0
20-29	2	6
30-39	2	7
40-49	3	3
50-59	5	1
60-69	5	0
70+	1	0

The qualitative study focuses on care for people who are receiving much care, but it is important to remember that this is relative – amounts and types of care differ vastly across households, just as the conditions of ill people differ. In one household, an ill person may be bedridden and entirely dependent on caregivers for all their care needs (e.g. the Ndaba household), while another ill person may be going to health facilities on their own to obtain medication and receiving no personal care (e.g. the Shibe household).

It should also not be assumed that caregivers are themselves healthy. Thandazile Dladla indicated that she was HIV-positive and could not always care properly for her ill son, Bulelani. As noted, Sanile Ntini had been sick and died while fieldwork was underway, a few months before Daniel, her ill son, died. Eunice Shibe, already a mother to five young children and caring for her ill husband, was pregnant, undoubtedly experiencing some of the symptoms of pregnancy such as extreme tiredness, nausea etc. In a number of cases caregivers were elderly and themselves not physically strong.

In most households only one ill person was receiving care from a family caregiver, but in some more than one person was receiving care. For a certain time in the Ngidi household there were two people needing care: the mother of the caregiver, 36, and the caregiver's aunt, Siyanda, 25. Not only did Thenjiwe the caregiver have to divide her time between care for her aunt and her mother, but her child of one year and her aunt's child also needed her attention, and this on a 24-hour basis. In the Sibiyo household, apart from the ill person, his niece was also being cared for. Nonkululeko was severely disabled – she could not talk and could not walk without assistance – and her grandmother, Miriam, was receiving a Care Dependency Grant on her behalf. When the ill person started to require much care, Miriam hired someone to look after Nonkululeko and to help with the domestic chores. Apparently the grant was used to pay this non-household member for her work. It seems the amount of care required was too great for household members alone to provide.

Other households with multiple care needs include the Madondo household in which the caregiver's husband was not well; the Dladla household in which the caregiver's elderly mother had had a stroke; the Cibane household in which the ill person's HIV-positive daughter needed additional care. In many of the households there were children and this care also had to be fitted in between child care provision. Apart from the Cibane household, four ill people had children who lived with them. What care provision do these children receive and from whom? In the Mbongeni household the ill person's daughter is looked after by her grandmother. The case of the Ngidi household has already been mentioned. In the Shibe household the ill person's children are cared for by their mother, the main caregiver. Quite clearly the ill persons' care needs add to the existing and multiple care needs in these households.

In three households the caring tasks were shared by two caregivers. In each of these cases the dynamics of caring that results from the presence of more than one caregiver and how caring tasks were shared is described. In the Luthuli household Mbeje's mother and nephew cared for him. The caring tasks themselves were not shared, but instead tasks were divided up between the two caregivers, and these seemed to fall along gendered lines. For instance, readying bath water, preparing food, doing laundry were all undertaken by Mbeje's mother. Taking him to health facilities, keeping him company, helping him walk outside, boiling traditional medication and taking it to him, walking him to the toilet and back, emptying his toileting bucket into the toilet were all undertaken by Mbeje's nephew. No conflict was noted between the two caregivers.

In the Sibiyo household Mzwandile's mother, Miriam, and sister, Siphokazi, cared for him. Here too there was no conflict between caregivers. From their comments it seems that having more than one caregiver is beneficial to the extent that the two are able to support each other. As in the Luthuli household the caregivers each did different care tasks for the ill person, but here the tasks seemed to be allocated along the lines of skill level and in line with the relationship of the caregiver and the ill person. Siphokazi was a nursing assistant, and therefore had certain skills in care provision already. Some tasks seem appropriate for a sister to do but not for a mother to do. These caregivers seem have decided on which tasks each will do, and they seem to share the workload well. For instance, Siphokazi baths her brother, then Miriam rubs his body with ointment. Miriam gives him his medicine in the morning while Siphokazi gives him his medicine in the afternoon. Miriam keeps him company during the day, while Siphokazi checks on him at night. Siphokazi is the only person who cleans Mzwandile when he is incontinent, and this creates difficulties when he messes himself and Siphokazi is not around.

Finally, in the Mngadi household, Thembi, the ill person, was initially cared for by her daughter, Zodwa, and then her cousin, Gladys, moved from Johannesburg to Urban 2 to assist in care provision. Unlike in the other two households, here most of the care tasks are shared between the two caregivers. Together Zodwa and Gladys rub/massage Thembi, help her to eat and drink, help her to get in and out of bed and turn/move her in bed, take linen off and put it on the bed, wash Thembi's laundry, accompany her to the private doctor, traditional healer and hospital. Separately Zodwa goes to the pharmacy to get medication for her mother, while Gladys goes to the traditional healer to do the same. Interestingly Zodwa undertakes personal care tasks alone: she baths, dresses, helps with toileting and gives medication to her mother. Also unlike in the other two households, there is conflict between the two caregivers. At first Zodwa did not want Gladys to care for her mother. Gladys indicates that Zodwa is not always co-operative with regard to the care that needs to be given to Thembi and that she does not always communicate with Gladys. It is not possible to draw any conclusions from these few care situations about shared caring, nevertheless they provide insight into situations where there is more than one caregiver for an ill person within the home.

In terms of care provision by children, in three households the children were too young to provide care and in a further two households information was not provided on this issue. Of the remaining 13 households, in four the children did not provide any assistance or care provision. In the eight households in which they did, the following tasks were undertaken: often children were sent to the shops to buy odd items for the ill person (e.g. cigarettes, Coca Cola); also frequently mentioned were children being sent to fetch something and bring it to the ill person (e.g. water or food).

As already outlined, in the Ngidi household, Thenjiwe, a child of 16, cares for her mother, her aunt, her child and her aunt's child. The demands placed on this young girl are extreme, and of deep concern on a number of levels. Apart from Thenjiwe only one child undertook personal care for an ill person. In the Mbongeni household the ill person's daughter rubbed and massaged her mother. Therefore in the five households in which the ill person had children of his/her own, in only two cases did these (or any other) children assist with actual care provision, seeming to indicate that caregiving remains the domain of the main caregivers who are nearly always adult. In some households children did other household tasks (for instance, cooking, cleaning, fetching water) which was likely to free up caregivers to care for the ill people. In the Shibe household the children were sent to sell vetkoek that their mother had made because she could not do so.

In only six of the households did the ill person move from an urban to a rural or less urban area in order to receive care. One ill female moved with her daughter caregiver from a metropolitan area to an urban area a few hours away where she received care from her cousin in addition. In five cases the person was a male, and in all instances the person was working before their return. In most cases these households are losing income received before. In four of the five cases the ill male was cared for by his mother – two mothers are in their fifties and two in their sixties. The ill person's return did not result in care for more than one ill adult in these households.

Table 5.12 shows the known income to households, and where employment income is not known the type of regular or irregular employment is stated in order to get some idea of the additional type of earnings to study households. While it would be ideal to calculate these financial costs as a proportion of household income, this is not possible for all households as total household income is in many cases unknown. This was information that not all respondents were willing to supply, hence the gaps in information.

Table 5.12: Grant and remittance income to households (Rands), and employment within households

Household	OAP/ DG/ CDG	FCG	CSG	Remit tance	Regular employment	Irregular employment
Yengwa	740	-	170	-	-	Traditional healer
Sibiyo	2,220	-	-	-	-	Nursing assistant
Khubona	740	-	-	-	-	-
Luthuli	740	500	340	-	Factory door maker	-
Mfeka	740	-	170	-	Welder; community health worker; factory worker	-
Mncube	740	-	-	-	Security guard	Informal food seller
Thwala	740	-	340	-	-	Cultivation work
Cibane	-	-	170	-	-	Cultivation work
Mngadi	-	-	340	-	Factory worker; vegetable weigher	Traditional healer
Mbongeni	740	-	-	1,800	Teacher	-
Ngidi	-	-	-	-	500	-
Ndaba	1,480	-	-	-	-	Selling wattle logs
Madondo	1,480	-	-	-	-	-
Shibe	-	-	340	-	-	Informal food seller
Tembe	740	-	170	-	-	-
Dladla	740	-	170	-	-	-

Note: DG=disability grant, CDG=care dependency grant, CSG=child support grant, FCG=foster care grant, OAP=old age pension

What is striking is the reliance on grant income among study households that receive no other income source, and also the fact that grant income is received in virtually all study households. In most households at least one ‘large’ grant (such as the old age pension or the disability grant) is received, in many households one or two child support grants are received, and in some both. It is however important to remember that the size of grant income is always overestimated relative to income from other sources, as it is widely known and it is a regular amount, compared to the income from informal economy and agricultural activities and remittances which tends to be understated because it is usually varied, inconsistent and unreliable (Ardington & Lund, 1996; Lund, 1999).

Finally, it is useful to reflect on the findings from the 2004 KIDS on access to health services among the cared-for. The only assistance from formal caregivers is received outside of the home, with ill people and their caregivers visiting public and private doctors, nurses and traditional healers, often at great financial cost. Although in some cases hospitals fill a gap in provision, this response is *ad hoc* and not substantial. These family caregivers are in most cases not linked to HBC organizations, usually because such programmes are present in few communities, relative to the extent of need. A considerable number of households in which care is taking place receive no visit from community caregivers, who are present in most communities and most of whom have been trained in aspects of care provision. When visits are received, these occur extremely infrequently, and a definite problem is that there are not enough community caregivers to visit households in need.

The 2004 KIDS also contains information on access to health services. Table 5.13 shows that for almost three-quarters of those who died and for almost half of the ill, a public health facility was the last person or service they consulted. For two-thirds of those who died this facility was a public hospital, a finding which echoes Booysen et al.'s (2003). Moreover, relatively few of those who died (16 percent), and a third of the ill, accessed private health care, mainly private doctors. Case, Menendez and Ardington (2005) find similarly that 88 percent of adults in their study in rural KwaZulu-Natal sought treatment from a public clinic or public doctor prior to death, and 97 percent had some contact with a public clinic or a private doctor. Further, in households in KwaZulu-Natal relatives and friends play a greater role in HCBC than community caregivers. Overall, care provision from community caregivers was small (14 percent for the dying, seven percent for the ill), while almost half of the dying and a quarter of the ill received care from a friend, a family member or a neighbour from outside of the household.

Table 5.13: Last person cared-for consulted

Person last consulted	Person died (n=246)	Person did not die (n=417)
PUBLIC HEALTH FACILITY	71.5	46.7
Government/public hospital	63.8	21.8
Community health centre /government/mobile clinic	7.7	24.9
PRIVATE HEALTH CARE	15.5	33.6
Private doctor	9.8	25.7
Private clinic/hospital	3.3	0.2
Traditional healer	2.4	5.3
Pharmacy	0	2.4
OTHER	1.2	1.9
Visit from HBC programme person	0.4	0
Visit from primary health worker	0.4	0.5
Workplace clinic	0.4	1.4
NO-ONE	11.8	17.7

5.2.2 Gendered care provision

It is women who take prime responsibility for care provision within the home. All but one of the main caregivers was female. The only male was the nephew of the ill person in the Luthuli household, who shared the care task with his grandmother. This finding is also evident from the 2004 KIDS findings.

It seems to be socially and culturally unacceptable for men to provide care to women. This finding is evident from households where the ill person was female and there were resident males, who in all cases, although present, did not assist with caregiving. For instance, in the Ngidi household, despite the fact that Thenjiwe’s uncle shared the same household and was not employed, he did not assist in care provision, although Thenjiwe was caring for her mother, her aunt, her child and her aunt's child for some time. Therefore, if a female is being cared for it is unlikely that males will be involved in any aspect of caring.

However if a male is receiving care, other resident males, usually younger men, may be involved in some care tasks, without taking responsibility for day-to day care provision (apart from in the Luthuli household where a male was also a main caregiver). In these households it is clear that care tasks are divided up along gendered lines, in line with Akintola (2006). The Yengwa household is a good example of this. Some care work appeared to be women's work and was not undertaken by males (such as helping the ill person to bath and undress/dress, preparing food, giving medication), but other care work was done by men and women (such as helping the ill person to move in bed). Some care tasks were undertaken by male household members only. These included helping the ill person to and from the toilet, rubbing/massaging him, obtaining medication, obtaining special food and helping him to health facilities. The males who undertook this care were his brothers (aged 13 and 18) and his cousin (aged 14), all of whom are boys rather than men.

From a review of other study households in addition, care provision by males therefore appears to depend on the sex of the cared-for, although it does not take place in all households in which males are present. Where males do undertake care tasks they are for other males in the household, they tend to be tasks that are not housework related (these are the preserve of women only), occur outside of the household (such as going to a health facility with the ill person) and in some cases are personal care tasks.

6 RESULTS – MEASURING AND VALUING UNPAID CARE PROVISION

While unpaid labour has been valued in the South African context (Budlender, 2008; Budlender & Brathaug, 2002), the specific activities that make up the unpaid care of ill people by caregivers in the home – a component of unpaid care work – have not been counted and valued. The intellectual and conceptual work of this thesis consists of applying methods developed elsewhere and elaborating new techniques to count the time spent on different care activities by household caregivers, and to place a cost on this unpaid care work. The financial costs involved in providing this unpaid care work are also counted. These calculations are the focus of this chapter. Together the labour costs and financial costs of unpaid care work are referred to as the costs of unpaid care provision.

6.1 LIMITATIONS OF THE SAMPLE

To begin, it is important to emphasize that the sample used to derive estimates from is small and localized to one region in South Africa: 17 terminally ill people in 16 relatively poor African households, being cared for by 19 main caregivers in the province of KwaZulu-Natal. It is therefore not possible to generalize from the findings from this study sample to other parts of South Africa. It is also not possible to generalize from the findings from this study with regard to HBC in general, since it focuses on HBC for people in the late stages of HIV/AIDS during intensive illness episodes. Nevertheless the findings represent the best possible estimate on such a small sample, and within the constraints of undertaking such research.

The rigour attempted in gathering in-depth information, even though on a small sample, is a way of uncovering and bringing to the surface the realities of unpaid care work in a resource-poor environment. Applying estimated earnings rates to time spent in unpaid care work is also undertaken, and both of these processes provide insights for a future survey on care provision on a larger sample, for other areas in South Africa, or even for the country as a whole.

6.2 COSTS MEASURED AND 'VALUING' APPROACHES ADOPTED

Only some of the costs of providing care are measured in this thesis. The focus here is on the labour involved in unpaid care provision and the financial costs associated with unpaid care provision. Consequently, household caregivers' labour costs and financial costs to households are measured, and a total figure is obtained. This thesis considers the household caregiver(s) as the providers of care in terms of time, and the household as the provider of care in terms of financial costs.

The following equation describes what the costed unpaid care provision in this research comprises:

> *Costed unpaid care provision = costs of household caregiver(s)' unpaid care work time + household's financial costs*

In terms of estimating the value of the caregivers' labour time, input-related methods rather than output-related methods are adopted, since an explicit aim of this study is to make visible all aspects of women's work. All four input-related methods for measuring labour time outlined in section 3.3.1 are applied, which enables the comparative effect to be seen. This has already been undertaken for South Africa (see Budlender, 2008; Budlender & Brathaug, 2002), although in these studies only the labour inputs to unpaid care work were estimated. This thesis includes one of the non-labour inputs to unpaid care work, namely financial costs to households. Therefore, the contribution of this thesis lies in estimating not only labour inputs but also non-labour inputs to unpaid care work, and in assessing which method is more appropriate to the developing country context in KwaZulu-Natal, South Africa.

6.3 METHODOLOGY FOR COUNTING UNPAID CARE WORK TIME

One of the key purposes of this thesis is to develop a method to cost unpaid care provision for ill people within the home in poor African households in KwaZulu-Natal. Netten (1993, p. 55), referring to opportunity costing, but an argument also relevant to costing more generally, notes that any attempt to provide a detailed opportunity costing “requires that the assumptions and estimates are open to question. This is especially so in this relatively new area where conventions have yet to be agreed”. As such the methods used to count caregiver’s time and the decisions on how to do this will be recorded as part of the main text, instead of as footnotes. It is also useful to keep the following in mind with regard to the process of estimation: “two leaps of faith are frequently required: between pure theory and the feasible, and between the feasible and the available” (Netten, 1993, p. 56).

6.3.1 Tools used

As noted in Chapter 3, extended SNA work includes (a) household maintenance, management and shopping for own household; (b) care for children, the sick, elderly and disabled for own household; and (c) community services and help to other households. Within the study households any care provided for the ill person was counted. Apart from this, household activities were not counted nor included. Therefore category (b), and specifically care of the sick, are the activities that are counted in this study.

As noted in Chapter 4, a care survey and a mini-events map were the main tools used to count care time. The benefits of using a time diary are outlined in section 3.2.2. However this was not used as the principal method of time-use data collection because of the limited amount of time for the care component which was only one of five research themes, the amount of time necessary to introduce this method to caregivers, the fact that many were not literate and since this method was likely to add to their time burdens which were already great. It was also not possible to apply the time diary to a number of the care situations as eight of the 17 illness periods occurred prior to the fieldwork period.

While it would have been useful for comparative purposes to use the questions and codes relating to care activities that were applied in South Africa's TUS, these survey codes did not have the necessary level of detail on care activities. The findings recorded in the 2004 KIDS qualitative study are far more detailed and specific to the unpaid care of persons than those of the TUS.

Not all mini-events maps of illness periods were recorded with the same amount of accuracy and detail by field researchers. This variation in quality also occurred with the SEPPI (see Adato et al., 2007), and seems not that unusual. The care survey material was more consistently recorded across surveys, and was taken as the first point of reference, with the mini-events map information used to help understand the survey information where unclear, to solve some of the problems the survey presented (especially with regard to over counting), and also to estimate frequency or duration when these were missing in the care survey.

The literature specifies that the study questions be asked of all main caregivers should there be more than one. This is because different caregivers may undertake different tasks and information on caregiving could therefore be missed if all caregivers are not interviewed. However, in practice it was not always possible to do this. In the Sibiyo household responses were received from one of the caregivers only, as the other caregiver was no longer staying in the household at the time the study information was collected. The caregiver responded on behalf of herself and her daughter, and her estimates included the time spent undertaking caring tasks by the daughter. The mother and daughter team worked together closely in their caring role, thus it is likely that the mother was able to account relatively accurately for her daughter's caregiving time.

6.3.2 Daily unpaid care work time per ill person

The main caregiver's time was counted, but where help was received from other household members, this was also counted. In other words, all care provision was counted, whether by the main caregivers, stand-in caregivers or *ad hoc* caregivers. This was done with the aim of obtaining a daily amount of total time spent in unpaid care work per ill person.

The frequency and duration of each care activity was multiplied by the number of people who provided that care activity, and then, if the care activity had not occurred daily, this amount was divided by the relevant unit (e.g. days in the month if it occurred only on one day a month), to obtain time spent on that care activity per day.

In order to estimate the time spent in unpaid care work across households a common unit had to be used. The time spent caring for the ill person is estimated on a daily basis since the length of illness periods differs. Most information about care activities was asked per day. Buying special food was asked per week and the estimate was divided by seven to obtain a daily figure. Visits to health facilities with and for the person were asked with reference to an average month, and questions about oral and non-oral medication and treatment related to the previous month, and in these instances the number was divided by the average days in a month to obtain a daily figure. For some activities (for example, linen and clothes laundry) the respondent was asked to say how often this occurred, and the relevant unit was then used to obtain a daily amount of care time spent.

6.3.3 Selection of the illness period

Field researchers were told to ask the care survey questions for a time when the person 'was very ill' and 'required a lot of care'. This was defined as the illness period. This could result in some over-estimation, as they might have spoken about the very worst period of the illness, whereas the boundaries of this period may have been a bit less labour-intensive. In some cases field researchers were stricter about identifying this time period than in others. However, all illness periods were checked with the field researchers in order to be certain that more or less the same definition of an illness period was applied across study households.

Illness periods for four ill people were not amended (i.e. Sibiyo, Ngidi-Zinhle, Thwala, Mncube). The remainder were made more accurate through a reading of the mini-events maps. In the Cibane and Ndaba households there were no specific months stated as an illness period by respondents, therefore along with field researchers the relevant time periods were selected from the mini-events maps and applied. The following additional steps were taken:

- time spent in hospital was subtracted
- time when a lot of care was not received was subtracted
- time over which the person was recovering or not in need of much care (when they 'could help themselves') was subtracted
- time that could not be applicable was subtracted (i.e. in the Shibe household the stated illness period included a time when the ill person was not at home)
- time when the second main caregiver was not present in the household was subtracted (i.e. Luthuli household),
- time which was applicable and referred to in the care survey was added to the stated illness period (i.e. Shibe household).

The frequency with which something occurred over the illness period was then revised in line with the new length of the illness period. In this way any discrepancies were 'smoothed over' and should not affect the calculations. Despite attempting to make all of these consistent, it is nevertheless inevitable that the intensity of care varies within cases and across households over these illness periods.

As already noted, for eight of the 17 ill people the illness period occurred prior to fieldwork. In these cases the care survey questions were asked retrospectively, with reference to the time when the person received a lot of care. Although this might affect recall, this was experienced as positive for field researchers and some respondent caregivers, since it was easier to refer to a prior time and not the present time. For many caregivers an earlier time was more distant and less emotionally difficult to speak about than present circumstances.

6.3.4 Care activities included

Information was obtained for a variety of care activities through the stylized questions in the care survey. In this section detail is provided on which activities were counted. This is a core part of the thesis: to make transparent the logic used and to make more visible the methodological problems in measuring unpaid care work. The following information was obtained and used in the estimation of time.

- Activities undertaken for the ill person only – for example, preparing special food for the ill person and no-one else.

- Information on time spent preparing special food and drink for the ill person, and time taken to help him/her eat and drink.

- Time spent washing linen in the Shibe household where the ill person and his wife shared a sleeping space and the wife washed the bed linen everyday, it seems because he sweated profusely.

Information for some care activities was not obtained across study households, since they were not asked about as part of the stylized questions. However field researchers did record some additional time-use information on other care activities provided by caregivers. These activities are listed below and this time has been counted:

- Time taken to clean the ill person once he/she soiled him/herself.

- Time taken to wake up the ill person and sit him/her up in order to give him/her food, drink or medication.

- Time taken to take the washing off the line, fence, rocks or grass where it was put to dry.

- Time taken to buy care items (e.g. blankets, bedpans) for the ill person, that is, the time taken to get to and from the shops, and the time to buy the item, although the trip to and from the shops may have also been for the purpose of purchasing other items not related to care provision.

- Time spent preparing for a trip to a health facility with the ill person.

The following time information was not counted as part of the time spent on unpaid care activities by household caregivers:

- Time spent buying care items or other items for the ill person by a non-household member.

- Time spent buying items that were bought many years ago but were used at the time of the study for care purposes, such as a bucket or bedpan, since this care time was spent prior to the illness period.

- Time spent buying items, both for the ill person and for other household members (such as washing powder), although the ill person consumed these items. While it is likely that more washing powder had to be purchased for the care of the ill person after they became ill than before, it is extremely difficult to isolate this additional time from the time spent buying washing powder for all household members.

- Time spent preparing food or drink for both the ill person and other household members. These activities would have been undertaken for the ill person before they became ill, and so, strictly speaking are not illness-related care activities.

- Time spent keeping the ill person company and keeping an eye on them. This activity occurred in most of the study households to greater or lesser degrees and while respondents gave estimations of how long this took, these were regarded as unreliable. Respondents indicated that it was difficult to put a time to this kind of care activity as it was done in between and at the same time as other activities. In the Mncube household, for instance, the caregiver described time spent keeping the ill person company as follows: "*…it is not easy to count because we spend the whole day in the house; friends come and sit for hours*". Nevertheless, an analysis of simultaneous time-use for activities such as this was undertaken on the 24-hour time diaries, and is documented in section 6.3.6.

- Time spent caring if someone provided care only in exceptional circumstances, where it is very difficult to estimate frequency. For example, in the Ngidi household, Thenjiwe, the caregiver, always gave medication to her mother, but she rarely gave it to her aunt.

- The counting of time was done separately for household and non-household members who provided care. This was done in order to distinguish between care provided by family members and 'community care'. Time spent on care activities by non-household members was not counted as part of household care time. In the Mngadi household, one of the main caregivers, Gladys, came from Johannesburg to look after her ill cousin. Gladys was defined as a household member because she lived in the household for the duration of the illness period. In the Mbongeni household care was provided mainly by the ill person's mother, Ayanda, but at times assistance was received from an aunt who visited for two weeks and from a neighbour. Both the aunt and the neighbour were defined as non-household members because they did not live in the household for the duration of the illness period.

6.3.5 Approaches used

In some instances frequency or duration of a care activity had to be estimated where these were not clearly stated by respondents. In making these estimations the focus was on being as logical as possible, applying common sense, being cautious, and the dictum 'underestimate rather than overestimate' was applied.

The following was decided with regard to the examples that are listed below, and similar approaches were applied to similar cases across study households.

- In the Ngidi household, with regard to assistance for Zinhle with walking outside, the caregiver noted that "*if it happens it is once a day, but it does not happen every day*". Therefore an estimation of 0.5 times a day was applied.

- Likewise, in the Ngidi household Zinhle was helped onto a sponge mattress two times a day, when it happened, but it occurred "*very rarely*". From his observations the field researcher indicated that the mattress was taken outside for Zinhle to lie on every day towards the start of the illness period, but according to the mini-events map, later on Zinhle would crawl there on her own. Therefore it was estimated that she was helped 0.5 times a day to cover all of these options over the illness period.

- Where "*more than*" or "*less than*" a figure was stated the actual figure was used, as it was not possible to work out how much more or less than the stated figure the duration or frequency was, but the figure itself is certain. For example, with regard to "*more than 10 times a day*" the amount was taken as 10 times a day.

- In the Cibane household it is noted that the caregiver would make juice three times a day, but not every day. Therefore the estimate was taken to be three times a day every second day.

- “*A few minutes*” was taken to be three minutes.

- Where it was noted that sometimes one person helped with a care activity and at other times two people helped, it was estimated that 1.5 people helped over the illness period. For example, in the Ndaba household one caregiving activity was usually undertaken by one caregiver or if she was not there it was done by two others. Therefore it was estimated that 1.5 people undertook the activity to account for the possibility that more than one person was sometimes doing it.

- In order to determine the amount of care time that was undertaken by non-household members, the calculated caregiving time was divided up and apportioned. In the Sibiyo household where a friend drove the ill person and his sister to hospital – the care time was estimated as half for the sister (household member) and half for the friend (non-household member). In the Mbongeni household some care activities were undertaken by the ill person’s mother or by the daughter and the aunt or by the daughter and the neighbour. Here the care time was divided by six, with the mother undertaking two-sixths, the daughter undertaking two-sixths, the aunt undertaking one-sixth and the neighbour undertaking one-sixth.

- In the Shibe household the ill person’s chest was rubbed “*when it was congested*”. It was estimated that this happened once a day over the illness period.

- If something was done “*only when requested*” it was estimated as occurring 0.5 times a day. This was the case with regard to rubbing or massaging Zinhle in the Ngidi household.

- Also in the Ngidi household, it was noted that Zinhle ate “*once a day, sometimes none*”. Therefore it was estimated that she ate 0.5 times a day over the illness period.

- Some of the figures given by respondents seemed questionable. For example, in the Mbongeni household the caregiver stated that it took 20 minutes to pour lucozade into a cup, put a straw in the cup, and then place it in front of the ill person. Another example was in the Ngidi household where it took 45 minutes to turn/move the ill person in bed and this was done over ten times a day. While this may not be reflective of the time actually taken to undertake the activity, it could be reflective of caregivers' perceptions of how long it took, which is also important to take into consideration. Nevertheless, where figures were clearly overestimates these were halved. Therefore instead of 20 minutes, the estimate for the Mbongeni household was taken to be 10 minutes, and instead of 450 minutes a day, the estimate for the Ngidi household was taken to be 225 minutes a day.

- If a care activity only occurred once over the illness period the minutes taken to do the care activity were divided by the number of days in the illness period. For example, in the Luthuli household the minutes taken to go to the hospital with the ill person were divided by the number of days in the illness period to obtain the number of minutes it took per day over the illness period.

- With regard to counting the time taken to buy special food, in some cases respondents gave only the time taken to get to the shops, in some instances they stated time to and from the shops, in other cases they gave buying time only, and in a few instances they gave time to and from the shops as well as buying time. These time estimates were simply used as is, in line with the approach of underestimating. There were no overestimates with time taken to buy special food, only a full estimate or an underestimate.

In a number of cases a decision was taken to estimate figures by calculating the average of stated figures. The following are examples of estimated averages in the study. These cover most of the cases that were presented in the study findings, with only slight variations across households in terms of amounts stated:

- In the Ngidi household, some medication was given to Siyanda two times a day, and other medication was given three times a day. Therefore the estimate was taken as the average of the two: 2.5 times a day.

- Similarly, in the Ngidi household the estimation for the number of times that food was prepared for Siyanda and the number of times she was helped to eat per day was given as "*1 or 2 or 0 times*", therefore the frequency was taken as the average of the three: one time.

- The time spent bathing the ill person in the Yengwa household was stated as "*45 to 60 minutes*". Therefore the estimate was taken to be the average of 52.5 minutes.

- Where there were inconsistencies an attempt was made to find an 'average' estimate. For example, in the Mbongeni household the ill person was dressed twice a day and undressed 3.5 times a day. The number of times the person was dressed and undressed should be the same as it is only possible to undress and dress one after the other. Therefore the average of the two figures was taken: the ill person was undressed and dressed 2.8 times a day.

- If the number of people stated as doing a certain care activity was "*one or two*", the care activity was multiplied by 1.5 to account for the fact that more than one person was doing the caring activity for some of the time. For example, in the Mbongeni household some personal care activities were undertaken by Ayanda or by Ayanda and Aunt Pretty, therefore by 1.5 people.

- If there was no estimate for duration or frequency for a few households, or where it was not possible to make estimates, the average of the stated duration or frequency for a particular activity across all other study households was calculated. Estimated averages were not calculated where information across most of the households was missing (apart from the time taken to empty a bedpan/bucket, see below). Estimating averages was only necessary for some care activities, and these are listed below:

  - The number of times he/she was bathed
  - The number of times he/she was taken in or out of the bed
  - The number of times he/she was turned or moved
  - The number of times he/she was helped to walk outside
  - The time taken to help him/her to and from the toilet

  - The time taken to help him/her use the toilet
  - The time taken to help him/her use the bedpan/bucket
  - The time taken to rub or massage him/her
  - The number of times he/she was rubbed or massaged
  - The time taken to prepare and pour a drink and help him/her drink or give him/her their drink
  - The number of times to prepare and pour a drink and help him/her drink or give him/her their drink
  - The time taken to prepare food and help him/her eat or give him/her their food
  - The number of times to prepare food and help him/her eat or give him/her their food
  - The number of times special food was bought for him/her
  - The time taken to prepare special food
  - The number of times special food was prepared
  - The time taken to put the linen on/off the bed
  - The time taken to wash his/her washing where this was done separate to the household's washing
  - The time taken to or from the taxi rank without him/her

- The time taken to empty a bucket/bedpan was not specifically asked about in the care survey. However, it seems reasonable to assume that the bucket/bedpan was emptied each time it was used. It therefore makes sense to apply an average time taken to empty the bucket/bedpan for those cases for which it was provided (in some of these cases it was only emptied, and in others it was emptied and rinsed) to the remainder of cases. This time was assigned to the person(s) who assisted with use of the bedpan/bucket.

- Caregivers' time was not only spent on care activities for the ill person, but also on activities for the ill person and the household. Regarding laundry washing, if the ill person's laundry was done with that of the rest of the household it was possible to divide the time estimation for the household's washing by the number of household members in order to arrive at a time estimation for the ill person. However this was not likely to be accurate as the ill person probably had proportionately more washing than the average household member, since illness usually generates more washing. Therefore the time taken to do the ill person's washing was likely to be proportionately more than the time taken to do the other household members' washing. In five households the ill person's linen and/or clothes washing was done separately to the washing of other household members. Information existed for four ill people on time taken to do their clothes washing separately from other household members' washing (an average of 31.1 minutes per day) and for four ill people on time taken to do their linen washing separately from other household members' washing (an average of 24.0 minutes per day). These average time estimates were added to the time spent providing care in households in which the ill person's washing was done together with that of the rest of the household.

- The time it took to get to the taxi rank or bus stop without the ill person in order to go to a health facility was not obtained from respondents directly. This information was obtained from two of the three field researchers after fieldwork was complete. This was not seen to be problematic as the field researchers were very familiar with the time taken, since they lived in the study areas and used these forms of transport. However, it was not possible to obtain this information from the third field researcher as he died. Therefore, the average of estimates for the four study areas was applied to the remaining two study areas. No estimations were given for how long it took for the ill person to get to a bus stop or taxi rank.

6.3.6 Simultaneous time-use

In Chapter 3 the challenge of measuring simultaneous activities was highlighted. In this section how this was taken into consideration for this study is discussed. The 24-hour time diary is analysed in order to gain insight into simultaneous time-use in households in which an ill person is receiving care. Main caregivers were asked to describe the activities they undertook in the 24 hours preceding the interview and field researchers recorded these activities (see '24 hour activity diary' in Appendix D).

In nine households the reference period was current and therefore valid 24-hour diaries were obtained for these ill people. Analysis of the 24-hour diaries shows that some simultaneous caregiving activities did occur. Examples are as follows:

- In the Luthuli household one of the caregivers cleans the ill person's room and talks to the ill person at the same time;
- In the Khubona household the caregiver cooks porridge for breakfast/supper at the same time as boiling water for the ill person's bath;
- In the Khubona household the caregiver talks to the ill person while cooking.

The occurrence of simultaneous activities was not noted often. This could be as a result of caregivers not regarding some activities as actual activities – such as keeping the ill person company, or keeping an eye on the ill person. In some of the relevant households no simultaneous activities were noted (e.g. Shibe household).

What is apparent across study households, and particularly in households in which the ill person is very ill and often bedridden, is the extent of multi-tasking that caregivers undertake – that is, moving from one task to the next, and having a large number of tasks to attend to, both caregiving and non-caregiving. In the Ndaba household the caregiver literally moves from one chore – caregiving or not – to the next without end, and this is even more noteworthy because of her old age. Many caregivers also experience much interruption from ill people, who require constant attention in some cases, while doing their various household and caregiving tasks. When the ill person's condition is noted as 'bad', more caregiving tasks are stated, and less household tasks and caregiving tasks for other household members. In the Mngadi household in which the ill person was bedridden, any tasks for main caregivers and any household activities in between caregiving activities were hurried in order to prioritize the ill person and her care. When asked how the events of the preceding 24 hours compared to the average day, Thenjiwe in the Ngidi household indicated that

> … the sequence followed while looking after Siyanda was different from [that followed] where … conditions are normal. Under normal conditions, her duties are well spaced out

> and not hectic. In this scenario, Thenjiwe said she had to keep Siyanda at the back of her mind and consequently forgot other activities. (Rural 1 Ngidi-Siyanda)

The care of household members other than and in addition to care of the ill person is also apparent in a number of households.

There is not enough information in the 24-hour diaries to draw strong conclusions about multi-tasking, but it seems that there is little difference between multi-tasking and simultaneous activities in that what is often reported as simultaneous would really be task-switching. It is likely, however, that terminal illness care means that contrary to other types of care activities, only one care activity occurs at a time. This in turn could contest the commonly-held assumption about the extent of multi-tasking in care provision.

6.4 COUNTED UNPAID CARE WORK TIME

The approaches outlined in previous sections were applied and the data was then analysed using Microsoft Office Excel 2003.

6.4.1 Daily time spent on unpaid care work

When reading the findings in this section it must be borne in mind that study households were selected for the presence of terminally ill people and data was collected on specific intensive illness periods, therefore the time spent looking after these ill people is not representative of the time spent in HBC in KwaZulu-Natal in general. Table 6.1 shows the daily time in hours spent on unpaid care work per individual ill person (Appendix H provides greater detail on the daily time taken per care activity per ill person). On average 10.1 hours are spent daily caring for the ill people by household members. This is longer than the average paid working day of eight hours. This time ranges from 3.0 hours to 25.8 hours per day per ill person. It is possible for the total care time per day to exceed 24 hours, because the total care time per ill person was counted per day and this usually constituted care by more than one main or household caregiver. In the Mbongeni and Ndaba households there were four and five people providing care respectively. Apart from these cases, the total time spent in unpaid care work in other households did not exceed 14.0 hours.

Table 6.1: Daily time spent in unpaid care work for an ill person by household and non-household members (hours)

Ill person	Main care-giver 1	Main care-giver 2	Other female HH member/s	Other male HH member/s	Total HH	Total non-HH	HH & non-HH
Yengwa	8.8	n/a	2.6	1.7	13.0	0.0	13.0
Sibiyo	5.5	2.3	0.0	0.0	7.8	0.2	8.0
Khubona	3.1	n/a	0.0	0.4	3.5	0.0	3.5
Luthuli	2.1	0.8	0.0	0.0	3.0	0.0	3.0
Mfeka	4.2	n/a	0.6	0.0	4.8	0.0	4.8
Mncube	5.6	n/a	0.0	0.0	5.6	0.0	5.6
Thwala	12.4	n/a	1.6	0.0	14.0	0.0	14.0
Cibane	10.9	n/a	0.0	0.0	10.9	0.0	10.9
Mngadi	3.4	8.0	0.0	0.0	11.4	0.0	11.4
Mbongeni	15.5	n/a	10.3	0.0	25.8	9.6	35.4
Ngidi-S	12.1	n/a	0.0	0.0	12.1	0.0	12.1
Ngidi-Z	8.6	n/a	0.0	0.0	8.6	0.0	8.6
Ndaba	11.5	n/a	7.3	2.9	21.7	10.7	32.4
Madondo	10.1	n/a	0.0	1.4	11.5	0.0	11.5
Shibe	3.2	n/a	0.0	0.0	3.2	0.0	3.2
Tembe	8.4	n/a	0.0	0.0	8.4	0.3	8.7
Dladla	7.1	n/a	0.0	0.0	7.1	0.0	7.1
Average	8.4		1.3	0.4	10.1	1.2	11.4

Note: HH=household; totals may not add up due to rounding; care time for the two ill people in the Ngidi household was counted per ill person; for average caregiving time for main caregiver 1 and main caregiver 2, where there was more than one main caregiver, caregiving time was totalled per ill person and then averaged across all ill people

In three households there were two main caregivers and in the remainder there was one. The average hours spent providing unpaid care by main caregivers across ill people is 8.4 hours per day or 58.8 hours per week – over the maximum 45 ordinary hours of work per week stipulated in the Basic Conditions of Employment Act. Care provided by main caregivers constitutes the bulk (90 percent) of care provision time across ill people. In five households the main caregiver(s) were the only people providing care (in one of these households there were two main caregivers, and in one of these households there were two ill people). Therefore in a number of households in which care took place the responsibility for care and the actual care provision itself fell on one person only. In half of the households, more than one household member provided care to the ill person. It is noteworthy that of all main caregivers the time spent providing unpaid care was the least for the only male main caregiver.

In six of the households one or more female household members assisted the main caregiver in care provision. The daily hours spent caring by female household members other than main caregivers ranged from 1.7 minutes to 10.3 hours per ill person. The average hours spent providing unpaid care to ill people across households by female household members (that is female main caregivers and female household members who were not main caregivers) was 9.7 hours – that is, 96 percent of all household time spent in unpaid care work. Clearly, women within homes in KwaZulu-Natal are accounting for the bulk of the time spent providing care for terminally ill people.

Across all households males spent a marginal amount of time providing care for ill people, and the picture was not substantially different if only the households in which males provide care were considered. In the five households in which males provided care, the average time spent on care provision by males was 1.4 hours per ill person. Interestingly, three of the four male household members who assisted in care provision individually spent more time providing care per ill person than the one main caregiver who was male (50.2 minutes). It is important to remember that caregivers were defined as being main caregivers by household members, so whether main caregivers spent more or less time caring than other household members should not be a consideration.

In terms of the contribution of non-household members, in seven of the 16 households external help was received, and only in one of these households was this help received from a male. Therefore the bulk of non-household members who provided some form of assistance were female. Across all households, the average daily time spent caring by non-household members was 1.2 hours per ill person. Interestingly this was greater on average than the time spent caring by male household members. Therefore, while non-household members were making a time contribution towards the care of ill people within the home, this was limited in comparison with the contribution of household members, especially females.

Finally, the average daily time spent providing care for an ill person within the home by both household and non-household members amounted to 11.4 hours. The total time spent caring by household and non-household members for an ill person ranged from 3.0 hours per day to 35.4 hours per day.

6.4.2 Operationalising Parker and Lawton

Table 6.2 shows the proportion of time spent on different types of unpaid care activities in the qualitative study, classified according to the typology of care tasks outlined in Parker (1992). ‘Emptying bucket/bedpan’, ‘putting on and taking off linen savers’ and ‘putting on and taking off plastic (sheeting)’ are defined as ‘help with personal care’ as it usually involves dealing with the person’s bodily excretions. ‘Rubbing/massaging’ is defined as ‘giving medication’, since this is something that a nursing assistant might do and because it may involve using medication. With regard to ‘preparing food/drink’ and ‘helping the person to eat/drink’, Parker and Lawton (1990, as cited in Parker, 1992, p. 10) classify the former as ‘practical help’ and the latter as ‘personal care’. However, in the qualitative study time spent ‘making food/drink’ and ‘helping the person eat/drink’ was recorded together where the food or drink was simple and quick to prepare. For instance, mixing some juice or pouring water in a glass or mixing porridge mixture with water. Preparation of ‘special’ food or drink was recorded separately. Making ‘special’ food/drink and helping the person to eat/drink are tasks that a nursing assistant might undertake. Because of the way in which the questions for the qualitative study were structured, and because of the reasons outlined above, these care tasks were classified separately as ‘making food/drink/helping to eat/drink’.

Table 6.2: Proportion of daily time spent on types of care activities defined by Parker and Lawton

Type of care/help	Average (hours)	Range (hours)	Percentage of total hours
Personal care	2.5	0.0 - 7.3	24.6
Physical help	2.6	0.0 - 10.4	26.0
Paperwork/financial matters	0.0	0.0	0.0
Practical help	1.7	0.8 - 2.5	16.5
Taking person out	0.5	0.0 - 4.0	4.9
Giving medication	0.7	0.1 - 2.5	7.0
Making food/drink / helping eat/drink	2.1	0.4 - 5.1	21.0

It can be seen that, on average, physical help took up the greatest proportion of daily time spent in unpaid care work, just over a quarter of the time. Personal care work took up slightly less but almost the same amount of time. As indicated in section 2.3, Parker (1992) considers personal and/or physical care as a proxy measure for heavy involvement. If this notion is applied to the data it is clear that the majority of carers’ caring load was ‘heavy’. Preparing food/drink and helping the person to eat/drink took up a fifth of the time on average. Together these three types of activities took up over two-thirds of the total time spent in unpaid care work. Practical help took 17 percent of the time, and giving medication and taking the person out (to health facilities) took the least amount of time.

Help was received with paperwork/financial matters – specifically the application for a disability grant – for six of the ill people in all. The disability grant is a social assistance payment paid to poor people with temporary or permanent disabilities. At the time the qualitative study was undertaken, the disability grant could be obtained in KwaZulu-Natal by adults in late-stage

HIV/AIDS – either if they were in WHO stage three or four or if they had a CD4 count of less than 200 –subject to the decision of a District Surgeon (Hunter, 2005). Only in the Ndaba household was this help with paperwork/financial matters received over the reference period. This time does not appear to be reflected in the table because it was only 1.2 minutes per day when evened out over the reference period. There is therefore undercounting of this type of care activity because the reference period biases the kinds of activities that take place: the ill people were generally too ill to apply for the disability grant.

All ill people received practical help, had medication given to them and had food/drink made for them or were helped to eat/drink. Personal care was received for all but one ill person and physical help was received for all but two ill people. 'Taking the person out' occurred for 13 of the 17 ill people.

Operationalising Parker's (1981) definition of tending in a similar way is constrained because the qualitative study sample is biased to high-intensity care. That is, most of the ill people in the study were very dependent on caregivers and required much caregiving. This is therefore not undertaken.

6.5 VALUING UNPAID CARE WORK TIME

The four methods used to value unpaid care work time are outlined in the box below, which serves as a reminder of the methods and the broad purpose of the methods outlined in section 3.3.1.

Box 1: Brief description of methods used to value unpaid care work time

The average earnings method: The average earnings in the economy as a whole is estimated and assigned to each hour of unpaid work. The mean is estimated separately for males and females. This approach lowers the overall estimated value of unpaid work because women generally perform more unpaid work than men, and the average female wage is usually lower than the average male wage.

The opportunity cost method: The normal wage or income from paid work that the person would be doing if they were employed is taken as the value of the opportunity cost. This method generally gives the highest values of all the methods, and it will give the widest range of estimates for a particular amount of time spent on care, depending on the skills and the opportunity wage of the individual performing it.

The average earnings and opportunity cost methods are useful if the aim is to work out what the caregiver would have earned if she or he were working instead of providing unpaid care.

The generalist method: The mean wage of workers performing similar work to the unpaid work is used. For instance, for housework the wage of a paid domestic worker could be used, and for care of an ill person, the wage of a nursing assistant could be used. The generalist method usually gives the lowest values of all the methods, since domestic workers are generally at the low end of the wage hierarchy, (and there are so many of them).

The specialist method: This method focuses on the activity and not on the person who undertakes the activity. For each activity the wage earned by paid workers, whose functions and circumstances match the unpaid care work undertaken, is used. For instance, time spent on cooking activities could be valued at the wage of a paid chef or cook, while time spent on cleaning activities could be valued at the wage of a paid cleaner. The specialist method will tend to generate estimates that will be relatively high, and will be more indicative of the market value of household production.

The generalist and specialist approaches are useful if the aim is to estimate the value of care provision for the cared-for, the focus will be on estimating what the cared-for would have had to have paid to purchase in such care services.

Source: adapted from Budlender (2002) and Budlender (2008)

The September 2004 LFS was selected for analysis to obtain hourly earnings to assign to the time spent providing unpaid care by unpaid caregivers in the qualitative study, because it fell within the time period of the study. According to the statistical release accompanying this data (Statistics South Africa, 2004, p. i),

> the LFS is a twice-yearly rotating panel household survey, specifically designed to measure the dynamics of employment and unemployment in the country … Detailed information was collected about the labour market situation of approximately 68,000 adults of working age (15-65 years) living in over 30,000 households across the country.

While the LFS provides an underestimate of actual earnings as respondents tend to under-report income of all kinds, it is the best source available in terms of coverage of both the formal and informal economies (Budlender & Brathaug, 2002).

Budlender and Brathaug's was the first research to value unpaid labour in the South African context, using the national TUS of 2000. As noted, this has recently been followed up by further work on the TUS by Budlender (2008) which includes a more specific focus on the unpaid care of persons.[11] Costing unpaid care work is a relatively new area where conventions are yet to be agreed (Netten, 1993). In this thesis the approaches introduced in Budlender and Brathaug (2002) and Budlender (2008) are taken forward and 'tried out' in more detail.

In giving a value to the time spent providing unpaid care, the question is how much one would pay to buy such services in the market or how much someone would earn if they were doing paid work instead (Budlender, 2008). The focus is not on obtaining representative findings on distribution of earnings. Budlender and Brathaug (2002) estimated earnings for employees only, while Budlender (2008) estimated earnings for all the employed for the average earnings

---

[11] This latter paper follows the approach of Budlender and Brathaug (2002) closely, although there are some changes. This thesis aims to keep the approach to data analysis as similar as possible to this later paper, because it is more recent and updated. Thus any changes stated by Budlender (2008) were adopted, and where they did not differ, the approach of Budlender and Brathaug was used. Some of the specifics of how the analysis was conducted by Budlender have not been explicitly noted where these are the same as that of Budlender and Brathaug.

approach, and earnings for employees only for the generalist approach. In this thesis the earnings estimations have been done for all the employed who work for pay (employees, self-employed, own-account workers) for the average earnings and opportunity cost approaches, and for employees only for the generalist and specialist approaches. While the self-employed may also undertake work that is ‘bought in’ by a household, the earnings of these workers are not included because it is difficult to distinguish between the self-employed who would have done this care work, and those who would not have.

Budlender and Brathaug (2002) estimated mean earnings while Budlender (2008) estimated median earnings. Budlender argues that it is preferable to estimate median earnings:

> Theoretically, the median is chosen because earnings tend to be skewed towards the lower end. The mean thus tends to over-state the true ‘middle’. Practically, using the median avoids the problem of how to deal with outliers, at least some of which probably represent incorrect capture of data (Budlender, 2008, p. 34).

In this thesis both the ordinary mean and median earnings are estimated, in order to be able to compare the two estimations and comment on the preferable approach for the African poor in KwaZulu-Natal.

The merged LFS data files ‘worker’ and ‘person’ were used to estimate hourly earnings for the employed or employees for whom there was a non-zero answer to the following questions: total salary or wage at his/her main job, including overtime, allowances and bonus before any tax or deductions; and, either income brackets per week, per month or per year, or an indicated salary period – either per week, per month or per year. While it would be preferable, as argued in section 3.3, to use the net wage for the average earnings and opportunity cost approaches, this was not possible because only the total salary/pay (including overtime, allowances and bonus, before any tax or deductions) was obtained in the LFS. Those with recorded earnings of more than R1,000 per hour would have been excluded (in line with Budlender, 2008), although no respondents earned these amounts.

For those respondents who gave their earnings by indicating an income bracket, the approximate midpoint of the bracket was assigned. For instance, if the income bracket was R1,001 to R1,500, a midpoint of R1,250 was assigned. Following Budlender and Brathaug (2002), for the bottom bracket an amount equal to two-thirds of the top cut-off was used, while for the top bracket, an amount equal to double the top cut-off of the income bracket second from the top was used.[12] Income that was stated per month or per annum was converted to weekly income.

Another question in the LFS asks how many hours per week, including overtime, the respondent usually works in his or her main job or activity. Weekly earnings were divided by the number of hours worked per week to arrive at hourly earnings per worker. For respondents who did not state the number of hours usually worked in a week, 45 hours was assigned (following Budlender & Brathaug, 2002), since this is the maximum number of ordinary work hours per week specified in the Basic Conditions of Employment Act. Any employed person who worked more than 140 hours per week was excluded (since it would seem physically impossible to undertake more than this number of hours per week). This resulted in two exclusions.

Budlender and Brathaug (2002) note that the inclusion of possible overtime could result in higher than normal average earnings, but they argue that the long hours spent by some in unpaid work on top of their paid work justifies some adjustment for overtime. In contrast, they also note that since there are no estimates of additional payments by employers, and since cash wages reported could understate the true value of compensation (the questionnaire specified that payment could be in cash, in kind or accommodation) the calculations will be underestimates. Budlender and Brathaug do not believe this to be problematic since for many workers in South Africa there are no contributions or very small contributions by employers.

---

[12] The two-thirds cut-off was reportedly suggested by Charles Simkins who argued that for the lowest bracket income would not be clustered near the bottom. Budlender and Brathaug (2002) used the logarithmic mean for all the ordinary brackets. More recently Budlender (2008) has used the ordinary mean since clustering downwards of income for the full population does not mean that income clusters downward in each of arbitrary brackets. The decision on the top bracket was an arbitrary one. Since there are relatively few cases in the top bracket the approach used is not of great concern (personal communication, Debbie Budlender, 21 April 2008).

Finch and Groves (1983) indicate that a distinction needs to be made between caring that is entirely substituted for paid work and caring that is to varying extents combined with paid work. These authors are likely concerned with whether unpaid care work keeps people out of paid work. In a developing country context, within extended households, where there is someone in paid work there are usually others who are not in employment or who are in part time employment who can pick up the care work. For this reason the need to distinguish between caring that is entirely substituted by or combined with paid work is not great. The concern of this thesis is not so much with what individuals would be doing economically if they were not caring, but rather it is looking at the aggregate of this care work and how it is valued in terms of the various approaches.

The analysis of LFS data was restricted to Africans only, in line with the fact that all of the households and caregivers in the qualitative study were African. Further, the analysis was restricted to KwaZulu-Natal only, since the qualitative study took place in this province only and since other analyses in this thesis are focused on KwaZulu-Natal only.

It could be argued that pensioners should be excluded from the estimation of earnings rates because they will not be having opportunity costs to their employment. As Posel states: “The issue for pensioners perhaps is that they typically withdraw from the labour market when the social pension is received ... If all pensioners withdrew upon receipt of the pension, then there would be no trade-off between working and providing caring labour.”[13] This should not be of concern. Not all people stop working at 60 or 65, also not all people receive old age pensions, and in this analysis opportunity costs are not the only costs estimated. In the weighted September 2004 LFS, nine percent of African women of pensionable age (N=1,493,331) and 14 percent of African men of pensionable age (N=618,817) were employed. Moreover, Lam, Leibbrandt and Ranchhod (2005, p. 8) find a participation rate for women of 20 percent at age 60 and five percent at age 70, and note that employment rates at older ages may increase in the future since schooling levels rise rapidly from older ages to younger ages, particularly for Africans.

---

[13] Personal communication, Dori Posel, 10 September 2008.

In the qualitative study two of the six pensioners providing care were undertaking work, usually informal work, in addition to receiving a pension. Simply because one is receiving a pension does not mean that one will stop working or stop looking for work, not least because the value of the old age pension is in many cases not enough to sustain those dependent on it. It may be that in caring households more of those of pensionable age work than in other types of households, possibly due in part to the provision of care within the home. It therefore does not seem necessary for this analysis to estimate separate earnings rates for those 60 and over and not working, and for those under 60 who are not working. By applying the same earnings rate to those aged 15 to 59 and those aged 60 and over, the argument is that there is an opportunity cost to providing care at all of these ages.

The LFS is restricted to those aged 15 and older. The main caregivers in the qualitative study ranged in age from 16 to 72, and the household caregivers ranged in age from six to 75. It could be argued that the time spent providing unpaid care by caregivers under 15 and over 65 should not be valued (that is, wage rates should not be assigned to their time spent providing unpaid care) because they are not counted as part of the labour market. However, the LFS was collected for purposes that are different to this study. This thesis focuses on indigenizing the process of valuation to a developing country context, where those very young and very old are involved in care provision. Not valuing the time of these individuals would mean that all the inputs into and facets of unpaid care work are not accounted for (three of the main caregivers were over the age of 65, for instance), and it would therefore not give an accurate representation or valuation of this type of work. Therefore the unpaid care work time of all household caregivers in the qualitative study was included.

Valid non-zero responses were obtained to earnings questions and the question on the number of hours worked for 4,045 (unweighted) African respondents in KwaZulu-Natal (1,987 males and 2,058 females). In all, 81 percent are employees who work for pay, five percent are self-employed who employ others, and 14 percent are self employed own-account workers. The dataset was weighted for the analysis. When weighted the number of cases totals 1,440,718.

6.5.1 The average earnings method

The average earnings approach estimates the average earnings for the economy as a whole. Using the restrictions outlined above, when all the employed with valid earnings data are included, the median hourly earnings for men is R7.92 (N=776,250) and R4.58 for women (N=664,468). The mean hourly earnings are R12.95 for men and R8.89 for women. In table 6.3 the median and mean earnings rates are assigned to the time spent in unpaid care work according to sex.

Table 6.3: Value in rands of female and male unpaid care work per ill person (average earnings method)

Ill person	Female UCW hours per ill person	Value using median earnings (female)	Value using mean earnings (female)	Male UCW hours per ill person	Value using median earnings (male)	Value using mean earnings (male)
Yengwa	11.4	52.21	101.35	1.7	13.11	21.43
Sibiyo	7.8	35.72	69.34	0.0	0.00	0.00
Khubona	3.1	14.20	27.56	0.4	2.93	4.79
Luthuli	2.2	10.08	19.56	0.8	6.63	10.83
Mfeka	4.8	21.98	42.67	0.0	0.00	0.00
Mncube	5.6	25.65	49.78	0.0	0.00	0.00
Thwala	14.0	64.12	124.46	0.0	0.00	0.00
Cibane	10.9	49.92	96.90	0.0	0.00	0.00
Mngadi	11.4	52.21	101.35	0.0	0.00	0.00
Mbongeni	25.8	118.16	229.36	0.0	0.00	0.00
Ngidi-S	12.1	55.42	107.57	0.0	0.00	0.00
Ngidi-Z	8.6	39.39	76.45	0.0	0.00	0.00
Ndaba	18.8	86.10	167.13	2.9	23.06	37.71
Madondo	10.1	46.26	89.79	1.4	10.96	17.91
Shibe	3.2	14.66	28.45	0.0	0.00	0.00
Tembe	8.4	38.47	74.68	0.0	0.00	0.00
Dladla	7.1	32.52	63.12	0.0	0.00	0.00
Average	9.7	44.53	86.44	0.4	3.33	5.45

Note: UCW=unpaid care work

If median earnings for females in the economy as a whole are assigned to the hours spent undertaking unpaid care, the daily cost of this work ranges from R10.08 per day to R118.16 per day (R19.56 per day to R229.36 per day using mean earnings). For the five households in which there were male caregivers, the remuneration ranges from R2.93 per day to R23.06 per day if median earnings are used (R4.79 to R37.71 per day using mean earnings). If the median and mean earnings rates for men and women respectively are assigned to the number of hours worked on average among the sexes (9.7 hours and 0.4 hours respectively), R44.53 and R86.44 are obtained for women and R3.33 and R5.45 for men, highlighting how little of this unpaid care work is undertaken by men, on average, when compared to women.

Most of the main caregivers who were working in the study were self-employed. The self-employed tend to earn less than most wage workers, especially in rural areas. Although, their sample of wage workers was biased in terms of the number of higher earning civil servants, Lund and Ardington (2006) in a study in Kwamsane in KwaZulu-Natal find that the median income for the self employed is about half that for wage workers (Lund & Ardington, 2006, p. 23). It may therefore be preferable to use the earnings of the self-employed rather than wage earners when estimating the average earnings approach. Using the LFS, the median hourly earnings for self-employed men is R6.10 (N=127,884) while the median hourly earnings for self-employed women is R3.43 (N=136,475). The mean hourly earnings is R12.73 for men and R6.14 for women.

Table 6.4: Value in rands of female and male care work per ill person (earnings of self-employed)

Ill person	Female UCW hours per ill person	Value using median earnings (female)	Value using mean earnings (female)	Male UCW hours per ill person	Value using median earnings (male)	Value using mean earnings (male)
Yengwa	11.4	39.10	70.00	1.7	10.10	21.07
Sibiyo	7.8	26.75	47.89	0.0	0.00	0.00
Khubona	3.1	10.63	19.03	0.4	2.26	4.71
Luthuli	2.2	7.55	13.51	0.8	5.10	10.65
Mfeka	4.8	16.46	29.47	0.0	0.00	0.00
Mncube	5.6	19.21	34.38	0.0	0.00	0.00
Thwala	14.0	48.02	85.96	0.0	0.00	0.00
Cibane	10.9	37.39	66.93	0.0	0.00	0.00
Mngadi	11.4	39.10	70.00	0.0	0.00	0.00
Mbongeni	25.8	88.49	158.41	0.0	0.00	0.00
Ngidi-S	12.1	41.50	74.29	0.0	0.00	0.00
Ngidi-Z	8.6	29.50	52.80	0.0	0.00	0.00
Ndaba	18.8	64.48	115.43	2.9	17.76	37.07
Madondo	10.1	34.64	62.01	1.4	8.44	17.61
Shibe	3.2	10.98	19.65	0.0	0.00	0.00
Tembe	8.4	28.81	51.58	0.0	0.00	0.00
Dladla	7.1	24.35	43.59	0.0	0.00	0.00
Average	9.7	33.35	59.70	0.4	2.57	5.36

The value of the time spent providing unpaid care by women comes to R33.35 on average using the median earnings of the self-employed and R59.70 using mean earnings, as table 6.4 shows. The same figures for all the employed women (table 6.3) are R44.53 and R86.44. The hourly labour costs of unpaid care work using the average earnings of the self-employed are much lower than those of the average earnings approach for all the employed, highlighting how much less the self-employed earn on average than all the employed. For this study it seems to be more appropriate to use the earnings rates of the self-employed only when adopting the average earnings approach, since almost all of the unpaid caregivers in employment are self-employed.

6.5.2 The opportunity cost method

As noted in section 3.3.1, it could be argued that because of the very high unemployment rates that prevail in South Africa the unemployed should have an opportunity cost of zero or that the wage the person would have earned in a full employment economy should be discounted by the percentage chance of getting work. However since this thesis focuses on obtaining estimates as if there were these labour market related alternatives, opportunity costs to unpaid care work are estimated using two broad approaches: using the education information for all household caregivers and the employment information for all main caregivers (employment information was not obtained on all caregivers).

Regardless of whether caregivers are employed or unemployed, their caregiving time can be assigned an earnings rate based on their highest level of education and other characteristics. Table 6.5 shows the education level of all household caregivers in the qualitative study except those under the age of 15, since it was not possible to estimate the hourly earnings of those under 15 in the LFS. It can be seen that most of these caregivers, like those in the 2004 KIDS, have very low levels of education.

Table 6.5: Education level of household caregivers

Education level	Main caregiver-female	House-hold caregiver-female	Main caregiver-male	House-hold caregiver-male
No schooling	1	0	0	1
Primary/incomplete primary (gd 1-7)	11	1	1	0
Incomplete secondary (gd 8-11)	4	4	0	2
Matric (gd 12) +	2	1	0	0

Budlender and Brathaug (2002) estimated mean earnings for different education–sex categories only. However, sex and level of education are not the only predictors of earnings, and other factors such as age and whether the person lives in a rural or an urban area also determine what the person is likely to earn. For this study earnings rates were estimated for each of the household caregivers aged 15 and over using the September 2004 LFS [14]. Ordinary least squared regressions were run for Africans in KwaZulu-Natal who worked 140 hours or less per week and those earning over R1 an hour. Coefficients for age, age squared, four education categories (with 'no schooling' as the reference category), and metropolitan area were estimated. These coefficients are for wage earners and while those in employment may have some unobserved characteristics that may be missing amongst the unemployed (motivation, for example), interrogating the psychological aspects of labour lies beyond the scope of the thesis. Findings show that the imputed hourly earnings for the 16-year old caregiver were negative in all models. Therefore it was not possible to estimate hourly earnings for the caregivers in the study using ordinary least squared regressions.

---

[14] The coefficients were estimated by Dori Posel, 3 October 2008.

Table 6.6: Mean and median hourly earnings by level of education, sex and metropolitan area (Rands)

Education level	Metro male	Non-metro male	Metro female	Non-metro female
No schooling	3.05 / 7.60 (N=24,880)	3.62 / 6.37 (N=39,348)	4.13 / 4.22 (N=7,249)	3.05 / 3.86 (N=43841)
Primary / incomplete primary (gd 1-7)	9.15 / 10.60 (N=47,779)	4.09 / 7.34 (N=93,101)	3.81 / 4.89 (N=52,580)	3.24 / 4.24 (N=99,025)
Incomplete secondary (gd 8-11)	8.47 / 10.25 (N=154,585)	6.10 / 9.15 (N=165,203)	4.16 / 6.11 (N=116,014)	3.81 / 5.93 (N=129,770)
Matric (gd 12) +	15.26 / 18.03 (N=109,180)	11.44 / 16.99 (N=115,414)	8.24 / 12.04 (N=79,280)	10.30 / 15.72 (N=112,477)

Note: median hourly earnings stated first, mean hourly earnings stated second

Table 6.6 shows the average and median hourly earnings for different sex and metropolitan/non-metropolitan areas by level of education. Hourly earnings tend to increase with level of education (in particular, having a matric or more has a substantial impact on hourly earnings), be higher for males than females, and be higher for those living in metropolitan versus non-metropolitan areas. What is striking is the effect having a matric or more has on earnings rates, across sex and areas.

Table 6.7: Household caregivers' earnings according to education level (opportunity cost method)

Main & other household caregivers	Sex	Highest level of education (grade)	Metro (M)/ non-metro (NM)	Median hourly rate (Rands)	Mean hourly rate (Rands)	Daily hours of UCP	Daily earnings – median (Rands)	Daily earnings – mean (Rands)
Yengwa-H	F	4	NM	3.24	4.24	8.8	28.51	37.31
Yengwa-A	F	4	NM	3.24	4.24	0.3	0.97	1.27
Yengwa-N	F	12	NM	10.30	15.72	2.3	23.69	36.16
Yengwa-S	M	9	NM	6.10	9.15	1.5	9.15	13.73
Sibiyo-M	F	3	M	3.81	4.89	2.3	8.76	11.25
Sibiyo-S	F	12	M	8.24	12.04	5.5	45.32	66.22
Khubona-P	F	4	NM	3.24	4.24	3.1	10.04	13.14
Khubona-D	M	11	NM	6.10	9.15	0.1	0.61	0.92
Luthuli-Z	M	4	NM	4.09	7.34	0.8	3.27	5.87
Luthuli-P	F	0	NM	3.05	3.86	2.1	6.41	8.11
Luthuli-H	F	11	NM	3.81	5.93	0.0	0.00	0.00
Mfeka-B	F	10	M	4.16	6.11	4.2	17.47	25.66
Mfeka-S	F	11	M	4.16	6.11	0.7	2.91	4.28
Mncube-B	F	5	NM	3.24	4.24	5.6	18.14	23.74
Thwala-N	F	4	NM	3.24	4.24	12.4	40.18	52.58
Thwala-Z	F	9	NM	3.81	5.93	1.7	6.48	10.08
Cibane-T	F	6	NM	3.24	4.24	10.9	35.32	46.22
Mngadi-G	F	8	M	4.16	6.11	3.4	14.14	20.77
Mngadi-Z	F	12	M	8.244	12.04	8.0	65.95	96.32
Mbongeni-A	F	8	NM	3.81	5.93	15.5	59.06	91.92
Ngidi (S)-L	F	5	NM	3.24	4.24	12.1	39.20	51.30
Ngidi (Z)-L	F	5	NM	3.24	4.24	8.6	27.86	36.46
Ndaba-V	F	5	NM	3.24	4.24	11.5	37.26	48.76
Ndaba-P	F	11	NM	3.81	5.93	7.4	28.19	43.88
Madondo-M	F	4	M	3.81	4.89	10.1	38.48	49.39
Madondo-J	M	0	M	3.05	7.60	1.5	4.58	11.40
Shibe-E	F	9	NM	3.81	5.93	3.2	12.19	18.98
Tembe-T	F	5	M	3.81	4.89	8.4	32.00	41.08
Dladla-T	F	5	M	3.81	4.89	7.1	27.05	34.72

Note: the female caregiver, Luthuli-H, worked 1.5 minutes per day, which equates to no hours in unpaid care work

In Table 6.7 these hourly earnings are applied to the daily hours spent in unpaid care work in order to estimate daily earnings. The highest daily cost of unpaid care work was R65.95 using median earnings and R96.32 using mean earnings. The lowest for both earnings rates was R0 because of the small number of minutes worked by a caregiver in the Luthuli household.

An attempt was made to estimate the opportunity costs to unpaid care work time using employment information. Main caregivers in the qualitative study undertook an array of 'main' activities (employment information was only collected for main caregivers and not for all household caregivers). As with the 2004 KIDS where only a few of the day-to-day caregivers were in formal education, only one of the main caregivers in the qualitative study was studying towards a post-school qualification (in computer studies).

As Table 6.8 shows, a further six of the main caregivers were receiving an old age pension. The situation in the 2004 KIDS is not very different with between 20 and 35 percent of caregivers retired or pensioners. A quarter of the main caregivers in the KIDS study were employed, while about half (nine in total) were in employment when they started their caregiving duties (two of these were pensioners). The table shows in detail what the employment status of main caregivers was at the start of the reference period.

Table 6.8: Employment status of main caregivers at the start of the reference period

Main caregiver	Employment status
Yengwa	Traditional healer
Sibiyo-M	Pensioner
Sibiyo-S	Nursing assistant
Khubona	Pensioner
Luthuli-P	Pensioner
Luthuli-Z	Unemployed
Mfeka	Unemployed
Mncube	Informal seller
Thwala	Subsistence worker, cultivation for pay (very rare)
Cibane	Subsistence worker, cultivation for pay (very rare)
Mngadi-G	Traditional healer
Mngadi-Z	Student
Mbongeni	Pensioner, subsistence worker, livestock producer
Ngidi	Unemployed
Ndaba	Pensioner, subsistence worker
Madondo	Pensioner
Shibe	Informal seller
Tembe	Unemployed
Dladla	Unemployed

In the qualitative study a number of open-ended questions were asked that relate to opportunity costs to providing unpaid care to ill people. The questions are as follows: 'What have you stopped doing because you have to care for the ill person?', 'If you were not caring, what would you be doing during the time that is now spent looking after the sick person?' and 'What do you not do because you have to care for the ill person? In answer to one or more of these questions, some caregivers noted that care provision had had implications in terms of their employment (or potential employment).

A number of those family caregivers who were working gave up their work, or substantially reduced their work activities, in order to care for the ill person. This was the case for the two traditional healers who both gave up their work for some of the time during the care period. One, Gladys, left Johannesburg and came to Urban 2 to care for her cousin, Thembi, who died during the course of fieldwork.

She said at Urban 2 there are her clients and all over KwaZulu-Natal and she cannot attend to them as they demand since she is caring for Thembi. She also mentions that there is no one who is taking care of her clients in Johannesburg. (Urban 2 Mngadi)

Two family caregivers sell goods informally – in the case of both this work was curtailed or stopped over the time that the ill required a lot of care. For instance, Babongile Mncube explained that her small business of selling sweets at the local school was interrupted when her daughter, Sanaz, was very ill:

She says when Sanaz was very sick she couldn't go to school and sell. This meant that her business would be disturbed. (Rural 2 Mncube)

One of these caregivers sold pecan nuts and second-hand clothes before the person became very ill, but then had to stop selling these items in order to provide care to her ill husband:

She would be selling vegetables, going from door to door within the community. She cannot do that now because she has the responsibility to keep an eye on her husband ... She has stopped going to church or even going to sell the vetkoeks at the local school which is only ten paces away. This has given her children the opportunity to misuse [the money] as they are the ones who are now selling the vetkoeks. (Rural 1 Shibe)

A number of caregivers in rural areas indicated that they no longer do the subsistence work that they did before the ill person needed to be cared for. Virginia, who cares for her son, Ntokozo, says that if she was not caring she would be:

… in the fields preparing for the cultivation and planting activities. (Rural 3 Ndaba)

Another caregiver, Ayanda Mbongeni had to get other women to cultivate her land as she was unable to do so because of her care obligations. Evidently care provision has an impact on the ability of some caregivers to continue with their employment as it was before the need for care arose.

What about the caregivers who are unemployed? Five of the 19 caregivers (or 26 percent) were unemployed. Similarly in the 2004 KIDS 29 percent of caregivers were unemployed. Providing unpaid care within the home may not only impact on the ability to work for the employed, but also on the ability to search for employment for those who are unemployed. Three of the caregivers indicated that caregiving had affected their ability to look for employment. The following narrative gives the perspective of one of them:

Thabile says that she used to go to town … to look for employment but she has stopped because she has to do the caring for Gloria … She can't go in another area for many days in terms of looking for a job because Gloria cannot manage without her assistance. (Rural 2 Cibane)

In the weighted September 2004 LFS five percent of Africans in KwaZulu-Natal who provided a reason for not trying 'to find work / start a business in the past four weeks', attributed this to 'family consideration/child care'. If the analysis is restricted to females only (N=37,871) it rises to eight percent. At least a portion of the 'family consideration' component must be care for unwell family members within the home, although this is probably not much since some respondents would not consider looking after ill people as 'family consideration' and the next option is 'child care', which would skew the perception of 'family consideration'. Yet it is certain, not least from the qualitative study, that the unpaid care of family members within the home means that some unemployed caregivers are hindered from searching for work.

The occupations of caregivers in the qualitative study who were in employment are classified according to the occupational codes in the September 2004 LFS (question 41 in the survey). Appendix I contains the detailed occupational descriptions that fall under each broad occupational code used in this study, obtained from the South African Standard Classification of Occupations code list. Clearly there are a number of different types of occupations linked to each code and not all of these fit the occupations specified in this research. While this is not ideal, it is not possible to break the codes down to a more specific level.

There are no female cases for KwaZulu-Natal for code 9113 (‘door-to-door and telephone salesperson’) in the September 2004 LFS, therefore for the informal sellers code 5230 (‘stall and market salespersons’) is used. There are also no female cases for code 6210 (‘subsistence agricultural and fishery workers’) for KwaZulu-Natal in the LFS. What is the best way to apply a value to subsistence work? It is to a large extent a special case – subsistence work is irregular, seasonal and dependent on the labour that is around. No previous attempts at estimating a value for subsistence work on the basis of the hours worked could be found. Statistics South Africa estimates a value for subsistence on the basis of output, and not on the basis of hours worked. It is possible to apply a rural agricultural wage or the unskilled wage rate for agriculture, although it could be argued that someone who runs their own production unit is not unskilled. However, this would not be in line with the approach of using occupational codes in the LFS. Therefore for those working in subsistence agriculture or undertaking cultivation for pay the average earnings of a farm labourer are used (code 9211).

In addition to undertaking subsistence work, one of the caregivers, Ayanda Mbongeni, was a livestock producer, however, there were no female livestock producers in KwaZulu-Natal in the LFS data, and no other occurrences in similar types of employment, and therefore it was not possible to estimate an earnings rate for this type of employment. The earnings calculated for this caregiver is therefore an underestimate, since it is based solely on the earnings of a farm labourer.

Code 5132 (‘institution-based personal care workers’) is used for the nursing assistant. The number of LFS respondents (weighted and unweighted) for each of the main caregivers’ occupations, and the mean and median hourly earnings for females, estimated using the LFS (none of the main caregivers who worked or had worked when caring began were male) are shown in table 6.9.

Table 6.9: Number of respondents and earnings assigned using the opportunity cost method

Occupational code	Occupation	n (unweighted)	N (weighted)	Median hourly earnings (females)	Mean hourly earnings (females)
5132	Institution-based personal care workers	5	1,614	18.12	13.49
3241	Traditional medicine practitioners	16	4,758	3.81	4.74
5230	Stall & market salespersons	7	1,979	1.83	1.66
9211	Farm-hands & labourers	144	24,536	3.18	3.51

Some of the imputations are based on unweighted sample sizes that are very small, and hence the imputations for these are not very reliable. The rates for institution-based personal care workers were very high and there is a big difference in value between the mean and the median hourly earnings. This shows the problem of tiny sub-samples, but is not the case with the other types of work. Apart from this category nearly all of those who were in employment at the start of the illness period were likely to have been earning very low incomes if these earnings rates are considered.

These hourly earnings are assigned to the time spent undertaking unpaid care work by each main caregiver who was in employment when they started to provide care, shown in Table 6.10. Since the time spent in unpaid care was not costed for all household members, these figures per ill person are not representative of the true cost of this work per ill person. Only in the cases of the ill people in the Mncube, Shibe and Ngidi households does this cost represent the full cost of providing unpaid care, since no other household members were involved in care provision. If female median earnings are considered this work ranges in value from R5.86 per day to R99.66 per day among these caregivers (R5.31 per day to R74.20 per day using the mean earnings approach).

Table 6.10: Mean and median earnings per occupation assigned to daily unpaid care work time (opportunity cost method)

Main caregiver	Occupational code	Daily hours of UCW	Median earnings rate	Daily earnings (median)	Mean earnings rate	Daily earnings (mean)
Yengwa	3241	8.8	3.81	33.53	4.74	41.71
Sibiyo-S	5132	5.5	18.12	99.66	13.49	74.20
Mncube	5230	5.6	1.83	10.25	1.66	9.30
Mngadi-G	3241	3.4	3.81	12.95	4.74	16.12
Mbongeni	9211	15.5	3.18	49.29	3.51	54.41
Ngidi-S	9211	12.1	3.18	38.48	3.51	42.47
Ngidi-Z	9211	8.6	3.18	27.35	3.51	30.19
Ndaba	9211	11.5	3.18	36.57	3.51	40.37
Shibe	5230	3.2	1.83	5.86	1.66	5.31

It should be noted that earnings rates estimated from the work of caregivers are not always higher than earnings rates estimated from level of education. For example, Eunice Shibe has as her highest level of education ‘incomplete secondary schooling’ (or grades 8 to 11). Therefore she should earn R39.14 per hour using the opportunity cost method that uses education levels. However, Eunice worked as a fruit and vegetable seller before her husband required care, and based on this fact she should earn R1.83 per hour using the median, and R1.66 per hour using the mean. In this case, having worked before she provided care for her husband actually reduced the value of her time spent in unpaid care work using the opportunity cost method. Clearly the opposite is also true. In some cases the earnings rates based on employment information are higher (Siphokazi Sibiyo and Ayanda Mbongeni are examples of this), but in cases where the work undertaken is of a low market value, using education levels to estimate the value of unpaid care work could result in higher values for this work.

6.5.3 The generalist method

Other analysis of the qualitative study data indicates that the time spent providing unpaid care by household caregivers consists of domestic work and nursing-type work (see Hunter, 2005). In this section five approaches were calculated as part of the generalist method (Appendix J provides the tables for the first four approaches). The aim was to find out whether it makes any difference which of the five approaches is used, and since the results from the approaches vary, although often by not that much, it shows that it does. The first two approaches defined the time spent in unpaid care work as consisting only of domestic-type work: the domestic worker minimum wage and next the wages of domestic helpers and cleaners were assigned to this time. However these approaches are inadequate as unpaid care work consists not only of domestic work but also of nursing-type work. The earnings rates for personal care workers were also assigned to the time spent undertaking unpaid care work, yet this too is inadequate because no account is taken of the domestic-type work that unpaid caregivers do. As a fourth approach the earnings rates for work similar to domestic-type work and nursing-type work were assigned to the unpaid care work time (following Budlender & Brathaug, 2002). While this is an improvement on the previous approaches, this earnings rate is assigned to the overall time spent in unpaid care work, taking no account of the proportion of time taken for domestic-type and nursing-type activities.

A fifth approach is chosen as the most appropriate one. It involves identifying the work of caregivers in the qualitative study according to nursing-type work and domestic-type work (see

Appendix K), and applying an earnings rate for personal care work to the nursing-type work and a domestic worker earnings rate to the domestic-type work.

Table 6.11 shows the breakdown of this work time per ill person. With regard to the different types of care provision, across ill people, on average 2.2 hours (or 29 percent of daily care provision time) was spent on domestic-type care work per day and 7.9 hours (or 72 percent of daily care time) was spent on nursing-type care work per day. For all but four of the ill people in the study the amount of nursing-type work exceeds the amount of domestic-type work as a proportion of overall unpaid care work. Therefore, substantially more nursing-type work as opposed to domestic-type work is undertaken by caregivers for ill people across study households – approximately three-quarters, as opposed to one quarter. This seems to be reflective of the terminal conditions of the ill people. As a percentage of overall care work per day across ill people in study households, domestic-type work ranged from eight percent to 58 percent across households, while nursing-type work ranged from 42 percent to 92 percent.

Table 6.11: Domestic-type work and nursing-type work as a proportion of daily unpaid care work time

Ill person	Hours of domestic-type work per day	Hours of nursing-type work per day	Domestic-type work as percent of UCW time	Nursing-type work as percent of UCW time
Yengwa	2.0	11.0	15.3	84.7
Sibiyo	1.5	6.2	19.7	80.3
Khubona	1.8	1.7	51.1	48.9
Luthuli	1.7	1.3	58.0	42.0
Mfeka	1.6	3.1	34.2	65.8
Mncube	2.1	3.5	37.5	62.5
Thwala	1.8	12.2	13.0	87.0
Cibane	5.6	5.3	51.2	48.8
Mngadi	3.0	8.4	26.2	73.8
Mbongeni	2.7	23.1	10.5	89.5
Ngidi-S	3.1	9.0	25.3	74.7
Ngidi-Z	2.0	6.6	23.5	76.5
Ndaba	1.7	20.0	8.0	92.0
Madondo	1.8	9.7	15.3	84.7
Shibe	1.9	1.3	58.4	41.6
Tembe	1.0	7.3	12.0	88.0
Dladla	1.9	5.2	26.8	73.2
Average	2.2	7.9	28.6	71.4

Note: domestic-type work and nursing-type work hours per household may not equal totals calculated elsewhere due to rounding

If the median earnings for ‘domestic helpers and cleaners’ (occupational code 9131) is applied to the average hours spent per day on domestic-type work per ill person it results in an amount of R7.55 per day (R8.05 per day using mean earnings). If the value of unpaid care work time is estimated for all the personal care workers in the September 2004 LFS (occupational codes 5131, 5132, 5133 and 5139), the median and mean hourly earnings for these workers are substantially higher than the earnings rate for domestic-type work. If these earnings rates are applied to the average daily hours of nursing-type work undertaken by caregivers in the study, it is valued at R60.28 if median earnings are used and R90.38 using mean earnings. Table 6.12 shows the earnings for this work per ill person, using the proportionate approach.

Table 6.12: Daily earnings rates for domestic-type work and nursing-type work assigned to daily unpaid care work time using the proportionate approach (generalist method)

Ill person	DW hrs/ day	NW hrs/ day	Hrs* median DW hourly earnings	Hrs* median NW hourly earnings	Total median value	Hrs* mean DW hourly earnings	Hrs* mean NW hourly earnings	Total mean value
Yengwa	2.0	11.0	6.86	84.21	91.07	7.32	126.26	133.58
Sibiyo	1.5	6.2	5.27	47.66	52.93	5.62	71.46	77.09
Khubona	1.8	1.7	6.07	12.95	19.02	6.48	19.41	25.89
Luthuli	1.7	1.3	5.96	9.61	15.58	6.36	14.41	20.78
Mfeka	1.6	3.1	5.57	23.88	29.45	5.94	35.81	41.75
Mncube	2.1	3.5	7.21	26.71	33.92	7.70	40.04	47.74
Thwala	1.8	12.2	6.25	92.87	99.12	6.67	139.24	145.91
Cibane	5.6	5.3	19.12	40.52	59.64	20.40	60.75	81.15
Mngadi	3.0	8.4	10.25	64.09	74.34	10.94	96.10	107.03
Mbongeni	2.7	23.1	9.26	176.34	185.60	9.88	264.40	274.28
Ngidi-S	3.1	9.0	10.50	69.00	79.50	11.21	103.46	114.66
Ngidi-Z	2.0	6.6	6.96	50.37	57.33	7.42	75.52	82.95
Ndaba	1.7	20.0	5.96	152.23	158.19	6.36	228.25	234.60
Madondo	1.8	9.7	6.03	74.34	80.37	6.43	111.46	117.89
Shibe	1.9	1.3	6.40	10.16	16.56	6.83	15.23	22.07
Tembe	1.0	7.3	3.45	56.04	59.49	3.68	84.03	87.71
Dladla	1.9	5.2	6.54	39.73	46.27	6.98	59.56	66.54
Average	2.2	7.9	7.51	60.63	68.14	8.01	90.91	98.92

Note: DW=domestic-type work, NW=nursing-type work

The overall value of the work of caregivers within study households using this proportionate approach – that is, adding the values of domestic-type work and nursing-type work per day – is

R68.14 per day if the median is used, and R98.92 if the mean is used. Compared to the respective amounts of R41.27 (using the median) and R36.28 (using the mean) which are obtained if a wage rate for both domestic-type work and nursing-type work is applied to the total hours worked, without dividing it into the different types of work, it is clear that the proportionate approach arrives at a higher value for the work of caregivers within households. This is because nursing-type work has a higher earnings rate than domestic-type work and the combination of the two, and account is taken of the greater amount of time spent on nursing-type work as opposed to domestic-type work when the proportionate approach is used.

6.5.4 The specialist method

The specialist method focuses on the activity and not on the person undertaking the activity. Budlender (2008) describes the specialist approach as complex, and points to the difficulty of finding the appropriate paid workers for all tasks, and this is confirmed in this section. A number of occupational codes in the LFS were selected that represented work similar to the different care activities undertaken by caregivers in the qualitative study. These occupational codes are slightly different to the ones selected for a similar Canadian study. Fast and Frederick (1999, p. 3) chose the following occupations in the Canadian context to derive replacement costs: janitors, charworkers and cleaners for ‘preparing meals and housework’; taxi drivers and chauffeurs for ‘shopping and transportation’; nursing aides and orderlies for ‘personal care’. In this study, instead of a code that contains different types of activities (such as ‘preparing meals and housework’), codes specific to one activity have been applied (such as ‘preparing meals’, for which there is a code ‘cook’). Likewise for ‘shopping and transportation’ there are two codes: ‘buyer’ and ‘messengers, package and luggage porters and deliverers’. The Canadian study uses ‘nursing aides and orderlies’ for personal care work, yet there is no code as specific to the tasks undertaken in the LFS and ‘nursing and midwifery professionals’ is used.

Appendix L gives the care activities undertaken by the caregivers in the study and the South African Standard Classification of Occupations codes applied to each activity using the specialist method. Code 3226 (‘physiotherapists and related professionals’) was initially selected for the task ‘rubbing/massaging’, but this occupational code does not occur in the September 2004 LFS. Therefore the next closest code was selected for this care task: ‘nursing and midwifery professionals’ (code 2230).

In Table 6.13 can be seen a breakdown of the number of respondents in the LFS for each relevant occupation and the number undertaking these occupations. The mean and median earnings per hour for each occupational code are also shown. The preferred code for travelling to and from health facilities and waiting at health facilities is 5142 (companions and valets) but there are no respondents in the LFS who did this work and therefore code 9151 (messengers, package and luggage porters and deliverers) was chosen in its place. In some cases the number of LFS respondents was low, and these findings should therefore be treated with caution. However, as with the methods applied in the previous sections, despite the fact that these estimates are likely to be unreliable, a decision was taken to obtain a finding with caveats rather than none at all as part of an effort to be comprehensive in the approaches covered.

Table 6.13: Number of respondents and earnings assigned using the specialist method

Code	Occupation	n (unweigh-ted)	N (weigh-ted)	Median hourly earnings	Mean hourly earnings
2230	Nursing & midwifery professionals	3	962	26.70	24.56
3416	Buyers	12	7,596	14.24	11.98
5122	Cooks	27	8,684	5.72	6.64
9133	Hand launderers and pressers	4	662	6.57	9.50
9151	Messengers, package & luggage porters & deliverers	6	3,951	5.40	11.35

As with the generalist approach, with the specialist approach no sex disaggregation occurs. It can be seen that the highest mean and median wages are earned by nursing professionals. The earnings rates for buyers are about half those of nursing professionals. The earnings rates for cooks, hand launderers and pressers, and 'messengers' are all quite similar, using the median and the mean.

Table 6.14: Proportion of time in minutes undertaking unpaid care work by profession (specialist method)

Ill person	Nursing	Buying	Cooking	Laundering	Messenging
Yengwa	616.6	3.3	45.6	116.3	0.4
Sibiyo	334.8	0.0	40.0	69.4	22.8
Khubona	79.8	16.0	22.0	88.3	1.9
Luthuli	45.6	4.4	30.0	86.5	13.4
Mfeka	187.8	7.0	0.0	81.7	8.7
Mncube	180.0	6.0	30.0	86.6	33.6
Thwala	670.3	0.0	60.0	86.6	22.7
Cibane	288.6	2.0	30.0	86.4	246.1
Mngadi	488.0	0.0	16.0	95.1	84.3
Mbongeni	1,365.4	1.1	21.3	141.8	19.2
Ngidi-S	542.6	0.0	0.0	96.3	87.4
Ngidi-Z	396.1	0.0	0.0	96.3	25.4
Ndaba	1,195.0	0.8	2.1	88.1	15.3
Madondo	404.6	0.0	180.0	90.7	14.7
Shibe	79.9	0.7	0.0	111.3	0.0
Tembe	435.7	0.0	5.0	47.8	12.5
Dladla	312.4	0.0	0.0	87.3	27.1
Average (min)	448.4	2.4	28.4	91.6	37.4
Average (hrs)	7.5	0.0	0.5	1.5	0.6
% of total time	73.7	0.4	4.7	15.1	6.1

Table 6.14 shows the time spent per ill person on care activities defined according to the different professions. There is variation across ill people, but it is clear that the amount of time spent

undertaking the work of professional nurses is by far the greatest in terms of daily unpaid care work – about three-quarters of the total time spent on care activities. In two households the time spent on nursing work exceeds 19 hours per day. Apart from the work of nursing professionals, the time spent laundering is the next greatest (15 percent of the total time). In most households about one-and-a-half hours are spent undertaking laundering work for the ill person per day. Time spent doing the work of cooks and messengers is approximately the same as a proportion of overall care time, and very little in all (around half an hour per type of specialist work). The work of buyers takes up the least amount of daily care time, a very minimal two minutes per day. Table 6.15 shows what the value of these different types of work would be if the median earnings rates shown in Table 6.14 are assigned to this care time.

Table 6.15: Median earnings assigned to daily unpaid care work time by profession (specialist method, Rands)

Ill person	Nursing	Buying	Cooking	Laundering	Messenging	Total value
Yengwa	274.39	0.78	4.35	12.73	0.04	292.29
Sibiyo	148.99	0.00	3.81	7.60	2.05	162.45
Khubona	35.51	3.80	2.10	9.67	0.17	51.25
Luthuli	20.29	1.04	2.86	9.47	1.21	34.87
Mfeka	83.57	1.66	0.00	8.95	0.78	94.96
Mncube	80.10	1.42	2.86	9.48	3.02	96.89
Thwala	298.28	0.00	5.72	9.48	2.04	315.53
Cibane	128.43	0.47	2.86	9.46	22.15	163.37
Mngadi	217.16	0.00	1.53	10.41	7.59	236.69
Mbongeni	607.60	0.26	2.03	15.53	1.73	627.15
Ngidi-S	241.46	0.00	0.00	10.54	7.87	259.87
Ngidi-Z	176.26	0.00	0.00	10.54	2.29	189.10
Ndaba	531.78	0.19	0.20	9.65	1.38	543.19
Madondo	180.05	0.00	17.16	9.93	1.32	208.46
Shibe	35.56	0.17	0.00	12.19	0.00	47.91
Tembe	193.89	0.00	0.48	5.23	1.13	200.72
Dladla	139.02	0.00	0.00	9.56	2.44	151.02
Average	199.55	0.58	2.70	10.03	3.36	216.22

If unpaid care work is valued in this way, the work of nursing professionals undertaken by caregivers comes to an average of R199.55 per day. In two cases the work of nursing professionals would be valued at over R500 per day, which reflects the amount of time spent on this type of work but also the relatively high earnings rates when compared to the rates of pay for the other occupations listed here. The caregivers' laundering work would be valued at R10.03 per day, while the other specialist work (messenging, cooking, and especially buying) would be valued at even lower levels due to the fact that, on average, only a minimal amount of this work is undertaken on a daily basis, and the rates of remuneration are not very high for these occupations. The total average value of the care work is R216.22 per day if specialist median earnings rates are assigned. Likewise, Table 6.16 shows what the value of these different types of work would be if mean earnings rates are assigned to the time spent in unpaid care work.

Table 6.16: Mean earnings assigned to daily unpaid care work time by profession (specialist method, Rands)

Ill person	Nursing	Buying	Cooking	Laundering	Messenging	Total value
Yengwa	252.39	0.66	6.87	18.41	0.08	278.41
Sibiyo	137.04	0.00	6.03	10.99	4.31	158.37
Khubona	32.66	3.19	3.31	13.98	0.36	53.51
Luthuli	18.67	0.88	4.52	13.70	2.53	40.29
Mfeka	76.87	1.40	0.00	12.94	1.65	92.85
Mncube	73.68	1.20	4.52	13.71	6.36	99.47
Thwala	274.38	0.00	9.04	13.71	4.29	301.42
Cibane	118.13	0.40	4.52	13.68	46.55	183.29
Mngadi	199.75	0.00	2.41	15.06	15.95	233.17
Mbongeni	558.90	0.22	3.21	22.45	3.63	588.42
Ngidi-S	222.10	0.00	0.00	15.25	16.53	253.88
Ngidi-Z	162.14	0.00	0.00	15.25	4.80	182.19
Ndaba	489.15	0.16	0.32	13.95	2.89	506.47
Madondo	165.62	0.00	27.12	14.36	2.78	209.88
Shibe	32.71	0.14	0.00	17.62	0.00	50.47
Tembe	178.35	0.00	0.75	7.57	2.36	189.03
Dladla	127.88	0.00	0.00	13.82	5.13	146.82
Average	183.55	0.49	4.27	14.50	7.07	209.88

Using mean earnings rates, the total average value of this work undertaken by the caregivers in the study is R209.88 per day. The work of nursing professionals is valued at an amount very close to this. The work of cooks, messengers and buyers that caregivers in the study undertook was not substantial and not frequently done, and it is relatively poorly paid and therefore its value is not great.

6.5.5 Comparing results from the various methods

By applying all four methods, as well as variations of the methods, the aim has been to assess which method is most appropriate to KwaZulu-Natal. In this section the different methods are compared through an assessment of the mean and median earnings rates generated by the various methods. Specifically, understanding what explains the difference between the methods will be a central focus of this section. Also considered is which method is appropriate to the limitations of the LFS data.

Table 6.17: Earnings across methods (Rands)

Method	Approach	Median hourly earnings	Mean hourly earnings	Median earnings as % of mean earnings
Av earnings (emp)	Female average earnings	4.58	8.89	51.5
	Male average earnings	7.92	12.95	61.2
Av earnings (self-emp)	Female average earnings	3.43	6.14	55.9
	Male average earnings	6.10	12.73	47.9
Opportunity cost - education	Male metro – no schooling	3.05	7.60	40.1
	Male metro – primary/inc primary	9.15	10.60	86.3
	Male metro – inc secondary	8.47	10.25	82.6
	Male metro – matric plus	15.26	18.03	84.6
	Male non-metro – no schooling	3.62	6.37	56.8
	Male non-metro – primary/inc primary	4.09	7.34	55.7
	Male non-metro – inc secondary	6.10	9.15	66.7
	Male non-metro – matric plus	11.44	16.99	67.3
	Female metro – no schooling	4.13	4.22	97.9
	Female metro – primary/inc primary	3.81	4.89	77.9
	Female metro – inc secondary	4.16	6.11	68.1
	Female metro – matric plus	8.24	12.04	68.4
	Female non-metro – no schooling	3.05	3.86	79.0
	Female non-metro – prim/inc primary	3.24	4.24	76.4
	Female non-metro – inc secondary	3.81	5.93	64.2
	Female non-metro – matric plus	10.30	15.72	65.5
Opportunity cost – work	Female – inst. based pers. care workers	18.12	13.49	134.3
	Female - traditional med. practitioners	3.81	4.74	80.4
	Female – salespersons	1.83	1.66	110.2
	Female - farm-hands & labourers	3.18	3.51	90.6
Generalist	Proportionate-dom-+ nursing-type work	3.43+7.63	3.66+11.44	93.7+66.7
Specialist	Nursing	26.70	24.56	108.7
	Buying	14.24	11.98	118.9
	Cooking	5.72	6.64	86.1
	Laundering	6.57	9.50	69.2
	Messenging	5.40	11.35	47.6

Table 6.17 shows the mean and median earnings rates across the approaches for all the methods. The results are likely to differ from Budlender's (2008) findings because this small localised sample is not nationally representative. However, the results are compared to Budlender's (2002) recommendations on what the lowest, highest and widest range of estimates should be.

The lowest earnings rates, using both the mean and median, are for a female salesperson, using the opportunity cost method that uses employment information. This finding is in contrast to Budlender's (2002) forecast that the generalist method will produce the lowest values of all the methods. While domestic workers may be at the low end in terms of earnings, there were caregivers in the qualitative study who were earning even less informally, hence the difference from Budlender's recommendation.

The highest earnings rates using both mean and median are for nurses using the specialist method. Since the bulk of caregivers' activities consist of nursing type work and the earnings rate for nurses is the highest for all the occupations considered for the specialist method, the value of unpaid care work is very high using this method. Part of the reason why this profession has the highest earning rates is because the earnings for nursing and midwifery professionals was used and not the earnings of nursing assistants. This is because there were no nursing assistants in the September 2004 LFS. If there had been such an occupational code it would have reduced the earnings rates substantially. This finding is in contrast to Budlender's description of the opportunity cost method as the one that produces the highest values, but this could be attributed to the occupational code selected, as described above.

The widest range of estimates, using both the median and mean earnings rates, is produced by the specialist method, reflecting the wide array of professions cited. This is in contrast to Budlender's prediction that the opportunity cost method gives the widest range of estimates. However she qualifies this by stating that it depends on the skills and the opportunity wage of the individual performing it. Budlender's recommendation would have been true for this study too, if the nursing and midwifery professionals code had not been used in the specialist method, since the opportunity cost method that uses education information produces the 'next' widest range of estimates. A lot therefore depends on what occupational codes are available to be used, and therefore much depends on what the limitations of the data set are from which earnings rates are imputed. Clearly the limitations of the September 2004 LFS data for KwaZulu-Natal have steered the findings in a certain direction, accounting in part for the differences from Budlender's (2002) description of what the findings are likely to be.

What explains the difference between the methods? The two average earnings methods both result in a single earnings rate per sex, and for the remainder of the methods there are an array of earnings rates determined by level of education or the selected occupational codes. The occupational codes are determined to some extent by the occurrence of cases in the LFS data.

Which methods are appropriate to the limitations of the LFS data? For the opportunity cost approach that uses employment information and the specialist method, the sample sizes were very small, so small as to be considered unreliable, which brings into question the use of these earnings rates. Nevertheless, these approaches were still applied to the study data for the sake of being comprehensive. The findings from these approaches should however be treated with caution, particularly with regard to the particular professions that had very low sample sizes in the LFS, and this limits the usefulness of these approaches using the LFS data. The two average earnings methods, the opportunity cost method that uses education information and the selected generalist method all seem robust when using the LFS data.

6.5.6 The method and earnings rates most appropriate for the African poor in KwaZulu-Natal

Which is the method most appropriate to the eastern seaboard region in South Africa, when placing a value on unpaid care work time? As a reminder, Budlender (2008) indicates that the average earnings and opportunity cost methods have in common that they seek to put a value to the time that could have been spent in paid work if the caregiver was not providing care. The generalist and specialist methods estimate the value of care provision if the care service were to be purchased.

The various methods present particular challenges. Earnings rates for the average earnings method (using earnings of the employed and the self-employed) are much higher for males than females because of the marked earnings differentials by sex across occupations, which are partly caused by men and women tending to be in different occupations and sectors. However, because of the minimal time spent in providing unpaid care by males, and because females spend so much time providing unpaid care, the value of the work of males is much lower than that of females using the average earnings method. Despite this, the average earnings method – especially the approach that uses the earnings of the self-employed – tends to undervalue women's unpaid care of ill people. Nevertheless, the average earnings method using the earnings of the self-employed represents an important innovation for the South African context.

With regard to the opportunity cost method that uses education information, having a matric and over as the highest education level has a large impact on hourly earnings but very few of the household caregivers in the study have this level of education. Since most of the household caregivers have very low levels of education, this method results in a relatively low value for the work of most caregivers.

Only a few caregivers in the qualitative study were in employment at the start of the illness period, and therefore the opportunity cost findings based on employment information do not give an idea of the value of unpaid care work for all caregivers. Apart from the institutional-based personal care worker, the caregivers in employment would not have earned very much had they been working. As already noted, earnings rates based on occupation are not always higher than earnings rates estimated using education levels. This means that using the education approach, the value of the time spent in unpaid care work by an unemployed person could be higher than the value of the same time spent by an employed person using the employment approach. The opportunity cost method is therefore problematic in the South African context where very high rates of unemployment prevail.

A further difficulty of the opportunity cost method that uses employment information is that it is not likely that the very long hours spent each day in unpaid care work would have been spent on the relevant occupation. For eight of the ill people more than nine hours were spent per day providing unpaid care, longer than the maximum length of a work day of nine hours (according to the Basic Conditions of Employment Act). Therefore the calculated values of time spent in unpaid care work do not accurately represent the value of time in employment that has been lost.

Changing focus to the two methods that attempt to estimate the value of unpaid care work if the household bought in the care, the generalist method that uses a proportionate approach puts the value closer to that of a personal care worker than a domestic worker, which is appropriate considering that about three-quarters of the work of caregivers consists of nursing type work. This approach therefore takes account of the time weighting of work instead of finding an average of domestic worker and personal care worker wages and assigning it to the entire time spent in unpaid care provision.

The specialist method is not as appropriate as the generalist method which uses the proportionate approach. While the specialist method would be the best method to estimate the value of the unpaid care work for a caregiver who is a nurse, most of those undertaking unpaid care work do not have the knowledge nor the skills of professionally qualified nurses, and many of the tasks undertaken by the caregivers are basic domestic tasks, and this would therefore not seem to be an appropriate way to value their work.

With regard to mean and median earnings rates, it has been noted (see Budlender, 2008) that using the median to estimate earnings is better than using the mean – since earnings tend to be skewed toward the lower end, because the mean tends to over-state the true ‘middle’, and because using the median avoids the difficulty of having to deal with outliers. In Table 6.17 the median earnings rate is estimated as a percentage of the mean earnings rate in order to get an idea of how far apart the two estimations lie. This is not a perfect approach but simply one which helps to understand the difference between the two. Smaller percentages indicate that the distance between the two measures is larger, while larger percentages indicate that the difference between the two is relatively small.

In 87 percent of cases the median earnings rate is lower than the mean earnings rate. On average, for all approaches for which mean and median earnings are estimated within the various methods (except the proportionate approach, for which it is difficult to do so) the median earnings rate is 76 percent of the mean earnings rate. It is only with regard to some of the approaches that the difference between the two earnings rates is great. For instance, the median earnings for 'male metro – no schooling' using the opportunity cost approach that uses education information is 40 percent of mean earnings. This indicates that the mean is overstating the true middle by just under half. In this case it would be safer to take the median earnings rate as a reference point. On the other hand, the median earnings for 'female metro – no schooling' using the same approach is 98 percent of mean earnings, indicating that the two earnings rates fall very close together and there is not much difference between them. It also means that the mean earnings lie very close to the midpoint. In this case it would be relatively safe to use the mean earnings rate in addition to the median earnings as the reference point. However, in 13 percent of cases the median earnings rate exceeds the mean earnings rate. For instance, for female institutional based personal care workers (using the opportunity cost method that uses employment information) the median earnings rate is 134 percent of the mean earnings. Here the mean earnings rate is lower than the midpoint. Therefore the mean is understating the true middle, and here again the median earnings rate is preferred. Finally though, it is important to note that with some of these categories, for instance 'messengers' using the specialist method, there are so few observations that neither the mean nor the median is reliable.

Based on these study findings, conclusions can be drawn relating to the method for valuing unpaid care work most appropriate to the African poor in KwaZulu-Natal. To begin, the methods that value unpaid care work by asking what it would cost to buy in the care are preferable to the methods that seek to find out what the value of caregivers' time would be if they were not providing unpaid care. This is simply because of the very high unemployment levels that prevail in South Africa, and because of the low chance of employability of most of the caregivers. In other words, it is unlikely that many of the caregivers who are unemployed would find work easily, especially considering their low levels of education.

With regard to the approach that seeks to find out what it would cost to buy in the care, the specialist approach would seem inappropriate in the South African context, not least because of the high unemployment levels already referred to. It is highly unlikely that these caregivers would be remunerated at such high rates of pay for the different activities they undertake – the market would simply not see this through. The generalist method is a more appropriate method to adopt, since the work of personal care workers and domestic workers comprises most of the activities that they undertake, and because the earnings rates estimated for this work are, for the most part, in line with market-related wages for this type of work. Of all the approaches that fall within the generalist method, the proportionate approach – which is essentially a simple specialist approach – seems most appropriate and accurate in terms of valuing this work among the African poor in KwaZulu-Natal. Unpaid care work consists not simply of domestic work, nor is it entirely the work of personal care workers. It is made up of both types of work and it therefore seems reasonable to value it proportionately according to how these different types of work are weighted. In other words, this approach represents well the hours spent on the different activities that comprise unpaid care work. It neither values unpaid care work too high nor too low – and it therefore seems to be an appropriate input-related method to choose for the valuation of the work that goes into caring for ill people in the home.

It also seems that the median earnings rate is the preferable rate to use when valuing the time spent in unpaid care work for ill people within the home. Whether the mean earnings rate falls above or below the median earnings rate (whether it over- or under-states the true middle), it is the latter that represents the true middle. Unlike the mean, the median is not affected by outliers. For the types of employment for which earnings are estimated in this study, earnings are very much skewed towards the lower end, and the mean is therefore inappropriate to use. These are the reasons Budlender (2008) gives for choosing the median and these are the reasons that apply in this study as well. Therefore in section 6.8 in which costed unpaid care provision is estimated per method, only median earnings are applied.

6.6 METHODOLOGY FOR COUNTING FINANCIAL COSTS

Netten (1993) earlier defined financial costs of unpaid care work to include goods and services which would not have been purchased in the absence of disability, distinguishing between consumption goods and capital goods. Some of the consumption goods paid for within households for the ill person's care were counted over the illness period. In this section, how these costs have been calculated as a daily financial cost per ill person will be detailed.

6.6.1 Tools used

As noted, the central tool used to collect financial cost information was a financial cost document (see Appendix F). Most of the information contained in the financial costs document was derived from the care survey and then verified with the caregiver(s). Essentially, the information provided through these tools should be the cost of an item or a trip and the frequency with which this was purchased or undertaken.

Where the financial costs document and the survey differed in the costs stated, the information was taken from the financial costs document, as this was the chief source of information on financial costs, the contents of which had been verified with the caregiver(s). At times there was a disparity between findings on the same issue, obtained from the different data collection tools. For instance, with regard to the same visit to a health facility, in the Madondo household the following occurred: in the visits to health facilities section in the care survey (see pages 320 and 321 of Appendix D) the frequency was stated as "*once a month*", in the oral medication section of the care survey (page 324 of Appendix D) "*once only*" was stated, and in the mini-events map "*twice over the illness period*" was stated. When it was necessary to choose between information from different parts of the care survey and the mini-events map, and when estimates were not very different, the care survey information was given precedence over mini-events information, as with the approach to counting time spent in unpaid care provision. Moreover, where the findings differed within the care survey, the sections covering visits to health facilities were given priority over the oral and non-oral medication sections (pages 324 and 325 of Appendix D respectively). However, when the sections on visits to health facilities were vague, and the sections on oral and non-oral medication were specific, the latter information was chosen.

Indirect costs that were not counted are the economic costs that having to provide care bring about. For example, in the Sibiyo household when Mzwandile required a lot of care his mother said she had to employ someone to do the cleaning and to care for her grandchild who was disabled and on whose behalf she received a care dependency grant. In line with the approach described above, the cost of employing someone to care for the grandchild was not counted. Moreover, in the Mngadi household, Gladys, the ill person's cousin, travelled from Johannesburg to Urban 2 to care for her cousin. These transport costs to and from the ill person's home were also not counted.

6.6.2 Financial costs counted

The financial costs of the following were counted for the care of each ill person, where applicable:

- Items to do with care provision (e.g. plastic sheeting to cover the bed, disinfectant) including items not usually bought (e.g. slippers, blankets, bedpan/bucket);
- Medication or ‘treatment’ or other medical expenses;
- ‘Special’ food or drink for the ill person (even although other household members may have eaten some of this);
- Trips to buy special food or care items;
- Trips to health facilities for the ill person or with the ill person if he/she was accompanied by the caregiver or someone else from within or outside of the household;
- Consultations for the ill person at health facilities, when accompanied;
- Telephoning relatives about the ill person’s condition.

The following financial costs were not counted:

- The cost of food that was bought for all household members, which the ill person may also have eaten. Special food was bought expressly for the ill person because of their condition, while food for the household was not, and it is difficult to work out proportionately what the ill person’s consumption of this would have been, in addition to the fact that they would have eaten anyway if they were not ill.

- Medical expenses for the Mbongeni household which had access to a medical aid.

- The costs of washing powder and soap. It is likely that more washing powder or soap was used and therefore having to be bought because of the ill person, since ill people tend to generate more washing than those who are well, because of soiled clothing and linen, for example. If the cost of washing powder and soap used for all household members was to be made specific to the ill person some type of adult equivalence would have to be calculated, and it was not possible to work out how much additional washing powder the ill person used compared to other household members, since this information was not obtained.

- Costs not directly related to unpaid care provision. For instance, a trip to apply for a disability grant or a trip to get a medical report to obtain the disability grant. While these activities could be argued to be care activities as they could assist in the care of the ill person, it could also be argued that this is not the case because these were not costs related to care for the ill person. A conservative approach was applied in this instance, and these costs were not counted.

- Costs associated with visiting an ill person in hospital (if the ill person was admitted to hospital). Only costs associated with unpaid care provision in the home were counted.

- The cost of an item that was bought years ago for a reason other than care provision, but which was used for care purposes (e.g. a bedpan or a bucket).

- Costs relating to the ill person's care but picked up by someone living outside of the household. For example, in the Sibiyo household Balungile, the ill person's sister who lived in Cape Town, regularly bought medication for the ill person. Only direct costs carried by household members were counted.

6.6.3 Assumptions/approaches used

The same basic approach and assumptions used to calculate time spent on care activities were used to calculate financial costs. Examples are as follows:

- If a range of frequencies or costs was given, the average of these was calculated. For instance, if an item was bought every two to three months, it was counted as having been bought every two-and-a-half months.

- If the frequency at which something was bought was not stated, or if the frequency was stated but the meaning was ambiguous (e.g. "*once a month, when necessary*"), and if the cost of the item was stated, it was assumed that the item was bought once only, since, having been mentioned as a cost, it was certain that it was bought at least once over the illness period.

- In some households the frequency with which an item was bought was not stated, and therefore this frequency had to be estimated. For instance, in the Ngidi household cabbage was bought once a week, if the household had the money. Therefore it was assumed that cabbage was bought once every two weeks.

- For the households in Rural 3 a different cost was stated for using a taxi to the same location. Although it may not be accurate to do so, these costs were kept at the amount stated, as these are the answers the respondents gave, and answers which the researcher was ethically bound to use.

- In the Ndaba household the caregiver bought groceries on pension pay day, but she did not take transport every time, but sometimes walked. Therefore, it was assumed that she took transport every second time.

- In the Madondo household, the mother and father of the ill person were both pensioners and both went to buy groceries that included special food on pension pay day. However only the costs to buy groceries of one, and not both, of the ill person's parents were calculated, as this was a care activity that could be undertaken by one person only.

- For one month in the Ngidi household two sisters were cared for by the same caregiver. The cost of care items that were used for the care of both ill people over this time was divided equally between the two.

- In the Thwala household the caregiver made the ill person ‘amahewu’ (or Zulu beer) from mielie meal, but since the amount of mielie meal used to make the amahewu was not known it was not possible to calculate its price, and it was therefore not counted. Likewise, in the Shibe household, the ill person ate bread crumbs, but the amount of breadcrumbs was not known and so it was not possible to estimate this cost.

- If the cost of a trip was missing it was left as missing. This is because it was not certain what form of transport was used, and even if it was assumed that a taxi was used, it was difficult to obtain this information after having completed fieldwork in the study area.

- If the cost of an item was missing, and it was not stated elsewhere among study households the aim was to obtain this cost by phoning shops where it may have been purchased. However, in the one instance in which this was necessary it was not possible to obtain a price because the quantity of the item was not provided.

- In one household the cost of an item was missing: E-pap obtained at a pharmacy in Durban by the Mfeka household. However, because the quantity was not specified, its price was not ascertained, and its possible cost was excluded from the cost calculations.

- In the Mbongeni household the caregiver went once a week to buy groceries in Highflats, and she also went once a week to the traditional healer and to the private doctor, also in Highflats. It was assumed that all of these visits occurred on the same day each week.

- The cost of a trip to buy an item not frequently bought (e.g. slippers, a towel) was not counted as a trip that was made for this purpose alone. Rather, it was assumed that purchasing these items was slotted in with other regular trips to shops, such as trips to buy groceries.

- Respondents were not always specific in terms of stating the frequency with which something was purchased or undertaken, and therefore some study information is missing. For example, the following was stated with regard to frequencies across study households: “*bought if* *needed*", "*seldom bought*", "*not often*", "*made now and again*", "*if has a headache*", "*once a month, when necessary*", "*when there was pain*", "*a luxury*" and "*bought very rarely*". In these instances, this information was recorded as missing.

6.7 COUNTED FINANCIAL COSTS

Based on the approach described in section 6.6, total financial costs per ill person were calculated and this amount was divided by the number of days in the illness period. In this way a daily financial cost of care provision was calculated. Table 6.18 shows these financial costs.

Table 6.18: Daily financial costs per ill person (Rands)

Household	Daily financial cost per ill person	Monthly financial cost per ill person
Yengwa	32.55	995.84
Sibiyo	36.25	1,108.95
Khubona	14.12	431.86
Luthuli	13.48	412.27
Mfeka	25.96	793.98
Mncube	23.36	714.43
Thwala	14.28	436.78
Cibane	6.99	213.79
Mngadi	78.16	2,390.91
Mbongeni	63.47	1,941.70
Ngidi-S	13.48	412.37
Ngidi-Z	2.74	83.81
Ndaba	20.54	628.19
Madondo	15.04	460.18
Shibe	2.57	78.64
Tembe	11.69	357.55
Dladla	14.22	434.86
Average	22.75	699.79

Daily financial costs ranged from R2.57 per ill person in the Shibe household (or R83.81 per month) to R78.16 per ill person in the Mngadi household (or R2,390.91 per month). There is quite a wide variation in the estimates, and since the sample is small the average is not very dependable, since simply adding one other outlier can have a big effect on the average.

In the Shibe household, where the least was spent on an ill person’s care, Simon and his wife, Eunice, had five children, and she was pregnant with a sixth. At the time of the study the only income to the household was two child support grants and any money that could be made from selling ‘vetkoeks’ made by Eunice for sale at the nearby school. In this household relatively little was spent on Simon’s care over the 92 days in which he received ‘a lot of care’, for the most part it seems because there was relatively little to spend. In all, monthly spending on Simon’s care came to 23 percent of the grant income per month. Items bought ranged from food such as ‘maas’, pain-relief medication and non-oral treatment. A blanket was bought for R80, and two trips were undertaken to buy the items stated.

The picture was different in the Mngadi household where the most was spent on an ill person’s care across households. Over the illness period the bulk of spending was on medication: a supplement immune booster (R800), ointment (R14), cough mixture and tablets for appetite (R30), and each of these items were purchased three times. Transport to get this medication was R10 per trip. A trip was also made to a traditional healer for medication worth R25. Therefore the total amount spent on medication and transport to get this medication was R2,681 over the illness period. In all, R698 was also spent on consultations with various health providers: three consultations with a different traditional healer cost R50 each, as well as R15 for transport each time; consultations with a private doctor cost R135 and transport was R38; three trips to the nearby public hospital cost R80 each in a hired taxi, while each consultation at the hospital cost R30. In comparison very little was spent on items other than medication and consultations. R65, including transport costs, was spent on special food for Thembi, while R45 was spent on a bed pan and on its acquisition. Finally, R100 was spent on telephone calls to inform relatives of Thembi’s condition.

In the Mncube household an amount of R23 was spent per day on the ill person’s care, close to the average of financial costs across households. In this household the bulk (R1,023) of spending on Sanaz’s care was on consultations with health care providers and related transport costs. A private doctor was consulted a number of times and together with transport costs this totalled R441; a nearby public hospital was visited half a dozen times and consultation fees and transport costs together totalled R546; a number of trips to a public clinic cost R36. Special food and transport to obtain it was the next biggest overall cost (R840). Finally, spending on medication was also noteworthy. Medication from a traditional healer (R50 bought twice) was purchased by a neighbour who made two trips (costing the household R13 each) to obtain it on behalf of a group of HIV-positive women living in the area, of whom Sanaz was one. Pain killers and other commercially produced immune boosters were purchased locally.

In section 5.2.1 the grant and remittance income to households and employment within households was outlined. From Table 5.12 it is clear that in households such as the Khubona's where Patricia's old age pension is the only stated income source or the Dladla's where the old age pension and the child support grant are the only income sources, it is possible to be relatively conclusive about total household income. Fifty-eight percent of household income is spent on Sibusizo's care in the Khubona household while 45 percent of household income is spent on Bulelani's care in the Dladla household. Grant income is enabling these households to meet the costs of some care provision within the home, but probably not as much as needed.

In both the Dladla and the Tembe households the main income sources were a 'large' grant and a child support grant. It seems that other income may have been received when necessary – from a sister who worked in the area in the first household, and from the ill person's mother who lived nearby in the second. However it is not known how much these amounts were and when they were received. If the grants are taken to be the only income sources to these households each month, then the monthly financial expenses on the cared-for constitute 39 and 48 percent of monthly household income respectively. In the Tembe household the only household members are three adults, and therefore the ill person's monthly costs comprise just over a third of household income. However in the Dladla household there are six adults and two children living off this income, and here the ill person's care costs the household almost half of its monthly income. Clearly, providing for the care of an ill person within the home has different implications for different households depending on the income to the household and the needs apart from the ill person within the household.

Currently the Treasury and Statistics South Africa are considering introducing a poverty line for South Africa. In February 2008 the Statistician General of Statistics South Africa announced that the design of the pilot poverty line was nearing completion (Lehohla, 2008), however no further information on the progress on this could be established. Since the total household income is not known for all study households, and as there is no national poverty line, the monthly financial costs of care provision per ill person are compared to: (1) an indigence level; (2) the value of the old age pension in order to illustrate the proportions of these measures financial costs on ill people's care constitute. At present, in some municipalities 'indigent' households are defined as those with incomes below R800, and are meant to be distinguished from other households and given a subsidy in respect of water and electricity (Budlender, 2008).

In most of the study households substantial portions of the old age pension and the indigence level are spent on the care of ill people. These daily costs ranged from a tenth in the Shibe household to about three times the indigence level and the value of the old age pension (in the Mngadi household), among study households. Strikingly, in four of the households the monthly amount spent on the ill person substantially exceeded the value of the old age pension and the indigence level. In the Khubona household where the old age pension was the only income source, the financial costs relating to the ill person's care came to 58 percent of the old age pension – more than half of the income that the household received, a substantial amount for this household.

Finally the KIDS quantitative data provides some useful information on expenditures on ill and dying people. However, comparing the expenditures from the quantitative and qualitative studies is problematic because in the KIDS the cause of death or ill health was not recorded and attributable to a much broader range of illnesses than in the qualitative study (that is, it included all illnesses and not only those associated with HIV/AIDS), and therefore the expenditure data is not directly comparable. The highest average expenditure for dying people was on health care providers (made for under half of the dying), followed by expenditure on medicine (for over half), followed by expenditure on hospital accommodation (for half). While less on average was spent on transport, this expenditure was made for 80 percent of those who died, pointing to the importance of money for transport for those receiving HBC if they are to access health facilities. A tenth of those who died in the quantitative study received state assistance in the form of a government grant. Since the remainder of those who died were unlikely to be receiving an income, the expenditures outlined above were probably provided by other household members or by non-household members. The highest average expenditure for ill people was on medicine (for a third of ill people), followed by health care providers (for a quarter), followed by transport (for over half) and hospital accommodation (for a tenth).

6.8 COSTED UNPAID CARE PROVISION

In this section the financial costs of providing care for the ill person borne by the household and the value of the care provided to the ill person by one or more household caregivers will be added, per method and per specific approach, in order to arrive at various costs of unpaid care provision. The value of unpaid care provision is based on median earnings and not mean earnings, as explained in section 6.5.6. In this section total costs are reflected as monthly costs, where a working month is taken to be all the days in a month including weekends and public holidays, since this is how unpaid care within the home is provided. It must be remembered that these costs of unpaid care provision represent the labour and financial costs of caring for people in end-stage HIV/AIDS over intensive illness episodes, and as such are likely to be higher than the same costs calculated for all of those receiving HBC. Nevertheless, the costs calculated are highly relevant since the bulk of HBC in KwaZulu-Natal is for people with HIV/AIDS.

Table 6.19: Costed unpaid care provision – all methods (median earnings, monthly)

Ill person	Average earnings (employed)	Average earnings (self employed)	Opportu-nity cost (education)	Opportu-nity cost (employ-ment)	Generalist (propor-tionate)	Specialist
Yengwa	2,993.83	2,500.66	2,902.20	2,021.33	3,781.54	9,936.86
Sibiyo	2,201.68	1,927.29	2,763.29	4,157.49	2,728.02	6,078.23
Khubona	955.89	826.24	757.84	n/a	1,013.75	1,999.67
Luthuli	923.28	799.31	708.37	n/a	888.95	1,479.03
Mfeka	1,466.61	1,297.75	1,417.66	n/a	1,694.99	3,698.94
Mncube	1,499.15	1,302.16	1,269.61	1,028.07	1,752.20	3,678.45
Thwala	2,398.26	1,905.76	1,863.94	n/a	3,468.91	10,088.89
Cibane	1,740.94	1,357.49	1,294.14	n/a	2,038.21	5,211.31
Mngadi	3,988.08	3,587.04	4,841.05	2,787.18	4,664.98	9,631.26
Mbongeni	5,556.18	4,648.58	3,748.04	3,449.33	7,619.05	21,126.07
Ngidi-S	2,107.59	1,681.93	1,611.60	1,589.40	2,844.26	8,361.78
Ngidi-Z	1,288.70	986.16	936.18	920.39	1,837.54	5,868.39
Ndaba	3,967.66	3,144.20	2,630.56	1,746.99	5,467.35	17,244.50
Madondo	2,210.25	1,777.93	1,777.16	n/a	2,918.59	6,836.87
Shibe	526.94	414.37	451.57	257.75	585.19	1,544.18
Tembe	1,534.46	1,238.96	1,336.60	n/a	2,177.40	6,497.62
Dladla	1,429.72	1,179.95	1,262.48	n/a	1,850.39	5,054.69

Table 6.19 shows the monthly costed unpaid care provision amounts using median earnings per method. Appendix M details the costed unpaid care provision calculations per method. Looking within methods, the lowest costs are recorded in the Shibe household for all methods and the highest in the Mbongeni household for all except the two opportunity cost methods. Per household across methods, different variations and patterns are generated depending on the type of employment of caregivers for the 'employment' opportunity cost method, generalist method and specialist method, and on the level of education of caregivers (and metropolitan/non-metropolitan area and sex) for the 'education' opportunity cost method.

Table 6.20 shows the range of values for costed unpaid care provision for all methods applied in the study, using median earnings rates. In this section the ranges are stated and no reference is made to averages, since the sample is relatively small, hence averages are not very reliable. The intention is to be illustrative of the range of total costs in the study households. When analysing this table it must be borne in mind that these figures should not be compared directly with daily and monthly wages for other professions, since the aim here is to determine value and not to calculate pay.

Table 6.20: Range of values for costed unpaid care provision – all methods (monthly, Rands)

Method	Lowest	Highest
Average earnings-employed	526.94	5,556.18
Average earnings-self-employed	414.37	4,648.58
Opportunity cost-education	451.57	4,841.05
Opportunity cost-employment	257.75	4,157.49
Generalist (proportionate)	585.19	7,619.05
Specialist	1,544.18	21,126.07

Overall, the opportunity cost approach that uses employment information results in the lowest total cost and the ‘lowest’ range of total costs, while the specialist method results in the highest total cost, the ‘highest’ range of total costs and the widest range of total costs among all the methods. It has already been argued that the proportionate approach (that falls under the generalist method) seems to be the most appropriate to the eastern seaboard region of South Africa, in terms of its ‘method’. When compared to the total values generated by the other approaches, the range of values from this approach is at the higher end but not the highest.

7 RESULTS – COMPARING THE COSTS OF UNPAID CARE PROVISION WITH THE COSTS OF ALTERNATIVE POLICY INTERVENTIONS

7.1 INTRODUCTION

What can the calculated cost of providing unpaid care be compared to, in order to get a realistic idea of the relative worth of this care work? Budlender (2006) suggests that the imputed value of unpaid care work done for ill people in the home and community be compared to the monetary value of care provided through the public and private health care systems. Such comparisons provide an idea of the relative value of unpaid care work undertaken within the home.

A number of interventions for the care of ill people in KwaZulu-Natal are funded by government or other institutions. These include publicly provided hospital care, inpatient care provided by NGOs/FBOs/community-based organizations (CBOs), privately provided paid HBC, and HBC provided by NGOs/FBOs/CBOs. Through the funding of these interventions an unspoken assumption is that they have value. By comparing one of the calculated costs of unpaid care provision in the home (arrived at using the proportionate approach which is part of the generalist method) and other public and private interventions that are similar in nature it is possible to understand something of the contribution that unpaid care provision within the home makes.

Budlender cautions, however, that if such calculations are attempted, they should be restricted to the economy and society as a whole, and not done at the household level. This is because such a calculation "might be interpreted as implying that households where care is provided for no pay by family members are as 'rich' as those families that buy care almost entirely from the market once the 'real value' is included in the calculation" (Budlender, 2006, pp. 51-52).

For each intervention outlined, a key policy question is stated as Box 2 shows. This is in line with the research objective of showing the effects of the choice of HCBC as opposed to other policy choices. It is not always the case that there is a choice or trade-off between policy choices – sometimes more than one policy option is in place. For instance, while HBC is the government's chosen response to the care needs presented in society, some individuals are being cared for as inpatients in public hospitals.

Box 2: Interventions and key policy questions addressed

Intervention	Key policy question(s)
Privately provided HBC by caregivers/enrolled nursing assistants	What are the inequality-creating effects of the HCBC policy between households?
Public hospital inpatient care	What is the government saving in the health budget by limiting the provision of hospital care?
NGO/FBO/CBO inpatient care	How do the costs of unpaid care provision and inpatient care as delivered by NGOs, FBOs and CBOs compare? To what extent can inpatient care by NGOs, FBOs and CBOs meet the need for care where neither HBC nor hospital care are available as options?
NGO/FBO/CBO HBC	Is there a fair way of sharing the costs of care, which limits the poverty and inequality creating effects of the HCBC policy? How do the costs of unpaid care provision and HBC as delivered by NGOs, FBOs and CBOs compare, and to what extent is this intervention able to deliver to all of those in need of HCBC when compared with the former?

The lowest and highest costed unpaid care provision estimates are compared to the lowest and highest cost estimates of the different interventions in order to get an idea of the range of costs these interventions involve.

Costed unpaid care provision was estimated in Chapter 6 for the 2004/2005 financial year, roughly the period over which the qualitative study took place. In this chapter too, the costs of comparative interventions have been estimated for this time period or for 2004. However, since this time there has been a dramatic increase in the cost of living, driven in no small part by the global financial crisis, which has seen an increase in formal job losses and an increase in informal work. In order to make the comparisons of costed unpaid care provision and the cost of similar interventions more relevant to the present day, the costs have been adjusted to 2008 prices in line with the consumer price index for all urban areas calculated by Statistics South Africa (2009). 2008 is the most recent full year for which the consumer price index for all urban areas is available. The cost comparisons are therefore for 2008.

There are a number of challenges relating to comparisons of the costs of interventions. For one, like is not always being compared with like. As an example, the Department of Health (2002) compares the cost per day of keeping a person in hospital (R650 at the time for KwaZulu-Natal) and the cost of providing HBC (estimated between R30 and R35 per visit by a caregiver on a HBC programme), and argues that the latter is substantially cheaper than the former. However, the former is 24-hour care provision within a hospital setting by medical and nursing professionals, while the latter is not 24-hour, and often actual care is not given. The type and quality of care is very different in the two settings, and the comparison is therefore neither appropriate nor useful. In addition, all of the costs of care provision in the latter case have not been estimated. Rather, only the costs relating to caregivers' work on a HBC programme are estimated and none of the costs of care provision by the person's family who are likely providing 24-hour care within the home. With regard to hospital care the burden of care falls on the state, while the costs of HBC fall on the family of the person in need of care, and yet only the costs of the caregiver working on a HBC programme are being compared to hospital provision.

With regard to this study, some interventions that the costed unpaid care provision estimates are compared to are very similar to the provision of care by family caregivers. For instance, inpatient care as provided by NGOs/FBOs/CBOs, state hospital inpatient care and privately provided HBC. In the case of non-state inpatient care and state hospital inpatient care, care is provided or the caregiver is available to the cared-for constantly over a 24-hour period, as is the case with regard to a person being cared for by a family caregiver within the home. In the case of privately provided HBC, care may only be provided for part of a 24-hour period with one or more family members providing the remainder of care over this period. Other interventions such as HBC provided by NGOs/FBOs/CBOs are even less similar. Here the interaction between caregiver and patient does not take place over a 24-hour period but consists of a visit that may be once a week or once a month or some other frequency. In this instance, as with the example above, the comparison is not of ‘like with like’ but is nevertheless illustrative.

On another level too, like is not being compared with like: the quality of care will also tend to differ between and also within different types of care environments. One form of care provision is never better than the other on every level – rather, each form of care provision provides differently with regard to different aspects.

On yet another level, comparing the costs of unpaid care provision with some other intervention is not always realistic in the South African context. For instance, comparing the costs of hospital-based care and costed unpaid care provision is not always reasonable when government explicitly states that people with AIDS should not be admitted into hospital to be cared for. It is reasonable to do so in a country where the two ‘interventions’ are very real alternatives. In the United Kingdom, for instance, if someone eligible for some form of HBC provision by the local authority does not receive this, they would be entitled to be admitted for some sort of institutional care. While such comparisons are made in this chapter for illustrative purposes, these issues must be borne in mind.

Finally, GDP is produced by labour and capital, and is an outcome of labour. However, unpaid care provision in the home will not be calculated as a percentage of GDP, since this has already been undertaken by Budlender (2008) on survey data (see section 3.3.2), and there will be little value added in doing so using this qualitative data for a small sample. Moreover, this is neither part of the work nor purpose of this thesis, which is to show that unpaid care work is labour, just as similar paid care work is labour, and that this labour has value.

7.2 APPROACH TO ESTIMATING COSTS

One way of categorizing costs is that financial costs refer to the actual money incurred and paid for by an organization on a programme, while economic costs also include the true costs of setting up and running the programme which are not paid for by the organization. Economic costs include the value of donated goods such as supplies, medication, time or voluntary labour. Costs incurred by the family that provide care and support for an ill person are not included here. Economic costs include financial costs and constitute the total cost of service. Importantly, "analyses using economic costs do not replace those using financial costs, but supplement them with additional information useful for decision-making" (Creese & Parker, 1994).

When comparing across programmes Johnson et al. (2001) argue that economic costs should be used. Creese and Parker (1994) indicate that for many resource inputs in health programmes little or no money is paid by the programme. Therefore "things have a value that might not be fully captured in their price" (1994, p. 57). These authors further point to the fact that such calculations enable an understanding of the full resource consequence of implementing a health programme. Everatt and Solanki (2005) provide even more reasons to consider the importance of estimating economic costs in the South African context. They indicate that almost all (93 percent) of the respondents in a nationally representative survey on social giving gave in the month before being interviewed – time, money or goods, to a cause or individual. Therefore giving in-kind and in time appear to be widely practised in South Africa. Finally, estimating economic costs makes sense in this study in particular, since the comparator – unpaid care provision – consists not only of financial costs but primarily of economic costs.

Economic costs were however only comprehensively estimated for two of the comparisons in this chapter: NGO/FBO/CBO inpatient centres and NGO/FBO/CBO HBC organizations. With regard to privately provided HBC the focus is on the labour only costs relating to this form of care provision, and therefore it is sufficient to compare the rate charged by agencies to private individuals to the labour only costs of unpaid care provision.

For public inpatient care there are unlikely to be donated goods or in-kind costs relating to the provision of care. Moreover, it is unlikely that any of the workers providing care for patients are doing so on a voluntary basis. More importantly, although there are capital costs made at health facilities these are not all included in the total expenditure per facility that is used to estimate the cost of patient day equivalents (to be described in section 7.4). While the total expenditure figure includes current and capital expenditure, it is only relatively small capital expenditure that is made by the facility that is included. The figure does not include large and usually once-off spending on capital, which is recorded in a separate programme and spent external to the facility. It is very difficult to identify the spending on large equipment and on facilities maintenance for each health facility that goes through this separate programme. Additional administrative expenditure is made by the provincial Department of Health and is also not included in the expenditure per facility that is used for the patient day equivalent estimation. Therefore there is additional expenditure that is incurred for health facilities but not spent by these facilities, but this expenditure is not included in the cost per patient day equivalent estimation because it is very complex to isolate as a result of the way that the health expenditure is constructed.[15] For these reasons, for the comparison of the cost of keeping a patient in a public hospital per day and the cost of unpaid care provision, the full economic cost is not used.

For the two interventions for which economic costs were calculated the following approaches were adopted. Inpatient centres were contacted telephonically for the costs of keeping a patient per day, and HBC organizations were contacted telephonically for the financial costs of operation per programme, in order to estimate the cost per patient per contact hour. Next the lowest and highest ‘cost’ organizations were selected from the inpatient centres and from the HBC

---

[15] Personal communication, official, KwaZulu-Natal Department of Health, 4 August 2008.

organizations, and the economic costs were estimated for these four organizations. This approach means that there is the possibility that an organization with low financial costs has high economic costs, and an organization with high financial costs has low economic costs, and therefore the organizations with the lowest and highest total costs are not actually selected.

As noted earlier, for all types of programmes an attempt was made to obtain cost information for 2004 or for the 2004/2005 financial year in order to be able to compare the costs of unpaid care provision and the costs of the various interventions for the same year. The costs of state inpatient care in KwaZulu-Natal were obtained for 2004/2005 from the provincial Department of Health. For many of the other interventions the financial costs could not be obtained for 2004. Some of the service providers were not in existence in this year, while others were not willing to provide the figures from earlier years, and many no longer had these figures. Where the organizations could not provide 2004 costs, but could provide information in order to estimate these costs (such as the increase in rates charged over different years for private HBC), these were estimated. If the organization was able to provide an estimate of what they believed the cost to be in 2004, based on their knowledge of price increases over time, these were applied. If the organization was able to provide the researcher with a method to estimate the costs, this approach was adopted. In some instances organizations were only able to provide current costs, or costs from a year other than 2004. In these cases CPIX (consumer price index for metropolitan and other urban areas) was used to estimate inflation-adjusted costs for 2004. This was undertaken whether or not an organization had been in existence or was operating in 2004, in order to increase the number of estimates to which to compare the costs of unpaid care provision.

With regard to estimating economic costs, this study attempts to follow the approach of Johnson et al. (2001) who put a cost to the services provided by four South African HBC organizations. These authors were informed by Creese and Parker (1994) whose manual on how to conduct cost analysis in primary health care is something of a standard. However, where the approach of these two texts differs, the approach of the latter is applied since this is regarded as being more definitive.

The costs analysed for the different interventions were based on the most recent year for which a complete set of financial information was available. This is because additional costs not on the financial statements could be recalled relatively easily by staff at the organization. If an audited financial statement was available this was used. After the costs were totalled, the final costs were adjusted to 2004.

Capital items are defined as inputs that last for more than one year and have a replacement cost of greater than R1000; recurrent costs fall within a period of one year and are usually purchased regularly (Johnson et al., 2001). The approach used to cost the capital and recurrent expenditures estimated in this study will be outlined below. Specifically, it should be noted that a discount rate of nine percent is applied to estimate the economic cost of equipment on an annualized basis, following the guidelines provided by the National Treasury (Republic of South Africa, 2006).

7.2.1 Capital and start-up costs

Creese and Parker emphasize the importance of applying the current cost of capital items and not the cost of buying the item in the past. If an item exceeds the expected working life stated then it is considered to be written-off. Start-up costs refer to the initial capital outlay needed to start up the programme.[16]

Buildings, space

Unlike Johnson et al. (2001) who estimate building costs, an approach recommended by Creese and Parker (1994) is adopted in this respect. These authors mention that an alternative to estimating building costs is to obtain an estimate of the annual price charged for renting similar space. In this way buildings are treated as recurrent rather than capital inputs. Therefore the costs of buildings and space (and relatedly, rates) are not included as a cost in this study, but the costs of renting are.

---

[16] Social mobilization as both a capital and a recurrent cost was not recorded by any of the selected low- or high-cost organizations and is therefore not outlined here.

Vehicles

For all vehicles on each programme the current selling price of the type/model of the vehicle is applied. The lifespan of vehicle capital costs is taken to be five years.

Electronic equipment

The current prices at retail cost are applied to electronic equipment. Where current prices cannot be obtained the current value is estimated using CPIX. The lifespan of this equipment is taken to be three years.

Non-electronic equipment

For all equipment, including furniture, office equipment and medical equipment the current prices at retail cost are applied. Where current prices cannot be obtained the current value is estimated using CPIX. The lifespan of this equipment is taken to be five years.

Training, non-recurrent

This refers to training as a capital investment. The expenses and time spent on initial training that occurs once or rarely is counted. Initial training refers to training undertaken to enable members of staff to carry out the programme activities. It also includes the cost of meals, transport and supplies associated with this training. The useful lifespan of this training is taken to be three years.

Social mobilization, non-recurrent

This refers to initial meetings to encourage support from the community/stakeholders. Examples include promotion and publicity campaigns that occur once or rarely. The following is costed: time and other inputs required to plan and run these meetings, the time spent on each meeting, and transport costs to undertake these meetings (calculated by using cost per kilometre).

7.2.2 Recurrent costs

Personnel

Creese and Parker (1994, p. 58) recommend the following for costing personnel:

> For volunteer labour, you could find out whether those people receive a salary or wages elsewhere and use that to cost their donated time ... If they are not currently employed, you could use wage rates paid to workers who do equivalent work in the health system, or the average agricultural wages in the area, or the current minimum wage.

In a country such as South Africa with such high unemployment levels, the first suggestion is not appropriate. Naidu (2005) assigns the value of stipends to community caregivers' volunteer time. However, Johnson et al. (2001) assign the government's salary level for nursing assistants to these volunteers' time, since these authors regard this as the job category that most closely matches the level of training and experience of community caregivers. There are a range of different types of community caregivers doing similar but also different work and receiving varying wages whether from government or NPOs, and it is difficult to settle on an appropriate earnings rate for these workers. Therefore, in this study volunteer workers are assigned the wage rates paid to workers who do equivalent work in the health system. For community caregivers this is the starting salary for a junior enrolled nursing assistant (see Department of Public Service and Administration, 2007).

Vehicles operation and maintenance

Actual project expenditure on petrol, diesel, lubricants, tyres, spare parts, registration, vehicle maintenance and service, and insurance payments. Johnson et al. (2001) used the University of the Witwatersrand's rates per kilometre in their study. In this study the kilometres travelled per month are multiplied by the standard rate used by the UKZN at the time: R2.46 for 2007 and prior to 1 April 2008, R2.92/km as of 1 April 2008.

Buildings operation and maintenance

This includes electricity, water, heating, fuel, telephone, fax, insurance, cleaning, painting, repairs to electrical supply/appliances, plumbing and roofing. If the building was owned or donated the estimated equivalent of annual rent was used.

Training, recurrent

This refers to training undertaken in the current period to enable members of staff to carry out the programme activities. For instance, short in-service training. It also includes the cost of meals, transport and supplies associated with this training.

Social mobilisation, recurrent

This refers to meetings during the current period to encourage support from the community/stakeholders. The following is costed: time and other inputs required to plan and run these meetings, the time spent on each meeting, and transport costs to undertake these meetings (calculated by using cost per kilometre).

Supplies

This includes medical supplies as well as food and other supplies. The current market values of these items are applied.

Other operating costs not included above

For instance, stationery, photocopying costs.

7.3 PRIVATE SECTOR HOME-BASED CARE

> *Key policy question: What are the inequality-creating effects of the HCBC guidelines among households?*

Many wealthier families can afford to employ caregivers to visit and care for ill people in their own homes. Gender intersects with class with wealthy women able to hire poorer women in a chain of care provision (Chen et al., 2005; Glenn, 1992). What does it cost families to provide care for a family member by a private caregiver or a private enrolled nursing assistant, and how does this compare to the costs of providing care within the home by unpaid caregivers? In this section, the labour only costs of unpaid care provision are compared to the costs of hiring a private caregiver (who has completed a HBC course) and a private enrolled nursing assistant to provide home nursing care in KwaZulu-Natal. The two types of 'intervention' are very similar, making a comparison quite straightforward. The bulk of private nursing care that takes place within the home is care for the elderly. Yet it can be argued that while the emotional aspect of caregiving is different for the elderly and for the terminally ill (the terminally ill are often in a lot of pain, and their condition is often unexpected and therefore traumatic), the actual hands-on care is not very different, making this comparison viable.[17]

The cost of hiring a private home-based caregiver is likely to be lower than the cost of hiring a private ENA. Similarly the costs of hiring a private caregiver can vary greatly depending on whether the caregiver is hired through a nursing agency or via a not-for profit facilitator. The same applies to hiring a private ENA. Therefore a range of costs of privately provided care are compared to the costs of unpaid care provision.

As a first step all the organizations or individuals in the 2007/2008 Durban and Pietermaritzburg Yellow Pages under 'Nurses and Nurses' Institutes', 'Nursing Homes' and 'Nurses – Private Practitioner (Member of South African Nursing Council)', as well as 'Health Clinics' were contacted. If these were the providers of the service under review the relevant information was obtained from them. If they were not such service providers they were asked for recommendations of any organizations or individuals who provided these services. In this way the names of nursing and caregiver training institutions were obtained, and also contacted for service provider details. Therefore as many of the organizations or individuals who provide a private nursing/caregiver service in KwaZulu-Natal as possible were contacted. Some of these

---

[17] Personal communication, Nursing Manager, Khanya Hospice, 29 April 2008.

organizations are registered as nursing agencies, while others are not. A total of 26 organizations/individuals provided information that could be used.

In the case of private caregivers, a distinction can be made between the rates that for-profit agencies or businesses charge that include an administrative and/or profit overhead, and not-for profit rates which do not include a mark-up for the facilitator of the service. With regard to the latter, the rates are negotiated between the private caregiver and the family of the person who will be receiving care, although the facilitator usually suggests a going rate to work from, and the money is paid directly to the private caregiver. The facilitator is usually undertaking the role as a community service. For-profit rates are paid to the agency or business for services rendered and a cut is taken by the agency before the caregiver is paid what remains. There is likely to be a noteworthy difference in the average of the two types of rates, with those paid to caregivers directly being much less than those paid to caregivers working through an agency. A few of the for-profit agencies and not-for profit facilitators charge a once-off placement fee. In 2008 prices these include R50, R100, R150, R250 and R2650 for private caregivers, and a placement fee of R2650 among those who place private ENAs. The highest placement fee is unusual in that it includes one or two visits a week by a qualified nursing sister, as well as guaranteed supervision and professional guidance by her. All placement fees are ignored for the estimations in this section.

Table 7.1: For-profit agency rates charged for private caregivers (2004)

Agency (for profit)	Day workers per hour	Areas served
All Africa Nursing Care	7.25	Durban & surrounding
Ambition 24 Hours	20.17	KwaZulu-Natal
Clinicare	15.39	North of Durban
Console Care Agency	7.77	-
Espanini Health Services	15.43	Pinetown
Florence Nightingale	7.64	KwaZulu-Natal
Helping Hands	10.00	Howick
Hillcrest Resident Care	9.50	Highway
Mbango Home Care Services	8.84	South Coast
NIDO	14.67	PMB & surrounding
Nursing Services of Natal	8.96	Durban & surrounding
Nursing Services of South Africa	24.74	KwaZulu-Natal
Nursing Services of the North	9.98	Durban & surrounding
Quality Healthcare Services	15.60	KwaZulu-Natal
Professional Health Services	19.48	-
Rafa Health Care	19.56	-
Skilled Domestics	12.61	Durban & surrounding
Vital Skills Agency	10.84	North of Durban
Average	13.18	-

As Table 7.1 shows, there are a range of hourly rates charged for employing private caregivers within a private home for 2004 – from R7.25 to R24.74 per hour. The lowest rate is not very different to the minimum wage for a contract cleaner for the period from 26 November 2004, which was R7.71 for metropolitan areas and R6.61 for other areas in KwaZulu-Natal [18]. The

---

[18] The Bargaining Council for the Contract Cleaning Industry in KwaZulu-Natal was responsible for these minimum wage rates.

average rate per hour is R13.18. The areas served by these agencies include the whole province in some cases, while the others tend to serve only the surrounding population dense areas.

Table 7.2: Not for-profit rates charged for private caregivers (2004)

Information source	Day workers per hour	Areas applicable to
Camphors	6.50	Highway
Cathe Ludick	6.30	South Coast
Riverside Park	7.78	Pietermaritzburg
TAFTA	7.00	Durban & surrounding
Vital Skills Agency	8.40	North of Durban
Average	7.19	-

Seemingly the profit made by some of the for-profit agencies must be high, since the average paid directly to private caregivers hired through non-profit facilitators is estimated to be much lower, at R7.19 per hour, as Table 7.2 shows.

Table 7.3: For-profit agency rates charged for private ENAs (2004)

Agency (for profit)	Day workers per hour	Areas served
Ambition 24 Hours	33.94	KwaZulu-Natal
Espanini Health Services	24.00	Pinetown
Flo-Line Services	11.71	-
Highway Home Nursing	8.35	Highway
Hillcrest Resident Care	17.60	Highway
Nurserve	9.29	Durban & surrounding
Nursing Services of South Africa	51.12	KwaZulu-Natal
Quality Healthcare Services	23.38	KwaZulu-Natal
Visiting Nurses Agency	27.23	PMB & surrounding
Average	22.96	

Table 7.3 indicates how much more private ENAs receive for caregiving work than private caregivers, at an average of R22.96 per hour. These rates range widely from R8.35 per hour to R51.12 per hour. Fewer agencies provide private ENAs as opposed to private caregivers because of their higher cost and limited demand.

Table 7.4: Average labour costs of private home care

Labour costs of private home care	Per hour (2004)	Per hour (2008)
Average for-profit agency rate charged for caregivers	13.18	14.31
Average not for-profit rate charged for caregivers	7.19	7.80
Average for-profit agency rate charged for ENAs	22.96	24.92

The average labour costs of private home care range from R7.80 to R24.92 per hour for 2008, as Table 7.4 shows. The labour costs of unpaid care provision, using the proportionate approach from the generalist method, range from R0.55 to R6.59 per hour for 2008. The range of costs of unpaid care provision is lower than the not-for-profit and the for-profit agency rates charged for private caregivers and ENAs.

The findings show that the HCBC guidelines indeed have inequality-creating effects: wealthier families may be able to buy in care if necessary, while poorer families have to provide this care themselves.

7.4 PUBLIC HOSPITAL INPATIENT CARE

> *Key policy question: What is the government saving in the health budget by limiting the provision of hospital care?*

What does it cost the provincial Department of Health to provide hospital care for those in advanced stages of HIV/AIDS, and how does this compare to the costs of providing care within the home by unpaid caregivers? In this section, unpaid care provision costs (caregiver's labour costs and financial costs to the household) are compared to the costs of providing a person bed per day in various types of public hospitals in KwaZulu-Natal. The latter includes 24-hour provision of medication, food, care by nurses and doctors, and various levels of specialised care, depending on the type of hospital.

A community health centre is defined as a facility which is open 24 hours a day, seven days a week, at which a broad range of primary health care, accident and emergency and midwifery services are offered, including a short stay ward (Department of Health, 2006, p. 9). Patients are referred to a district hospital where necessary (KwaZulu-Natal Department of Health, 2008). Moreover

> District hospitals and provincial [or regional] hospitals cater for those patients who require admission to hospital for treatment at general practitioner level, and at specialist level, respectively ... Central and tertiary hospitals provide facilities and expertise needed for sophisticated medical procedures (Province of KwaZulu-Natal, 2008).

There is only one central hospital in KwaZulu-Natal – Nkosi Albert Luthuli Central Hospital – which provides 'super-specialized' care, as opposed to the specialized care provided in Grey's Hospital, the only tertiary hospital in 2004/2005.[19] Ill people in the qualitative study had visited, and in some cases been admitted to, all four levels of hospital, which makes this comparison more pertinent.

Dori Posel speculates that there is an opportunity cost to providing care in the hospital since hospital beds are over subscribed.[20] If care is provided to some there are others who cannot receive care in the same beds. The average monthly bed occupancy rates across the various types of hospital are shown in Table 7.5. The highest occupancy rate is found in regional hospitals, while district, tertiary and central hospitals have a similar occupancy rate at just over half. These

---

[19] Personal communication, Chief Technical Advisor: Hospital Systems, KwaZulu-Natal Department of Health, 23 April 2008.

[20] Personal communication, Dori Posel, 10 September 2008.

occupancy rates do not show over-subscription, meaning that the opportunity cost to providing this type of care is questionable.

Table 7.5: Average monthly bed occupancy rates across types of hospital (2004/2005)

Type of hospital	Average monthly bed occupancy rate
District hospital	55.5
Regional hospital	63.3
Tertiary hospital	54.9
Central hospital	56.5

Source: own calculations from bed occupancy rates provided by the KwaZulu-Natal Department of Health.

An attempt was made to obtain the average cost of a person bed per day for someone with HIV/AIDS stage three or four, for the different types of hospitals for 2004/2005. However this information is not available with regard to disease status, but only across patients in general. A cost per patient day equivalent estimation was obtained for each hospital. The patient day equivalent is

> a weighted combination of inpatient days, day patients, and out patient department (OPD)/emergency total headcount, with inpatient days multiplied by a factor of 1, day patient multiplied by a factor of 0.5, and OPD/emergency total headcount multiplied by a factor of 0.33.[21]

The cost per patient day equivalent is estimated by dividing the total expenditure for a health facility by the patient day equivalent for that health facility. Since most of the patients do not stay overnight in health facilities, the overall cost estimated using this approach is likely to be lower than it would have been if only inpatient days were used.

---

[21] Personal communication, Principal Technical Advisor: Data and Information Management, KwaZulu-Natal Department of Health, 7 July 2008.

It is likely that the average cost of a bed per day across community health centres will be lower than the average cost for district hospitals, since the latter is a higher cost institution that the former. In a similar way this applies to the other types of hospitals. Therefore there should be high and low figures with which to compare the costs of unpaid care provision. Indeed, Table 7.6 verifies this. While it would be expected that the costs of keeping a patient in a district hospital would be lower than keeping a patient in a regional hospital, the average per patient day equivalent cost in district and regional hospitals is surprisingly similar. This could be explained in part by Mowatt and Quinlan's (2003) finding that the burden of HIV/AIDS is experienced more at the level of district than regional hospitals, and felt more acutely at the inpatient than the outpatient level. As expected, the cost for the tertiary hospital is three times the amount of the lower level hospitals, while the cost for the central hospital is almost double that of the tertiary hospital.

Table 7.6: Expenditure per patient day equivalent in public hospitals in KwaZulu-Natal (2004/2005)

Type of hospital	R/day	R/hour
Community Health Centre	97.75	4.07
District hospital	736.00	30.67
Regional hospital	754.00	31.42
Tertiary hospital	2183.00	90.96
Central hospital	4051.00	168.79

Source: R/day information for district, tertiary and central hospitals taken from the data used for the 2004/2005 annual report of the KwaZulu-Natal Department of Health; R/day information for regional hospitals taken from the 2007 Annual Performance Plan for the KwaZulu-Natal Department of Health; 2006/2007 R/day information for community health centres taken from calculations provided by the Principal Technical Advisor: Data and Information Management, KwaZulu-Natal Department of Health, 15 August 2008, and adjusted to 2004 figures to account for inflation.

Are these costs an underestimate or an overestimate with regard to HIV stage three or four individuals? Mowatt and Quinlan (2003) in a study in KwaZulu-Natal's Addington and Osindisweni Hospitals (regional and district hospitals respectively) find strikingly similar costs for HIV-positive and HIV-negative inpatients. Moreover, although slightly higher for HIV-positive patients, the costs of treatment are relatively similar for both types of patient. However, the costs of keeping a patient in hospital are also dependent on length of stay. Shisana et al. (2002, p. xiii) find that AIDS patients stay in hospital longer (mean stay of 13.7 days) than non-AIDS patients (mean stay of 8.2 days), which in turn means that the costs of accommodating these patients in hospital should be higher overall.

How do publicly provided inpatient care and unpaid care provision in the home differ? Differences may include varying levels of individual attention (the latter is likely to provide a lot more of this than the former). In the former, at minimum, care is provided by an enrolled nursing assistant for a number of patients at one time. In the home environment usually one family caregiver provides care for usually one ill person only. In contrast, those being cared for in a public hospital are more likely to have better access to health professionals and medication than those being cared for in the home environment. It must not be assumed, however, that the quality of human care at home will be better because it is one-on-one, and because the relationship between caregiver and cared-for is close.

The costs of public hospital inpatient care for 2008 range from R106.10 per day for a community health centre, around R800 per day for district and regional hospitals, just over R2000 per day for the tertiary hospital and R4397 per day for the central hospital. The selected costs of unpaid care provision range from R20.76 to R270.34 per 24-hour day. Most of these costs fall substantially below the costs of providing public inpatient care, bar in a community health centre.

From these estimations alone it is clear that the government is saving substantially on the health budget by limiting the provision of public inpatient care, although it is not clear by how much overall.

7.5 NGO/FBO/CBO PROVIDED INPATIENT CARE

> *Key policy question: How do the costs of unpaid care provision and inpatient care as delivered by NGOs, FBOs and CBOs compare, and to what extent can the latter meet the need for care where neither HBC nor hospital care are available as options?*

A range of not-for profit inpatient care provision exists within KwaZulu-Natal for terminally ill and step-down care patients. The Department of Health (2006, p. 8) defines step-down care as:

> Inpatient care that follows or forms the latter part of an acute episode in which the patient has been investigated, diagnosed, is in a stable condition and has a treatment plan but requires ongoing inpatient nursing or rehabilitation care for less than 90 days.

According to the Department of Health (2006, p. 10), patients in units providing step-down care services can be cared for mostly by professional nurses or allied professions, rather than requiring doctors. Such patients are clinically stable, have a final diagnosis, treatment plan and prescribed medication. A hospice unit is defined as catering for terminally ill patients requiring palliative care or respite care. Such units are staffed by professional nurses, allied professions and specialist nurses, and may be on or off hospital site (Department of Health, 2006, p. 11). While some organizations are referred to as hospices very few of them have an inpatient centre which is traditionally what a hospice has been known as. Nearly all of the hospices in South Africa as their main programme practice HBC with a strong palliative care component – nurses and trained caregivers visit patients in their homes.

Inpatient care centres in KwaZulu-Natal were located through a search on the HIV/AIDS Network website (http://www.hiv911.org.za) using the keywords “hospice care” within “KwaZulu-Natal” province (there was no search option for step-down care). Through telephone conversations with these organizations it was possible to obtain the names of some additional organizations providing inpatient care. In all, information was obtained via telephone from fifteen inpatient care centres in KwaZulu-Natal and the descriptive information in this section is derived from interviews with individuals at these inpatient centres.

The aim of this section is to understand what the range of costs are that these organizations bear in order to provide inpatient care, and how this compares to the costs of providing care within the home by unpaid caregivers. At some of these institutions care is provided only by trained caregivers, in others only various categories of nurses provide care, and in still others there is a combination of both caregivers and nurses. It is therefore to be expected that some of the costs per patient per day will be lower in some institutions than in others. Moreover costs at centres which use donated equipment and materials are likely to be lower than at centres in which these items are purchased.

Information from all inpatient centres was obtained over the telephone and site visits were undertaken to four of the centres. Those involved in care provision or in the finances were asked for their estimates of the costs of keeping a patient in the care centre per day in 2004, or in current prices if this earlier information was not available (listed in Table 7.7 as ‘provided’). It is not clear in all cases exactly how these costs were estimated, although it is clear that they did not include most of the economic costs outlined in section 7.2. Two of the step-down facilities used a calculation that included patients’ average length of stay. One organization (Philanjalo Hospice) provided the amount that it is funded per patient per day, in the absence of any other patient day costs.

For some of the organizations the costs were estimated by the researcher using expenditure and patient information provided by the organization (listed in Table 7.7 as ‘estimated’). Two main methods were used by the researcher, depending on the information provided. For some of the organizations total expenditure per year was divided by the total number of inpatient days in order to arrive at the cost of keeping a patient in the inpatient unit per day. For the other organizations the occupancy rate was used to estimate the cost per patient per day. For Kwa St Vincent an amount per patient that is given by the treasurer to the overseer of the hospice was used to estimate overall costs. The average length of stay estimate for patients was then used to estimate this cost.

For all organizations obvious costs of care provision such as labour, food, medication, electricity and water were included. Capital expenditure was not included, but only recurrent expenditure. Many of the inpatient centres own the buildings in which care is provided, and in this way their costs are lowered since rental or mortgages do not have to be paid, although other expenses such as rates and maintenance do. Moreover, most of the inpatient centres receive in-kind donations of food, medicine, equipment, linen or clothing, and these are not included in the estimates given, since the economic cost is not being estimated here. The financial cost estimates shown in the table below are therefore likely to be underestimates of the cost of providing inpatient care.

Table 7.7: Expenditure estimates per patient per day in inpatient centres in KwaZulu-Natal (2004)

Inpatient facility	Location	Provided/ estimated	Cost per patient per day
Hospice Assoc. KwaZulu-Natal			
Brotherhood of Blessed Gerard	Mandini	Provided	144.15
Chatsworth Hospice	Chatsworth	Estimated	406.59
Highway Hospice	Sherwood	Estimated	729.78
Holy Cross AIDS Hospice	Mtunzini/Gingindlovu	Provided	167.93
Philanjalo Hospice	Tugela Ferry	Provided	176.32
South Coast Hospice	Port Shepstone	Estimated	419.42
Step-down & other inpatient			
Anonymous Care Centre 1	Confidential	Estimated	64.23
Anonymous Care Centre 2	Confidential	Estimated	50.15
Anonymous Care Centre 3	Confidential	Estimated	32.32
Duduza Health Care Centre	Near Glencoe	Provided	104.95
Ethembeni Care Centre	KwaMbonambi	Provided	98.00
Genesis Care Centre	Port Shepstone	Provided	267.00
Haven of Rest Hospice	Tongaat	Provided	127.62
Kwa St Vincent	Shakaskraal	Estimated	57.01
The Dream Centre	Pinetown	Provided	155.80
Vulamehlo Health Resource Centre	Groutville	Estimated	66.77

Note: figures for later years adjusted to 2004 using consumer price index for metropolitan and other urban areas; not all of those listed under step-down care define themselves as step-down care facilities, however they are listed under the heading here for simplicity since they all seem to meet the definition of step-down care; the treasurer who was treasurer for all three Anonymous Care Centres did not want the names and locations of these organizations made public

A range of types of care at inpatient centres is shown in Table 7.7. Some are affiliated to the Hospice Association KwaZulu-Natal, and provide palliative care to HIV/AIDS and sometimes cancer patients. This includes pain or symptom control, end-of-life care and respite care.[22] Most of these care centres have only professional nurses as care providers, while at the other centres trained caregivers are the main care providers, with professional nurses usually not present on a 24-hour basis. None of the centres charge patients, although one takes 40 percent of the patient's old age pension or disability grant over the duration of their stay, if the patient is receiving one. At some of the high-cost care centres where patients are on medical aid, the cost of their stay is claimed from the medical aid. Some interviewees at the care centres noted that the cost of providing care depends on what the needs of the patient are, for instance, if the patient requires scheduled medicine or not; if the patient dirties his/her clothes and linen constantly or not, and so on. A few interviewees mentioned that providing care for the terminally ill is expensive in terms of the caregiver's time but not in terms of food.

It can be seen that there are a range of costs of keeping individuals in inpatient centres. Hospice Association KwaZulu-Natal centres in urban areas have the highest costs per patient, while those in rural areas and some of the step-down facilities have similar costs per patient. The costs of this form of care provision range from a low of R32.32 for an Anonymous Care Centre in the greater Durban area to a high of R729.28 per patient per day for Highway Hospice. Some patients at some of the inpatient centres are on anti-retrovirals (ARVs) and this means that terminal illness care is not taking place. This is the case at the three anonymous care centres and at Vulamehlo Health Resource Centre. Therefore such centres will not be included for selection for the comparative costing since the participants in the qualitative study were all not on ARVs, and care provision for those on ARVs is a different type of care provision to terminal illness or palliative care.

Taking this into consideration the low-cost care centre selected for the cost comparison is Kwa St Vincent, funded by the Catholic Church through the Society of St Vincent de Paul. It is located in Nokobongo which is part of Shakaskraal, north of Ballito (see the map of KwaZulu-Natal in section 4.2.1). Appendix N provides an outline of the economic costs of operation for the inpatient centre at Kwa St Vincent. Since this is only one of the services offered at Kwa St

---

[22] Personal communication, Hospice Palliative Care Association Advocacy Manager, 25 March 2008.

Vincent many of the costs were estimated as a proportion of total costs. The economic costs of providing this service in 2004 – R662 per patient – are strikingly higher than the financial costs of R57 per patient as estimated based on total actual costs divided by overall length of stay.

The high-cost care centre, Highway Hospice is located in Sherwood, a suburb of Durban, close to the Berea (see Appendix O for a map of the greater Durban area). The latest full year for which expenses are recorded and identifiable separately for the inpatient centre is 2006. The buyer for Highway Hospice was consulted to verify the amounts on the statement: where he was in agreement, the costs were left as is; if he was not in agreement the actual amounts given in financial statements for later years were cited. Additional costs were also provided by him. Amounts for other years were adjusted to 2006 using CPIX. Where an expense was for the inpatient unit and another hospice programme the proportion of expenses for the inpatient unit were estimated based on the buyer's or the quality assurance manager's estimates. The proportion of staff time for housekeeping and for cooking was used to estimate proportion of costs for cleaning supplies and meals respectively. While there are additional costs that could be attributed to the inpatient unit, some of these are very difficult to assign. For instance, to raise funds four shops are run by Highway Hospice but because of the diversity of services offered by the organization, apportioning this expenditure is extremely complex. This is also the case with administrative expenditure. Appendix P shows the expenses for the inpatient unit for the 2006 calendar year. The economic cost is R1,397 per patient per day for 2004, much higher than the financial cost of R730.

With regard to comparing the costs of unpaid care provision and inpatient centres, in the case of mostly low-cost inpatient centres in which the care is provided by trained caregivers who are reimbursed little if at all and no medical care is given, there are many similarities between the two comparators. In the case of high-cost care centres that provide medical attention and where ENAs and professional nurses provide the care, a somewhat different services is being provided to unpaid care provision in the home. Like is not being compared with like to the same extent as with low-cost centres and costed unpaid care provision.

Using 2008 prices the costs of keeping a patient in a low-cost inpatient centre per day come to R718.05, and the same figure is R1,516.43 per day for a high-cost centre. These costs are substantially higher than the low and high costs of unpaid care provision in 2008 prices of R20.76 and R270.34 per day respectively.

Although the cost per patient per day for inpatient centres is lower than that for tertiary and central hospitals, and while the cost per patient per day for the low-cost inpatient centre is slightly lower than the cost per day of district or regional hospitals, in answering the key policy question, because of the high costs of operation of both high- and low-cost inpatient centres, it seems that it will be difficult for government to agree to extend this care to the population at large.

7.6 NGO/FBO/CBO PROVIDED HOME-BASED CARE

> *Key policy question: Is there a fair way of sharing the costs of care, which limits the poverty and inequality creating effects of the HCBC policy?*
>
> *Key policy question: How do the costs of unpaid care provision and HBC as delivered by NGOs, FBOs and CBOs compare, and to what extent is this intervention able to deliver to all of those in need of HCBC when compared with the former?*

HBC and HCBC has already been defined in section 2.6. Parenzee and Budlender (2007) note that since KwaZulu-Natal has the highest HIV/AIDS rates it is a province in which HCBC has been more developed up to the present than in most other provinces. The provincial Department of Health and Department of Social Development fund HCBC through various NGOs/FBOs/CBOs. In addition, HCBC is funded by municipalities, and through the expanded public works programme. While the Department of Public Works' quarterly reports on the expanded public works programme from 2005/2006 contain social sector information from the KwaZulu-Natal Department of Health and the KwaZulu-Natal Department of Social Development (see http://www.epwp.gov.za/index.asp?c=Downloads), according to the provincial Department of Health no expanded public works programme funding has been received as yet for HCBC in KwaZulu-Natal, and no new programmes have come about in the province as a result of such funding,[23]. These figures are therefore likely to reflect HCBC programmes that were already functioning in the province as funded through these departments, similar to Parenzee and Budlender's (2007) finding. Some studies have attempted to cost this HCBC service (Fox, Fawcett, Kelly, & Ntlabati, 2002; Johnson et al., 2001; Naidu, 2005) but these costs are not comparable to the costs of unpaid care provision as estimated in this study.

The names of 297 HBC organizations were obtained using the key word search "home based care" for "KwaZulu-Natal" province on the HIV911 database. The brief description given of each organization revealed that not all provide HBC in the way it is defined in this research. Rather a broad definition of HBC seems to be applied similar to that adopted by the Department of Social Development (see section 2.6). An attempt was made to isolate those organizations that focus on HBC for people with HIV/AIDS and not on orphans or other services. This was done in order to simplify the costing, making it unnecessary to apportion costs between services. This process resulted in few organizations as most combine a number of programmes. A number of these organizations were contacted in order to establish their costs of care. Many could not be reached because their telephone numbers were no longer in service or because the number no longer existed. The aim was to obtain a range of costs of care, with a focus on obtaining the highest and lowest costs of this form of care provision. As with Naidu (2005), the range of costs obtained is not representative of the actual range of costs of providing this service, and there is a bias towards higher cost and more formalized interventions which are easier to locate.

To begin with low-cost organizations, a number of organizations that were anticipated to be at the low end in terms of cost were contacted in order to estimate their costs of providing a home care service per hour. Each organization provided a list of their monthly expenses for the home care programme as well as the number of community caregivers who work on the programme and the time spent visiting patients, all for the same month. The service costed here includes time taken to get to and from patients as well as the time taken on actual visits. However, since most of these

---

[23] Personal communication, Manager: HBC programme, KwaZulu-Natal Department of Health, 2 April 2009.

community caregivers live in close proximity to those they visit, the time taken to get to and from the patients is relatively negligible.

Table 7.8: Cost per hour of delivering a home-based care service by low-cost NGOs/FBOs/CBOs in KwaZulu-Natal (2004)

HBC organization	Cost of delivering HBC service per hour	Location
National Multi Skills Development Trust	3.34	Groutville Mission
Sinethemba Home Care	6.03	Umlazi Z section
Isandla Home Care	4.37	Umlazi Z section
Ziphatheleni Home Care	5.09	Umbumbulu

Table 7.8 shows the financial costs of providing HBC per hour by some low-cost NGOs/FBOs/CBOs. The cost per contact hour ranges from R3.34 to R6.03 per hour. Since many of the community caregivers in these organizations are not reimbursed at all for their work and those that are do not receive a market related wage, the expenditures in these organizations are very low. These organizations also have few administrative costs, and community caregivers walk to and from the patients, thus not incurring transport costs.

Isandla Home Care, located in Umlazi a former township on the southern side of Durban (see Appendix O), was selected as the low-cost organization. While not the lowest cost organization, it is one at which none of the community caregivers receive a stipend, placing it at the informal end, as opposed to the National Multi Skills Development Trust where many of the community caregivers receive a stipend. In Appendix Q an economic cost of R166.60 per contact hour is placed on the work of Isandla Home Care (based on their work over 11 to 15 August 2008).

Turning to high-cost organizations that deliver a HBC service, an integrated community-based care (ICHC) model has been implemented by the Hospice Association in KwaZulu-Natal at a number of sites within the province. The model links a number of major partners – people living with HIV/AIDS and their families, community caregivers, hospices, clinics and hospitals – in a continuum of care. It aims to deliver quality of care from diagnosis to death and to bereavement (Akintola, 2004; Lauden, 1999). The national Department of Health assembled this as a best practice model, however it has argued that this model is too expensive for government to financially support mass roll-out.[24] For these reasons this model can be regarded as HBC at the high-cost end.

A number of hospices in KwaZulu-Natal use the ICHC model to deliver HBC.[25] Each employs one or more professional nurses and trained community caregivers to visit HIV/AIDS and cancer patients in their homes. Patients are categorized as to whether they are category one (usually HIV-positive but not sick), category two (needing some medical/nursing care in addition to psycho-social care) or category three (home or bed bound and receiving significant clinical care). With regard to HIV/AIDS, category three patients are equivalent to the WHO clinical stage four. A usual visit entails the patient being examined physically and treated medically. Medication is only handed out if prescribed by a doctor for that patient. The patient may be referred for specialized care or medication at clinics or hospitals or other organizations. The patient may also be bathed, nutritional and hygiene training may be given and he/she may be assisted with accessing grants.

In KwaZulu-Natal there are 17 hospices affiliated to the Hospice Palliative Care Association, and only four of these carry out HBC as their single programme. The remainder undertake other programmes in addition to HBC, such as children's programmes, day care programmes, etc. Only these four hospices were contacted for their cost information since their expenditure could be assumed to be on HBC only. A professional nurse at each of these hospices provided patient information for a particular month in 2008 as follows: the number of patients in each category, the average time per visit for patients in each category, the estimated number of visits per patient per month (estimated and not actual number of visits were used because the actual number of visits can differ from month to month).

---

[24] Personal communication, Clinical Co-ordinator, South Coast Hospice Global Fund Project, 19 October 2005.

[25] The following information on hospices was obtained from the Hospice Palliative Care Association Advocacy Manager, 25 March 2008.

Only patient costs for category three patients are reflected in the comparison since this is the most accurate representation of terminal illness care. Cost per contact hour was estimated using total time spent by hospice nursing sisters and caregivers with patients and the expenditure for the hospice for the same month. Any expenditure which did not have to do with the running of the HBC programme was excluded. It is important to note that only the contact time with patients – what the service of HBC consists of – and not the time taken to get to and from patients is included in the estimation. While not ideal, it is simply too complex to estimate the time taken to get to and from patients for the period under review. This approach does not take into consideration the time spent on the initial admission process and whether the patient is seen to by a professional nurse and community caregivers or by caregivers only, which has a bearing on cost. The cost estimation does not differentiate between cancer and HIV/AIDS patients.

In Table 7.9 the relatively high cost of providing a HBC service by these hospices is evidenced. The cost per contact hour of delivering this service to category three patients ranges from R72.32 to R783.98 for 2004.

Table 7.9: Cost per hour of delivering a home-based care service to category three patients using the ICHC model for NGOs in KwaZulu-Natal (2004)

KwaZulu-Natal Hospice Palliative Care Association affiliated hospice	Cost of delivering service per hour	Location
Estcourt Hospice	121.62	Estcourt
Khanya Hospice	783.98	Umkomaas
Ladysmith Hospice	545.52	Ladysmith
Vryheid Hospice	72.32	Vryheid

Note: Patient numbers for each category of patients, number of visits per patient per month, estimated time per visit and total expenditure per hospice was obtained from each hospice; total expenditure was apportioned to the three categories of patients according to overall time spent visiting; the time was given a cost using this expenditure

The highest-cost NGO that provides HBC is Khanya Hospice. It is located in Umkomaas, just north of Scottburgh on the south coast of KwaZulu-Natal (see map in section 4.2.1). Appendix R details the economic costs per contact hour for the ICHC and cancer programmes at Khanya Hospice for the 2007/2008 financial year. The economic cost per contact hour for 2004 has risen only slightly to R807 from the financial cost of R784, reflecting the fact that there is very little unpaid volunteer time and relatively few donated items at this hospice.

In terms of comparing the costs of low- and high-cost HBC organizations and the costs of unpaid care provision, caution should be attached to doing such a comparison. The two forms of intervention are quite different: in the case of community caregivers, the service that is delivered is overseeing the work of family caregivers, and providing training, and in fewer cases undertaking actual care activities; family caregivers on the other hand provide the actual care provision of HBC often on a 24-hour basis. The economic cost of low-cost HBC comes to R180.82 per hour for 2008, while the economic cost of high-cost HBC comes to R875.99 per hour. In contrast, the costs of unpaid care provision using the selected approach range from R0.87 to R11.27 per hour, substantially less overall than the cost of providing HBC by someone from outside of the home.

While there is a more just way of sharing the costs of care – by introducing more HBC as delivered by NGOs/FBOs/CBOs – it comes at a high cost. Therefore, the potential for this intervention to deliver to all of those in need of HBC, when compared with unpaid care provision, may not be great, again because it does not seem that government would be willing to do so, because of the high cost.

7.7 SPENDING ON UNPAID CARE PROVISION

In concluding this chapter, in nearly all cases the comparisons show that the range of costs of providing unpaid care to people in late-stage HIV/AIDS within the home are substantially lower than the costs of providing this type of care provision in other environments or by other individuals. The one exception is the cost of staying in a community health centre, which is lower than some of the study households' costs of unpaid care provision.

Table 7.10: Low- and high-cost unpaid care provision as a percentage of low- and high-cost interventions (2008 costs)

Intervention	Low-cost unpaid care provision as % of low-cost intervention	High-cost unpaid care provision as % of high-cost intervention
Private home care	7.1	26.4
Public inpatient care	19.6	6.1
NGO/FBO/CBO inpatient care	2.9	17.8
NGO/FBO/CBO HBC	0.5	1.3

The percentage of the low- and high-cost of each type of intervention that unpaid care provision constitutes is shown in Table 7.10. The percentage does not exceed 26 percent. At minimum it is half a percent, in the case of low-cost unpaid care provision as a percentage of low-cost NGO/FBO/CBO HBC. Overall, and as expected, unpaid care provision within the home for people in late-stage HIV/AIDS is cheaper than similar public and private interventions in KwaZulu-Natal. Yet this service of unpaid care is being provided within the home for virtually no cost to government, the private or NGO sectors.

By taking the costs estimated in this thesis into consideration, how are the contributions of the health and welfare sectors to HBC provision understood? Hunter (2005) has shown the amounts allocated towards and spent on HBC by the KwaZulu-Natal Department of Health and the KwaZulu-Natal Department of Social Development in 2004/5, and these are documented in the table that follows.

Table 7.11: Provincial allocation and spending on home-based care (2004/5, R million)

Provincial Department	Allocation	Spending
Health	28.5	15.7
Social Welfare & Population Development	8.9	12.4

Source: Hunter (2005)

What does this spending translate into? Essentially the provincial government uses this money to fund HBC as carried out by NGOs/FBOs/CBOs, that is visits by community caregivers to ill people in households. As shown, these visits are usually social in nature and usually do not include ‘practical’ caregiving activities.

It is possible to estimate what the spending on unpaid care provision for people in late-stage HIV/AIDS would be if this work were to be reimbursed, that is if family caregivers were paid for the time spent in unpaid care work and households were reimbursed for their financial costs. However it must be borne in mind that the time-use data from the qualitative study are not representative of the time spent caring for AIDS sick people in KwaZulu-Natal because the data were collected on intensive illness episodes. That is, the data represent an overestimate of the overall time spent caring for AIDS sick people in KwaZulu-Natal, and similarly the costs obtained will also be overestimates. Nevertheless, in the absence of other similar data it provides a unique opportunity to speculate about the costs of providing unpaid care for AIDS sick people in KwaZulu-Natal. This is not unrealistic because in KwaZulu-Natal most of the time spent in HBC is on those who are in late stages of HIV/AIDS.

This calculation is therefore done as follows for 2004/2005:

- The number of AIDS sick (people with AIDS-defining conditions) in KwaZulu-Natal in 2005 was 181,694 (using ASSA 2003) (Actuarial Society of South Africa AIDS Committee, 2009) ;
- This is multiplied by the monthly ‘low’ estimate of unpaid care provision (R585.19) and separately by the monthly ‘high’ estimate of unpaid care provision (R7,619.05) in order to

get an idea of the low and high estimates of this 'intervention' in KwaZulu-Natal per month.

The low estimate of the cost of unpaid care provision for 2004/5 comes to R106,325,512 million per month, and the high estimate totals R1,384,335,671 million per month. This 'spending' translates into caregiving activities by one or more family members in addition to the financial costs of caring borne by households.

This spending exceeds the monthly provincial health and welfare spending on HBC of R2.3 million by R104,025,512 million if the low estimate is used. It emphasizes just how small the HBC spending of the provincial health and welfare departments is and how much labour time and financial costs are being committed within homes by the families of people in late-stage HIV/AIDS. These government departments are not taking responsibility for this care provision within the home, and instead, in Urdang's (2006) words, unpaid care work is subsidizing the national economy, which is in turn able to limit its expenditure on care provision.

If the two cost estimates per person per month are increased in line with inflation (using Statistics South Africa, 2009), for 2008 the low estimate would be R614.56 and the high estimate would be R8,001.44 per person per month for unpaid care provision that takes place seven days a week and 10 hours per day.

What do these estimated amounts mean? A substantial portion of the financial costs portion of the R614.56 would have come from grant income that was intended for someone else. Without having to spend most of this money on the ill person's care, much of it could have been spent on household assets or enterprises or better opportunities for alleviating poverty. Even if not, the wellbeing of the household would have been better secured if the money had been available to the household for purposes other than the ill person's care. Likewise, much of the labour costs portion of the estimate of R614.56 per month could have been spent on seeking employment or undertaking informal employment or doing subsistence agriculture activities which would all have benefited the household, in the absence of caregiving, to the benefit of the household.

8 DISCUSSION

The chapter begins with a reflection on some of the key findings from the 2004 KIDS and the 2004 KIDS qualitative study. Next the focus is on understanding how the study findings answer the questions addressed in the theoretical approaches and models reviewed at the beginning of the thesis, specifically with regard to gender and the economy of paid and unpaid work. Following this is an assessment of how a particular classification system of care activities, put together in and for a developed country, applies to the KwaZulu-Natal developing country setting. Next the methodology of counting unpaid care work time adopted in this study is discussed followed by a discussion of the process of valuing unpaid care work. After this is a critique of which methodologies used in this study get at which information best. Finally, the focus falls on specific aspects of this study that could be changed in future similar studies and what the best instruments to collect this information are.

8.1 FINDINGS FROM THE 2004 KIDS AND THE 2004 KIDS QUALITATIVE STUDY

The ‘health’ and ‘death’ components of the 2004 KIDS are an important resource for highlighting aspects of care provision in households in the province. Most of the care that happens within these households is for one ill person only and usually one person within the household takes responsibility for this care. Extremely burdensome care situations where one or more ill people are receiving care from one or more caregivers – the focus of the 2004 KIDS qualitative study – are not as common.

More of those being cared for are female than male, and they tend to be a generation younger than the household head. In contrast, nearly all of those who care for ill or dying people are female, most are in their late forties, and they tend to be of the same generation as the household head. Most of the caregivers are not very well educated, and over half are unemployed or retired or pensioners, with only a quarter employed.

Almost three-quarters of those who died consulted a public health facility as their last consultation, while a third of the ill people visited private health care providers last. Moreover, in KwaZulu-Natal relatives and friends play a greater role in HCBC than community caregivers, with strikingly few of the ill being visited by the latter. Since community caregivers' involvement represents government's engagement in HBC, this highlights government's limited role in providing care within the home.

The above paints a broad picture of care provision in KwaZulu-Natal for those over ten and under 60. It gives an idea of what tends to be common across these households. The 2004 KIDS qualitative study focused on 16 households in KwaZulu-Natal in which high-intensity care provision was taking place. A number of important insights were obtained from this qualitative research that provides depth of insight not obtained with the 2004 KIDS. Nevertheless, it must be remembered that the sample is not representative and therefore the findings cannot be generalised to the situation with regard to home-based care in general in KwaZulu-Natal.

Firstly, it is important to remember that amounts and types of care differ vastly across households, just as the conditions of ill people differ. Moreover, the health of caregivers is not always assured and plays a role in determining the type and quality of care that can be provided. In some households there are multiple already-existing care needs for adults and children that have to be met, in addition to the needs of the ill person.

As with the quantitative study, it is women who take prime responsibility for care within the home, but also for household tasks. Resident males do not provide care for resident females, although in some households they do provide some types of care for other males. These tasks are never household chores, include tasks that take place outside of the household and only in some cases are personal care tasks.

Although not as frequently evidenced, in some households there is more than one main caregiver per household. When the caregiving load is shared one person is not so incredibly burdened. These shared care situations unfold variously across households.

Children do not seem to be actively involved in providing care, and rather caregiving remains the domain of the main caregivers who are nearly always adult. Caregiving tasks undertaken by children include going to the shops or elsewhere to buy or fetch odd items for the ill person. In some households children do other household tasks which free up caregivers to undertake personal and other care tasks for the ill people. There are isolated incidences of child involvement in very extreme cases, such as 16-year old Thenjiwe Ngidi who cares for two ill family members and two children with virtually no support.

As with the 2004 KIDS households, in most households very little care provision is undertaken by those from outside of the household. However there are a few cases where extended family and neighbours help substantially with actual care provision. In almost all cases, visits by community caregivers are ‘social’ in nature, with no care provided. The term ‘home-based care’ seems more applicable than the term ‘community-based care’ to the care that is being provided to ill people in the study.

In most of the households the ill person did not move to a different household to receive care, although in six cases the ill person, who was previously employed, moved from an urban to a rural or less urban area to receive care. In most cases these households are losing income that was received before.

What is evident from looking at the financial costs of providing care is that the ill person is extremely embedded in the household, not just in terms of relationships but in terms of shared consumption. A ‘patient-in-hospital’ in contrast seems to be an atomised individual, regarded only in terms of individual health-related costs. Moreover, in four of the households the monthly amount spent on the ill person substantially exceeds the value of the old age pension and the indigence level. These findings on financial costs are extraordinary, important and noteworthy.

The welfare grant to the poorest elderly is subsidizing the health services. The Department of Social Development is paying for these health care needs through a grant that is intended for elderly people.

8.2 THE LITERATURE ON GENDER AND THE ECONOMY OF PAID AND UNPAID WORK

How do the study findings answer the questions addressed in the theoretical approaches and models reviewed with regard to gender and the economy of paid and unpaid work? To begin, Chen et al. (2005) raised various issues to do with women's paid and unpaid work and these were confirmed by the 2004 KIDS qualitative study findings. Women took primary responsibility for providing care. They spent more time than men in unpaid care work and housework, and some did paid and unpaid market activities in addition. This is clearly illustrated in the context of illness that pervaded study households. The ability of women to participate in and get ahead in the labour market is contingent on other demands on their time, especially unpaid care work. Those women who were working were undertaking part time and informal work – the types of work that unpaid care work tends to channel women into. Many of these women were reconciling paid and unpaid work but they were poor, and they were receiving no state support for their contribution to the production of labour.

The WHO's continuum of paid and unpaid care provision as outlined in section 2.2 does not seem to exist in reality. Ill people in the qualitative study had very limited access to the specialists and specialized care facilities that make up tertiary health care. Some had access to some secondary health care at certain times but not always when this care was required. With regard to primary health care, it is not clear what is meant by health posts, but ill people did access dispensaries and traditional care. However much of this was privately paid for which limited access to this form of care. Community-based care did not seem to exist. Where community caregivers from NGOs and government and members of churches and other volunteers external to the household did visit ill people in their homes these visits were almost always social in nature, with little, if any, actual caregiving. Finally, HBC was provided by virtually no-one except family caregivers, with very little support to these caregivers. Very few of these caregivers had received training in how to provide HBC. Overall, care did not seem to extend through various levels of care, but was concentrated in the home. Ill people received more HBC than other types of care, regardless of their needs. Overall, less paid care and more unpaid care was received by ill people within the home.

Much of how care was defined in the literature was confirmed through the study findings. In this study unpaid care work did indeed occur in the context of family relationships, but not frequently within a marital relationship. The findings confirmed that intimate personal care is indeed heavily gendered (Twigg & Atkin, 1994) and that women bear the main costs of unpaid caring in terms of actual care, foregone income and emotional strain (Bubeck, 1995).

A major focus of this study was on indigenizing the process of costing unpaid care work to a South African context, specifically the eastern seaboard region of KwaZulu-Natal. In order to cost this work it was necessary to count the time spent in unpaid care work, and in order to do this it was necessary to use some classification of care activities. A typology of care activities developed by Parker and Lawton (1990, as cited in Parker, 1992, p. 10), based on the eight tasks the United Kingdom's GHS had defined, was used to develop the questions relating to caring activities for this study. Caregivers in the 2004 KIDS qualitative study spent on average a quarter of their time on physical help and a quarter of their time on personal care – there was therefore heavy involvement by caregivers in care provision. The only exception to how the typology defined caring tasks was 'making food/drink' and 'helping eat/drink' which were recorded together – this took over a fifth of the caregiving time.

A further focus of the study was on the double burden of market and non-market production often borne by women. The study findings from the United Kingdom confirmed that the division of paid and unpaid work between men and women is very unequal (Lewis, 2001), that the sexual division of labour in the household is highly resistant to change and that an unequal burden is placed on women (Bakker, 1994). The findings also showed that, as Blackdon and Wodon (2006) say, the disproportionate cost borne by women of reproductive work in the household economy restricts women spatially and culturally to activities compatible with domestic obligations. In South Africa, as in other developing countries, there has been an increase in women in the labour market, and this has been largely accounted for by increased numbers of women entering the informal economy (Casale, 2004; Chen et al., 2005). Most of the caregivers in the qualitative study that were employed were self-employed and working informally. Informal economy employment means low earnings and insecure working conditions. Chen et al. (2005) emphasize how women are now faced with the double burden of market and non-market production. Although only some of the caregivers in the study were working in the market, this is the reality in these instances. Some of the caregivers reduced their work in order to care, thereby accommodating the need for care provision in the absence of government provision.

Various authors describe how the reproductive economy impacts on the productive economy. Elson (1994, p. 41) notes that "macro-policy generally takes the 'reproductive economy' for granted, assuming it can continue to function adequately no matter how its relation to the 'productive economy' is disrupted", and Chen et al. (2005) argue that the reproductive economy impedes women's ability to earn a livelihood. It is however not clear to what extent this is the case in South Africa, where there is a strange employment situation, with both formal and much informal employment, high unemployment and complex family structures.

Community care is the broad policy framework within which care provision takes place in South Africa. A number of critiques of community care were outlined in the literature review and many of these were shown to be true from the study findings. While a basic tenet of community care is that the 'community' must accept and participate in the rehabilitation of the individual (McGovern, 1989), the study findings are in line with Dalley's (1988) description of what occurs in reality: that voluntary organizations, friends and neighbours play only a sporadic and irregular role in care provision, if any, and that it is women in the caree's family who undertake virtually all of the actual care work.

A broad criticism of community care, outlined by Dalley (1988), is that there is a belief that the family is the appropriate location for care and that the dependent person can best achieve privacy and independence in their own home. These assumptions were shown not to be the case from the study findings. At least one desperate care situation in the Ngidi household, where a child was singly caring for her dying mother and her aunt in addition to caring for two children, with no support from outside of the household, demonstrates that the home is not always the most appropriate location for care. Some of the ill people could have achieved dignified independence outside of the home environment. Here Mbeje Luthuli who remained in his room, in an unclean and unhygienic state, comes to mind.

Another criticism of community care policies was also given credence through the study findings: Dalley (1988) argued that community care policies do not always correspond to the needs or wishes of all dependent people, and that community care is not appropriate to all categories of dependency. While the qualitative material indicated that most of the ill people preferred being in the home rather than in a hospital setting, clearly some of them were too seriously ill to be cared for by family caregivers within a resource-limited home environment. Zinhle Ngidi is a case in point. This form of care provision was not appropriate for her or for the person who provided care.

Ungerson (1987) provides a final critique of policies for community care, noting that they are incompatible with policies for equal opportunity for women. South Africa subscribes to a gendered discourse and rights for women. The results in this thesis about the costs being borne by unpaid family caregivers, however, belie the discourse.

In South Africa HCBC is a function of both the provincial Department of Health and the Department of Social Development where it falls in line with the policies of primary health care and developmental social welfare respectively. As already noted, the chief way that HCBC is put into practice by government is through funding NPOs to provide HBC, and this largely translates into community caregivers visiting ill people within their homes. However, in practice provision of this kind to the household is not extensive and not sufficient, as the study shows. In fact, the findings seem to indicate that HBC is regarded by government as a soft social service issue rather than a health issue.

The bulk of the Department of Health's and the Department of Social Development's work of HBC is undertaken by unpaid family caregivers within homes across South Africa. While hospital provision of care has been reduced, HBC services have not been increased to a commensurate level, as was the case in the United Kingdom. Present HBC support through a limited number of organizations and community caregivers is not nearly meeting the needs of caregivers and care recipients within the home. The state's contribution to HBC is extremely minimal, and the work of HBC is left almost exclusively to the families of ill people. The government is explicit about capping the number of people with HIV/AIDS who can receive care in a hospital setting. Yet the study findings confirm Tollman and Pick's (2002) observation that community-based health care is poorly developed in practice. Moreover, the individualization of care is evident, in line with Patel's (2005) description: there is a shift in responsibility for social welfare from the state to individuals and families. While family caregivers pick up the care responsibilities in households across the country, they are not given priority in the HCBC guidelines and in government action with regard to HBC. Also shown to be true from the study findings is Ogden et al's. (2004) statement that in the majority of AIDS affected families caregivers are not linked to nor supported by formal HIV/AIDS care programmes, and Wallwork's (2006), Akintola's (2004) and Hunter's (2005) findings on the disconnect between caregivers and the health system.

The study findings also bear out further findings from two other South African studies on caregiving. The following from Akintola's (2006) study were confirmed: the gendered nature of HBC and the gendered division of caring roles; health-related burdens associated with caregiving experienced by caregivers; female caregivers' multiple caring commitments in addition to caring for the ill person, with little support from other family members. Akintola concludes the following about HBC in South Africa, which is borne out by the study findings, namely that HBC policies and programmes assume family members are available, willing and capable of caring for ill family members in their homes (which is not always the case); these policies and programmes transfer responsibility for care to those already burdened by poverty and other care commitments; and they exacerbate existing gender inequalities. Orner (2006) finds the following, also confirmed by the study findings: caregiving negatively impacts on the mental health of caregivers; family caregivers have little support, are poor, lack basic resources and have other caregiving responsibilities; and caregiving impacts negatively on normal working and social patterns.

8.3 THE UNITED KINGDOM'S TYPOLOGY OF CARE ACTIVITIES AS APPLIED TO KWAZULU-NATAL

While it would be ideal to compare issues relating to care in South Africa to another developing country such as Uganda, there exists no comparable data on which to build such a comparison. Instead in this section the following is established: the relevance to a southern setting such as KwaZulu-Natal of the United Kingdom's typology of care, developed in the north. The following sections focus on how care tasks are classified in the north, how these tasks are classified in the south, what the differences in approach are and why, and what should be done differently in future.

There are two broad issues to bear in mind when applying knowledge from the north to a southern setting. Firstly, the populations being cared for differ in the two contexts. The United Kingdom's GHS asked about care for the sick, handicapped or elderly. It was also interested in carers for chronically sick or handicapped children, elderly relatives or friends, as well as "those who visit or provide some regular service (e.g. shopping, odd jobs) for someone who is sick, handicapped or elderly" (Office of Population Censuses and Surveys, Social Survey Division, 1988, p. 46). Even although the care component of the GHS was undertaken over two decades ago, the cared-for population in the United Kingdom has not changed much in this time, despite an increase in the proportion of elderly people – something that is likely to be driving the understanding of care in the United Kingdom context. In South Africa it is the large number of

HIV/AIDS ill, the largest group of dependent people in need of care, who are informing the understanding of care.

Secondly, a number of assumptions are implicit in the structuring of the United Kingdom typology of care activities, specific to the context in which they are established, that might not apply to a developing country context. Family structure is one of these. In a developed country such as the United Kingdom, most families are nuclear and there are many instances where people, even elderly people, live on their own. This is infrequently the case in a developing country context including South Africa where immediate and extended family, and also non-family members, often live together and share resources, as described in section 2.5.

With regard to the labour market, notwithstanding the fact that caring can have adverse effects on people's employment prospects (Laczko & Noden, 1992), in the United Kingdom it is more likely than in South Africa that caregivers will be able to find some paid employment as an alternative to care provision within the home. Although in the United Kingdom it is not so much a matter of people leaving work in order to care, but continuing to work and care, as found by Hutton and Hirst (2000, p. 31): 83 percent of carers in the first six waves of the British Household Panel Study remained in the same work status as before care started. In a developing country context, particularly that in South Africa, if caregivers were not providing care they would in many cases be unlikely to find paid employment.

With regard to the provision of health services, in a northern setting it is assumed that the state will pay for care provision of some sort. Citizens in welfare states will receive either HBC with some form of case management where someone from the state will visit the person within their home, or institutional care, or some other form of care. This is a very different starting point to that in a developing country. In South Africa, those dependent on the public health system will either receive HBC or no other certain or reliable care. While the government explicitly tries to curb the entry of AIDS-ill people into hospital beds, it does not provide a viable alternative for the care of these people. There is therefore no assumption that the state will pay for care provision. In South Africa the link is broken between the home and the state, but this is not the case in developed countries, or even in some developing countries where care provision is seen as something that needs to be provided by government in some way. Uganda is one example of such a country and Akintola (2004) provides a description of this.

Therefore there are clearly many different assumptions that underlie health and welfare policies in these different contexts, which mean that one single categorization of care activities cannot simply be applied blindly across contexts, but needs to be tailored to the particular context. Box 3 details some of the assumptions particular to poorer households in KwaZulu-Natal, gleaned from the qualitative study findings and compares these to assumptions on the same issue in the United Kingdom. The contrast between the assumptions in the two locations is striking.

Box 3: Assumptions specific to the United Kingdom and the KwaZulu-Natal study

Issue	United Kingdom	KwaZulu-Natal
Bed	Traditional bed – not moved	Sleeping mat – takes time to move inside and outside
Hanging up washing	On washing line	On fence, rocks, grass
Electricity	Yes – may continue care tasks/chores after dark	Not always – difficult to continue care tasks/chores after dark
Refrigeration	Yes – may not need to remix juice, for example	None – make juice three times a day, for example
Sleeping arrangement for cared-for and caregiver	Separate beds	Possible bed sharing
Toilet	Inside, therefore may not need bedpan	Outside, therefore need bucket/bedpan
Transport	Ambulance	No ambulance, sometimes great distance from transport

Some care activities that were included in the United Kingdom's typology of care were not mentioned as occurring in the KwaZulu-Natal study households. For instance, very little help with paperwork and financial matters was recorded (examples of this in the United Kingdom typology include writing letters, sending cards, filling in forms, dealing with bills, banking). The scant mention of this care activity could be attributable to the fact that most of the ill people in the KwaZulu-Natal study are not financially well-off, do not deal with banks, and therefore would not need assistance with bills and banking. Writing letters and sending cards is not common, especially among people with low levels of education, so would also not be expected. However, it is likely that many of the ill people would have been involved in paying for school fees. The only mention of 'paperwork and financial matters' in the KwaZulu-Natal study was with regard to applications for the disability grant. Six of the ill people applied for the grant but only for one ill person did this application occur over the time when they were very ill – the period under review for this study – and this activity therefore appears to be undercounted.

In addition, giving injections was not mentioned among the KwaZulu-Natal study households, although it is listed in the United Kingdom's typology of care under 'giving medication'. Changing dressings, which is given as an example of 'giving medication' in the United Kingdom's typology was only mentioned once. The most likely explanation for this is that the level of care provided within the home in a developed country is a lot more sophisticated than that provided in a southern setting, for the most part because of the relatively high level of support available to caregivers within the home in the north. In the United Kingdom the policy of HBC has been in place for many years and the level of government intervention is high in comparison to countries in the south. Moreover, most households in the south, without government assistance, cannot afford materials such as dressings and injections, although the latter is less likely an issue of affordability than of legality, with doctors and nurses being the ones to administer injections.

In the United Kingdom context 'taking the person out' refers to taking them out socially (the examples given are taking the person out for a walk or a drive, and taking the person to see friends or relatives). It does not refer to taking them to a health facility which was when the ill people in the KwaZulu-Natal study were ‘taken out’. In the KwaZulu-Natal study there were no examples of ill people being taken out socially, but this is probably because of the extent of illness of these people, as noted in the previous section. It could also be that those receiving HBC in the United Kingdom do not frequently go to health facilities but instead that health professionals visit them in their homes if they require medical assistance which a family caregiver cannot give. The option for a health visit outside of the home was listed under ‘practical help’ in the United Kingdom’s typology.

Finally, a few care activities were not asked about in the KwaZulu-Natal study but appear as examples in the United Kingdom’s typology, namely doing his/her shopping, doing housework, gardening, decorating, doing household repairs. The reason for their not being asked is that they seem quite particular to a developed country context. One can imagine a home visitor in the United Kingdom context volunteering to do an elderly person’s shopping or a neighbour helping him/her with gardening chores or a relative coming to do some household repairs over a weekend. In a southern setting most of these seem to be secondary activities not vital to the wellbeing of the cared-for. Most of these activities are also not widely practiced in a third world setting with high poverty levels. They do not stand out as activities that have to be undertaken for the cared-for person, mainly because of unemployment and how households are constituted. In the KwaZulu-Natal study the Tembe household consisted of three adults, with one of the ‘well’ adults receiving a disability grant and the other receiving a child support grant. The ill person did not receive any income and was dependent on what could be provided to him by the other household members. It is hard to imagine gardening, decorating and household repairs being done for the ill person. Moreover, the housework and shopping that was done before he became ill was done for all household members and this continued after he became ill.

A number of activities were not mentioned in the United Kingdom’s typology but were enquired about in the KwaZulu-Natal study, mainly because they were raised as issues in the pilot study: rubbing and massaging; special food shopping; helping the person to eat or drink; and going to a health facility or shop to get medication for the ill person. None of these activities were mentioned in Parker's (1992) outline of the United Kingdom's typology, although this does not necessarily mean that they did not occur in that context.

8.4 THE METHODOLOGY OF COUNTING UNPAID CARE WORK TIME

In this study the stylized approach was used to enquire about the frequency and duration of caregiving activities. The amount of time it took to answer the questions did not seem to be a major problem for respondents, except with regard to the amount of information – the sheer number of activities asked about and the detail on the activities – that had to be recalled (as Juster (1985) and Kan (2006) predicted). This seemed to result in some respondent and field researcher fatigue. Budlender (2006) highlighted some issues relating to when the study takes place, and the effect of this on the findings. In some cases the time lapse between when the activity occurred and when it was recorded was great, and some respondents did complain of memory lapse. Obtaining information on many rather than few days also seemed to result in respondent fatigue for some. In contrast to Folbre (2000) this study found that the stylized approach was not able to estimate non-activity-based caregiving. Yet it does seem to be the case, as the United Nations (2005) describe, that the time diary is a more certain option than other methods for collecting information on simultaneous activities.

One of the central purposes of this thesis has been to cost unpaid care provision for ill people in the home in KwaZulu-Natal. Since the time spent undertaking specific care activities for ill people within the home and the financial costs of care provision had not been counted before in this context, this necessitated the researcher's establishing how to do so epistemologically. This meant that the researcher had to make decisions on the best way to count time spent providing unpaid care work by family caregivers and financial costs by households. Tools had to be chosen to do this within the constraints of the study. The units of analysis had to be determined and applied consistently across information from study households.

As already mentioned, the United Kingdom's typology of care activities was used as a working guideline for classifying care activities that were then counted. It is not certain to what extent using another typology would have impacted on the data collected, but if it is amended to the study context this approach to classifying care activities is a suitable methodology to use in the future. The researcher did not base the counting of financial costs on any other research. In all, the approach to counting time spent in unpaid care work was common sense; under- rather than over-estimation; consistency in applying approaches across cases; thoroughness; other case studies as points of reference where unsure; and obtaining the advice of the same person across time when unsure (in the case of this thesis it was the researcher's supervisor).

The time spent in unpaid care work counted as part of this study is an underestimation of the time spent in unpaid care work in these households. The use of under- rather than over-estimates and using caution throughout was chosen as a strategy. One of the main points of this thesis is to draw attention to the invisibility of women's unpaid care work, and it is more likely that this will be successfully achieved if the approach is a cautious one. There have been a number of other attempts or initiatives at raising the visibility of women's status and work (Budlender, 1996, 1997, 1998, 1999), children's status and work (Cassiem, 2000; Robinson, 1999), and the informal economy (Budlender, Skinner & Valodia, 2004). All of these initiatives have tended to use the same approach of caution.

The person's illness brings with it additional care needs – the care of the ill person's children, for instance – and since only the time spent caring for the ill person was counted, there is an overall underestimation of time spent in providing care in these households as a whole. Moreover, the time spent in providing public goods which may also be for the ill person was not counted, hence there is again an underestimation of time-use. In addition, since more than one activity at one time was not included in the time estimation, due to the questionable reliability of the time-use information that resulted from the stylized questions on simultaneous time-use, this also results in underestimation of time spent in unpaid care provision. Therefore, although some authors caution that the stylized approach results in overestimation (Juster & Stafford, 1985; Van den Berg &

Spauwen, 2006), the underestimation described above is likely to have exceeded any overestimation.

8.5 VALUING UNPAID CARE WORK

The process of applying methods that value unpaid care work to the counted unpaid care work time presented a few difficulties. To begin, there are a number of occupations that fall under one South African Standard Classification of Occupations code – in other words one code may encompass a diverse range of occupations. The codes were used to estimate earnings rates in that an occupation (defined by the code) can be assigned an average or median earnings rate. It should be borne in mind that these codes were not set up for this reason. But because of the diverse range of occupations that fall under one code, a particular code is not always the most adequate to use.

Another similar problem stems from there not always being any respondents, or enough respondents, to whom a particular code applies. This problem was highlighted in the application of the specialist method. Specifically, no earnings information was supplied in the September 2004 LFS for nursing assistants in KwaZulu-Natal, and therefore the earnings rates of 'nursing and midwifery professionals' had to be used. Part of the reason why nursing work using the specialist method had the highest earnings rate was because of this.

Also, it is not clear how to apply a wage rate if the person does part-time versus full-time work, and the hours of part-time work are neither regular nor specified. For the average earnings and opportunity cost approaches where the aim is to estimate what the person would have earned had they been working instead of providing unpaid care work, if the earnings are part time they should be lower than the earnings of someone in the same type of employment who is working full time. However, it is not possible to account for such a difference in the current approach.

Another issue for discussion is using the earnings rates of employees only when estimating costs using the generalist and specialist methods. The earnings of the self-employed are excluded, and these earnings include a wide range from very low to very high. By excluding the earnings of the self-employed important earnings information is lost since there are a number of those among the high earners who, while they have no actual employee, are still being remunerated. While it is not possible to distinguish between the the self-employed using the LFS, it is also not accurate to use the earnings of all the self-employed. Therefore there remains no other option but to use the earnings of employees only for these methods.

For the opportunity cost approach that uses employment information and the specialist method the sample sizes were often very small, so small as to be considered unreliable, which brings into question the use of these earnings rates. Yet despite being less than satisfactory these earnings rates were estimated for the sake of being comprehensive. Ideally earnings rates drawn from larger sample sizes in representative survey data should be applied in future studies. The qualitative study too had a very small sample size and it is preferable to have a larger sample to which to apply earnings rates.

A wide range of estimates stems from all five generalist approaches, reflecting the widely different ‘methods’ used per approach. An important outcome may be that the proportionate approach is a simple specialist approach. While the specialist method is generally not applied because of the complexity of assigning professions to individual types of work, the proportionate approach is much more user friendly. It is slightly simpler – because only the earnings of two types of professions are applied to the time spent in unpaid care – and yet the time spent in different types of work is still accounted for. The fact that this was selected as the approach of choice for valuing in this study testifies to these positive attributes.

Finally, although the average earnings approach is not proposed as an appropriate approach for KwaZulu-Natal, a recommendation for similar future research in which this approach is used is that the earnings of the self-employed instead of the earnings of all the employed be used. This is because more of the caregivers were self-employed than employed as wage earners. In addition, for the opportunity cost method, discounting the wage the person would have earned in a full employment economy by the percentage chance of getting work, may represent an important future innovation. This approach would accommodate in the analysis South Africa's high unemployment rate, something which is a shortcoming of the opportunity cost method as applied in this thesis.

Were the findings from the literature on valuing unpaid care work time confirmed when these methods were applied to the study findings? The results were compared to Budlender's (2002) recommendations on what the lowest, highest and widest range of estimates should be. The limitations of the LFS 2004 data in providing data for all occupational codes for KwaZulu-Natal pointed the findings in a certain direction, accounting in part for the differences from Budlender's description of what the findings are likely to be. Much depends on what occupational codes are available to be applied, and therefore much depends on what the limitations of the relevant data set are. The study sample also contained very low informal earners, lower than domestic workers referred to by Budlender as being at the low end, and accounting for the other aspect of difference.

These methods for valuing unpaid care work are the most appropriate input-related approaches to use and worked well apart from some of the difficulties mentioned above. Care should be taken to select the approach or approaches most suitable to the study sample. Ultimately having a larger more representative sample from which earnings rates can be generated means that there is a better likelihood of obtaining realistic earnings rates from a data set.

8.6 METHODOLOGIES USED IN THIS STUDY

This thesis is about advancing understanding, therefore a core question is what has been learnt from this study, and relatedly, what is the best that each methodology can offer? This section contributes to and constitutes a deeper discussion about the reliability of our knowledge.

The task of this study – to cost caregivers' labour time spent in unpaid care work and to count the financial costs borne to households – meant that three central steps had to be undertaken. That is, unpaid care work time had to be (1) counted and subsequently (2) valued, and financial costs had to be (3) counted. In order to do this multiple methodologies, both qualitative and quantitative, were used across multiple fields of inquiry. The different methods enabled different types of information to be collected, and a key focus of this section is on what information different methods were able to obtain well.

Firstly, because the type of information being collected was emotionally sensitive it was necessary to use a method that would allow field researchers to locate themselves appropriately in the study areas and in relation to study households in order to obtain this information. To this end an ethnographic method – the extended case study method – was used. It was necessary and worked well, and it is quite certain that the same amount, quality and reliability of information would not have been achieved if it had not been for this method. A relationship was established between field researchers and caregiver participants through spending time together and through the field researchers living nearby. However, it was difficult for field researchers as they not only worked but also lived in the study areas, with local people in these often poor areas having access to them almost on a 24-hour basis, something which was often extremely burdensome to them.

The second broad field of inquiry was that of time-use research, and here various methods – both quantitative and qualitative – were used to obtain information on time spent in unpaid care work. Stylized questions, direct observation and 24-hour 'yesterday' time diaries were used. Stylized questions formed the central means by which caregiving time information was obtained. This approach was positive in terms of the fact that it comprehensively covered the various caregiving activities, specifically their frequency and duration. However, it had a number of drawbacks. It was not easy for respondents to answer the questions, especially when they had to reflect back over a lengthy time period. The answers required were numeric, something that the participants found particularly difficult, and many said they were unsure about the estimates they gave. Also, this method did not get at difference but only commonality because of the way questions were framed, and the fact that respondents were not asked to report on when an activity occurred differently.

The mini-events map, which obtained information on when events occurred over the illness period, seemed easier for participants to engage with than the stylized questions. This is because it was interactive and participants could raise issues again and correct incorrect information. In contrast to the stylized questions the mini-events map was able to get at difference over time. It is also fairly accurate if done with care by the field researcher.

Stylized questions were also used to obtain information on the financial costs incurred by households for the cared-for, in the same care survey in which the time-use stylized questions were located. It did not seem very difficult for respondents to provide this financial information, and this method got at this information well. A financial costs document simply restated the costs stated in the care survey and then these costs were either confirmed or corrected where necessary and additional costs were stated where relevant. This approach was relatively straightforward and seemed to work without any difficulties.

It seems that the level of detail on how often and for how long caregiving activities took place using a method that required them to reflect over an often long period of time (an average of three months) was simply too difficult and tiring for informants. It also seems that there is a trade off between getting good information on time spent, and good information on money spent using the same data gathering tool. It seems to be easier for informants to recall financial cost as opposed to time-use data.

Finally, as evident in the previous section, in order to value time spent in unpaid care work a national level data set was used to estimate average and median earnings per hour. These earnings were then assigned to the time spent in unpaid care work by caregivers in the study, an unproblematic process. While the LFS was undoubtedly the best dataset available to use to estimate earnings it was not unproblematic for this purpose. Where sample sizes for a particular occupation were representative and large enough – for domestic workers, for instance – the earnings estimated were relatively accurate. However, where sample sizes for particular occupations were very small, or where these did not exist and other similar occupations had to be selected, the dataset proved inadequate. This points to the problem of occupational codes in the LFS not always providing enough detail for the purposes of a valuation exercise such as this.

8.7 IMPLICATIONS OF THIS STUDY FOR IMPROVED FUTURE DATA COLLECTION ON UNPAID CARE WORK

How can this time-use and financial cost information be better collected? Future studies of this nature should preferably be dedicated solely to the issue of care time-use and costs associated with care provision, and not split between other topics or themes as was the case with this study. Collecting information of this nature is very time consuming and also emotionally draining for the field researchers, and a more focused smaller workload overall would ensure that this data gathering process is better achieved.

The rigour attempted in gathering in-depth information was a way of uncovering the realities of unpaid care work in a resource-poor environment, namely the lack of support from the health services, poor transport systems, inadequate electricity and water, poor education. These are things which are not taken into account in analyses of care work in more advanced countries, and an understanding of such factors can be used to inform larger surveys of care in South Africa in future.

Studies of this nature that gather detailed time-use information are burdensome to caregiver respondents compared to the population at large because of their particular circumstances. Ultimately, it would be ideal for a larger study in a similar vein to this one to be undertaken with the aim of obtaining information that can feed into other (national) surveys, instead of this information being repeatedly collected from caregiver respondents as part of smaller studies. It is a ‘rougher’ approach that would make crude estimates, in a similar vein to poverty research that rather than trying to achieve a multitude of detail on income and expenditure, uses an index of assets owned by the household to get at this income information. For instance, if a larger time-use study could obtain information on an average time taken to clean an incontinent person, their clothes and their bedding, this average time could simply be used in other national studies, instead of being collected again from respondents.

Stylized questions are an unconstrained method, where the activities do not have to add up to 24 hours, and therefore this does not give a comprehensive account of the time spent in unpaid care over a 24-hour period. A time diary allows one to get at what care provision means in this regard, and what the components are that make it up. It is an option to undertake 24-hour diaries through face-to-face interviews with household respondents in order to get at time-use information in a detailed fashion. However, this provides only a snapshot of the previous 24 hours, and would not account for difference in activities undertaken on other days. Undertaking a detailed time diary should also ideally be done more than once to ensure this difference is accounted for, yet this is likely to take an inordinate amount of time and be relatively burdensome to caregiver respondents who are already extremely burdened. Moreover, for such a method a large sample would also be necessary.

It is therefore not certain that it is possible to get at some information without using some type of survey question. How can survey-type questions be used in a way that will avoid the pitfalls of using stylized questions? Some surveys ask ‘tell me about the last time you did a certain activity’ and then, ‘is it ever different’, and this seems to be a better approach than asking about the number of times an activity occurred. It is also possible that a mini-events map could allow one to get at ‘what care provision means’, if used in conjunction with stylized questions. If done properly, these methods in combination could be a less time consuming and less costly alternative to a 24-hour time diary. The mini-events map is undoubtedly an excellent tool to use to get at how often activities occur over time, and results in a more accurate picture in measurement terms, as opposed to an estimation of the number of times a day or month an activity occurred using stylized questions. In this study a mini-events map was used to ascertain when over the illness period the person had hospital stays, visited health facilities, was bedridden etc. The mini-events map guideline as it stands in Appendix E resulted mainly in information on events over time, and very little on the caregiving that took place and the symptoms of the ill person.

In a possible future study the steps that follow could be undertaken. Firstly, a mini-events map would be completed, but with an amendment to the last section that tries to get at the care provided by family caregivers over this time. Some of the central events and broad conditions (for example, whether the person is bedridden or not) would be recorded over the illness period. In addition the field researcher would ask questions about when oral or non-oral medication was obtained over this time, for or with the ill person from a supermarket/spaza, traditional healer, hospital, private doctor, clinic or other provider.

As a second step detailed time-use and financial cost information would be obtained about these actual consultative visits to health facilities and about the visits to get oral and non-oral medication, along the lines of the questions asked in the care survey (see 'survey type questions' in Appendix D).

As a third step instead of asking about activities over the entire time period of caregiving, the focus would be on the shorter time periods over which the person was bedridden and when not, and specific questions would be asked about caregiving activities over these periods. Being bedridden seems to be a particular marker of more serious illness for those with HIV/AIDS. WHO clinical stages are defined in part by performance scales: for those in clinical stage three this scale indicates that they were bedridden for less than half of the day during the last month, and those in clinical stage four were bedridden for more than half of the day during the last month (Evian, 2003, p. 118). A question would be asked, per activity (e.g. bathing, giving medication) about when it was that that the activity occurred last. Following this, detailed questions similar to those in the care survey would be asked per activity. After this the caregiver would be asked whether it was ever different over this bedridden/non-bedridden period. If it was, the same questions would be asked relating to the particular activity, as well as the length of time over which this occurred.

This method ‘short-cuts’ the 24-hour diary. The latter obtains information on what happens over the previous 24 hours at a certain point in time. Using the mini-events map in conjunction with survey-type questions allows the time over the illness period to be covered but in a less generalized fashion than using stylized questions only. These tools do not do away with all the challenges for informants – it is still difficult information for them to give and it will still be time consuming. But having the ‘map’ to refer to should facilitate the process and make it easier for informants to complete. It may also be advisable to have a break of a day or more over the course of filling out the mini-events map, and a good juncture for a break would be between steps two and three, and also within step three. With regard to the latter it may be advisable to ask about bedridden periods on one day, and about non-bedridden periods on another day. The entire mini-events map, however, should be completed over a relatively short period of time in total – probably not more than a week.

Information on ‘keeping an eye on the person’ and ‘keeping the person company’ would however have to be obtained using a 24-hour diary along the lines of that used in this research, but with a more explicit focus on these often simultaneous activities. The tricky bit will be to ask this information at the right time, which unfortunately does not always coincide with when the field researcher is undertaking fieldwork. Ideally two 24-hour diaries should be completed: one over a time when the cared-for is bedridden and one over a time when the person is not bedridden. In a best case scenario these time periods should fall over the reference period. If they do not, the caregiver should be asked how different the ‘keeping an eye on the person’ and ‘keeping the person company’ time spent was when recorded and when it occurred on the mini-events map (that is, over the reference period) for the bedridden and non-bedridden times.

Information on the quality of caregiving – that is, the standard of caregiving or how well it was carried out – was not collected, but such information would have added much to the study, and should be included as part of a future study of this nature to complement the time-use information. An example of this is health-related quality of life information for caregivers as obtained by Van den Berg and Spauwen (2006).

Finally, field researchers were asked additional questions per household by the researcher in order to understand aspects of the research process and the participants in more depth. For example, how certain were the field researchers about the time-use and financial cost estimations that respondents gave; was the reference period applied consistently throughout the recording of the stylized questions; and who were the respondents for each of the sections in the care structured guide. This information enabled the researcher to understand the actual research process better and to gain general insights which would otherwise have been missed. This process goes beyond mere quality control and constitutes a deeper level analysis that should be formalized as part of a future study.

Further aspects of this study that should be amended are highlighted in detail in Appendix S.

9 CONCLUSION

By and large it is only the public expenditure costs of community care that are considered. Not regarded are the costs to caregivers within the home (Fast & Frederick, 1999; Rimmer, 1983). This thesis has largely focused on the issue of unpaid and also paid health and social care work for people in late-stage HIV/AIDS over intensive illness episodes. The finding show that the resources spent on health and welfare through the state, the private sector and the not-for-profit sector are only a small part of health and welfare provision. Most of the health and welfare work in relation to care for AIDS sick people is undertaken for no pay by female family members. This thesis is largely about the gender-aware methodology that has been used to count and cost this unpaid care provision in order to make the unpaid care work of family caregivers visible. Costing this work is described by Ogden et al. (2006, p. 340) as "a necessary first step to recognizing, valuing and including unpaid HIV/AIDS care work in public health and other policy-making processes".

If these costs are taken into account in what ways does this change how the health and welfare sectors are understood? In what way can this knowledge be used to provide support to unpaid carers? In this chapter the findings are used to reassess the provision of unpaid care within the home in South Africa and to suggest alternative policy options. While doing so the perspectives of various, often oppositional, role players in this arena will be considered and put forward.

9.1 RELEVANT SOCIAL POLICY DEVELOPMENTS

What effect will ARVs have on the nature of care work? How different is caring for people with ARVs as compared to caring for people not on ARVs? Do people who have been on ARVs die differently and what implications does this have for care provision? These questions are ready for research. While with ARVs HIV/AIDS need no longer be a terminal illness and can be managed as a chronic illness (Lund, 2008b), those on ARVs will still die and need care before they die.

Ogden et al. (2006) also believe that the presence of ARVs in poor countries underscores the importance of a ‘care agenda’ because many people will either be unable to access ARV programmes, will drop out of such programmes or will fail to respond to available treatment. Indeed, Ford, Mills and Calmy (2009) point to the fact that relatively few of those with HIV/AIDS are receiving ARV treatment, too much time is elapsing before treatment begins and when there is a failure in treatment too much time passes before a new treatment regimen is applied. Therefore the need for care will not go away with ARVs, but its face will change for those on regular ARV treatment, and it will remain the same for those who do not have access to treatment (Ogden et al., 2006).

As noted earlier in the thesis, there are very high unemployment rates in South Africa, and at the same time there are expanding ‘work’ or voluntary work opportunities for poorer women as community caregivers in line with the government’s policy of HCBC. This form of care work offers opportunities to some women to enter the labour market. However there are some developments that are of concern for those working in this area. For one, government is increasingly contracting out services, and an important example of this is government contracts to NGOs/FBOs/CBOs to ‘employ’ community caregivers to do care work. These non-profit organizations (NPOs) are sub-contracted by government to recruit and manage the community caregivers who are “radically underpaid, and are not recognised as workers” (Lund, 2008b, p. 24).

At the same time task shifting is occurring. According to Lund (2008, p. 19), “task shifting is the process in which tasks that have been defined as able to be done by those with a particular level of skill or qualification are delegated to those of a different level of skill or qualification – sometimes upwards, but most commonly downwards, allowing more, less formally skilled people to do more demanding kinds of work”. Through task shifting downwards, some tasks that were done by nurses are now undertaken by HBC workers. International evidence indicates that for task-shifting to be successful in the health sector, it has to be well-resourced and properly trained for, however in reality “it is often resorted to in situations of stress and scarcity, to solve a resource problem, as is happening in the face of the HIV/ AIDS crisis at present” (Lund, 2008b,

p. 20). The danger exists of task-shifting displacing care responsibilities downward and outward onto unresourced communities, volunteer workers and unpaid workers in households – and some research (Hunter, 2005, 2007) shows that this is happening in practice.

Lund (2008b) believes that the international campaign for task-shifting has presented an opportunity within South Africa to re-open the possibility of getting community health workers recognised as part of the comprehensive health approach, and part of the district health team. The policy framework for community care workers hopefully signals that community caregivers in general will be more clearly defined, better regulated and supervised. The main difference between unpaid caregivers and other similar groups to whom tasks have been shifted is that the former are not actually remunerated in some way for their work. Estimating the cost of unpaid care provision enables this work by family caregivers to be more visible in the chain of task shifting. This costing also presents an opportunity for unpaid family caregivers similarly to be recognized as part of a comprehensive health approach and the district health team.

However, as previously noted, while the government explicitly tries to curb the entry of AIDS-ill people into hospital beds, it does not provide a viable alternative for the care of these people. In South Africa the link is broken between the home and the state, and there is no assumption that the state will pay for care provision, meaning that the responsibility remains in the hands of female family caregivers.

9.2 SOCIAL POLICY ROLE OF THE STATE WITH REGARD TO CARE

Where should the responsibility for providing care for dependent people lie? The policy of HCBC rests on the assumption of ‘ubuntu’, ‘community’ and ‘voluntarism’. Principles of communitarianism and mutual assistance and ideas of community-level resilience and solidarity underpin ‘ubuntu’, and such notions serve to justify HCBC as a policy approach (Marais, 2005). On the other hand are a host of arguments against the sufficiency of the community to carry the responsibility for care provision. As Marais points out, ‘ubuntu’ also operates in a context of poverty, joblessness and disease, which makes those in the community even less able to offer support. According to Ogden et al. (2006), “a strategy of simply downloading responsibility for care onto women, families and communities can no longer be a viable, appropriate or sustainable response”. The findings of this thesis underscore the need for support to those providing care in the home environment.

Jönsson et al. (2006) point to the fact that the costs of unpaid care increase significantly with disease severity. This study counted time spent in care for the very ill, and it was clear that for almost all of the ill people the amount of nursing assistant work exceeded the amount of domestic work as a proportion of overall unpaid care provision (about three-quarters overall). This is largely attributable to the conditions of the ill people in the study. In the United Kingdom these people would be either in hospital or receiving a home nursing service. What should the state be providing for people in the late stages of HIV/AIDS in South Africa? What are realistic options for support?

A compromise between the form of care that should be taken and the form of care that it is possible to take seems appropriate. For Parker (1981, p. 32) a central issue is how responsibility for tending “can be shared in a more equitable fashion and be offered at a high and acceptable standard”. Parker contends that the role of the state remains crucial in this. He argues that social policies for tending should be designed and implemented that: reflect and incorporate a generalized social concern for dependent people; reduce the inequalities between those who tend and those who do not; secure high standards; and respect the sensitivities of the dependent person.

Since care is an activity that involves costs, including financial costs, it is important to consider how the costs involved in care are shared, both at an individual level and on a macro level (Daly & Lewis, 1998). According to Standing (2001), in industrialized countries the state has had three main approaches to enhancing income security for those providing or receiving care: the social insurance approach; the social assistance approach; and the citizenship rights approach. Thus far the need for care and the need to give care have been omitted from citizenship rights, in no small part because unpaid work has traditionally not been recognized socially or economically.

White (2000, pp. 515-516) describes care work as a form of productive contribution and argues that care workers whose work is not remunerated in the market are nevertheless “providing productive services of sufficiently significant benefit to the wider community as to justify public recognition and subsidy”. Specifically White maintains that there should be a decent share of the social product for those meeting a minimum standard of productive participation, as well as equitable treatment of different forms of productive participation. Lund (2009) reports that within the World Bank there is a move to a citizen-based model of social protection in which states provide a minimum coverage of sorts. This opens up opportunities for groups such as unpaid care workers who provide productive services – something this thesis clearly illustrates – to receive some form of social protection based on the fact that they are citizens.

In the United Kingdom the carer has been included in government action with regard to care provision since the 1990s. This is also the case in other industrialized countries. Yet in some, such as the United States, this has not been the case. Arno et al. (1999, p. 187) refer to unpaid caregivers as the “bedrock of our nation’s chronic care system” (ibid, p. 187), and the “core long-term care providers in the US health care system” (ibid, p. 182). Yet they argue that these caregivers are not usually part of policy discussions about how to deliver care or save money, they are seldom adequately trained and they are almost never offered appropriate follow-up services, re-evaluation of care arrangements, nor referrals to community services.

Twigg and Atkin (1994, p. 10) emphasize that carers cannot simply give up when they feel it would be preferable to do so, because of the relationships which they are bound into. In addition, doing care work affects the position of women in the labour market and the ability of women to get ahead in the labour market. Twigg and Atkin argue that because of the fact that carers cannot simply give up, they “pose moral responsibilities to welfare agencies precisely because they cannot be assumed to pursue their interests in a straightforward way. For this reason their needs and interests must be incorporated into public policy”. In this light Parker (1992) proposes that services be provided or developed on the basis of what carers do – the caregiving activities they undertake – and not on who they are – for instance, their age, sex and other demographics. Finally, Kipp et al. (2006) recommend that the caregiver burden be acknowledged and that 'care for the caregiver' be included as a funded component of all HIV/AIDS programming.

9.3 POLICY OPTIONS FOR SOUTH AFRICA

In the United Kingdom there has been a shift in the role of the state from the direct provision of services for dependent people, to supporting those who become increasingly responsible for providing most of the care, namely relatives, friends and neighbours (Glendinning, 1992; Parker, 1992). In South Africa this 'support' aspect is missing. How can the findings from this thesis, which focus on care in the home for people in the late stages of HIV/AIDS in KwaZulu-Natal, be used to see that care is better provided, and carers better supported in South Africa?

It has already been shown how the main way government funds HBC is through paying NPOs to compensate community caregivers, yet this type of provision is not extensive and not sufficient. Findings from both the 2004 KIDS and the qualitative study data show that strikingly few of those who died and those who were ill and receiving care within the home were visited by a community caregiver. Visits are social, sometimes involving emotional support, and seldom include any actual caregiving of the ill person. Family caregivers are in fact the main providers of care to people within the home, but most family caregivers are disconnected from the health and social welfare system, and not linked to HBC programmes. They have received little, if any, training, guidance or support from other stakeholders, as outlined in the HCBC guidelines. While the state expects families to pick up on care needs, it in turn is not fulfilling its duty to train these family caregivers in how to care for their ill relatives. The formal health-care system does not bear the bulk of the care burden (Hunter, 2005).

The HCBC guidelines seem to assume that care needs can simply be absorbed by those in the ill person's home, but this is not always possible, nor appropriate. There are often other care needs within households and it may not always be suitable for the person who is available to provide care to be doing so, because of their age or due to their physical wellbeing. The HCBC guidelines are resulting in cost-effectiveness for government, but not for those in home environments undertaking care work. The balance of responsibility lies unevenly between the state and individual family caregivers (Hunter, 2005, 2007).

As Ogden et al. (2006, p 339) argue:

> the contributions of untrained, unremunerated and unsupported family members to the care of people with HIV infection need to be seen as a distinct domain of care provision because the needs, resources and constraints of these providers are different, and because the mechanisms required for meeting those needs will be different.

These caregivers of very ill people clearly need support but what form should this support take?

When considering policy options, the institutional context within which the policy will unfold is important. Jochimsen notes that “any useful inquiry into these matters must take the context in which caring situations are provided into account and seek to understand how caring situations are accomplished in concrete political and historical settings” (Jochimsen, 2003, p. 120). She reminds that “what must be carefully considered is the degree to which asymmetries and dependencies are created, reinforced, or continued by specific institutional arrangements, independent of the realm of the economy in which they are provided” (Jochimsen, 2003, p. 110). One context related issue is the policy of community care that is already in place in South Africa. As noted, in the countries that consider care to be a policy issue, there seems to be consensus that this is the policy of choice when it comes to the care of dependent people.

The economic environment is also important, not least because social policy is regarded as residual to economic policy, and is seen as something that can mop up the inequality effects of economic policy. In South Africa there is huge structural unemployment, there is a mismatch between the skills of workseekers and the work that is available to them, and there is a noteworthy youth unemployment problem. These all need to be addressed in addition to any policy that attempts to dealt with the issue of HBC.

The following are policy options for addressing the costs of unpaid care provision, as part of a broader development approach.

9.3.1 Improve and expand the service of home- and community-based care

Community care is probably the most viable strategy for care provision in a developing country but South Africa is a very well-resourced developing country and a lot more is possible with regard to HBC than in other developing countries. It is very unlikely that the HCBC guidelines will be abandoned, but HBC should be redesigned to address the problems highlighted in section 8.2, and resources need to be earmarked for its implementation which needs to be radically improved.

As a first step efforts should be made to expand and improve the implementation of the service of HBC in South Africa. The HBC service should be explicitly implemented as part of the primary health care strategy and planned for as part of the district health system. But these efforts should also expand beyond the health sector, with HBC supported as a part of development expenditure. HBC interfaces with poverty reduction, health, education and sustainable development. Public health infrastructure (such as water, sanitation, primary health care), agriculture, nutrition and housing are all important. Such expansions will have budgetary implications. HBC is not a cheap alternative to public health service provision (Ogden et al., 2006). There is a need for more financial resources for HBC services in order for these services to be improved, and for the finances that are allocated towards HBC to be spent.

In the HCBC guidelines much detail is given on what case management plans should consist of. However these plans have largely not been a part of the service of HBC, and especially where there are no health or welfare services, implementing this suggestion will pose a challenge. Yet it is important to include ill people and their caregivers as part of a referral system and to tie them into the necessary forms of support. Indeed, when it comes to improving the implementation of HBC, the findings from this study show that family carers should be central in terms of the support given. These carers need to be adequately trained and receive follow-up services, care arrangements should be evaluated and referrals to other service providers should be undertaken where necessary. But how can this take place? Who will do this and who will see that this is undertaken?

Community caregivers are best placed to support family caregivers in an array of tasks. Training, specifically in palliative care, would equip caregivers to better deal with care situations. A caregiver relief plan, as referred to in the HCBC guidelines, including respite care, should be available to caregivers in households where the situation is desperate, as in the Ngidi household. On the practical side, HBC kits – and gloves in particular – would address the lack of basic resources to provide care, and caregivers should be trained in their use. With high levels of poverty among many of the households in which care is provided, there is a need to ensure that these households are linked into welfare provision of some sort. Clearly community caregivers seem to be the most appropriately placed to undertake all of these tasks, and to tie caregivers into relevant forms of support. Yet it is important that they too receive adequate support and are not overly stretched. There also need to be enough of these workers, and this will have budgetary implications. Schneider, Hlophe and van Rensburg (2008) suggest that issues relating to sustainability be addressed in order to maintain the community health worker base, and therefore the receipt of some form of stipend or allowance is vital. The proper implementation of the proposed community care worker policy will also be crucial.

Further areas for action with regard to HCBC include support groups, as well as special radio and television programmes for family caregivers. Associations of retired nursing professionals should be tapped for education and support purposes.

9.3.2 Make payment for caregiving

In section 2.3, Jochimsen (2003) noted that the caring relationship needs to be sustained materially and financially if it is to continue. The right to adequate income for carers and carees for the provision of adequate care seems reasonable. What are the possibilities for ensuring that this caring relationship is financially sustained? In developed countries there is a move to commodify caring services, which has been triggered by financial considerations and budget constraints (Jochimsen, 2003, p. 112). In the United Kingdom and Europe, policy developments – especially with regard to payment – are dissolving the boundaries between formal and informal care (Ungerson, 1995). Standing (2001) outlines the following options that represent a form of compensation for care work: paying the carer; paying the cared-for; family based benefits or tax credits; direct public or private provision of care.

Ungerson (1995) provides more detail through an elaboration of the United Kingdom and European benefit systems with regard to caregiving. Firstly, in these developed countries there have been symbolic payments to volunteers, which are nominal and take no account of the time spent by the volunteer with the care recipient, but are conditional on evidence that specific work has been undertaken. Secondly, a benefit payment directly to carers, which in the United Kingdom aims to increase carers' incomes but is not based on any contract to carry out care (this benefit is very rarely applied across European countries). Thirdly, a benefit payment to care recipients, which is not primarily designed to represent or pay for market-related wages or to cover the costs of purchase of personal care but rather to contribute to the extra costs entailed by disability. In many European countries there is an expectation that the care recipients will use these monies to purchase care or to reimburse their informal care. Such allowances are usually small and they are therefore largely symbolic payments to people whom the care recipients have known for years rather than to strangers working for a rate of pay.

Not surprisingly, there is opposition to systems that pay women for undertaking care work. There are issues relating to moral hazard and monitoring problems which could occur. In this case moral hazard refers to the incentive to exaggerate or invent a need because the person who needs care or who provides it would be paid. It is also important to remember that individuals are not equal in their bargaining position or with regard to information needed to make optimal decisions (Standing, 2001). Some opposition to systems of payment for caregiving have come from feminists. For instance Lister (1994, as cited in Standing, 2001, p. 29) argues that commodifying care strengthens the sexual division of labour with women still doing most of the care and being confined to a lower status role that is socially excluding and a form of inequality. Similarly, Molyneux (2006, p. 31) notes that even though women may be empowered by managing a subsidy, programmes such as Oportunidades programme in Mexico "reinforce the social division through which gender asymmetries are reproduced". Ungerson (1995) observes that symbolic payments for care provision can be entrapping rather than liberating in that they constitute an extra pressure on women to give up more conventionally paid work. And Folbre (1995) describes how many feminists who believe that non-market caring labour has intrinsic value fear that this value would be undermined by putting a value on it. As a result, some believe that the only way to preserve the true value of this work is by not paying for it. However, the extent to which these arguments apply in developing countries where issues of poverty tend to override concerns about the sexual division of labour, particularly for the poor, is under debate.

There are also a number of reasons for considering some form of income support to caregivers. According to Jochimsen (2003, pp. 123-124), fostering the entry of potential caregivers into caring situations, and their continuation in them, involves questions of equity. Promoting caregiver equity would mean reducing material dependency of caregivers, by ensuring their adequate access to resources and improving their relative income situation, and adequately paying dependency workers. Standing (2001, p. 31) describes how "payment for care, although commodification, represents legitimisation of work that is not labour". Payment also constitutes recognition of this work (Ungerson, 1995). Arno et al. (1999, p. 186) describe how "paying some categories of informal caregivers under clearly defined circumstances may provide a level of flexibility and continuity that is difficult to attain in the formal system". The Equal Opportunities Commission in the United Kingdom (EOC, 1982, as cited in Ungerson, 1987, p. 11) argued that carers are only visible to policy-makers when they receive some type of state benefit, and that policy-makers are able to ignore the consequences of care by the community because of "the official invisibility of women". Placing a cost on the unpaid caring work of family caregivers increases their visibility, and payment for this care service increases their visibility even more.

With the above in mind, what are the options relating to payment for caregiving in South Africa? It seems clear that any payment system would have to be of a social assistance rather than a social insurance approach since the bulk of those who provide unpaid care provision and need some type of support are either very low earners or unemployed. From the perspective of a conservative treasury minister, the approaches to valuing time, and the theoretical assumptions behind the approaches, are not sensible because many of these caregivers are unemployed and so would not be earning anyway. For such a minister, the fiscus would not be able to sustain payment for caregiving to all of those who provide it or to those who receive it. Others would argue for payment for various reasons, and these perspectives are outlined below.

Payment to the cared-for

Two grants in the South African social assistance system are paid on the basis of caregiving. A care dependency grant, which is the same value as the disability grant (R740 per month in 2004 and R1010 from 1 April 2009), is payable to the legal parent or foster parent of a care-dependent child. A care dependent child is defined in terms of the Social Assistance Act as "a child between the ages of one and 18 years who requires and receives permanent home care due to his or her severe mental or physical disability". Medical proof that the child is disabled must be provided, and the grant is means tested based on the income of the family. The beneficiary of the care-dependency grant loses his or her entitlement to the grant if he or she is admitted into an institution to receive care (Hunter et al., 2003).

A grant-in-aid – R160 in 2004 – consists of an additional grant payable to a person who receives an old age pension or a disability grant and who requires full-time attendance by another person owing to his or her physical or mental condition. The grant-in-aid is not meant to be a stand-alone grant, rather it is used in addition to one of the other two grants (Hunter et al., 2003).

As noted earlier, the disability grant is a social assistance payment for poor people with temporary or permanent disabilities. Since the disability grant is not part of the ‘caregiving’ benefit system, there is no expectation that care recipients who receive this grant will use it to purchase care or to reimburse their care by family caregivers. However, payment to a care recipient would enable more of the costs of care to be met by the cared-for themselves. Two of the ill people in the study (who were in late-stage HIV/AIDS) received the grant over the fieldwork period and it is useful to reflect on the uses to which this money was put, since both of these ill people were receiving care within the home at the time of its receipt. Both of these grant recipients spent part of the money on food for the household every month. The female spent part of the money on the building of a mud brick dwelling into which the household members were to move, since the building they were living in was falling apart. The male recipient spent the remainder of the grant money on his own entertainment.

In terms of a payment for caregiving to care recipients, a new grant would have to be introduced that only some current disability grant recipients could be eligible for. It is not possible to change the definition of the present disability grant to incorporate payment for the receipt of caregiving in the home. This is because many of those receiving the disability grant do not need care as much as independence. Recently a chronic diseases grant was proposed by the South African National AIDS Consortium’s Technical Task Team on Treatment, Care and Support (see Booth & Silber, 2008). Were it to be adopted, the possibility exists for such a grant to be used to pay for caregiving.

From the perspective of those receiving care, this form of payment would enable them to meet more of their own financial costs associated with their illness and need for care, in a similar way to the two ill people in the study who received disability grants. It would make them less dependent for their care provision on caregivers and others in the household.

Payment to family caregivers

From the perspective of family caregivers, it costs a great deal financially and in terms of time to care for a family member. This is evident from the costing undertaken in this thesis. This time and money could be spent on other things. Payment for caregiving would assist caregivers in meeting some of the financial costs of care provision and compensate them for their caregiving labour time.

Payment to family caregivers for caregiving is a means by which part of the social product could go to unpaid care workers for their productive participation, in line with White's (2000) suggestion. It has not been part of the landscape of social provision in South Africa and it may not be easy to introduce. Although Ungerson (1995) emphasizes that the care work undertaken in formal and informal settings is not that different, some differences can be noted. Domestic work and nursing assistant work that is waged has expectations attached to it: it consists of fixed hours and there is some type of quality control. Unpaid care work, on the other hand, involves tasks that are premised on the ill person's need. There is also more flexibility in terms of what the caregiver can do. There is little or no quality control, bar the possible visit of a community caregiver, and even then proper quality control is difficult. Any monetary payment to caregivers would therefore more likely be symbolic than an actual market-related reimbursement for the time spent undertaking care work, for one simply because fiscally and administratively such an option could become a challenge. Verifying that caregivers are in fact caregivers would require visits by social workers to households. To then also have to verify hours spent in care work in order to properly reimburse this time would be completely unfeasible. The other challenge is the often irregular or indeterminate length of illness periods. Care may not be provided for very long, or it may be provided for a certain period of time, halted when the person's health improves, and then reintroduced when necessary, and caregiving may be brought to an end by the death of the cared-for. All of this requires administration of some sort, which pushes up the costs of introducing such a grant. With the social assistance payment system already in place, the actual payment process should not be much of a hurdle, however.

Payment to community caregivers

As with family caregivers, community caregivers are participating productively and, White (2000) would argue, should receive a share of the social product too. There are an array of different types of community caregivers across KwaZulu-Natal (directly observed therapy workers, community health workers, home-based caregivers, to name a few), just as there are a variety of stipend amounts, and if this were to be the chosen policy option it would be important to ensure that the same amount is paid for the same type of work across the province. It would also be important to ensure – as in the United Kingdom case – that specific caregiving ‘work’ is undertaken where this is needed, and that the visit does not simply consist of a social visit if there are training or caregiving needs in the household.

Supporters of community caregivers argue that they are the people who can make the biggest difference to family caregivers in terms of offering them support. According to an advocate for community caregivers (Samson, 2008), although these workers are called volunteers, those who receive remuneration for labour performed are in actual fact employees and government and employer failure to acknowledge this and respect their labour rights is a violation of labour law.

9.3.3 Introduce the basic income grant

The basic income grant is being promoted strongly by many segments of civil society in South Africa. An unconditional basic income is an income grant paid to each citizen “as of right without any test of means or requirement of past, present or future productive contribution to the community” (White, 2000, p. 528). If the grant were to be introduced, family caregivers, the cared-for, all household members and community caregivers would be entitled to receive it. To what extent would this alleviate the financial costs of providing unpaid care work? A few of the study households were selected to investigate this question, based on the known income to each household.

Just because the basic income grant is received does not necessarily mean it will be spent on the financial costs of care provision. Yet it is likely that some of it will, if one considers the amounts spent on the ill people in the qualitative study. The labour costs of unpaid care work are also not taken into consideration here, so this is not a true reflection of the impact of the basic income grant on the caregiving process. The value of the basic income grant that is applied is R100, the minimum amount suggested by the basic income grant coalition a few years ago (Basic Income Grant Coalition, 2005). Two scenarios are outlined: the basic income grant received in addition to other grants and the basic income grant received in the absence of other grants.

Table 9.1: Financial costs as a percentage of income with and without the basic income grant in the presence and absence of social assistance grants (2004/5 costs, monthly)

Household	Financial costs	Income incl grants	Financial costs as % of income incl grants	Income incl grants, with BIG	Financial costs as % of income incl grants, with BIG	Income excl grants, with BIG	Financial costs as % of income excl grants, with BIG
Shibe	79	340	23.2	1040	7.6	700	11.2
Tembe	358	910	39.3	1210	29.6	300	119.2
Dladla	435	910	47.8	1710	25.4	800	54.4
Mbongeni	1942	2540	76.5	3140	61.8	2400	80.9

BIG=basic income grant

The Shibe household is a low income household, where the only income is two child support grants. The Mbongeni household is the highest income household, while the Tembe and Dladla households have middle of the range incomes. Since many of these households are very dependent on grant income for their household income, if this income falls away with the introduction of the basic income grant, overall household income will actually fall, as Table 9.2 shows, and in one household financial costs will exceed household income. If the grants are still received along with a basic income grant, financial costs as a percentage of overall household income decrease dramatically.

As a policy option, the basic income grant would simply alleviate the overall financial burden on households in which care is provided to ill people, although this relief would be greater if other grants were still received with a basic income grant. The assistance this would provide should not be understated as financial constraints make caregiving within the home difficult, and improved finances were noted by a number of caregivers as something that would make the most difference to their caregiving situations.

Proponents of a basic income grant would argue that the findings show that there are substantial financial and labour costs that are being met by very poor people for the care of their relatives, and this is ample evidence that they need to be supported financially as a citizen right. The introduction of a basic income grant will mean that all of those involved in care provision in the home – those receiving and providing care as well as community caregivers – will be assisted. From this perspective, if the basic income grant is introduced in addition to current social assistance grants it would make an important financial contribution towards the provision of care. However, from the perspective of a conservative treasury minister, introducing a basic income grant, particularly with other social assistance grants still in place, is not fiscally sustainable.

Finally, it should not be forgotten that there are possibilities for amending somewhat the proposal for a basic income grant as it currently stands. White (2000) outlines how the original basic income proposal could be reconceptualized so as to address the concern for reciprocity. One possibility is to attach a contribution condition to the basic income, for able-bodied working-age adults. This would entail satisfying a broad definition of productive participation in the community.

9.3.4 Introduce mass-based employment under the expanded public works programme

McCord (2005) notes that a recent innovation in public works is the inclusion of programmes which offer some form of service to those affected by HIV/AIDS or to orphans and vulnerable childrens as one of the ‘assets’ created in return for the public works wage, at the same time as easing the pressure on existing service providers. This approach is particularly attractive as a public works employment option, since it offers an opportunity to provide sustained part-time employment, raise skill levels and meet a recognized social need. Such programmes have the potential to absorb large numbers of workers through increased funding to the NGO or CBO sectors, and with the roll out of voluntary counselling and testing and ARVs the need for para-medical and social support are likely to increase further.

In South Africa, the need for an extension of social service provision combined with the recognition that the sector had the potential to absorb a large amount of labour led to the inclusion of social service provision in the national expanded public works programme launched in 2004 (McCord, 2005). In this context HCBC refers specifically to the provision of work opportunities and training opportunities for community health and development workers – people who render services such as counselling or nursing in the homes of individuals who are unable to access such services on their own. Much emphasis is on payment of stipends to volunteers for the work that they render as well as the provision of accredited training (Parenzee & Budlender, 2007). According to McCord, the HCBC programme is based on a relatively formal training model, involving multiple year accredited training modules.

Social sector workers are employed for up to two years in the expanded public works programme, during which time they are offered a stipend and training. The aim is for these workers to move into NGO, private or state sector employment. The programme is supported by a significant additional state allocation to social cluster line ministries, and indeed the programme's success and the subsequent employment of expanded public works programme graduates is contingent on ongoing and expanding state funding of NGO activity in the social sector (McCord, 2005).

A few years after its introduction the social sector was lagging behind the other expanded public works programme sectors in terms of achieving work opportunity targets. The figures cited here are open to question, but according to Friedman & Bhengu (2008, p. 22), by the end of August 2007, 68,178 community caregivers had received stipends, 699 of these had received training in basic HCBC and 2,809 had achieved Ancillary Health Care NQL level 1. It is difficult to know with certainty what funding is spent on expanded public works programme HCBC, something that Parenzee and Budlender (2007) also found.

What are the real possibilities held by the expanded public works programme for subsidizing care work, that is, for helping to sustain family carers? According to McCord (2005) a key concern with this type of programme relates to the quality of service provision, something also acknowledged by the national Department of Public Works (see Parenzee & Budlender, 2007). In the absence of functioning supervisory structures and an effective national coordinating mechanism, HBC service providers can operate with little quality control in terms of training and service provision, and there is a risk that poorly trained HCBC workers could actually have a negative rather than a positive effect on households. Quality therefore needs to become a key focus of the HCBC programme if it is to function effectively, and these programmes should receive increased coordination and support (McCord, 2005).

Parenzee and Budlender (2007) raise a number of additional concerns. They note that the way the employment targets have been amended decreases the emphasis on valuing the work of middle-aged women, and increases the focus on the employment of youth, which raises concerns about the value placed on and recognition that government gives to women’s work. They recommend a proper analysis of these programmes which should involve obtaining the perspectives of NGOs and caregivers involved in the implementation of HCBC programmes. In addition, budgetary allocations and expenditure for these HCBC programmes should be tracked in order to obtain clear information as to how much funding is allocated, how much is spent, on what the funding is being spent and who it is that is benefiting.

Making the expanded public works programme work better is one way to ensure that family caregivers receive better support. Under the expanded public works programme HCBC placement could also be a vehicle for getting entry into more secure and better paid care work for HCBC workers.

Family caregivers are not well supported nor are they adequately linked to programmes to facilitate their care work. From the perspective of someone trying to focus on support for community caregivers, more funding to programmes for payment to community caregivers and the expanded public works programme in particular will increase the number of these community caregivers and their ability to support family caregivers.

9.4 CONCLUDING REMARKS

This thesis has sought to make the costs of unpaid care provision visible through a careful counting of the time spent in unpaid care for people in late-stage HIV/AIDS by family caregivers and the financial costs of care provision in poor households in KwaZulu-Natal, and through valuing this time using various methods. It has been shown that these family caregivers carry the bulk of the costs of this care provision in the home: they are meeting a minimum standard of productive participation. Yet HBC is cost-effective for government but not for family caregivers. Because carers cannot simply give up on their care provision role, because they are not pursuing their own interests, they indeed pose moral responsibilities to the state. In this light the lack of service provision by government is unacceptable, and for these reasons these caregivers' needs must be incorporated into state policy and provision. Family caregivers who are productively participating in society are not being treated equitably when compared with other members of society that are productive, such as those engaged in paid work. In line with what global institutions such as the World Bank are calling for, a citizen-based model to social protection should be adopted. Policy options that fit within this framework have been presented. It is for government to acknowledge the important contribution of unpaid family caregivers and to decide on an appropriate means of support for these individuals, in order for there to be a substantial reduction in the costs of care provision to family caregivers and households.

10 REFERENCES

Actuarial Society of South Africa AIDS Committee. (2009). *Summary Statistics ASSA 2003*. Retrieved 15 March, 2010, from http://aids.actuarialsociety.org.za/ASSA2003-Model-3165.htm

Adato, M., Hunter, N., & van de Ruit, C. (2004). *Draft Concept Note: KwaZulu-Natal Income Dynamics Study 2004: Qualitative Research*. Washington, D.C., Durban and Philadelphia: International Food Policy Research Institute, University of KwaZulu-Natal and University of Pennsylvania.

Adato, M., Kadiyala, S., Roopnaraine, T., Biermayr-Jenzano, P., & Norman, A. (2005). *Children in the Shadow of AIDS: Studies of Vulnerable Children and Orphans in Three Provinces in South Africa*. Paper presented at the IFPRI/WFP project on Orphans and Vulnerable Children in sub-Saharan Africa, 'Trends, Vulnerability and Responses', Washington, D.C., July.

Adato, M., Lund, F., & Mhlongo, P. (2007). Methodological innovations in research on the dynamics of poverty: a longitudinal study in KwaZulu-Natal, South Africa. *World Development, 35*(2), 247-263.

Akintola, O. (2004). *A Gendered Analysis of the Burden of Care on Family and Volunteer Caregivers in Uganda and South Africa*. Durban: Health Economics and HIV/AIDS Research Division, University of KwaZulu-Natal.

Akintola, O. (2006). Gendered home-based care in South Africa: more trouble for the troubled. *African Journal of AIDS Research, 5*(3), 237-247.

Amoateng, A. Y., Heaton, T. B., & Kalule-Sabiti, I. (2007). Living arrangements in South Africa. In A. Y. Amoateng & T. B. Heaton (Eds.), *Families and Households in Post-apartheid South Africa: Socio-demographic Perspectives* (pp. 43-59). Cape Town: Human Sciences Research Council.

Ardington, E., & Lund, F. (1996). Questioning rural livelihoods. In M. Lipton, F. Ellis & M. Lipton (Eds.), *Land, Labour and Livelihoods in Rural South Africa. Volume Two: KwaZulu-Natal and Northern Province* (pp. 31-58). Durban: Indicator Press.

Arno, P. S., Levine, C., & Memmott, M. M. (1999). The economic value of informal caregiving. *Health Affairs, 18*(2), 182-188.

Bakker, I. (1994). Introduction: engendering macro-economic policy reform in the era of global restructuring and adjustment. In I. Bakker (Ed.), *The Strategic Silence: Gender and Economic Policy* (pp. 1-29). London and Ottawa: Atlantic Highlands, Zed Books and The North-South Institute.

Basic Income Grant Coalition. (2005). Basic Income Grant Coalition Reacts to Manuel's Budget. Retrieved 7 March, 2005, from http://www.big.org.za/index.php?option=news&task=viewarticle&sid=68

Beneria, L. (1992). Accounting for women's work: the progress of two decades. *World Development, 20*(11), 1547-1560.

Beneria, L. (1999). Structural adjustment policies. In J. Peterson & M. Lewis (Eds.), *The Elgar Companion to Feminist Economics* (pp. 687-695). Cheltenham and Northampton: Edward Elgar.

Bhorat, H., & Oosthuizen, M. (2006). Evolution of the labour market: 1995-2002. In H. Bhorat & R. Kanbur (Eds.), *Poverty and Policy in Post-Apartheid South Africa* (pp. 143-200). Cape Town: HSRC Press.

Blackden, C. M., & Wodon, Q. (2006). Gender, time use, and poverty: introduction. In C. M. Blackden & Q. Wodon (Eds.), *Gender, Time Use, and Poverty in Sub-Saharan Africa* (pp. 1-10). Washington, D.C.: The World Bank.

Bollinger, J., Stover, J., & Seyoum, E. (1999). *The Economic Impact of AIDS in Ethiopia*. Washington, D.C.: The Futures Group International, Research Triangle Institute and the Centre for Development and Population Activities.

Booth, P., & Silber, G. (2008). *A Draft Briefing Document for the Establishment of a Chronic Diseases Grant*. Treatment, Care and Support Technical Task Team, South Africa National AIDS Consortium. Retrieved 15 March, 2010, from http://alp.immedia.co.za/research/TTT%20CDG%20Position%20Paper%20FINAL.pdf

Booysen, F. l. R., Bachmann, M., Matebesi, Z., & Meyer, J. (2003). *The Socio-Economic Impact of HIV/AIDS on Households in South Africa: Pilot Study in Welkom and Qwaqwa, Free State Province*. Bloemfontein: Centre for Health Systems Research and Development, University of the Free State. .

Bubeck, D. E. (1995). *Care, Gender and Justice*. Oxford: Clarendon Press.

Budlender, D. (1996). *The Women's Budget*. Cape Town: IDASA.

Budlender, D. (1997). *The Second Women's Budget*. Cape Town: IDASA.

Budlender, D. (1998). *The Third Women's Budget*. Cape Town: IDASA.

Budlender, D. (1999). *The Fourth Women's Budget*. Cape Town: IDASA.

Budlender, D. (2002). *Why Should We Care About Unpaid Care Work?* Harare: UNIFEM Southern African Region Office.

Budlender, D. (2006). *A Critical Review of Selected Time Use Surveys*. Cape Town: Community Agency for Social Enquiry.

Budlender, D. (2008). *The Political and Social Economy of Care: South Africa Research Report 2*. Geneva: United Nations Research Institute for Social Development.

Budlender, D., & Brathaug, A. (2002). *Calculating the Value of Unpaid Labour: A Discussion Document*. Pretoria: Statistics South Africa.

Budlender, D., Chobokoane, N., & Mpetsheni, Y. (2001). *A Survey of Time Use: How South African Women and Men Spend Their Time*. Pretoria: Statistics South Africa.

Budlender, D., & Lund, F. (2008). *The Political and Social Economy of Care: South Africa Research Report 1*. Geneva: United Nations Research Institute for Social Development.

Budlender, D., Skinner, C., & Valodia, I. (2004). *Budgets and the Informal Economy: An Analysis of the Impact of the Budget on Informal Workers in South Africa*. Durban: School of Development Studies, University of KwaZulu-Natal.

Burawoy, M. (1998). The extended case method. *Sociological Theory, 16*(1), 4-33.

Cağatay, N., Elson, D., & Grown, C. (1995). Introduction. *World Development, 23*(11), 1827-1836.

Casale, D. (2004). *What Has the Feminization of the Labour Market 'Bought' Women in South Africa? Trends in Labour Force Participation, Employment and Earnings, 1995-2001*. Cape Town: Development Policy Research Unit, University of Cape Town.

Case, A., Menendez, A., & Ardington, C. (2005). *Health Seeking Behaviour in Northern KwaZulu-Natal*. CSSR Working Paper No. 116. Centre for Social Science Research, University of Cape Town.

Cassiem, S. (2000). *Are Poor Children Being Put First?: Child Poverty and the Budget 2000*. Cape Town: IDASA.

Charmes, J. (2006). A review of empirical evidence on time use in Africa from UN-sponsored surveys. In C. M. Blackden & Q. Wodon (Eds.), *Gender, Time Use, and Poverty in Sub-Saharan Africa* (pp. 39-72). Washington, D.C.: The World Bank.

Chen, M., Vanek, J., Lund, F., Heintz, J., Jhabvala, R., & Bonner, C. (2005). *Progress of the World's Women 2005: Women, Work and Poverty*. New York: United Nations Development Fund for Women.

Chimwaza, A. F., & Watkins, S. C. (2004). Giving care to people with symptoms of AIDS in rural sub-Saharan Africa. *AIDS Care, 16*(7), 795-807.

Community Agency for Social Enquiry. (2005). *A National Evaluation of Home and Community Based Care Researched for the Departments of Health and Social Development*. Braamfontein: Community Agency for Social Enquiry.

Creese, A., & Parker, D. (1994). *Cost Analysis in Primary Health Care: A Training Manual for Programme Managers*. Geneva: World Health Organization.

Dalley, G. (1988). *Ideologies of Caring: Rethinking Community and Collectivism* (2nd ed.). Houndmills and London: Macmillan Press Ltd.

Daly, M., & Lewis, J. (1998). Introduction: conceptualising social care in the context of welfare state restructuring. In J. Lewis (Ed.), *Gender, Social Care and Welfare State Restructuring in Europe* (pp. 1-24). Aldershot and Brookfield: Ashgate.

Daly, M., & Standing, G. (2001). Introduction. In M. Daly (Ed.), *Care Work: The Quest for Security* (pp. 1-11). Geneva: International Labour Organization.

Day, C., & Gray, A. (2007). Health and related indicators. In S. Harrison, R. Bhana & A. Ntuli (Eds.), *South African Health Review 2007* (pp. 215-343). Durban: Health Systems Trust.

Department of Health. (2000a). HIV/AIDS and STD Strategic Plan for South Africa 2000 – 2005. Retrieved 19 August, 2009, from http://www.doh.gov.za/docs/policy/aids-plan00-05.pdf

Department of Health. (2000b). Recommendations for the Prevention and Treatment of Opportunistic and HIV Related Diseases in Adults. Retrieved 19 August, 2009, from http://www.doh.gov.za/aids/docs/adult.html

Department of Health. (2001a). An Enhanced Response to HIV/AIDS and Tuberculosis in the Public Health Sector – Key Components and Funding Requirements, 2002/03-2004/05. Retrieved 19 August, 2009, from http://www.doh.gov.za/aids/docs/response.html

Department of Health. (2001b). National Guideline on Home-based Care/Community-based Care. Retrieved 19 August, 2009, from http://www.doh.gov.za/docs/factsheets/guidelines/homecare/

Department of Health. (2006). Health Facility Definitions. Retrieved 24 October, 2009, from http://www.doh.gov.za/docs/misc/nhrpl/hfd.pdf.

Department of Health and Department of Social Development. (2009). Community Care Worker Management Policy Framework. Draft Version 6.0. Retrieved 18 October, 2009, from http://www.doh.gov.za/docs/policy-f.html

Department of Public Service and Administration. (2007). Annexure B to DPSA Circular 1 of 2007. Salary Levels with Effect from 1 July 2007 for Full-time Employees: Public

Service Act Appointees. Retrieved 12 June, 2009, from http://www.dpsa.gov.za/documents/rp/2007/2007_scales.pdf

Department of Public Works. (2006). Defining the Social Sector. Retrieved 14 May, 2009, from http://www.epwp.gov.za/index.asp?c=SectorSocOver

Department of Social Development. (2002). National Guidelines for Social Services to Children Infected and Affected by HIV and AIDS. Retrieved 24 October, 2009, from http://www.doh.gov.za/docs/guidelines-f.html

Eisenhower, D., Mathiowetz, N. A., & Morganstein, D. (1991). Recall error: sources and bias reduction techniques. In P. P. Biemer, R. M. Groves, L. E. Lyberg, N. A. Mathiowetz & S. Sudman (Eds.), *Measurement Errors in Surveys* (pp. 127-144). New York: John Wiley and Sons.

Elson, D. (1991a). Male bias in macro-economics: the case of structural adjustment. In D. Elson (Ed.), *Male Bias in the Development Process* (pp. 164-190). Manchester and New York: Manchester University Press.

Elson, D. (1991b). Male bias in the development process: an overview. In D. Elson (Ed.), *Male Bias in the Development Process* (pp. 1-28). Manchester and New York: Manchester University Press.

Elson, D. (1994). Micro, meso, macro: gender and economic analysis in the context of policy reform. In I. Bakker (Ed.), *The Strategic Silence: Gender and Economic Policy* (pp. 33-45). London and Ottawa: Atlantic Highlands, Zed Books and The North-South Institute.

Elson, D. (2000). *Progress of the World's Women 2000. UNIFEM Biennial Report*. New York: United Nations Development Fund for Women.

Evandrou, M., Falkingham, J., & Glennester, H. (1990). The personal social services: 'everyone's poor relation but nobody's baby'. In J. Hills (Ed.), *The State of Welfare: The Welfare State in Britain since 1974* (pp. 206-273). Oxford: Oxford University Press.

Everatt, D., & Solanki, G. (2005). *A Nation of Givers?: Social Giving among South Africans*: Centre for Civil Society.

Evian, C. (2003). *Primary HIV/AIDS Care*. Houghton: Jacana.

Fast, J. E., & Frederick, J. A. (1999). *Informal Caregiving: Is It Really Cheaper?* Paper presented at the International Association of Time Use Researchers Conference, Colchester, 6-8 October.

Fast, J. E., Williamson, D. L., & Keating, N. C. (1999). The hidden costs of informal caregiving. *Journal of Family and Economic Issues, 20*(3), 301-326.

Finch, J., & Groves, D. (1983). Introduction. In J. Finch & D. Groves (Eds.), *A Labour of Love: Women, Work and Caring* (pp. 1-10). London, Boston, Melbourne & Henley-on-Thames: Routledge & Kegan Paul.

Flodman Becker, K. (2004). *The Informal Economy: Fact Finding Study*: Sida.

Floro, M. S. (1995). Economic restructuring, gender and the allocation of time. *World Development, 23*(11), 1913-1929.

Folbre, N. (1995). "Holding hands at midnight": the paradox of caring labor. *Feminist Economics, 1*(1), 73-92.

Folbre, N. (2006). Measuring care: gender, empowerment and the care economy. *Journal of Human Development, 7*(2), 183-199.

Folbre, N., & Nelson, J. A. (2000). For love or money - or both? *The Journal of Economic Perspectives, 14*(4), 123-140.

Ford, N., Mills, E., & Calmy, A. (2009). Rationing antiretroviral therapy in Africa - treating too few, too late. *New England Journal of Medicine, 360*(18), 1808-1810.

Fox, S., Fawcett, C., Kelly, K., & Ntlabati, P. (2002). *Integrated Community-based Home Care (ICHC) in South Africa: A review of the model implemented by the Hospice Association of South Africa*. Cape Town, Braamfontein, Grahamstown: Centre for AIDS Development, Research and Evaluation.

Friedman, I. (2002). Community-based health workers. In P. Ijumba, A. Ntuli & P. Barron (Eds.), *South African Health Review 2002* (pp. 161-180). Durban: Health Systems Trust.

Friedman, I. (2005). CHWs and community caregivers: towards a unified model of practice. In P. Ijumba & P. Barron (Eds.), *South African Health Review 2005* (pp. 176-189). Durban: Health Systems Trust.

Friedman, I., & Bhengu, L. (2008). *Fifteen Year Review of Income Poverty Alleviation Programmes in the Social and Related Sectors*. Report prepared for the Policy Coordination and Advisory Services Unit in the Office of the President, South African Government. Durban: Health Systems Trust.

Gelb, S. (2006a). Macroeconomic Policy in South Africa. From RDP through GEAR to ASGISA. Retrieved 19 August, 2009, from http://www.the-edge.org.za/content/view/14/28/

Gelb, S. (2006b). The RDP, GEAR and all that: reflections ten years later. *Transformation, 62*, 1-8.

Glendinning, C. (1992). 'Community care': the financial consequences for women. In C. Glendinning & J. Millar (Eds.), *Women and Poverty in Britain the 1990s* (pp. 162-175). Hemel Hempstead: Harvester Wheatsheaf.

Glenn, E. N. (1992). From servitude to service work: the historical continuities of women's paid and unpaid reproductive labour. *Signs, 18*(1), 1-44.

Goldschmidt-Clermont, L. (1982). *Unpaid Work in the Household* (Vol. 1). Geneva: International Labour Office.

Goudge, J., Gilson, L., & Msimango, L. (2003). *How to 'Roll-Out' CBO Provided Home-Based Care for AIDS: Government's Role?* Johannesburg: Centre for Health Policy, University of the Witwatersrand.

Graham, H. (1983). Caring: a labour of love. In J. Finch & D. Groves (Eds.), *A Labour of Love: Women, Work and Caring* (pp. 13-30). London, Boston, Melbourne and Henley-on-Thames: Routledge and Kegan Paul.

Haraldsen, G. (1999). *The Design of Time Use Surveys in Developed and Developing countries*. Paper presented at the International Association of Time Use Researchers Conference, Colchester, 6-8 October.

Heintz, J. (2007). Revisiting Labour Markets: Implications for Macroeconomics and Social Protection. Amherst: University of Massachusetts.

Heron, C. (1998). *Working with Caregivers*. London: JKP.

Hoogeveen, J.G., & Özler, B. (2006). Poverty and inequality in post-apartheid South Africa: 1995-2000. In H. Bhorat & R. Kanbur (Eds.), *Poverty and Policy in Post-Apartheid South Africa* (pp. 59-94). Cape Town: HSRC Press.

Hunter, N. (2005). *An Assessment of How Government's Care Policy is Working in Practice: Findings from KwaZulu-Natal*. Working Paper No. 42. Durban: School of Development Studies, University of KwaZulu-Natal.

Hunter, N. (2007). *"It's Like Giving Birth to the Sick Person for the Second Time": Family Caregivers' Perspectives on Providing Care*. Working Paper No. 44. Durban: School of Development Studies, University of KwaZulu-Natal.

Hunter, N., Hyman, I., Krige, D., Olivier, M., Dekker, A., Khandlhela, M., et al. (2003). *South African Social Protection Expenditure and Performance Review*. Durban and Pretoria: School of Development Studies, University of Natal and Centre for International and Comparative Labour and Social Security Law, Rand Afrikaans University.

Hutton, S., & Hirst, M. (2000). *Caring Relationships Over Time: End of Project Report*. York: Social Policy Research Unit, University of York.

International Labour Organization. (2004). *Global Employment Trends for Women 2004*. Geneva: International Labour Organization.

Ironmonger, D. (2003). *There are Only 24 Hours in a Day! Solving the Problematic of Simultaneous Time*. Paper presented at the Comparing Time, the 25th IATUR Conference on Time Use Research, Brussels, 17-19 September.

Jackson, H., & Kerkhoven, R. (1995). Developing AIDS care in Zimbabwe: a case for residential community centres? *AIDS Care, 5*, 663-686.

Jochimsen, M. A. (2003). *Careful Economics: Integrating Caring Activities and Economic Science*. Boston: Kluwer Academic Publishers.

Johnson, S., Modiba, P., Monnakgotla, D., Muirhead, D., & Schneider, H. (2001). *Home-based Care for People with HIV/AIDS in South Africa: What Will It cost?* Johannesburg: Centre for Health Policy, University of the Witwatersrand.

Johnson, S., Schierhout, G., Steinberg, M., Russell, B., Hall, K., & Morgan, J. (2002). AIDS in the household. In P. Ijumba, A. Ntuli & P. Barron (Eds.), *South African Health Review 2002* (pp. 203-216). Durban: Health Systems Trust.

Jönsson, L., Eriksdotter Jönhagen, M., Kilander, L., Soininen, H., Hallikainen, M., Waldemar, G., et al. (2006). Determinants of costs of care for patients with Alzheimer's disease. *International Journal of Geriatric Psychiatry, 21*, 449-459.

Joshi, H. (1992). The cost of caring. In C. Glendinning & J. Millar (Eds.), *Women and Poverty in Britain the 1990s* (pp. 110-125). Hemel Hempstead: Harvester Wheatsheaf.

Juster, F. T. (1985). Conceptual and methodological issues involved in the measurement of time use. In F. T. Juster & F. P. Stafford (Eds.), *Time, Goods, and Well-being* (pp. 19-31). Ann Arbor: Institute for Social Research, The University of Michigan.

Juster, F. T., & Stafford, F. P. (1985). Introduction and overview. In F. T. Juster & F. P. Stafford (Eds.), *Time, Goods, and Well-Being* (pp. 1-18). Ann Arbor: Institute for Social Research, The University of Michigan.

Juster, F. T., & Stafford, F. P. (1991). The allocation of time: empirical findings, behavioural models, and problems of measurement. *Journal of Economic Literature, XXIX* (June 1991), 471-522.

Kan, M. Y. (2006). *Measuring Housework Participation: The Gap between "Stylised" Questionnaire Estimates and Diary-based Estimates*. Colchester: University of Essex.

Kes, A., & Swaminathan, H. (2006). Gender and time poverty in sub-Saharan Africa. In C. M. Blackden & Q. Wodon (Eds.), *Gender, Time Use, and Poverty in Sub-Saharan Africa* (pp. 13-38). Washington, D.C.: The World Bank.

Kipp, W., Nkosi, T. M., Laing, L., & Jhangri, G. S. (2006). Care burden and self-reported health status of informal women caregivers of HIV/AIDS patients in Kinshasa, Democratic Republic of Congo. *AIDS Care, 18*(7), 694-697.

KwaZulu-Natal Department of Health. (2008). Community Health Centres. Retrieved 19 August, 2009, from http://www.kznhealth.gov.za/chc.htm

Laczko, F., & Noden, S. (1992). Combining paid work with eldercare: the implications for social policy. *Health and Social Care in the Community, 1*, 81-89.

Lam, D., Leibbrandt, M., & Ranchhod, V. (2005). *Labour Force Withdrawal of the Elderly in South Africa*. CSSR Working Paper No. 118. Cape Town: Centre for Social Science Research, University of Cape Town.

Lauden, M. (1999). *South Coast Hospice's Community Based HIV/AIDS Home-Care Model*. Pretoria: Department of Health.

Lehohla, P. (2008). Stats SA to Carry Out Targeted Survey to Assess Poverty Battle. Retrieved 13 April, 2009, from http://www.statssa.gov.za/news_archive/15February2008_1.asp

Leibbrandt, M., Poswell, L., Naidoo, P., & Welch, M. (2006). Measuring recent changes in South African inequality and poverty using 1996 and 2001 census data. In H. Bhorat & R. Kanbur (Eds.), *Poverty and Policy in Post-Apartheid South Africa* (pp. 95-142). Cape Town: HSRC Press.

Lewis, J. (2001). Legitimizing care work and the issue of gender equality. In M. Daly (Ed.), *Care Work: The Quest for Security* (pp. 57-75). Geneva: International Labour Organization.

Lund, F. (1999). Understanding South African social security through recent household surveys: new opportunities and continuing gaps. *Development Southern Africa, 16*(1), 55-67.

Lund, F. (2006). Gender and social security in South Africa. In V. Padayachee (Ed.), *The Development Decade? Economic and Social Change in South Africa 1994 – 2004* (pp. 160-179). Cape Town: Human Sciences Research Council.

Lund, F. (2008a). *Changing Social Policy: The Child Support Grant in South Africa*. Cape Town: HSRC Press.

Lund, F. (2008b). *The Political and Social Economy of Care: South Africa Research Report 4: Paid Care Providers: Nurses, Domestic Workers, and Home-based Care Workers*. Geneva: United Nations Research Institute for Social Development.

Lund, F. (2009). *Social Protection, Citizenship and the Employment Relationship*. Durban: School of Development Studies, University of KwaZulu-Natal and WIEGO.

Lund, F., & Ardington, C. (2006). *Employment Status, Security and the Management of Risk: A Study of Workers in Kwamsane, KwaZulu-Natal*. Durban: School of Development Studies, University of KwaZulu-Natal.

Marais, H. (2005). *Buckling: The Impact of AIDS in South Africa*. Pretoria: Centre for the Study of AIDS, University of Pretoria.

May, J. (2006). Constructing the social policy agenda: conceptual debates around poverty and inequality. In V. Padayachee (Ed.), *The Development Decade? Economic and Social Change in South Africa 1994-2004* (pp. 143-159). Cape Town: Human Sciences Research Council.

May, J. D., Agüero, J., Carter, M. R., & Timæus, I. (2007). The KwaZulu-Natal Income Dynamics Study (KIDS) 3rd wave: methods, first findings and an agenda for future research. *Development Southern Africa, 24*(5), 629-648.

May, M. (2003). The role of comparative study. In P. Alcock, A. Erskine & M. May (Eds.), *The Student's Companion to Social Policy* (2nd ed., pp. 17-24). Malden, Oxford, Melbourne and Kurfuerstendamm: Blackwell Publishing Ltd.

McCord, A. (2005). *Public Works in the Context of HIV/AIDS: Innovations in Public Works for Reaching the Most Vulnerable Children and Households in East and Southern Africa*. Cape Town: South African Labour and Development Research Unit, University of Cape Town.

McCoy, D., & Engelbrecht, B. (1999). Establishing the district health system. In N. Crisp & A. Ntuli (Eds.), *South African Health Review 1999* (pp. 131-146). Durban: Health Systems Trust.

McDaid, D. (2001). Estimating the costs of informal care for people with Alzheimer's disease: methodological and practical challenges. *International Journal of Geriatric Psychiatry, 16*(4), 400-405.

McGovern, P. (1989). Protecting the promise of community-based care. In H. W. Demone Jr. & M. Gibelman (Eds.), *Services for Sale: Purchasing Health and Human Services* (pp. 251-280). New Brunswick and London: Rutgers University Press.

Means, R., & Smith, R. (1998). *Community Care: Policy and Practice* (2nd ed.). Houndmills and London: Macmillan Press Ltd.

Molyneux, M. (2006). Mothers at the service of the new poverty agenda: the 'oportunidades' programme in Mexico. In S. Razavi & S. Hassim (Eds.), *Gender and Social Policy in a Global Context: Uncovering the Gendered Structure of "the Social"*. Houndmills: Palgrave Macmillan.

Moore, M. J., Zhu, C. W., & Clipp, E. C. (2001). Informal costs of dementia care: estimates from the National Longitudinal Caregiver Study. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 56*, S219-S228.

Moser, C. O. N. (1992). Adjustment from below: low-income women, time and the triple role in Guayaquil, Ecuador. In H. Afshar & C. Dennis (Eds.), *Women and Adjustment Policies in the Third World* (pp. 87-116). Houndmills and London: Macmillan.

Mowatt, R., & Quinlan, T. (2003). *A Rapid Appraisal of the Costs of HIV/AIDS Treatment to the KwaZulu-Natal Public Health Services*. Durban: Health Economics and AIDS Research Unit, University of Natal.

Mullagee, F., Nyman, R., Budlender, D., & Newman, N. (2001). *Developmental social welfare: Who benefits and who bears the costs?* Cape Town: IDASA.

Naidu, V. (2005). *The Evaluation of Costs and Process Indicators for Home Community-Based Care (HCBC) Programmes. Phase 2 Report.* Johannesburg: Health Economics Research Office, Wits Health Consortium.

Netten, A. (1993). Costing informal care. In A. Netten & J. Beecham (Eds.), *Costing Community Care: Theory and Practice* (pp. 43-57). Aldershot and Brookfield: Arena and Ashgate Publishing Company.

Netten, A. (1996). The costs of informal care. In C. Clark & I. Lapsley (Eds.), *Planning and Costing Community Care* (pp. 138-155). London & Bristol, Pennsylvania: Jessica Kingsley Publishers.

Netten, A., & Curtis, L. (2003). *Unit Costs of Health and Social Care 2003*. Canterbury: Personal Social Services Research Unit, University of Kent.

Nolan, M. (1994). Review of Gillian Parker and Dot Lawton, Different Types of Care, Different Types of Carer: Evidence from the General Household Survey. *Ageing and Society, 14*(4), 646-647.

Office of Population Censuses and Surveys, Social Survey Division. (1988). General Household Survey, 1985. Retrieved 12 June, 2009, from http://www.data-archive.ac.uk/findingData/snDescription.asp?sn=2349

Ogden, J., Esim, S., & Grown, C. (2004). *Expanding the Care Continuum for HIV/AIDS: Bringing Carers into Focus*. Washington, D.C.: Population Council and International Center for Research on Women.

Ogden, J., Esim, S., & Grown, C. (2006). Expanding the care continuum for HIV/AIDS: bringing carers into focus. *Health Policy and Planning, 21*(5), 333-342.

Orner, P. (2006). Psychosocial impacts on caregivers of people living with AIDS. *AIDS Care, 18*(3), 236-240.

Pakenham, K., Dadds, M., & Terry, D. (1995). Carers' burden and adjustment to HIV. *AIDS Care, 7*(2), 189-203.

Parenzee, P., & Budlender, D. (2007). *South Africa's Expanded Public Works Programme: Exploratory Research of the Social Sector*. Cape Town: On Par Development Agency and Community Agency for Social Enquiry.

Parker, G. (1992). Counting care: numbers and types of informal carers. In J. Twigg (Ed.), *Carers: Research and Practice* (pp. 6-29). London: HMSO.

Parker, R. (1981). Tending and social policy. In E. M. Goldberg & S. Hatch (Eds.), *A New Look at the Personal Social Service* (pp. 17-32). London: Policy Studies Institute.

Pascall, G., & Lewis, J. (2004). Emerging gender regimes and policies for gender equality in a wider Europe. *Journal of Social Policy, 33*(3), 373-394.

Patel, L. (2005). *Social Welfare and Social Development in South Africa*. Cape Town: Oxford University Press Southern Africa.

Province of KwaZulu-Natal. (2008). *Budget Statement 2. Vote 7: Health*. 2008/09 Budget Statements. Pietermaritzburg.

Republic of South Africa. (2006). Medium Term Expenditure Framework. Treasury Guidelines: Preparing Budget Proposals for the 2007 MTEF. Retrieved 24 October, 2009, from http://www.finance.gov.za/publications/guidelines/TG_170806.pdf

Rice, D. P., Fox, P. J., Max, W., Webber, P. A., Lindeman, D. A., Hauck, W. W., et al. (1993). The economic burden of Alzheimer's disease care. *Health Affairs, 12*(2), 164-176.

Rimmer, L. (1983). The economics of work and caring. In J. Finch & D. Groves (Eds.), *A Labour of Love: Women, Work and Caring* (pp. 131-179). London, Boston, Melbourne and Henley-on-Thames: Routledge and Kegan Paul.

Robinson, K. M. (1997). Family caregiving: who provides the care, and at what cost? *Nursing Economic$, 15*, 243-247.

Robinson, S. (1999). *Where Poverty Hits Hardest: Children and the Budget in South Africa*. Cape Town: IDASA.

Russell, M., & Schneider, H. (2000). *A Rapid Appraisal of Community-Based HIV/AIDS Care and Support Programmes in South Africa*. Johannesburg: Centre for Health Policy, University of the Witwatersrand.

Samson, M. (2008). *Organising Health Home and Community Based Workers in South Africa*. Johannesburg: NALEDI.

Schneider, H., Hlophe, H., & van Rensburg, D. (2008). Community health workers and the response to HIV/AIDS in South Africa: tensions and prospects. *Health Policy and Planning, 23*(3), 179-187.

Seeley, J., & Kajura, E. (1993). The extended family and support for people with AIDS in a rural population in south west Uganda: a safety net with holes? *AIDS Care, 5*(1), 117-124.

Shisana, O., Hall, E., Maluleke, K., Stoker, D., Schwabe, C., Colvin, M., et al. (2002). *The Impact of HIV/AIDS on the Health Sector. National Survey of Health Personnel, Ambulatory and Hospitalised Patients and Health Facilities*. Cape Town: HSRC Publishers.

Sienaert, A. (2008). *Labour Supply, Public Transfers and Household Welfare: Essays on South Africa.* Unpublished Doctoral Thesis, University of Oxford, Oxford.

Standing, G. (2001). Care work: overcoming insecurity and neglect. In M. Daly (Ed.), *Care Work: The Quest for Security* (pp. 15-32). Geneva: International Labour Organization.

Statistics South Africa. (2004). *Statistical release P0210. Labour Force Survey, September 2004*. Pretoria: Statistics South Africa.

Statistics South Africa. (2005). *Statistical release P0210. Labour Force Survey, March 2005*. Pretoria: Statistics South Africa.

Statistics South Africa. (2009). Annual Inflation on a Monthly Basis. Consumer Price Index (P0141). Metropolitan Areas - All Items. Retrieved 3 March, 2009, from http://www.statssa.gov.za/keyindicators/cpix.asp

Steinberg, M., Johnson, S., Schierhout, G., Ndegwa, D., Hall, K., Russel, B., et al. (2002). *Hitting Home: How Households Cope with the Impact of the HIV/AIDS Epidemic: A Survey of Households Affected by HIV/AIDS in South Africa*. Durban: Henry J Kaiser Family Foundation and Health Systems Trust.

Stommel, M., Given, C. W., & Given, B. A. (1994). The cost of cancer home care to families. *Cancer, 71*(5), 1867-1874.

The Presidency, Republic of South Africa. (2008). Development Indicators 2008. Retrieved 24 October, 2009, from http://www.pmg.org.za/files/docs/Development%20Indicators.pdf

Tollman, S. M., & Pick, W. M. (2002). Roots, shoots, but too little fruit: assessing the contribution of COPC in South Africa. *American Journal of Public Health, 92*(11), 1725-1728.

Twigg, J. (1992). Introduction. In J. Twigg (Ed.), *Carers: Research and Practice* (pp. 1-5). London: HMSO.

Twigg, J. (2003). Social care. In J. Baldock, N. Manning & S. Vickerstaff (Eds.), *Social Policy* (2nd ed., pp. 419-453). Oxford: Oxford University Press.

Twigg, J., & Atkin, K. (1994). *Carers Perceived: Policy and Practice in Informal Care*. Buckingham and Philadelphia: Open University Press.

Ungerson, C. (1987). *Policy is Personal: Sex, Gender and Informal Care*. London and New York: Tavistock Publications.

Ungerson, C. (1995). Gender, cash and informal care: European perspectives and dilemmas. *Journal of Social Policy, 24*(1), 31-52.

United Nations. (2005). *Guide to Producing Statistics on Time Use: Measuring Paid and Unpaid Work*. New York: Department of Economic and Social Affairs, Statistics Division, United Nations.

United Nations Development Programme. (2007). *Human Development Report 2007/2008. Fighting Climate Change: Human Solidarity in a Divided World.* New York: United Nations Development Programme.

United Nations Secretariat, Statistics Division. (1999). *Towards International Guidelines in Time-use Surveys: Objectives and Methods of National Time-use Surveys in Developing Countries.* Paper presented at the Economic and Social Commission for Asia and the Pacific Seminar on Time Use Surveys, Ahmedabad, 7-10 December.

Urdang, S. (2006). The care economy: gender and the silent AIDS crisis in southern Africa. *Journal of Southern African Studies, 32*(1), 165-177.

Van den Berg, B., & Spauwen, P. (2006). Measurement of informal care: an empirical study into the valid measurement of time spent on informal caregiving. *Health Economics, 15*, 447-460.

Van Rensburg, H. C., & Harrison, D. (1995). History of health policy. In D. Harrison & M. Nielson (Eds.), *South African Health Review 1995* (pp. 53-71). Durban: Health Systems Trust.

Wallwork, A. (2006). *Health Care Provision for People Living with AIDS*. Unpublished Master's Thesis, University of KwaZulu-Natal, Durban.

White, S. (2000). Social rights and the social contract: political theory and the new welfare politics. *British Journal of Political Science, 30*(3), 507-532.

Wilson, L. S., Moskowitz, J. T., Acree, M., Heyman, M. B., Harmatz, P., Ferrando, S. J., et al. (2005). The economic burden of home care for children with HIV and other chronic illnesses. *American Journal of Public Health, 95*(8), 1445-1452.

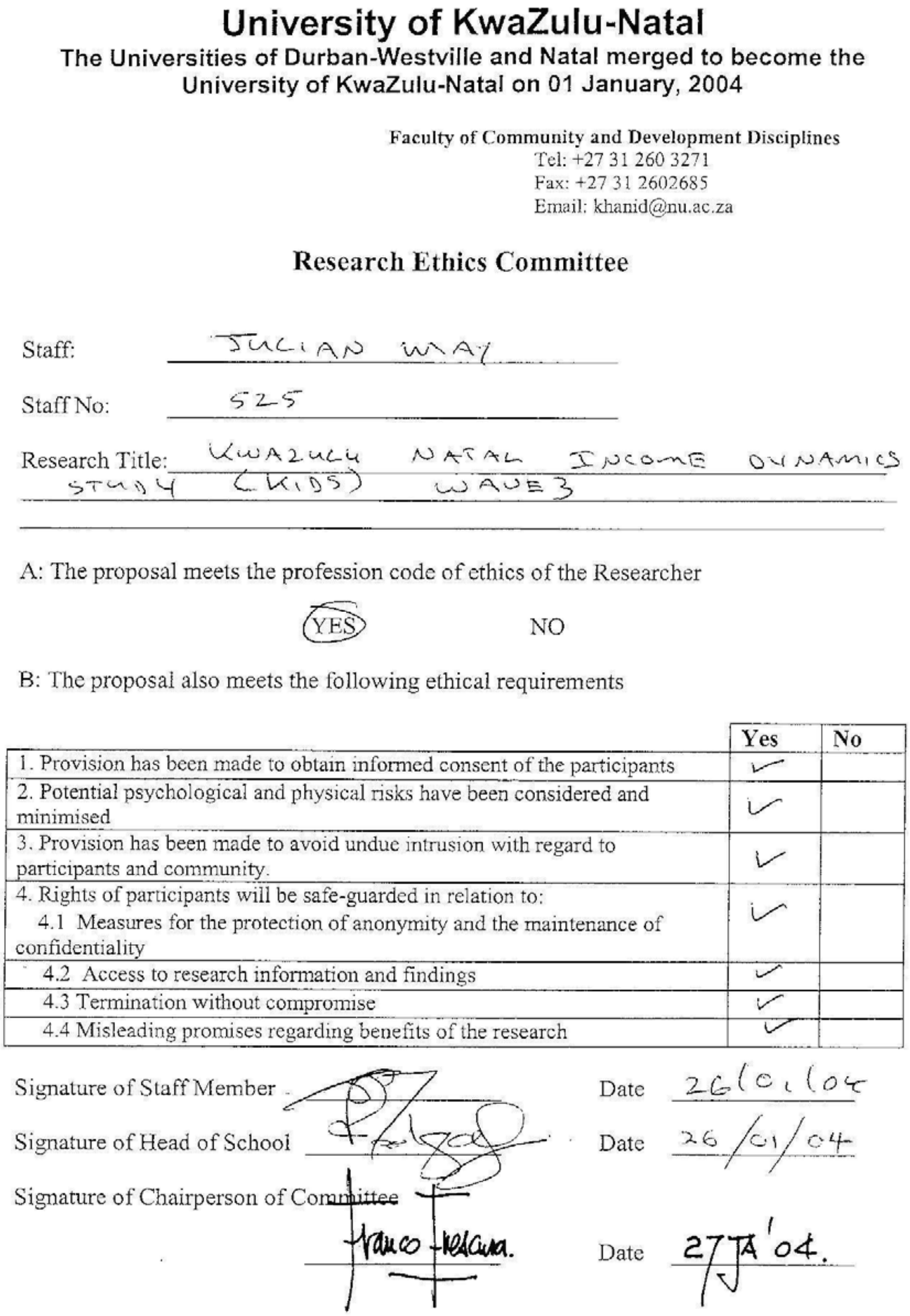
World Health Organisation. (2002). Fact Sheets on HIV/AIDS for Nurses and Midwives. Retrieved 24 October, 2009, from http://www.searo.who.int/LinkFiles/Publications_FactSheet-HIV-AIDSNurses.pdf

Yin, R. K. (1984). *Case Study Research: Design and Methods*. Newbury Park, CA: Sage.

Zick, C., & Bryant, W. (1983). Alternative strategies for pricing home work time. *Home Economics Research Journal, 12*(2), 133-144

11 APPENDICES

APPENDIX A – ETHICAL APPROVAL



University of KwaZulu-Natal

The Universities of Durban-Westville and Natal merged to become the
University of KwaZulu-Natal on 01 January, 2004

Faculty of Community and Development Disciplines
Tel: +27 31 260 3271
Fax: +27 31 2602685
Email: khanid@nu.ac.za

Research Ethics Committee

Staff: JULIAN WAY

Staff No: 525

Research Title: KWAZULU NATAL INCOME DYNAMICS STUDY (KIDS) WAVE 3

A: The proposal meets the profession code of ethics of the Researcher

[✓ YES] NO

B: The proposal also meets the following ethical requirements

	Yes	No
1. Provision has been made to obtain informed consent of the participants	✓	
2. Potential psychological and physical risks have been considered and minimised	✓	
3. Provision has been made to avoid undue intrusion with regard to participants and community.	✓	
4. Rights of participants will be safe-guarded in relation to: 4.1 Measures for the protection of anonymity and the maintenance of confidentiality	✓	
4.2 Access to research information and findings	✓	
4.3 Termination without compromise	✓	
4.4 Misleading promises regarding benefits of the research	✓	

Signature of Staff Member Date 26/01/04

Signature of Head of School Date 26/01/04

Signature of Chairperson of Committee

Franco Frescura. Date 27 JA '04.

C. Comments:

The following additional information may be helpful.

The KwaZulu-Natal Income Dynamics Study (KIDS) Wave 3 is the third wave of a panel study first undertaken in 1993. The survey used a random sample with clear procedures regarding replacements, exclusions and confidentiality. These procedures and the data have been in the public domain since 1995 (1st Wave) and 2000 (2nd Wave). KIDS 3 will be placed in the public domain in January 2005.

KIDS 3 is a collaborative study with the International Food Policy Research Institute (IFPRI), the University of Wisconsin-Madison and the London School of Hygiene and Tropical Medicine. Each wave of the study has required ethics clearance, and this clearance has already been given by the first two institutes for Wave 3, and is in process of obtaining clearance with the third. KIDS 3 is being financially supported by the South African Department of Social Development and the UK Department for International Development (DFiD).

The study comprises a household socio-economic questionnaire, the collection of anthropometric data from children 6 years and below, the administration of a literacy test to children 7-9 years, a qualitative component which comprises key informant interviews, focus group discussions and community and household case studies, combining ethnographic and interviewing techniques.

The KIDS 3 research team at the University of KwaZulu-Natal consists of Prof. Julian May, Dr. Myriam Velia, Mr. Thabani Buthelezi, Ms. Suraya Dawad, Ms. Nina Hunter and Ms. Masingita Khandlhela.

All members of the University research team have successfully completed the on-line course on Human Participants Protections Education for Research Teams course offered by the National Institutes of Health. Certificates of completion can be provided.

The questionnaire and an informed consent form will be translated into the language of the respondent, either English or Zulu. Approval must be obtained from legal guardian(s) for the participation of children under 14 years of age before any data collection can take place. Oral consent will be sought from children that are old enough to understand the request that is being made.

Respondents were asked during Wave 2 whether they were willing to be revisited. Only those that agreed will be approached for Wave 3.

Training on the collection of anthropometric data will be provided to the enumerators by members of the School of Public Health, and only women will be used to collect these data. Members of the University research team will provide ethics and sensitivity training to the enumerators.

Information packs will be provided to the administrative authorities (municipal offices and/or traditional leaders) in areas in which the study is being administrated. These packs will contain summaries of the results from previous rounds of research using KIDS and will also include development related material sourced from government and NGO's. A user-friendly, local language leaflet outlining the study and previous results will be provided to all respondents.

Participation in the study is voluntary and respondents may withdraw from the study at any point, or refuse to answer specific questions. An incentive will be given to the respondent in each household irrespective of their participation. This will be a household cleaning product (eg. soap etc.) or educational aid (eg. pencil case etc.).

Enumerators will carry identification, introduce themselves to respondents and provide letters of support from the University research team and the Department of Social Development. Permission to work in the survey areas will be obtained in advance from the relevant local and provincial authorities.

Records of the KIDS study have been placed in a controlled access environment and may not be removed from this room. All addresses and names have been removed from any public domain data and documentation, and an algorithm prevents inadvertent matching of the data to administrative records that might result in the disclosure of identifying information.

APPENDIX B – MINI SURVEY

Date: ____ May 2004

Interviewer: ____________________

Cluster number: _________________

Cluster name: ___________________

Household number: ________________

Mini-Survey on KIDS households

CARING FOR ILL PEOPLE

Possible ill person 1:

During the last 30 days, has anyone been <u>continuously</u> or <u>frequently</u> ill? Yes/No

Has anyone in this household been bedridden over the last month? Yes/No

Is anyone in the household being treated for TB at present? Yes/No

Has anyone in the household been admitted to hospital for pneumonia in the past month? Yes/No

If yes to any one of these questions, continue with this section.

What is the age of this person? _________

What is the sex of this person? _________

Is this person ill because of an injury? Yes/No

Does this person receive a Disability Grant? Yes/No

If yes when did the person receive the grant (please give year and month)

____

Is this person being taken care of by anyone? Yes/No (circle correct answer).

How many people are responsible for taking care of the person on a regular basis? ____________

Person 1: Age ______; Sex _________; Relationship to ill person ___________
Person 2: Age ______; Sex _________; Relationship to ill person ___________
Person 3: Age ______; Sex _________; Relationship to ill person ___________
Person 4: Age ______; Sex _________; Relationship to ill person ___________
Person 5: Age ______; Sex _________; Relationship to ill person ___________

Possible ill person 2:
During the last 30 days, has anyone else been continuously or frequently ill? Yes/No

Has anyone in this household been bedridden over the last month? Yes/No

Is anyone in the household being treated for TB at present? Yes/No

Has anyone in the household been admitted to hospital for pneumonia in the past month? Yes/No

If yes to any one of these questions, continue with this section.

What is the age of this person? ________

What is the sex of this person? ________

Is this person ill because of an injury? Yes/No

Does this person receive a Disability Grant? Yes/No

Is this person being taken care of by anyone? Yes/No (circle correct answer).

How many people are responsible for taking care of the person on a regular basis? ____________

Person 1: Age ______; Sex _________; Relationship to ill person ___________
Person 2: Age ______; Sex _________; Relationship to ill person ___________
Person 3: Age ______; Sex _________; Relationship to ill person ___________
Person 4: Age ______; Sex _________; Relationship to ill person ___________
Person 5: Age ______; Sex _________; Relationship to ill person ___________

Repeat again if there is another ill person in the household.

WHAT IS MEANT BY CARE
Help with personal care - bathing/washing, dressing, assistance with toileting, dealing with incontinence, feeding etc
Physical help - with walking, with getting in and out of bed etc.
Help with paperwork or financial matters - applying for a grant, assisting with the person's policies, tax, insurance etc
Other practical help - preparing meals for the person, housework such as changing the bed linen, doing the laundry etc
Keeping […] company
Taking […] out - accompanying them when they have to take transport to clinic/hospital etc
Giving […] medicine - giving injections, changing dressings, catheterisation etc
Keeping an eye on […] to see that the person is alright
Negotiation and liason with 'professional' caring agencies and staff – eg. clinic sister, community health worker

APPENDIX C – SELECTING CARE HOUSEHOLDS

It was relatively easy to find theme combinations that did not include the ‘care’ theme, since the criteria for the care them were not easily met. In the remaining 14 households selection was purposive. One or more of the community caregivers in the study area, or other key informants if these were not present (usually one or two individuals who the fieldworker had got to know and who knew the community members well), were approached for assistance in identifying possible ‘care’ households.

These individuals were told that the study team was interested in studying care within households in the area, and were asked to identify households in which there was someone who had been frequently or continuously ill over the last month, who was aged over 10 and under 60, who was not ill because of an injury, and who was receiving care by at least one other household member. The mini-survey was then administered in identified households, and if the requirements were met, households were selected on condition that another of the themes was met.

APPENDIX D – STRUCTURED GUIDE FOR THE CARE THEME

Cluster number: ____________

Household number: ____________

STRUCTURED GUIDE:
COSTING CARE FOR ILL PEOPLE

This component of the research focuses on care that takes place for people who are ill by other household member(s). The aim of this part of the study will be to put some kind of cost on the care that is taking place.

Framework for costing care:
What techniques can we use to make people see it as valuable work that has a material cost? We will need to deconstruct what care means and operationalise what care means. .

Need to frame the costs of care – Netten suggests the following options:

(a) the person is giving up non-waged time. If they weren't caring, what would they be doing during the time that is now spent looking after the ill person?

(b) or, we could say it is the same work that a domestic worker is doing. In line with this we would need to work out what "domestic worker" type work is being done for the ill person and the amount of time it is taking per day/week, and then cost this work.

(c) or, we could say it is the same work that a paid nurse or nursing assistant is doing – we could identify the "nursing assistant" work being done and the amount of time that is spent on this work per day/week; by illustrating the type of work being done we could insist on a skill level that is required to do this work

(d) or, working out the direct financial costs on goods and services – food bought, housework done, caring activities etc.

In general, for b, c and d, we need to find out what the carer is doing (general household tasks related to cared for and caring tasks for cared for) and the costs that are involved in caring for the person.

Therefore, a key question is: What **bundle** of tasks do carers have? What are your responsibilities/tasks for the person who is ill? What do you do to look after this person?

(e) or, another approach is to argue that the carer gives up career prospects - if you are able to find out what they had to give up on then you could use this approach. We will therefore collect information on work history.

(f) or, has the carer given up accommodation and moved to care for the ill person, or has the ill person moved in with the carer.

This information will be collected using this guide. The focus is very much on the main caregivers of ill people.

The following is in this structured guide:

- Identifying the main caregiver(s)
- Some information on the main caregiver(s) - asked of each main caregiver separately
- Education and work history of each main caregiver – asked of each main caregiver separately
- 24 hour breakdown of caring activities for ill person – asked of as many main caregivers together at one time
- Survey type questions to get at different types of care in detail and related costs associated with care - asked of as many main caregivers together at one time
- The experience of caring – asked of each main caregiver separately
- Caring and how it fits in with other productive, reproductive and leisure activities – asked of each main caregiver separately
- Additional support to ill person/main caregivers - asked of as many main caregivers together at one time
- Training received - asked of as many main caregivers together at one time
- Observation
- Recap and further probing on financial costs associated with care - asked of as many main caregivers together at one time

In addition, the following relating to care will be completed in each cluster:

- Focus group discussions with community health workers, with home-based care workers, family members and volunteers and support group members (if such programmes are present in the particular areas).
- Key informant interviews with the person in charge of the local home-based care programme, if such a programme is present in the area, and if there is no such programme the head of the nearest clinic.

Guidelines on questions to ask for these additional sections have not yet been developed but will be provided to you before these have to be completed, slightly later in the study.

General

❑ What is the definition of care? The following can be used as a guideline:

What is meant by "care" ("helping" or "assisting")
Help with personal care - bathing/washing, dressing, assistance with toileting, dealing with incontinence, feeding etc
Physical help - with walking, with getting in and out of bed etc.
Help with paperwork or financial matters - applying for a grant, assisting with the person's policies, tax, insurance etc
Other practical help - preparing meals for the person, housework such as changing the bed linen, doing the laundry etc
Keeping […] company – including reading to them and talking with them
Taking […] out - accompanying them when they have to take transport to clinic/hospital etc
Giving […] medicine - giving injections, changing dressings, catheterisation etc
Keeping an eye on […] to see that the person is alright
Negotiation and liason with 'professional' caring agencies and staff – eg. clinic sister, community health worker

❑ There may be households in which there is a person who has been frequently or continuously ill over the last two months, but there may not be a person who cares for them in these households. We will not select these households to be part of the study. We are specifically wanting to find out about **care** for ill people, and so will choose households in which care is taking place.

❑ In these households the ill person may be bedridden (as in the pilot), and there may be a lot of care that is taking place. However, the ill person may only be ill sometimes, and may be relatively well at the time of your interview. If this is the case many of the questions may not be applicable. PLEASE TRY AND ASK RETROSPECTIVE QUESTIONS – for instance, if they say "no, he/she does not need help with toileting" you can ask, "did they need help with toileting when they were ill?". If they say yes, ask them to describe the help that was given in the past, and fill out the questions in the past tense.

❑ If there is more than one person being cared for in a household –an adult who is bedridden and an elderly person who also receives care – we need to find out about this additional care as well. You will need to ask all the same questions relating to both people receiving care.

❑ If you hear about someone who is being cared for by non-household member(s) (ie. there is a sick person and there is no-one else who lives in the same household as that person to look after them, but they are provided with care by one or more persons from outside of their household) please make a note of this. We will try to conduct complementary interviews with this person's carers.

❑ You will need to be in households at different times of the day (in this way you will see different things and be able to speak to different people involved in care). Caring is a 24 hour job and we want to pick up on much of this as possible. The visits to households need to as far as possible be planned for different times for each household.

❑ Reference to a day is to a full 24 hour cycle. For instance, if inquiring about care over the last day, every detail of activity that has taken place from 24 hours ago, including during the night, needs to be probed. Reference to a week is a full 7-day week, including weekends.

- ☐ The bulk of the questions in this structured guide will be asked of the main caregiver(s) of the ill person. If there is <u>more than one main caregive</u>r, some sections (eg. survey type questions) should be asked of all main caregivers together. If only one caregiver is around when you are asking the questions, you could tell them that if they have any doubt, you could ask the other main caregiver at a later time. If there is more than one main caregiver, it will be important to pick up on the interactions between caregivers, how care work is shared/divided. Some sections (eg. education and work history; experience of caring) are to be asked of each caregiver separately.

- ☐ Information on help provided by other carers is asked for throughout the structured guide for the main caregiver. Please record this information carefully. From the information you collect on additional carers, we may put together further questions to be asked of additional carers.

- ☐ There are some questions that must be asked before others. Please pay attention to the notes that give you guidance on these. Be careful to ask the questions on time use at different times over your visits to the household. For example, there are questions in the survey section dealing with time use and the 24 hour breakdown of caregivers activities also looks at time use. DO NOT ASK THESE ON THE SAME DAY, ASK THESE IN DIFFERENT WEEKS. Apart from this, it is fine to move around the interview guide. As long as at the end of your time in the field information on all these issues has been provided by those who are meant to provide it.

- ☐ If you have additional questions that you want to ask, that flow from what the interviewees are telling you, go ahead and ask them!! In the pilot you all had a good feel for asking good additional questions.

- ☐ You are not going to be asking about symptoms directly. Rather, this should come out of the care that is described (eg. What medicine is obtained from the doctor? What is this medication for?). We would not like to upset the caregivers by talking too directly about the symptoms, and therefore it is not too explicitly stated. But, when you do find out what the person's symptoms are, please record these carefully.

- ☐ Finally, but most importantly, it is very likely that having to answer these questions will be distressing to the respondents. If you see that the respondent is getting upset, please ask them if they would prefer it if you would stop the conversation. Tell them that at any time they may ask you to stop asking questions. Related to this, to enable sensitivity, as far as possible, try to ask questions to each respondent privately. There may be information that the respondent will be far more comfortable to share in private. If the person who is sick is indoors, and you are wanting to speak to the main carer, ask if it will be possible to go outdoors and speak to them there. Likewise, if you are wanting to speak to the person who is sick, ask if it would be possible to speak with them alone.

NOTE:
Remember that at the beginning of your time in the household it is very important to build rapport with the household members, but especially the caregivers. Basically, this means getting to know them a little. This needs to be established before moving onto the questions about care. It will also be important to empathise with the caregivers.

QUESTIONS FOR THE MAIN CARE GIVER(S) OF A PERSON WHO IS SICK:

Filter question to identify main care giver(s) of sick person[26]:

☐ Who is responsible for the care of the ill person on a regular basis? (this is the definition of a main care giver)

☐ Is there more than one person responsible for the care of the ill person on a regular basis? (Probe. Repeat question if necessary)

☐ Please list the names of the main caregivers of the ill person

☐ Please rank the names of the main caregivers in order of importance in terms of care for the ill person

Address the following introduction to the main care givers of the ill person:
We are doing research to find out more about care that is given to people who are ill. We would like to understand the type of care that takes place and exactly what it is that you do for the person in your care. We hope that the findings from this research will be heard by people who make policy in South Africa, and that this will help people like you in some way. That is why we think it is important to get this information from you. However, if you feel upset or sad while I am asking you these questions, you must tell me if you would like me to stop answering the questions I have. At any time you can tell me if you would prefer to no longer answer the questions I have.

---

[26] The literature in the United Kingdom gives us some definitions of the domestic carer as "being responsible both for overall organization, and for the details of an individual's care" (James, 1992, as cited in Barnes, 2003:5). Another definition is as follows: "People who assume the major responsibility for providing caregiving services on a regular basis to someone who is incapable of providing for the personself" (Braithwaite, 1990, as cited in Barnes, 2003:10). In the South African context there is likely to be not only one person who cares for a sick person, as in the United Kingdom, but more than one person who provides care.

Rapport building questions

These questions are meant to help you get to know the main caregivers. Ask these questions before moving along in the guide. DO NOT WRITE DOWN THE ANSWERS TO THESE QUESTIONS.

Take care to back out of a discussion if it will break rapport. Follow through on a discussion if it might get the discussion required for the research going.

- What do you do?
- What did you do when you last worked?
- Where did you grow up?
- How did you meet your spouse?
- Have you travelled outside of this area?
- What places have you visited?
- What did your parents do?
- What do your children do?
- Have you got grandchildren?
- What do you think of South Africa being awarded the 2010 bid to host the soccer World Cup?

Questions for main care giver(s): (repeat for each main caregiver; if at a later time you find out that there is an additional main caregiver you need to get answers ask her/him these questions below)

MAIN CAREGIVER 1:
How are you related to the ill person that you care for? ____________________

Sex? ____________________________

Age? ____________________________

Name? ___________________________________

How long have you been staying in this house/homestead? ____________________________

Where did you stay before? ____

If place different to current place, ask following question: Why did you come to stay here?
____

For how long have you been responsible for caring for the person?
____

Have you cared for the person from when he/she first needed to be cared for until now? (*Please note when the caregiver started to care for the ill person, and when this finished, also if there have been any gaps in between*).
____
____
____

Who cared for the person before you started caring for him/her?
____
____

Is there more than one person who is responsible for the sick person's care? Who is/are these people?
____
____

MAIN CAREGIVER 2:
How are you related to the ill person that you care for? ____________________

Sex? ____________________________

Age? ____________________________

Name? ___________________________________

How long have you been staying in this house/homestead? _____________________________

Where did you stay before? ____

If place different to current place, ask following question: Why did you come to stay here?

____

For how long have you been responsible for caring for the person?

____

Have you cared for the person from when he/she first needed to be cared for until now? (*Please note when the caregiver started to care for the ill person, and when this finished, also if there have been any gaps in between*).

____

____

Who cared for the person before you started caring for him/her?

____

____

Is there more than one person who is responsible for the sick person's care? Who is/are these people?

____

____

MAIN CAREGIVER 3:

How are you related to the ill person that you care for? ____________________

Sex? ____________________________

Age? ____________________________

Name? ___________________________________

How long have you been staying in this house/homestead? ___________________________

Where did you stay before? ____

If place different to current place, ask following question: Why did you come to stay here?

____

For how long have you been responsible for caring for the person?

____

Have you cared for the person from when he/she first needed to be cared for until now? (*Please note when the caregiver started to care for the ill person, and when this finished, also if there have been any gaps in between*).

____

____

Who cared for the person before you started caring for him/her?

____

____

Is there more than one person who is responsible for the sick person's care? Who is/are these people?

____

____

Note: Repeat above questions for each additional person who is identified as a main care giver.

The experience of caring

This section is to be asked of each main caregiver. That is, all questions must be answered separately by each main caregiver. The questions are to be asked privately, without the presence of anyone else other than one or more of the main caregivers. You will get stories from the questions below – these questions aim to facilitate the stories on the caregivers' experience of caring.

- What is it like (caring for the ill person)?
- What is good about caring for this person (what makes you <u>feel good</u> about caring for the person)? What do you like about caring for the ill person? Probe: anything else?
- What is not nice about caring for the person? Probe: anything else?
- Do you get frustrated? Probe.
- What makes it difficult to care for the person at home?
- When has it become difficult to keep the person at home?
- Are you confident when you look after the ill person? When do you feel confident and when do you not?
- Do you sometimes feel that you don't know how to do something to care for the person? When does his happen? Describe.
- Do you feel isolated? When? Describe.
- In what ways has your social life changed now that you have to care for the ill person?
- Do you feel recognised for the care work that you do?
- Has caring for the person affected your physical health? In what way has it affected you physically?
- Do you feel there are needs and responsibilities in the household that you cannot meet because you have to care for the ill person? What are these?
- What would make the biggest difference to you in terms of caring for the person? What would help you most?
- Has care that is required for the person resulted in financial hardship? How has the household coped?
- Do you have to negotiate with the ill person? For what reason do you have to negotiate with the person?
- How do you feel about this?
- Do you have to negotiate with other carers over caring for the person? For what reasons do you have to negotiate with other carers? (*If they cant think of anything, you may be aware of various negotiations amongst carers, and could prompt using these examples*).
- How do you feel about this?
- What motivates you?
- What would help you most at this time?

Education and work history

This section is to be asked of each main caregiver (section to be duplicated for each main caregiver). You could use different coloured pens to fill out this section for the different caregivers, if there is space.

Education:

What is the highest level of education that you have completed?

- never went to school	- grade 9 or standard 7
- less than 1 year	- grade 10 or standard 8
- grade 1 or sub A/class 1	- grade 11 or standard 9
- grade 2 or sub B/class 2	- grade 12 or standard 10
- grade 3 or standard 1	- certificate
- grade 4 or standard 2	- diploma
- grade 5 or standard 3	- undergraduate degree
- grade 6 or standard 4	- honours/masters degree/higher
- grade 7 or standard 5	- other
- grade 8 or standard 6	- don't know

- ❖ In what year did you complete this year of education? ________

If the highest level of education was NOT school, ask:
What was your last completed school year? (grade/standard) ________________

If last school year was matric: Did you pass matric? Yes/No

- ❖ If no, why did you not pass matric?
  ____

- ❖ If yes, did you obtain a matriculation exemption? Yes/No

- ❖ If yes, did you obtain a senior certificate? Yes/No

If last school year was not matric: Why did you leave school?

Have you studied after school? Yes/No

- ❖ If yes, when did you study?
  Start __________________ (year/month)
  Finish _________________ (year/month)

- ❖ What did you study? ____

- ❖ Did you complete your studies? Yes/No.

- ❖ If no, why not? ____

- ❖ Did you study anything else, and if so what? _______________________________________

  Start __________________ (year/month)

Finish ________________ (year/month)

- Did you complete your studies? Yes/No.

- If no, why not? ____

Work history: please try and get a complete story of any work they have done over time, both paid and unpaid

WORK 1:
Have you ever worked for money (employed, self-employed, subsistence agriculture or any work to generate income)? Yes/No

- **If yes**, what work did you do?

- Did you work for yourself or for someone else?

- When did you do this work? _________________

  Start _________________ (year/month)
  Finish ________________ (year/month)

- Why did you stop doing this work?

- **If no**, what did you do after you left school?

- What did you do after that?

- Who has been supporting you? How did you get by? (*Careful, this could be sensitive*)

  Start _________________ (year/month)
  Finish ________________ (year/month)

- Why did you stop doing this work?

WORK 2:
Are you currently working for money (employed, self-employed, subsistence agriculture or any work to generate income)? Yes/No.

- **If yes**, what work do you do?

- Do you work for yourself or for someone else?

- When did you start this work? _________________ (month/year)

- How has caring for the ill person affected the work that you do?

- How has it affected the other things that you have to do outside of work?

- How has it affected your work opportunities?

- Have you had to miss work to care for the ill person ? Yes/No

- When did this happen? ___________________ (month/year)

- For what length of time did you have to miss work? (days/months)

- Did it happen again? Yes/No

- When did this happen? ___________________ (month/year)

- For what length of time did you have to miss work? (days/months) (Repeat for all possible times work was missed).

WORK 3:
<u>Have you ever done any work for money (employed, self-employed, subsistence agriculture or any work to generate income) other than the work you currently do? Yes/No</u>

- **If yes**, please think back on the first time you worked for money. What was the <u>first</u> work that you did?

- Were you working for yourself or for someone else?

- When did you start this work? _____________________(month/year)

- When did you finish this work? ____________________(month/year)

- Why did you stop doing this work?

WORK 4:
<u>Did you do any work (employed, self-employed, subsistence agriculture or any work to generate income) after that? Yes/No</u>

- **If yes**, please think back on the work you did <u>after</u> this work. What work did you do?

- Were you working for yourself or for someone else?

- When did you start this work? _____________________(month/year)

- When did you finish this work? ____________________(month/year)

- Why did you stop doing this work?

WORK 5:
<u>Did you do any work (employed, self-employed, subsistence agriculture or any work to generate income) after that? Yes/No</u>

- **If yes**, please think back on the work you did <u>after</u> this work. What work did you do?

- Were you working for yourself or for someone else?

- When did you start this work? ____________________(month/year)

- When did you finish this work? ___________________(month/year)

- Why did you stop doing this work?

Repeat if necessary.

WORK 6:

Have you ever done any work for board and lodging or for something other than money? Yes/No (*Careful, this could be sensitive*)

- **If yes**, describe the work you did.

- When did you do this work:
  Start ________________ (year/month)
  Finish ________________ (year/month)

Did you do any other work for board and lodging or for something other than money? Yes/No

- **If yes**, describe the work you did.

  Start ________________ (year/month)
  Finish ________________ (year/month)

Did you do any other work for board and lodging or for something other than money? Yes/No

- **If yes**, describe the work you did.

  Start ________________ (year/month)
  Finish ________________ (year/month)

Repeat if necessary.

Unpaid work

What do you do when you are **not** caring for the ill person, and (*if the person is working*) when you are **not** working? (this includes subsistence agriculture for no wage).

Please describe all these things you do, starting from when you wake up in the morning. Use the following prompts:

- What do you do in the early morning?
- What do you do in the morning?
- What do you do at midday?
- What do you do in the early afternoon?
- What do you do in the afternoon?
- What do you do in the evening?
- What do you do early at night?
- What do you do late at night?

Are there days that are different? Which days? Why are they different?

24 hour breakdown of carers' activities for ill person

These questions need to be addressed to at least one, but preferably to as many of the main caregivers as possible, all present at one time. If the relevant carer is not there to give you the care information over the time they looked after the person, fill in this information when you ask them for it at a later stage. For example, if the mother of the sick person usually cares for him/her at night, but is not there when you are asking these questions, ask the mother later, and then fill in the activities that she completed.

Ask the person to think back to 24 hours before now.

Ask the following, and fill in the information under the times provided on the next page:

What were you doing 24 hours ago? Describe in detail.

How long did it take to finish what you were doing?

When you stopped this activity, what did you do next? Describe in detail.

How long did it take/last?

Then, what was the next thing you did? Describe in detail.

How long did it take/last?

When the respondents say they went to sleep at night, ask:

Did any of you [main caregivers] wake up at night, and if so, why?

Did you have to do anything during the night for the ill person?

What was this? Describe in detail.

How long did it last?

Did it occur more than once?

What was the first thing that you did in the morning? Describe in detail.

How long did it last?

And so on, until they get to describing that they are now talking to you (24 hours later). This will also give you an idea of activities to prompt from for further questions below.

24 hour activity diary:

Record date today: ……………………..

Fill in activities for each hour, for 24 hours from the time you interview the person. If you speak to them at 9h00, then see that you fill in activities under each hour from "09h00 yesterday" to "09h00 today"
Please see that there is an activity recorded under every hour, even at night time. Probe to ask about care at night specifically).

08h00 yesterday

09h00 yesterday

10h00 yesterday

11h00 yesterday

12h00 yesterday

13h00 yesterday

14h00 yesterday

15h00 yesterday

16h00 yesterday

17h00 yesterday

18h00 yesterday

19h00 yesterday

20h00 yesterday

21h00 yesterday

22h00 yesterday

23h00 yesterday

24h00 today

01h00 today

02h00 today

03h00 today

04h00 today

05h00 today

06h00 today

07h00 today

08h00 today

09h00 today

10h00 today

11h00 today

12h00 today

13h00 today

14h00 today

15h00 today

16h00 today

17h00 today

When you have finished ask:

Ask the caregivers to compare this to the average day and to tell you about any differences that there may be.

Survey type questions – caring guide:

Please read this carefully before you complete the survey questions.

Please include any comments/additional things said in the grid. Try to include as much detail as possible. Do not feel restricted by the boxes! Sometimes stories are told while you are asking these survey type questions. Do not curb these! Get down as much information as possible in your notebook. These are good ways to get at the stories. However, try always to probe for why people say things, did things, felt things. The value of this type of research is in looking for motivations, reasoning and perceived causes.

Remember to include variations – they may say that they do this sometimes, and other times they do something different. Include all of this detail.

When filling out the information, work through the questions for each column at a time (moving from the top to the bottom of each column). See that all the applicable information per column is filled out.

Record time in hours and minutes (eg. 1hr 20min).

The person who provides each particular type of care needs to be the one to answer questions on the care provided. For example, if the mother of the person cares for them at night, she needs to be asked about any caring that happens at night. If one person is responsible for making food for the person, they need to be asked about anything to do with feeding the person.

If the person says that they "don't know" the answer to a question, and you feel that it is not because they have not understood the question, do not probe too much. If they do understand, but they give "don't know" as an answer, this is acceptable. Rather write "don't know" than 'second-guess' the person. An example where 'don't know' may come up is the question on special precautions taken.

Remember: many of these questions are probably sensitive. Be sensitive in asking the questions!

Respondent(s): ___________________

Time period of illness being refered to: (start: month/year – finish: month/year)

Help with personal care (ask questions column by column):	**Bathed/washed**	**Dressing**	**Undressing**
Does the person need help with ________?	Yes/No	Yes/No	Yes/No
Who usually does this?			
Is there more than one person who usually does this?	Yes/No	Yes/No	Yes/No
If yes, who is this other person?			
Does anyone else usually also help?	Yes/No	Yes/No	Yes/No
Who is this person?			
How many people help with _____ each time it is done?			
How often does this happen?	Times a day?	Times a day?	Times a day?
On average, how long does it take to do each time it is done?			
Are any precautions taken to see that the carer(s) is safe?	Yes/No/Don't know	Yes/No/Don't know	Yes/No/Don't know
What are these? (if gloves are used, how many pairs are used per day for each activity?)			
Have any clothes had to be bought for the person since they became ill, as a result of their illness?		Yes/No	
Have any blankets/linen had to be bought for the person since they became ill, as a result of their illness?		Yes/No	
If yes, please list each of these special clothes and state their cost next to each option			
Who bought these?			
Where were they bought?			

Where is the nearest toilet (ask questions in this row):	Inside the same building in which the sick person stays? Yes/No	Outside of the building in which the sick person stays? Yes/No	If outside, state distance (in metres) to toilet____________
Help with toileting (ask questions column by column; circle applicable option in last two columns):	Toilet	Commode/ bedpan/urine bottle/bucket/ other ___________	Commode/ bedpan/urine bottle/bucket/ other ___________
Does the person need help with using the _________?	Yes/No	Yes/No	Yes/No
Who usually does this?			
Is there more than one person who usually does this?	Yes/No	Yes/No	Yes/No
If yes, who is this other person?			
Does anyone else usually also help?	Yes/No	Yes/No	Yes/No
Who is this person?			
How many people help with ______ each time it is done?			
How many times a day does the person get assisted with ________?			
On average, how much time does it take to do each time it is done (total time for activity from start to finish)?	Get to & from toilet? Use toilet?		
Did you have to pay for the commode/ bedpan/urine bottle/bucket/other?		Yes/No.	Yes/No.
What was the cost?			
Where was it obtained?			
Who bought it?			
Are any precautions taken to see that the carer(s) is safe?	Yes/No/Don't know	Yes/No/Don't know	Yes/No/Don't know
What are these?			

Is the person incontinent (cannot stop going to the toilet when they need to)? Yes/No.			
Preventing wetting/soiling (ask questions column by column)	**Nappies**	**Linen savers**	**Plastic (sheeting)**
Are any of the following used to prevent wetting/soiling of clothes/linen?	Yes/No	Yes/No	Yes/No
Who usually puts these on/off?			
Is there more than one person who usually does this?	Yes/No	Yes/No	Yes/No
If yes, who is this other person?			
Does anyone else usually also help?	Yes/No	Yes/No	Yes/No
Who is this person?			
How many people help with _____ each time it is done?			
How many times a day is this done?			
On average, how long does it take to do each time it is done?			
How often are they obtained/bought?			
Where are they obtained?			
Who buys them?			
What do they cost?			
Are any precautions taken to see that the carer(s) is safe?	Yes/No/Don’t know	Yes/No/Don’t know	Yes/No/Don’t know
What are these?			

Giving medication / rubbing / applying dressings (ask questions column by column)	**Giving medication**	**Being rubbed/ massaged**	**Apply dressings**
Does the person need to be helped with __________?	Yes/No	Yes/No	Yes/No
Where are they rubbed/massaged/applied?			
Describe what is done			
Who usually does this?			
Is there more than one person who usually does this?	Yes/No	Yes/No	Yes/No
If yes, who is this other person?			
Does anyone else usually also help?	Yes/No	Yes/No	Yes/No
Who is this person?			
How many people help with _______ each time it is done?			
How many times a day is this done?			
On average, how long does it take to do each time it is done (from start to finish)?			
What is bought to do this? (eg. body cream, medicine measure)			
What does it cost?			
How often is it obtained/bought?			
Where is it obtained/bought?			
Who buys it?			
Are any precautions taken to see that the carer(s) is safe?	Yes/No/Don't know	Yes/No/Don't know	Yes/No/Don't know
What are these?			

Drinking/Eating (ask questions column by column) (Special drink/food is different from drink/food for other hh members)	**Drinking**	**Eating**	**Buying special drink/food**	**Preparing special drink/food**
What does the person usually __________?				
Does the person _____ the same as the other household members?				
Does the person need to be helped with __________?	Yes/No	Yes/No	Yes/No	Yes/No
Describe what is done				
Describe the preparation of the food or drink (eg. peeling, mashing)				
Is any special equipment used to eat/drink this special food? (eg. straws/special cup for drinking)				
Who usually does this?				
Is there more than one person who usually does this?	Yes/No	Yes/No	Yes/No	Yes/No
If yes, who is this other person?				
Does anyone else usually also help?	Yes/No	Yes/No	Yes/No	Yes/No
Who is this person?				
How many people help with ______ each time it is done?				
How many times a day is this done?			Times a week:	
On average, how long does it take to do each time it is done (from start to finish)?				
What does transport cost to get there?				
How much time does it take to get there?				

Drinking/Eating continued (ask questions column by column)	Drinking	**Eating**	**Buying special drink/food**	**Preparing special drink/food**
What is bought?				
Where is it bought?				
What does it cost?				
How often is it obtained/bought?				
Where is it obtained/bought? (list items and different places obtained)				
Where is it obtained?				
Are any precautions taken to see that the carer(s) is safe?	Yes/No/Don't know	Yes/No/Don't know		
What are these?				

Help with (ask questions column by column)	**Getting in and out of bed**	**Turning/ moving in bed**	**Walking inside**	**Walking outside**	**Getting into and out of a chair/onto or off a mat**
Does the person need help with ________?	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No
Who usually does this?					
Is there more than one person who usually does this?	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No
If yes, who is this other person?					
Does anyone else usually also help?	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No
Who is this person?					
How many people help with ____ each time?					
How often does this happen in the average day?					
On average, how long does it take to do each time it is done? (for one action – eg. getting outside; getting out of bed)					
Is the person bedridden?					
If yes, is he/she moved into a new position every few hours?					
Are any precautions taken to see that the carer(s) is safe?	Yes/No/Don't know	Yes/No/Don't know	Yes/No/Don't know	Yes/No/Don't know	Yes/No/Don't know
What are these?					
For what reason does the person walk? (eg. to go to the toilet, to sit outside)					

Help with financial matters/paperwork related to (ask questions column by column)**:**	**Applying for a grant**	**Policies (eg. funeral, insurance)**	**Membership of an organization (eg. stokvel, burial society)**	**Other (specify) ______________**
Does the person receive help with ________?	Yes/No	Yes/No	Yes/No	Yes/No
Who usually does this?				
Is there more than one person who usually does this?	Yes/No	Yes/No	Yes/No	Yes/No
If yes, who is this other person?				
Does anyone else usually also help?	Yes/No	Yes/No	Yes/No	Yes/No
Who is this person?				
How many people help each time with ____ ?				
What help is given? Describe.				
How often does this happen?				
On average, how long does it take to do each time it is done?				
If the person does not have ____, does anyone else in the household have ______ on the ill person's behalf?	▨	Yes/No	Yes/No	Yes/No
Who is this?	▨			
How much is paid each month?	▨			

Help with (ask questions column by column)**:**	**Putting linen on and taking it off bed**	**Linen laundry (includes sheets, blankets etc.)**	**Clothes laundry**
Does the person need help with ________?	Yes/No	Yes/No	Yes/No
Who (usually) does this?			
Is there more than one person who (usually) does this?	Yes/No	Yes/No	Yes/No
If yes, who is this other person?			
Does anyone else (usually) also help?	Yes/No	Yes/No	Yes/No
Who is this person?			
How many people help with _____ each time it is done?			
How long does it take?			
How often does ________ happen?			
Are the ill person's laundry washed together with the laundry of the rest of the household?		Yes/No	Yes/No
How long does it take to wash each time they have to be washed?			
How long does it take to hang them up each time?			
How long does it take to fold/iron them each time?			
Are any precautions taken to see that the carer(s) is safe?	Yes/No/Don't know	Yes/No/Don't know	Yes/No/Don't know
What are these?			

Help with (ask questions column by column) **(continued):**	**Putting linen on and taking it off bed**	**Linen and clothes laundry**
What does the soap/washing powder cost?		
How often is it obtained/bought?		
Where is it bought?		
Who buys it?		
How long does it take to get there from here?		
How much does it cost to get there?		
How often is linen washing done for the rest of the household?		
How long does it take to do this linen washing?		
How often is clothes washing done for the rest of the household?		
How long does it take to do this clothes washing?		

Keeping the person company

Does ___ get lonely?	Yes/No. Describe.
Does ___ get sad?	Yes/No. Describe.
Does ___ get anxious?	Yes/No. Describe.
Does anyone try and "be with" the person to keep the person company?	Yes/No.
Who is this?	
Does anyone else try and "be with" the person to keep the person company?	Yes/No.
Who is this?	
Does anyone try and "be with" the person to keep the person company?	Yes/No.
Who is this?	
If yes, how often during the day does someone try and "be with" the person?	
On average, how many days a week does someone try to "be with" the person?	
Tell me about the time spent together with the person. Describe. (eg. Is the person read to? Is the person talked to?)	

Keeping an eye on the person to see that they are alright:

	Keeping an eye on the person during the **day**	Keeping an eye on the person during the **night**
Does someone have to be with the person at all times or for some of the time?		
If someone has to keep an eye on the person some of the time, ask: For how much time in the average day?		
Who usually keeps an eye on the person?		
Does anyone else usually keep an eye on the person?	Yes/No	Yes/No
Who is this person?		
Does anyone else usually keep an eye on the person?	Yes/No	Yes/No
Who is this person?		
On average how often does the person need to be 'kept an eye on' (during the day/night)?		
Does the person need any assistance at night?		Yes/No
What type of assistance do they usually need?		
What type of assistance do they sometimes need?		
Over the last week, on how many nights has someone had to provide care to the person during the night?		

Going to ______ with the person (ask questions column by column)	**Hospital**	**Clinic**	**Private doctor**	**Traditional healer**	**Fetch social grant**
Does the person need help with ________?	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No. If yes, specify which grant _________
Who usually does this?					
Is there more than one person who usually does this?	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No
If yes, who is this other person?					
Does anyone else usually also help?	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No
Who is this person?					
How many people usually go with the person to _______?					
How often does this happen in the average month?					
How does the person and those accompanying him/her get there and back?					
How much does it cost to travel there and back per person?					
How long does it take to get there from here? (if with a taxi, find out how long it takes to get to taxi, and then how long from taxi rank to destination)					
Where is the _________					
On average, how much time is spent waiting at the place?					
Does a consultation/admission fee have to be paid?	Yes/No	Yes/No	Yes/No	Yes/No	
How much is the consultation/admission fee?					
How long did the person stay there the last time they were there?					

Going to ____ for the person (ask questions column by column)	**Hospital**	**Clinic**	**Private doctor**	**Traditional healer**	**Fetch social grant**
Does the person need someone to go to ________ for him/her?	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No. If yes, specify which grant _________
Who usually does this?					
Is there more than one person who usually does this?	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No
If yes, who is this other person?					
Does anyone else usually also help?	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No
Who is this person?					
How many people usually go with the person to _______?					
How often does this happen in the average month?					
How does the person(s) get there and back?					
How much does it cost to travel there and back per person?					
How long does it take to get there from here? (if with a taxi, find out how long it takes to get to taxi, and then how long from taxi rank to destination)					
Where is the __________					
On average how much time is spent waiting at the place?					
Does a consultation/admission fee have to be paid?	Yes/No	Yes/No	Yes/No	Yes/No	
How much is the consultation/admission fee?					
How long did the person stay there the last time they were there?					

Going to ____ with the person (ask questions column by column)	**Local municipality**	**Traditional authorities**	**Church**	**Other**
Does the person need someone to go to ________ with him/her?	Yes/No	Yes/No	Yes/No	Yes/No
Who usually does this?				
Is there more than one person who usually does this?	Yes/No	Yes/No	Yes/No	Yes/No
If yes, who is this other person?				
Does anyone else usually also help?	Yes/No	Yes/No	Yes/No	Yes/No
Who is this person?				
How many people usually go with the person to _______?				
How often does this happen in the average month?				
How does the person(s) get there and back?				
How much does it cost to travel there and back per person?				
How long does it take to get there from here? (if with a taxi, find out how long it takes to get to taxi, and then how long from taxi rank to destination)				
Where is the __________				
On average how much time is spent waiting at the place?				
Does a consultation/admission fee have to be paid?	Yes/No	Yes/No	Yes/No	Yes/No
How much is the consultation/admission fee?				
How long did the person stay there the last time they were there?		▨	▨	▨

Going to ____ <u>for</u> the person (ask questions column by column)	**Local municipality**	**Traditional authorities**	**Church**	**Other**
Does the person need someone to go to _________ for him/her?	Yes/No	Yes/No	Yes/No	Yes/No
Who usually does this?				
Is there more than one person who usually does this?	Yes/No	Yes/No	Yes/No	Yes/No
If yes, who is this other person?				
Does anyone else usually also help?	Yes/No	Yes/No	Yes/No	Yes/No
Who is this person?				
How many people usually go for the person to ________?				
How often does this happen in the average month?				
How does the person(s) get there and back?				
How much does it cost to travel there and back for the <u>per person</u>?				
How long does it take to get there from here? (if with a taxi, find out <u>how long it takes to get to taxi</u>, and then <u>how long from taxi rank to destination</u>)				
Where is the ___________				
On average how much time is spent waiting at the place?				
Does a consultation/admission fee have to be paid?	Yes/No	Yes/No	Yes/No	Yes/No
How much is the consultation/admission fee?				
How long did the person <u>stay</u> there the last time they were there?		▨	▨	▨

Oral medication = pills, syrup, drops, enema, muti etc.

Ask questions column by column	**Pharmacy**	**Supermarket/spaza**	**Traditional healer**	**Hospital**	**Private doctor**	**Clinic**	**Other (FILL IN – eg traditional home remedies) ____________**
Has medicine been obtained from ____________ over the last month?	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No
Where is ________							
How frequently was _____ visited?							
What medicine is it? (List all items obtained)							
What is the medicine for?							
What is the cost?							
When was it last obtained?							
How often is it obtained?							
Who went to get it?							
How did this person get to the ____?							
How much did it cost to get there and back?							
How long did it take to get there from here?							
For how long did the person have to wait at the ________?							

Non oral treatment = bandages, disinfectant, ointment, nappy rash cream, acqueous cream etc.

Ask questions column by column	**Pharmacy**	**Supermarket/spaza**	**Traditional healer**	**Hospital**	**Private doctor**	**Clinic**	**Other (eg traditional home remedies) ____________**
Has treatment been obtained from ____________ over the last month?	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No
Where is ________							
How frequently was _____ visited?							
What treatment is it? (List all items obtained)							
What is the treatment for?							
What is the cost?							
When was it last obtained?							
How often is it obtained?							
Who went to get it?							
How did this person get to the ____?							
How much did it cost to get there and back?							
How long did it take to get there from here?							
For how long did the person have to wait at the ________?							

Caring and how it “fits in”:

To be asked of each main caregiver. As above, these questions should facilitate stories. Concentrate on getting these stories.

- ☐ In what way have your activities (work and leisure) changed since you have had to look after the ill person?
- ☐ What do you not do because you have to care for the ill person? (this includes leisure and work activities)
- ☐ What have you stopped doing because you have to care for the ill person?
- ☐ If you weren’t caring, what would you be doing during the time that is now spent looking after the sick person (that is, what has the caring replaced)?
- ☐ Of all the household members who could be caring, why is it you (why are you doing this, and not someone else)? Probe.
- ☐ What are your other activities, apart from caring for ____? Probe. Try and get as complete a picture as possible. For example, if they have children – what do they do for the children each day? What other household jobs do they do?
- ☐ How do you fit in the caring that you do for the ill person with your other activities?

Additional support from outside of household:

Do you receive support/help/assistance from any of the following for the ill person OR do you go to visit any of the following for or with the ill person?

(CIRCLE CORRECT ANSWER; *please write down any comments that are given on each of the items as you go through them, even if there is a "no"*):

- ☐ A doctor? Yes/No.
- ☐ A nurse at a clinic? Yes/No
- ☐ A private nurse? Yes/No
- ☐ A hospital? Yes/No
- ☐ A psychologist? Yes/No
- ☐ A rehabilitation therapist? Yes/No
- ☐ A social worker? Yes/No
- ☐ Someone from an NGO/CBO/FBO (*list different options for each community – see telephonic interviews, information from community visits, and Focus Group Discussion information for your area*)? Yes/No
- ☐ A traditional healer? Yes/No
- ☐ A community leader (eg. an induna or a councillor)? Yes/No
- ☐ A community health worker? Yes/No
- ☐ Volunteers, such as support group members or health committee members? Yes/No
- ☐ Extended family? Yes/No
- ☐ Friend(s) of the ill person? Yes/No
- ☐ Friend(s) of the main caregivers? Yes/No
- ☐ Neighbour? Yes/No
- ☐ Employer? Yes/No
- ☐ Employee? Yes/No
- ☐ Other? Yes/No. Please describe who this is.
- ☐ Does anyone provide psychological support? Yes/No. Who is this?
- ☐ Does anyone provide spiritual support? Yes/No. Who is this?
- ☐ Does anyone provide some friendship, just someone you can talk to? Yes/No
- ☐ Does anyone provide financial/material support (money, food, clothes)? Yes/No

Please go to all the "yes" answers above, and then answer the questions below, for each type of support received.

Describe the assistance received. Can you describe what they do – how do they assist you?

How often do you see them (either through their visiting the household or the ill person visiting them)?

What difference does this assistance make to you?

Who in the household negotiates with the person who provides support?

What (other) types of support would you like to get? What (other) types of support would help you?

What has been the most frequent type of help that has been received from outside of this household? Prompt from the following: food, money, credit, clothing, child care, assisted household labour, nursing ___, medicine/treatment, advice/counselling? From whom has it been received?

If no support has been received from any of the above, ask:

Why do you think you have not received any support from outside of the household with caring for the person?

Why have you not sought assistance/support for the ill person?

Why is the sick person not in hospital at the moment?

Training received

Have any of the <u>main caregivers</u> received any of the following:

<u>Training on:</u>

- How to treat common illnesses? Yes/No. If yes, from whom? Tell me about the training received? *Probe.*
- How to institute universal precautions? Yes/No. If yes, from whom? Tell me about the training received? *Probe.*
- How to prevent HIV infection? Yes/No. If yes, from whom? Tell me about the training received? *Probe.*
- How to prevent accidents from happening in the home? Yes/No. If yes, from whom? Tell me about the training received? *Probe.*
- How to practice basic counseling skills? Yes/No. If yes, from whom? Tell me about the training received? *Probe.*
- How to practice basic nursing care? Yes/No. If yes, from whom? Tell me about the training received? *Probe.*
- How to practice palliative (terminal illness) care? Yes/No. If yes, from whom? Tell me about the training received? *Probe.*
- Proper nutrition? Yes/No. If yes, from whom? Tell me about the training received? *Probe.*
- The importance of cleanliness, proper hygiene? Yes/No. If yes, from whom? Tell me about the training received? *Probe.*
- The importance of exercise? Yes/No. If yes, from whom? Tell me about the training received? *Probe.*
- When to seek professional help? Yes/No. If yes, from whom? Tell me about the training received? *Probe.*
- What other training has been received? Describe.

<u>Training from:</u>

- ☐ Has your clinic helped with teaching you how to care for the person? Yes/No. If yes, describe the things that they taught you. *Probe until you have all the different things that were taught to the person.*
- ☐ Has your church helped with teaching you how to care for the person? Yes/No. If yes, describe the things that they taught you. *Probe until you have all the different things that were taught to the person.*
- ☐ Has a community health worker helped with teaching you how to care for the person? Yes/No. If yes, describe the things that they taught you. *Probe until you have all the different things that were taught to the person.*
- ☐ Has anyone else helped with teaching you how to care for the person? Yes/No. If yes, describe the things that they taught you. *Probe until you have all the different things that were taught to the person.*

Other people in the household:

Has anyone else in the household received any of the training listed above? Please describe who received the training and what training was received.

Has anyone else in the household received any other training relating to care for people who are ill, that is not mentioned above? Please describe who received the training and what training was received.

General observation (Do not ask these questions. Observe only)

Date: …………………….

- ☐ Is there clean water available to the household?
- ☐ Is there water available for hand washing?
- ☐ Is there enough water available for general use?
- ☐ Does the MCG use water to wash her/his hands? When?
- ☐ Do other carers use water to wash their hands? When?
- ☐ Are disinfectants available?
- ☐ Are disinfectants being used by the MCG? When?
- ☐ Are disinfectants being used by other carers? When?
- ☐ Is soap available?
- ☐ Is soap being used by MCG? When?
- ☐ Is soap being used by other carers? When?
- ☐ Are cloths/sponges available?
- ☐ Are they being used by MCG? When?
- ☐ Are they being used by other carers? When?
- ☐ Are boiling facilities available (eg. kettle, stove)? Describe.
- ☐ Are they used for sterilisation by the MCG? When?
- ☐ Are they used for sterilisation by other carers? When?
- ☐ Are boiling facilities used for anything else to do with the care of the ill person?
- ☐ Are any containers (eg. buckets, large bowls) used to help with the care of the person?
- ☐ Describe what containers these are and how they are used in caring for the ill person.
- ☐ Are gloves available?
- ☐ How many pairs are available for use?
- ☐ Are gloves being used in the care of the ill person? When?

- ☐ Are any protective garments available (eg. aprons)? Describe what these are.
- ☐ Are protective garments used when the MCG provides care? Describe.
- ☐ Are protective garments used when other carers provide care? Describe.
- ☐ Are there containers for the safe disposal of equipment/waste (eg. rubbish bin)? Describe.
- ☐ Are they being used to dispose of items related to care (eg. linen savers, dressings)? Describe.
- ☐ Where is toilet waste disposed? Describe.
- ☐ Is the home kept clean? Describe the cleanliness of the home.
- ☐ How regularly is it cleaned and by whom?
- ☐ Does the ill person have open wounds (where blood can be seen) on their skin? Describe.
- ☐ Are the wounds covered with a waterproof bandage or cloth? Describe.
- ☐ What are the symptoms that you can <u>see</u> that the ill person has? Please record these in detail.
- ☐ Do any of the other household members have open wounds that are not covered? Describe.
- ☐ Observe and record any physical effects of care on carers.
- ☐ Observe and record any emotional effects of care on carers.
- ☐ Observe general quality of care – what does it seem like?
- ☐ Do the carers do the minimum out of obligation or is there emotional nurturing attached? Describe.
- ☐ What is the relationship like between different carers? (eg. is there any arguing?).
- ☐ Do they seem to get on well and have a good understanding? Describe.
- ☐ What is the relationship like between the ill person and the carer(s)? Describe.
- ☐ Are any children helping to look after the ill person? (these may not be reported directly so observation is essential). Describe what any of the children do to help with care (specify which children).
- ☐ What do they do? Describe in detail.
- ☐ Does the person have any other symptoms that have not yet been recorded? Describe.
- ☐ Are there ever people present who are not mentioned by the respondent(s)? Follow up if there are, to see if they fit into the guide in some place.

☐ How has the respondent(s)'s attitudes to you changed over the time you have been with them? Describe.

☐ Is there anything else that you observe that is of interest? Please describe.

Financial costs

This section will be completed near the end of your time in the cluster. You will be provided with a chart on which to write up what you find below. You will be shown how to do this exercise in the first one or two households in which you need to record this information.

Begin as follows:
In addition to what you have already told me over the time I have been visiting you, are there any further financial costs that have arisen as a result of caring for the sick person? Many of these costs should have been covered in the care questions above. This section should be asked towards the end (probably during the last two week stay in each community). You will be joined for the initial visits and shown how to use a chart and probe for further costs over the time that the person has been ill. These additional costs may be as follows:

- Medicine (including off-the-shelf medication)
- Equipment to administer the medicine
- Health care providers eg. Doctors visits
- Hospital accommodation/admission fees
- Telephone costs

Some questions that will be asked: Where does the money come from to pay for these things? Have these additional costs made it difficult for this household to 'get by'? What has the household done to cope with these costs? (Here are some examples of what they could have done: sold something that belongs to the people in this household, used savings etc.)

Questions to ask the ill person (to be asked near the end of the household visits; to be asked with the person alone):

What did you do before becoming ill? What was your main activity? Probe.

For how long have you not been able to do what you usually did?

Has this been continuous or have there been times during which you could do normal activities?

Do you have children? Tell me about your relationship with your children.

How long have you been staying here?

Where did you stay before? (If place different to current place, ask following question).

Why did you come to stay here?

Who cares for you?

What do the people who care for you do for you?

Tell me about the 'care' / 'help' that you are being given by people who care for you?

Tell me about 'care'/'help' you receive from anyone else in the household?

Tell me about 'care'/'help' you receive from someone from outside of the household?

What would help you most at this time? Describe.

What would make the biggest difference to you in terms of care?

Would you prefer being here at home or in hospital?

Are you lonely? Are you left alone?

Do you feel you are getting enough support?

Do you feel comfortable? Clean? Warm enough? Safe?

APPENDIX E - MINI-EVENTS MAP FOR ILLNESS AND CARING PERIODS

When ill person first became ill:

- Ask: When did the person first need help in being cared for? Begin the map at this point, but leave a column before the first month for any events that happened before this. Write months from this given month until present month at the top of the page (if necessary use second paper).
- Why did she/he need to be looked after then (at start of illness period)?
- What were her/his symptoms at the time? Probe until you get all symptoms (prompt using parts of the body: "something to do with the **head**", "something to do with the **throat**", "something to do with the **chest**", "something to do with the **arm**", "something to do with the **abdomen**", "something to do with the **groin**", "something to do with the **leg**", "something to do with the **skin**").
- Give a brief outline of the ill person's condition before the start of this time.

Hospital stays:

- When did the person begin a stay in hospital?
- When did he/she get out of hospital? Repeat until they say the person did not stay in hospital again.
- Why did the person have to go to hospital? What were their symptoms – prompt as above. Ask for each hospital visit.
- What did the carer(s) do for the person when they were in hospital? Visit? How often did they visit? Buy things to take to him/her? Collect their grant? Probe.

Grant application and receipt:

- When did the person apply for a Disability Grant (or other grant, specify)?
- When did he/she receive a Disability Grant (or other grant, specify)?
- Does the ill person fetch the grant each month?
- If yes, have there been times when the ill person could not fetch the grant? Who fetched it then?

- If no, who fetches the grant. When has this been?
- Has anyone else fetched the grant? When has this been?

Visits to the following – record when these took place. Record who went with or for the person. Probe month by month:

- Hospital (record why visit took place: for a **consultation** and/or to receive **medication/treatment**)
- Clinic (record why visit took place: for a **consultation** and/or to receive **medication/treatment**)
- Private doctor (record why visit took place: for a **consultation** and/or to receive **medication/treatment**)
- Traditional healer (record why visit took place: for a **consultation** and/or to receive **medication/treatment**)
- Anyone else? (record why visit took place)

Visits from the following – record when these took place. Probe month by month:

- Community health worker (specify which CHW) (what did he/she do when they came to visit?)
- NGO/CBO/FBO (specify which) (what did he/she do when they came to visit?)
- Church members (what did he/she do when they came to visit?)
- Friends of ill person (what did he/she do when they came to visit?)
- Friends of carer(s) (what did he/she do when they came to visit?)
- Neighbours (what did he/she do when they came to visit?)
- Family (what did he/she do when they came to visit?)
- Anyone else? (what did he/she do when they came to visit?)

Training received by MCG and/or other carers:

- Was training received from the clinic? When? What training?
- Was training received from a community health worker? When? What training?

- Was training received from the church/NGO/FBO/CBO (specify which)? When? What training?
- Was training received from someone else or from another organization? When? What training?

Note: if training took place before start of illness period, specify when this was (month and year)

Bedridden (restricted to the bed):

- When has he/she been bedridden? Ask: from when, until when? Repeat: from when, until when? Repeat until you know the exact lengths of time for which the person has been bedridden from the start of the illness period.
- For each of these periods ask: What were his/her symptoms when he/she was bedridden? Prompt using parts of the body as outlined above.

Periods of not being bedridden:

- When has the person not been bedridden? Ask: from when, until when? Repeat: from when, until when? Repeat until you know the exact lengths of time for which the person has not been bedridden from the start of the illness period.
- For each of these periods ask: What were his/her symptoms when he/she was not bedridden? Prompt using parts of the body as outlined above.

Note: remember that there will be variations in the times when the person was not bedridden. During this time there would have been times when she/he was better, and times when he/she was worse. Please try to pick up on these variations by getting the story of this illness time.

Prompts for care that took place over these times (bedridden and non-bedridden). Ask for the bedridden periods and ask for the non-bedridden periods: what did the carer(s) do for the ill person? Record on events map:

- Bath/wash the person?
- Dress/undress the person?
- Help with toileting? (walk to toilet or help with toileting in room)

- Help with drinking? eating?
- Preparation of special food?
- Medication given?
- Rubbed/massaged?
- Treatment given (eg. dressings)?
- Help with moving in/out of bed?
- Help with turning in bed?
- Help with walking inside/outside?
- Help with moving into and out of chair/mat?
- Washing of ill person's linen/clothes?
- Keeping person company?
- Keeping an eye on the person during the day?
- Keeping an eye on the person during the night?

APPENDIX F – FINANCIAL COSTS DOCUMENT

1. Confirm when the period was for which survey information is relevant (identify it on the mini events map). Fill in here: start ________________; finish _________________

2. Confirm that the following was spent **over the caring period (for which the survey questions are answered**), item by item (if anything is incorrect, please correct it on this sheet):

3. Ask: were there any **additional costs**? Telephone costs? Further transport costs? Etc

4. Then refer to the time that the **ill person was in hospital**:

- The carer will have outlined what they did while the person was in hospital (in the mini-events map)– if not, please find this out: did they visit the person? How often? Did they take the person anything? How often?
- Try and obtain the costs involved in visiting (transport) and items brought for the person and any additional costs.

5. Try to find out the **sources of income to the** household over the caring period (which survey questions refer to). List the sources of income to the household over this time:

6. Try to find out what the **other expenditures were to the household over the caring period** (which survey questions refer to). List other expenditures to the household over this time:

7. Finally, ask, how did they manage to pay for all of these things? How did they cope with having to pay for these things?

APPENDIX G – RELEVANT KIDS QUESTIONNAIRE SECTIONS

KwaZulu-Natal Income Dynamics Study - 2004

Good (morning/afternoon/evening), I'm __________ and we are conducting a survey for the University of KwaZulu-Natal in Durban. The survey is part of a research project designed to understand people's living conditions and the impact of government policies on their lives. In 1993 and 1998 we interviewed you or another member of your family. The information given to us in these earlier studies has been used to inform government about how the economy works for people like you. As a follow-up to this earlier work, we would like to again ask questions about you and your family.

The survey will take about three hours to conduct. You will be asked questions about your daily life and work, and that of your family members. We would like to arrange two times when it is convenient for you to answer our questions.

We will want to speak to some other members of the household and to ask your primary-school age children a few questions about reading, writing and sums. We would also like to weigh and measure the height of the children in the household. By agreeing to participate in this study, you are giving us permission to weigh and measure the height of these children.

The study will pose no risks to you or to your child. You may refuse to answer any question without penalty. You may also choose to discontinue your participation in this study at any time.

You will not personally benefit from this study. We will however do our best to make sure that South Africa benefits from this study and what we can learn about how to make the economy and government work better for more people.

All information that you give to us will be kept confidential. You and your household members will not be identified by name or address in any of the reports we plan to write

DRAID
(Office Use)

Questionnaire No.
(Office Use)

2004 KWAZULU-NATAL INCOME DYNAMICS STUDY

A1. Cluster Number			**A2. HHID**	
A7. Name of Fieldworker			Date of Interview ***[dd/mm/yy]***	
A8. Name of Quality Controller			Date checked ***[dd/mm/yy]***	
A9. Name Supervisor			Date of Corrections Checked ***[dd/mm/yy]***	
A10. Selected for Callback	1 = Yes 2 = No		Callback record number	
Name of Office Quality Controller			Date checked ***[dd/mm/yy]***	
A11. Name of 1st Capturer			Date captured ***[dd/mm/yy]***	
A12. Name of 2nd Capturer			Date captured ***[dd/mm/yy]***	

ENUMERATOR DECLARATION

I declare that I have asked this entire questionnaire as it is laid out and as I have been briefed. I declare that I have interviewed in accordance with the instructions I received during training.

This questionnaire has been fully checked by myself.

PLEASE PRINT:

First Name	
Surname	
Signature	
Date	

KwaZulu-Natal Income Dynamics Study 2004

Contact Information

Enumerator: detach this sheet from the questionnaire and give it to the household head

Read this: Should you have any questions or complaints about this research project, you may contact any of the following people:

Julian May
School of Development Studies
University of KwaZulu-Natal
Durban
South Africa
031/260-2841

Michael R. Carter
Dept. of Ag & Applied Economics
University of Wisconsin
Madison, WI 53706
USA
Phone: +1/608/263-2478
FAX: +1/608/262-4376

Donna Jahnke
Institutional Review Board for Social and Behavioral Sciences
South Hall
University of Wisconsin
Madison, WI 53706
USA
+1/608/263-2320

Phakama Mhlongo
Suite 602, Maritime House
143 Salmon Grove
Durban, 4001
031/307-2366

Thabani Buthelezi
School of Development Studies
University of KwaZulu-Natal
Durban
South Africa
031/260-3035

KwaZulu-Natal Income Dynamics Study 2004

QUESTIONNAIRE NUMBER

HOUSEHOLD ID NUMBER

Q1. “I have read the information sheet about this study (or understood the explanation of it given to me verbally). I have had my questions concerning the study answered and understand what will be required of me if I take part. I agree to take part in this study”

Signature ……………………………..……. Date ………………………… Witnessed …………………………….
(or mark) **(ONLY IF ILLITERATE)**

KwaZulu Natal Income Dynamics Study 2004

1. DO YOU AGREE TO PARTICIPATE IN THIS STUDY? **Yes……………….1** *agree_yn*
No………………..2

HOUSEHOLD ID NUMBER *hhid*

NAME OF ISIGODI/SECTION *sect*

HOUSEHOLD SURNAME *hhsur*

GPS Information

lat Latitude: _ _° _ _ ’ _ _” E

lon Longitude: _ _° _ _ ’ _ _” S

alt Altitude: _ _ _ . _ _ m

2. IS THIS HOUSEHOLD IN THE SAME COMMUNITY AS 1998 ? *commun*

Yes 1
No 2

3. IS THIS HOUSEHOLD IN THE SAME ISIGODI/SECTION AS 1998? *section*

Yes………………………………………..1
No………………………………………...2

	Visit 1	**Visit 2**	**Visit 3**	**Visit 4**
3. Code of Interviewer:	*intvwr1*	*intvwr2*	*intvwr3*	*intvwr4*
4. Date:	*date1* _____ / _____ / 04	*date2* _____ / _____ /04	*date3* _____ / _____ / 04	*date4* _____ / _____ / 04
6. Time Began:	*began1*	*began2*	*began3*	*began4*
7. Time Ended:	*ended1*	*ended2*	*ended3*	*ended4*
8. Anthropometrist Code:	*anthcode1*	*anthcode2*	*anthcode3*	*anthcode4*

15. Name of Supervisor: *supname*

____

16. Code of Supervisor:

Signature of Supervisor to confirm transcription: _____________/Date:

Signature of Supervisor to confirm question-naire is complete:_____________/Date:

____

INDEX

Section Number	Section Name	Page Numbers	Check Box	Demographic characteristics of respondents (*)	Comments
1	Household Roster	7-16		All individuals	
2	Household Services	17-18		Household	
3	Food Spending and Consumption	19-20		Household	
4	Non-Food Spending and Assets	21-27		Household	
5	Remittances	28-31		Household	
6	Household Income from Non-Employment Sources	32-33		Household	
7	Economic Shocks	34-35		Household	
8	Agriculture	36-48		Best informed person	
9	Employment	49-59		16 years and older/ **Aged between 24-30**	
10	Health	60-64		**All/Women 15-49/ Core**	
11	Social Capital and Trust	65-68		**Core**	
12	Children	69-73		**Parental Care Giver**	
13	Tests of Learning and Anthropometry	74-77		**Aged 7, 8 and 9 / 6 months to 11 years**	

NOTE: Grey shaded section must be done during the first visit, and then interview must then be stopped. An appointment has to be made for a time when the selected members will be present, and the personal codes must be transcribed and checked by the supervisor

(*) Respondents in **bold** must be present during the interview in each section

Section 1: Household Roster - MAIN

Section 1.1: Household Members as Listed in the 1993 and 1998 Surveys

COMPLETE QUESTIONS FOR ALL PRE-PRINTED PERSONS

Relationship Code **Question 3**	**Activity Code** **Question N5**
1 = Resident Head	1 = Regular employment
2 = Absent Head	2 = Casual employment
3 = Wife or husband or partner of head	3 = Self-employed
4 = Son or daughter of head	4 = Housewife/Child rearing
5 = Father or mother of head	5 = Unemployed
6 = Grandchild of head	6 = Formal education/school /university /college
7 = Grandparent of head	7 = Crèche
18 = Great-grandchild of head	8 = Retired/Pensioner
8 = Mother- or father-in-law of head	9 = Other
9 = Son- or daughter-in-law of head	
10 = Brother- or sister-in-law of head	
12 = Brother or sister of head	
13 = Nephew or niece of head	
16 = Household help / herd boy (or relative of)	
17 = Lodger or relative of lodgers	
19 = Other relative	
20 = Other non-relative	
21 = Adopted or Foster child	

TO REMAIN A MEMBER OF THIS HOUSEHOLD (N3=1), AN INDIVIDUAL MUST HAVE:

(i) Lived under this "roof" or within the same compound/homestead/stand **15 days or more** out of the past year
(ii) Share food from a common source when they are here, and
(iii) Share in or contribute to a common resource pool

Section 1.1: Household Members as Listed in 1993 and 1998 Survey (Continued)

	Core (C) or child of core (K)	**Name**	**Person Code**	**3. What is [..]'s relationship to the person identified as household head in 1993?** **Relationship Code**	**4. Sex** **Male ..1 Female..2**	**N1. Is [..] alive?** **No..2 → GO TO NEXT PERSON** **Yes No**	**N3. Has [..] lived under this roof for more than 15 days *in the last year*? No..2 → GO TO NEXT PERSON** **Yes No**	**5. What is […] age in years today?** **Years**	**Q2. Date of birth ASK TO SEE DOCUMENTS. PROBE FOR MONTH, ESTIMATE FROM SEASON IF NECESSARY** **DD/MM/YY**	**N5. What is [..]'s *main* activity?** **PROMPT FROM** **Activity Code**	**12. Has [..] lived under this roof for more than 15 days *in the last month*?** **Yes No**
A	*cores*		*pcode*	*relhd93*	*gender*	*alive98*	*lived*	*age*	*dob_9398*	*activity*	*resident*
B					**1 2**	**1 2**	**1 2**		/ /		**1 2**
C					**1 2**	**1 2**	**1 2**		/ /		**1 2**
D					**1 2**	**1 2**	**1 2**		/ /		**1 2**
E					**1 2**	**1 2**	**1 2**		/ /		**1 2**
F					**1 2**	**1 2**	**1 2**		/ /		**1 2**
G					**1 2**	**1 2**	**1 2**		/ /		**1 2**
H					**1 2**	**1 2**	**1 2**		/ /		**1 2**
I					**1 2**	**1 2**	**1 2**		/ /		**1 2**
J					**1 2**	**1 2**	**1 2**		/ /		**1 2**
K					**1 2**	**1 2**	**1 2**		/ /		**1 2**
L					**1 2**	**1 2**	**1 2**		/ /		**1 2**

PASTE SECOND PAGE OF SECTION 1.1 HERE (IF THERE IS ONE)

BEFORE GOING TO SECTION 1.2:

1. **CIRCLE THE NAMES ON <u>HOUSEHOLD CARD</u> OF EVERYONE WHO ANSWERED YES=1 TO 12**
2. **COPY CURRENT AGES OF ALL PEOPLE ONTO HOUSEHOLD CARD**

Section 1.2: New Household Members

Relationship Code - Question 3	Activity Code - Question N5
1 = Resident Head 2 = Absent Head 3 = Wife or husband or partner of head 4 = Son or daughter of head 5 = Father or mother of head 6 = Grandchild of head 7 = Grandparent of head 18 = Great-grandchild of head 8 = Mother- or father-in-law of head 9 = Son- or daughter-in-law of head 10 = Brother- or sister-in-law of head 12 = Brother or sister of head 13 = Nephew or niece of head 16 = Household help / herd boy (or relative of) 17 = Lodger or relative of lodgers 19 = Other relative 20 = Other non-relative 21 = Adopted or Foster child	1 = Regular employment 2 = Casual employment 3 = Self-employed 4 = Housewife/Child rearing 5 = Unemployed 6 = Formal education/school/university/college 7 = Crèche 8 = Retired/Pensioner 9 = Other

READ ALOUD THE FOLLOWING AND LIST ALL NEW PEOPLE WHO MEET <u>ALL THREE</u> CRITERIA IN TABLE ON NEXT PAGE: Are there any people we have not already talked about who …

(i) Live under this "roof" or within the same compound/homestead/stand **15 days or more** out of the past year
(ii) Share food from a common source when they are here, and
(iii) Share in or contribute to a common resource pool

Section 1.2: New Household Members (Continued)

	2. Person's Name	1. Person Code	3. What is [..]'s relationship to [___________]? (HOUSEHOLD HEAD IN 1993) Relationship Code	4. Sex Male…..… 1 Female… …2	Q1. What is […] age in years today? Years	Q2. Date of birth ASK TO SEE DOCUMENTS. PROBE FOR MONTH, ESTIMATE FROM SEASON IF NECESSARY DD/MM/YY	N5. What is [..]'s *main* activity? PROMPT FROM Activity Code	12. Has [..] lived under this roof for more than 15 days *out of the last 30 days*? Yes No
A		*pcode*	*rhd93_04*	*gender04*	*age04*	*dob04*	*activit04*	*reside04*
B		**101**		**1 2**		/ /		**1 2**
C		**102**		**1 2**		/ /		**1 2**
D		**103**		**1 2**		/ /		**1 2**
E		**104**		**1 2**		/ /		**1 2**
F		**105**		**1 2**		/ /		**1 2**
G		**106**		**1 2**		/ /		**1 2**
H		**107**		**1 2**		/ /		**1 2**
J		**108**		**1 2**		/ /		**1 2**
I		**109**		**1 2**		/ /		**1 2**
J		**110**		**1 2**		/ /		**1 2**
K		**111**		**1 2**		/ /		**1 2**

BEFORE GOING TO SECTION 1.3:

1. **COPY THE NAMES, PERSON CODES, SEX, AND AGE FROM ABOVE TABLE TO HOUSEHOLD CARD**
2. **CIRCLE ALL NEW PEOPLE ON HOUSEHOLD CARD WHO ANSWERED YES=1 TO QUESTION 12**

Section 1.3: Deaths of Household Members

CHECK SECTION 1.1 - COPY THE PERSON CODE OF EVERY HOUSEHOLD MEMBER WHO HAS DIED SINCE 1998 (QUESTION N1 = 2) IN THE TABLE BELOW.

	Person Code of dead person **PERS ON CODE**	**Q1.** **When did [..] die?** **PROBE FOR MONTH; ESTIMATE IF NECESS-ARY. IF [..] DIED IN 2004, GO TO <u>NEXT DEAD PERSON</u>** **Month/Year**	**Q2.** **Did [..] die as the result of an injury (an accident or act of violence)?** **Yes No**	**Q3.** **For how long before dying was [..] too sick or injured to do what he or she normally did?** **IF LESS THAN 1 MONTH, WRITE 0, THEN → GO TO Q8** **Months**	**Q4.** **Which household member's usual activites were most limited by caring for […]?** **IF NO ONE WRITE 00 WRITE IN ONE PERSON CODE** **PERSON CODE**	**Q5a.** **During the illness or injury, did anyone in this household take time off work or school to care for […]?** **Yes No**	**Q5b.** **Who took time off work or school to care for [..}?** **WRITE IN PERSON CODE**	**Q6.** **Has anybody outside this household come to care for [..]? (e.g. Friends, neighours, other family members?** **Yes No**	**Q7.** **Was […] visited by a community health worker/ someone from a home based care programme ?** **Yes No**	**Q8.** **Who, if anyone, was <u>last</u> consulted about this illness or injury?** **WRITE CARE CODE** **IF CARE CODE = 3 OR MORE → Q10**	**Q9.** **Why was no health care provider consulted about [..]'s illness or injury?** **WRITE NON-USE CODE**	**Q10.** **Was […] covered by their own or another household member's medical aid?** **Yes No**
A	*pcode*	*die_date*	*dieinj_yn*	*die_time*	*dec_care*	*care_off*	*caregiv*	*care_out*	*care_wkr*	*care_cons*	*nocons*	*aid*
B		/	**1 2**			**1 2**		**1 2**	**1 2**			**1 2**
C		/	**1 2**			**1 2**		**1 2**	**1 2**			**1 2**
D		/	**1 2**			**1 2**		**1 2**	**1 2**			**1 2**
E		/	**1 2**			**1 2**		**1 2**	**1 2**			**1 2**

CARE CODE Question Q8		**NON-USE CODE Question Q9**	
1 = No-one	3 = Private doctor	1 = No need / pointless	2 = Sick person too busy
4 = Traditional healer (faith healer /sangoma/herbalist)	5 = Community Health Centre/Government Clinic /Mobile Clinic	3 = No-one available to go with him/her	4 = Health facility too far away
6 = Government/ Public Hospital	7 = Visit by Primary (Community) Health Worker	5 = Shortage of money for transport	6 = Shortage of money for consultation or medicines
8 = Pharmacy/Chemist	11 = Other (Specify)	7 = Queues / waits too long	8 = Staff unhelpful or lack skills to help
10 = Private Nurse	13 = Private Clinic or Private Hospital	9 = No medicines available at facility	10 = Could not decide what to do
12 = Workplace Clinic	14 = Someone from a home-based care programme	11 = Religious reason	12 = Fear / embarrasment
		13 = Other (Specify)	14 = Don't know

Section 1.3: Deaths of Household Members (Continued)

COPY FROM PREVIOUS PAGE THE PERSON CODE OF DEAD PERSON..

	Person Code of dead person **PERSON CODE**	Q11. Did […] receive a government grant before he/she died? **IF YES, WRITE GRANT CODE IF NO WRITE 0**	**Q12. How much in total did this household spend in order to bury [….] and on memorial service?** **RAND**	**Q13. How much of the burial costs was paid by a burial insurance / society or stokvel?** **RAND**	**Q14.** **How much in total was spent on health care for [..] <u>during the course of their illness/injury</u>?** **IF NOTHING, WRITE 00**					**Q15.** **How much of <u>these</u> health care, funeral and other expenses was paid from each of the following sources?** **IF NOTHING, WRITE 0**			
					Medicine **RAND**	**Travel (include cost for person who may have accompanied)** **RAND**	**Health care providers** **RAND**	**Hospital or clinic accommodation (including admission fees)** **RAND**	**Other (eg. Special food, telephone costs)** **RAND**	**Household savings or sale of household assets** **RAND**	**Gifts from family, friends or Community (eg. Church)** **RAND**	**Loans from family, friends or community** **RAND**	**Loans from a money lender, stokvel or bank** **RAND**
A	*pcode*	*grant*	*bury_c*	*bury_ins*	*med_c*	*travel_c*	*prov_c*	*hosp_c*	*other_c*	*savings*	*gifts*	*loans_f*	*loans_b*
B													
C													
D													
E													

GRANT CODE Question Q11

1 = Old Age Pension
2 = Disability Grant (over 18 years)
3 = Care Dependency Grant (under 18 years)
4 = Foster Care Grant
5 = Child Support Grant
6 = Multiple grants
7 = Other grant, type unknown
8 = Don’t know

Section 10: Health

Section 10.1: Health of All Resident Household Members

Think about the **last 15 days**. Has **any resident household member (CIRCLED ON HOUSEHOLD CARD)** been sick or injured during the past **15 days**? This includes both people who have now recovered and those with some form of permanent injury, disability, or illness.

Yes .... 1 *ill_yn*

LIST THE PERSON CODE OF EACH PERSON WHO HAS BEEN SICK OR INJURED IN THE LAST 15 DAYS ON NEXT TWO PAGES, THEN PROMPT: Anybody Else?

No 2

PROMPT FROM THE LIST OF ILLNESSES: For example, has anyone living in the household been sick with any of the following illnesses or with anything similar?

ILLNESSES	
Flu **High blood pressure** **Asthma** **Fever** **Diabetes** **TB**	**Disabled by a stroke** **Diarrhoea** **Mental disability** **Physical disability (e.g. blindness)** **Injury** **Other**

IF NO RESIDENT HOUSEHOLD MEMBERS SICK OR INJURED DURING THE LAST 15 DAYS → GO TO SECTION 10.2

Section 10.1: Health of All Resident Household Members (Continued)

	Person Code of sick or injured person PERSON CODE	**N1. Is [..] still sick or injured? Yes No**	**Q1. Is/Was […] injured (as the result of an accident or act of violence)? Yes No**	**Q2. How long has [..] been unable to do what he/she normally does because of this illness or injury? IF DID NOT LIMIT USUAL ACTIVI-TIES WRITE 0 / 0 Days/Months**	**Q3. Which household member's usual activities have been most limited by caring for […]? IF NO ONE CODE 00 WRITE ONE PERSON CODE PERSON CODE**	**Q4a. Has anyone in this household taken time off work or school to care for […]? Yes No**	**Q4b. Who took time off work or school to care for [..] WRITE IN PERSON CODE**	**Q5. Has anybody outside this household come to care for [..]? (e.g. Friends, neighours, other family members)? Yes No**	**Q6. Has […] been visited by a community health worker / someone from a home based care programme ? Yes No**	**8. Who, if anyone, was <u>last</u> consulted about this illness or injury? WRITE CARE CODE IF CARE CODE = 3 OR MORE → Q8**	**Q7. Why was no health care provider consulted about [..]'s illness or injury? WRITE NON-USE CODE**	**Q8. Is […] covered by their own or another household member's medical aid? → GO TO NEXT PAGE Yes No**
A	*pcode*	*sick*	*sic_acc*	*sic_time*	*sic_care*	*care_of2*	*caregiv2*	*care_ou2*	*care_wr2*	*care_con2*	*nocons2*	*aid2*
B		1 2	1 2	/		1 2		1 2	1 2			1 2
C		1 2	1 2	/		1 2		1 2	1 2			1 2
D		1 2	1 2	/		1 2		1 2	1 2			1 2
E		1 2	1 2	/		1 2		1 2	1 2			1 2

CARE CODE Question 8		**NON-USE CODE Question Q7**	
1 = No-one	3 = Private doctor	1 = No need / pointless	2 = Sick person too busy
4 = Traditional healer (faith healer/sangoma/herbalist)	5 = Community Health Centre/Government Clinic/Mobile Clinic	3 = No-one available to go with him/her	4 = Health facility too far away
6 = Government/ Public Hospital	7 = Visit by Primary (Community) Health Worker	5 = Shortage of money for transport	6 = Shortage of money for consultation or medicines
8 = Pharmacy/Chemist	11 = Other (Specify)	7 = Queues / waits too long	8 = Staff unhelpful or lack skills to help
10 = Private Nurse	13 = Private Clinic or Private Hospital	9 = No medicines available at facility	10 = Could not decide what to do
12 = Workplace Clinic	14 = Someone from a home based care programme	11 = Religious reason	12 = Fear / embarrasment
		13 = Other (Specify)	14 = Don't know

	Person Code of sick or injured person **PERSON CODE**	**9c.** **How much in total has been spent on health care for [..] in the last 15 days?** **IF NOTHING, WRITE 0**					**Q9. How much of these health care and other expenses was paid from each of the following sources?** **IF NOTHING, WRITE 0**			
		Medicine **RAND**	**Travel (include cost for person who may have accompanied)** **RAND**	**Health care providers** **RAND**	**Hospital or clinic accommodation (including admission fees)** **RAND**	Other (eg. Special food, telephone costs) **RAND**	**Household savings or sale of household assets** **RAND**	**Gifts from family, friends or community (eg. Church)** **RAND**	**Loans from family, friends or community** **RAND**	**Loans from a money lender or bank** **RAND**
A	*pcode*	*med_exp*	*trav_exp*	*care_exp*	*hosp_exp*	*oth_exp*	*savings*	*gifts*	*loans_f*	*loans_b*
B										
C										
D										
E										

SECTION 10.1 MAIN RESPONDENT PERSON CODE	

APPENDIX H – DAILY TIME SPENT PER CARE ACTIVITY BY HOUSEHOLD MEMBERS (MINUTES)

Care activity	Yengwa	Sibiyo	Khubona	Luthuli	Mfeka	Mncube	Thwala	Cibane	Mngadi	Mbongeni	Ngidi-S	Ngidi-Z	Ndaba	Madondo	Shibe	Tembe	Dladla
Personal care																	
Bathing/washing	131.3	60.0	19.5	0.7	0.0	60.0	120.0	40.0	90.0	67.5	45.0	45.0	78.8	40.0	0.0	60.0	30.0
Dressing	12.5	30.0	4.0	0.0	20.0	6.0	20.0	4.0	20.0	123.8	30.0	25.0	135.0	20.0	0.0	22.5	5.0
Undressing	12.5	15.0	4.0	0.0	20.0	5.0	20.0	8.0	20.0	92.8	25.0	25.0	135.0	20.0	0.0	22.5	5.0
Toileting																	
Helping to go to & from toilet	15.0	12.0	0.0	3.4	8.0	0.0	112.5	30.0	15.0	0.0	0.0	75.0	0.0	10.0	0.0	90.0	21.6
Helping to use toilet	5.0	10.0	0.0	0.8	12.0	0.0	0.0	15.0	15.0	0.0	0.0	50.0	0.0	10.0	0.0	45.0	12.1
Helping to use bucket/bedpan	0.0	1.4	0.0	4.0	3.0	0.0	0.0	18.8	64.0	112.5	60.0	35.0	30.0	6.0	0.0	8.0	0.0
Emptying bucket/bedpan	9.0	1.4	15.0	9.6	4.8	6.0	4.8	12.0	19.2	12.0	9.6	9.6	4.8	9.6	0.0	19.2	0.0
Wetting/soiling																	
Putting on & taking off plastic (sheeting)	1.8	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	30.0	0.5	0.0	0.0	0.0	0.0	0.0	0.0
Buying plastic (sheeting)	0.6	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Changing towel	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	33.8	0.0	0.0	0.0	0.0
Medication/rubbing/applying dressings																	
Giving medication	10.0	1.0	9.0	12.9	6.0	4.0	4.5	4.0	30.0	60.0	25.0	37.5	13.3	9.0	0.0	30.0	15.0
Rubbing/massaging	40.0	10.0	26.3	0.0	40.0	0.0	30.0	50.0	30.0	90.0	0.0	33.0	40.0	10.0	30.0	5.0	0.0
Buying ointment	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.7	0.0	0.0
Drinking/eating																	
Preparing drink, giving to drink	0.0	0.0	0.0	5.6	9.0	9.0	0.0	3.8	0.0	20.0	0.0	0.0	0.0	0.0	11.5	0.0	36.7
Preparing food, giving to eat	0.0	0.0	0.0	0.0	20.0	60.0	0.0	22.5	0.0	0.0	0.0	0.0	0.0	0.0	38.4	0.0	180.0
Preparing drink, helping to drink	15.0	0.0	2.0	0.0	0.0	0.0	22.5	0.0	4.0	0.0	22.5	22.5	60.0	50.0	0.0	60.0	0.0
Preparing food, helping to eat	202.5	120.0	0.0	0.0	0.0	0.0	180.0	0.0	132.0	135.0	25.0	15.0	101.3	80.0	0.0	60.0	0.0
Buying special food/drink	2.7	0.0	16.0	4.4	7.0	6.0	0.0	2.0	0.0	1.1	0.0	0.0	0.8	0.0	0.0	0.0	0.0
Preparing special food/drink	45.6	40.0	22.0	30.0	0.0	30.0	60.0	30.0	16.0	21.3	0.0	0.0	2.1	180.0	0.0	5.0	0.0
Movement																	
Helping to get in & out of bed	40.0	4.0	0.0	0.0	30.0	15.0	20.0	10.0	15.6	60.0	75.0	0.0	50.6	80.0	0.0	5.2	7.0
Helping to turn/move in bed	50.0	50.0	0.0	0.0	0.0	15.0	50.0	10.5	33.2	225.0	225.0	0.0	450.0	60.0	0.0	8.3	0.0
Helping to walk inside	0.0	0.0	0.0	0.0	0.0	0.0	6.0	0.0	0.0	160.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Helping to walk outside	40.0	0.0	0.0	8.6	0.0	0.0	60.0	60.0	0.0	160.0	0.0	13.5	0.0	0.0	0.0	0.0	0.0
Helping to get into/out of a chair on/off a mat	32.0	20.0	0.0	0.0	15.0	0.0	20.0	0.0	0.0	16.8	0.0	10.0	62.5	0.0	0.0	0.0	0.0

Care activity	Yengwa	Sibiyo	Khubona	Luthuli	Mfeka	Mncube	Thwala	Cibane	Mngadi	Mbongeni	Ngidi-S	Ngidi-Z	Ndaba	Madondo	Shibe	Tembe	Dladla
Laundry																	
Putting linen on & taking off bed	30.0	15.0	2.0	0.2	20.0	0.3	0.3	0.1	8.6	30.0	10.0	10.0	2.1	20.0	25.0	5.0	1.0
Washing linen	19.3	0.0	19.3	19.3	4.3	19.3	19.3	19.3	19.4	15.0	19.3	19.3	19.3	40.0	19.3	12.9	19.3
Hanging linen	7.9	0.0	7.9	7.9	2.1	7.9	7.9	7.9	8.0	13.1	7.9	7.9	7.9	10.0	7.9	2.1	7.9
Folding/ironing linen	5.2	0.0	5.2	5.2	1.4	5.2	5.2	5.2	5.2	7.6	5.2	5.2	5.2	5.0	5.2	4.3	5.2
Washing clothes	29.6	0.0	29.6	29.6	29.6	29.6	29.6	29.6	29.6	39.2	29.6	29.6	25.0	11.4	29.6	17.1	29.6
Hanging clothes	12.3	0.0	12.3	12.3	12.3	12.3	12.3	12.3	12.4	19.6	12.3	12.3	11.9	2.9	12.3	2.1	12.3
Folding/ironing clothes	12.0	0.0	12.0	12.0	12.0	12.0	12.0	12.0	12.0	17.4	12.0	12.0	16.7	1.4	12.0	4.3	12.0
Washing linen & clothes	0.0	42.9	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Hanging linen & clothes	0.0	8.6	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Folding/ironing linen & clothes	0.0	2.9	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Going with … to health facility																	
Travelling to & from & waiting at hospital	0.0	11.4	0.0	1.6	0.0	16.0	8.0	5.0	61.4	3.2	10.3	8.0	4.3	8.7	0.0	12.5	12.5
Travelling to & from & waiting at clinic	0.0	0.0	0.0	4.8	0.0	13.5	0.0	231.4	0.0	1.6	19.3	7.7	1.0	0.0	0.0	0.0	2.9
Travelling to & from & waiting at pvt doctor	0.0	0.0	0.0	0.0	0.0	3.0	0.4	0.4	9.4	4.7	7.3	3.2	1.1	6.0	0.0	0.0	0.0
Travelling to & from & waiting at trad healer	0.0	0.0	0.0	7.0	0.0	0.0	0.0	1.6	10.8	0.9	13.3	0.0	0.0	0.0	0.0	0.0	0.7
Going for … to health facility																	0.0
Travelling to & from & waiting at hospital	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	1.0	0.0	0.0	0.0	0.0
Travelling to & from & waiting at clinic	0.0	0.0	0.0	0.0	0.0	0.0	0.0	3.7	0.0	2.3	17.0	0.0	0.6	0.0	0.0	0.0	0.0
Travelling to & from & waiting at trad healer	0.0	11.4	0.0	0.0	4.6	0.0	0.0	2.1	0.0	1.9	11.0	0.0	3.3	0.0	0.0	0.0	0.0
Oral medication																	
Going to & from & waiting at pharmacy	0.0	0.0	0.0	0.0	4.1	0.0	0.0	0.0	2.3	0.3	0.0	0.0	4.0	0.0	0.0	0.0	4.0
Going to & from & waiting at supermarket	0.4	0.0	0.0	0.0	0.0	0.0	14.3	0.0	0.0	0.0	9.2	4.4	0.0	0.0	0.0	0.0	0.0
Going to & from & waiting at traditional healer	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.5	0.0	0.0	0.0	0.0	0.0	0.0	0.0	2.0
Going to & from & waiting at clinic	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	5.0
Going to & from & waiting at pvt doctor	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	4.3	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Going to & from & waiting at salesperson	0.0	0.0	0.8	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Non-oral medication																	
Going to & from & waiting at pharmacy	0.0	0.0	0.0	0.0	0.0	1.1	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Going to & from & waiting at supermarket	0.0	0.0	1.1	0.0	0.0	0.0	0.0	1.9	0.0	0.0	0.0	2.1	0.0	0.0	0.0	0.0	0.0
All care activities	782.2	467.0	208.0	179.9	285.2	336.2	839.6	653.1	683.6	1,548.9	726.3	517.8	1,301.4	690.0	191.9	501.0	426.8

APPENDIX I – SOUTH AFRICAN STANDARD CLASSIFICATION OF OCCUPATIONS CODES USED IN THIS RESEARCH

Note: bold headings in quotation marks are the South African Standard Classification of Occupations code names given in the September 2004 LFS; the professions listed are those that fall under each code name

2230 – "Nursing and midwifery professionals"
Matron
Nursing administrator
Manager/head nurse, nursing services
Nurse, professional
Nurse, professional, supervisory
Nurse, professional, clinic
Nurse, professional, district
Nurse, community
Officer, principal nursing, professional
Sister, nursing, professional
Nurse, operating theatre
Nurse, professional, anaesthetics
Nurse, professional, maternity
Nurse, professional, obstetrics
Nurse, professional, orthopaedic
Nurse, professional, pediatric
Nurse, professional, psychiatric
Health visitor
Nurse, professional, industrial
Nurse, professional, occupational health
Nurse, professional, consultative
Nurse, professional, school
Nurse, professional nec
Midwife, professional
Midwife, professional, district

3241 – "Traditional medicine practitioners"
Healer, drugless treatment
Healer, herbal
Healer, village
Naturopath
Muti seller
Sangoma

3416 – “Buyers”
Buyer
Buyer, merchandise, retail trade
Buyer, merchandise, wholesale trade
Purchaser, merchandise
Purchaser, merchandise, retail trade
Purchaser, merchandise, wholesale trade
Agent, procurement
Agent, purchasing
Buyer, supplies
Distributor
Merchandiser

5121 – “Housekeepers and related workers”
Housekeeper
Housekeeper, executive
Matron, housekeeping
Butler
Warden, camp
Warden, dormitory
Letter room
Landlady
Landlord
Taking in boarders/lodgers

5122 – “Cooks”
Chef de cuisine
Cook, head
Cook
Cook, restaurant
Cook, vegetable
Cook, ship
Cook, ship, mess
Cook, special diets
Cook, work camp
Cook, preserving

5123 – “Waiters, waitresses and bartenders”
Steward, mess
Steward, ship, dining saloon
Stewardess, mess
Stewardess, ship, dining saloon
Waiter
Waiter, railway dining car
Waitress

Waitress, railway dining car
Maître d’hôtel
Waiter, head
Waitress, head
Steward, ship, mess
Stewardess, ship, mess
Waiter, banquet
Waiter, formal
Waitress, banquet
Waitress, formal
Steward, wine
Stewardess, ship, wine
Waiter, wine
Waitress, wine
Bartender
Attendant, canteen
Attendant, restaurant seating
Chief steward, hotel
Chief stewardess, hotel
Steward, hotel
Steward, house
Stewardess, hotel
Stewardess, house

5131 – “Personal care of children and babies”
Attendant, schoolchildren
Assistant, child-care centre
Governess, children
Nanny
Nursemaid
Supervisor, nursery school
Daymother/baby minder

5132 – “Institution-based personal care worker”
Aid, dental
Aid, nursing, clinic
Aid, nursing, hospital
Assistant, nursing
Attendant, dental
Attendant, hospital
Attendant, nursing (except home)
Orderly
Ambulance man
Ambulance woman
Attendant, first-aid

5133 – “Home-based personal care worker”
Aid, nursing, home
Attendant, nursing, home

5139 – “Personal care and related workers not elsewhere classified”
Aid, pharmacy
Aid, veterinary
Health workers
Health, welfare and related services occupations not elsewhere classified

5230 – “Stall and market salespersons”
Salesperson, kiosk
Salesperson, market
Salesperson, street stall
Spaza shop operator

9131 – “Domestic helpers and cleaners”
Babysitter, private household (not farm)
Charworker, domestic (not farm)
Cleaner, domestic (not farm)
Cook, private household (not farm)
General domestic worker, full-time (not farm)
General domestic worker, day worker, part-time (not farm)
Helper, domestic (not farm)
Houseboy (not farm)
Housemaid (not farm)
Helper, domestic, parlour (not farm)
Helper, kitchen, domestic (not farm)
Domestic worker, private household (not farm)
Babysitter, private household (farm)
Charworker, domestic (farm)
Cleaner, domestic (farm)
Cook, private household (farm)
General domestic worker, full-time (farm)
General domestic worker, day worker, part-time (farm)
Helper, domestic (farm)
Houseboy (farm)
Housemaid (farm)
Helper, domestic, parlour (farm)
Helper, kitchen, domestic (farm)
Domestic worker, private household (farm)

9132 – “Helpers and cleaners in offices, hotels and other establishments”
Helper, kitchen, non-domestic
Chambermaid
Maid, chamber
Charworker, factory
Charworker, hotel
Charworker, office
Charworker, restaurant
Cleaner, hotel
Cleaner, office
Cleaner, restaurant
Cleaner, aircraft
Cleaner, bus
Cleaner, train
Hand, kitchen
Cleaner, factory
Washer, hand, dishes
Kitchen worker/pantry man/tea servant
Teagirl
Worker, businesses/hotels

9133 – “Hand-launderers and pressers”
Maid, linen
Launderer, hand
Washer, hand, laundry
Dry-cleaner, hand
Spotter, dry-cleaning
Ironer, hand
Presser, hand

9151 – “Messengers, package and luggage porters and deliverers”
Deliverer, hand
Messenger
Messenger boy
Messenger girl
Messenger, office
Messenger, telegraph
Post-runner
Runner post
Runner, messages
Deliverer, hand, newspapers
Attendant, lift
Bellboy
Caddie, golf
Cellarman

Cellarwoman
Porter, luggage
Assistant, delivery
Distributor, pamphlet
Pamphlet distributor

9211 – “Farm-hands and labourers”
Pastoralist
Hand, farm
Hand, harvest
Helper, farm
Labourer, farm
Labourer, farm, casual
Labourer, farm, migrant
Labourer, farm, seasonal
Hand, farm, field crops
Labourer, farm, field crops
Hand, farm, cotton picking
Labourer, farm, cotton
Cutter, sugar cane
Hand, harvest, field crops
Labourer, farm, potato digging
Picker, cotton
Hand, farm, citrus fruit
Hand, farm, fruit picking
Hand, harvest, orchard
Picker, fruit
Plucker, tea
Hand, farm, livestock
Stockman, livestock
Stockwoman, livestock
Cowherd
Hand, ranch, cattle
Labourer, cattle station
Stockman, beef cattle
Stockwoman, beef cattle
Hand, ranch, sheep
Stockman, sheep
Stockwoman, sheep
Hand, farm, fur-bearing animals
Cowboy
Cowgirl
Drover, cattle
Groom, stud
Stable lad

Hand, farm, dairy
Hand, farm, milch
Hand, farm, milking
Hand, farm, silk worms
Labourer, roustabout
Gardener

APPENDIX J – FOUR GENERALIST METHOD APPROACHES

Table I: Domestic worker minimum wage assigned to daily unpaid care provision time (generalist method)

Ill person	Rural/urban	Hourly earnings	Hours of UCP per household	Daily earnings
Yengwa	Rural	3.73	13.0	48.49
Sibiyo	Urban	4.60	7.8	35.88
Khubona	Rural	4.11	3.5	14.39
Luthuli	Rural	4.11	3.0	12.33
Mfeka	Urban	4.60	4.8	22.08
Mncube	Rural	3.73	5.6	20.89
Thwala	Rural	3.73	14.0	52.22
Cibane	Rural	3.73	10.9	40.66
Mngadi	Urban	4.60	11.4	52.44
Mbongeni	Rural	3.73	25.8	96.23
Ngidi-Za	Rural	3.73	12.1	45.13
Ngidi-Zi	Rural	3.73	8.6	32.08
Ndaba	Rural	3.73	21.7	80.94
Madondo	Urban	4.60	11.5	52.90
Shibe	Rural	4.11	3.2	13.15
Tembe	Urban	4.60	8.4	38.64
Dladla	Urban	4.60	7.1	32.66

Table II: Domestic helpers and cleaners' earnings rate assigned to daily unpaid care provision time (generalist method)

Ill person	Hours of UCP per household	Daily earnings (median)	Daily earnings (mean)
Yengwa	13.0	44.59	47.58
Sibiyo	7.8	26.75	28.55
Khubona	3.5	12.01	12.81
Luthuli	3.0	10.29	10.98
Mfeka	4.8	16.46	17.57
Mncube	5.6	19.21	20.50
Thwala	14.0	48.02	51.24
Cibane	10.9	37.39	39.89
Mngadi	11.4	39.10	41.72
Mbongeni	25.8	88.49	94.43
Ngidi-Za	12.1	41.50	44.29
Ngidi-Zi	8.6	29.50	31.48
Ndaba	21.7	74.43	79.42
Madondo	11.5	39.45	42.09
Shibe	3.2	10.98	11.71
Tembe	8.4	28.81	30.74
Dladla	7.1	24.35	25.99
Average	10.1	34.78	37.12

Table III: Earnings rate of personal care workers assigned to daily unpaid care provision time (generalist method)

Ill person	Hours of UCP per household	Daily earnings (median)	Daily earnings (mean)
Yengwa	13.0	99.19	148.72
Sibiyo	7.8	59.51	89.23
Khubona	3.5	26.71	40.04
Luthuli	3.0	22.89	34.32
Mfeka	4.8	36.62	54.91
Mncube	5.6	42.73	64.06
Thwala	14.0	106.82	160.16
Cibane	10.9	83.17	124.70
Mngadi	11.4	86.98	130.42
Mbongeni	25.8	196.85	295.15
Ngidi-Za	12.1	92.32	138.42
Ngidi-Zi	8.6	65.62	98.38
Ndaba	21.7	165.57	248.25
Madondo	11.5	87.75	131.56
Shibe	3.2	24.42	36.61
Tembe	8.4	64.09	96.10
Dladla	7.1	54.17	81.22
Average	10.1	77.38	116.02

Table IV: Earnings rate for work similar to domestic work and nursing assistant work assigned to daily unpaid care provision time (generalist method)

Ill person	Hours of UCP per household	Daily earnings (median)	Daily earnings (mean)
Sibiyo	7.8	31.75	66.43
Khubona	3.5	14.25	39.86
Luthuli	3.0	12.21	17.89
Mfeka	4.8	19.54	15.33
Mncube	5.6	22.79	24.53
Thwala	14.0	56.98	28.62
Cibane	10.9	44.36	71.54
Mngadi	11.4	46.40	55.70
Mbongeni	25.8	105.01	58.25
Ngidi-Za	12.1	49.25	131.84
Ngidi-Zi	8.6	35.00	61.83
Ndaba	21.7	88.32	43.95
Madondo	11.5	46.81	110.89
Shibe	3.2	13.02	58.77
Tembe	8.4	34.19	16.35
Dladla	7.1	28.90	42.92
Average	10.1	41.27	36.28

APPENDIX K – CARE TASK CLASSIFICATION (UK TYPOLOGY OF CARE AND GENERALIST METHOD)

Activity	**UK typology of care definition**	**Generalist method, proportionate approach**
Bathing/washing	Help with personal care	Nursing-type work
Dressing	Help with personal care	Nursing-type work
Undressing	Help with personal care	Nursing-type work
Toileting		
Helping to go to toilet	Help with personal care	Nursing-type work
Helping to get to toilet	Physical help	Nursing-type work
Helping to get back from toilet	Physical help	Nursing-type work
Helping to use bucket/bedpan	Help with personal care	Nursing-type work
Emptying bucket/bedpan	Help with personal care	Nursing-type work
Wetting/soiling		
Putting on & taking off nappies	Help with personal care	Nursing-type work
Obtaining/buying nappies	Other practical help	Domestic-type work
Putting on & taking off linen savers	Help with personal care	Nursing-type work
Obtaining/buying linen savers	Other practical help	Domestic-type work
Putting on & taking off plastic (sheeting)	Help with personal care	Nursing-type work
Obtaining/buying plastic (sheeting)	Other practical help	Domestic-type work
Medication/rubbing/applying dressings		
Giving medication	Giving medication	Nursing-type work
Obtaining/buying medication	Other practical help	Domestic-type work
Rubbing/massaging	Giving medication	Nursing-type work
Obtaining/buying ointment	Other practical help	Domestic-type work
Applying dressings	Giving medication	Nursing-type work
Obtaining/buying dressings	Other practical help	Domestic-type work
Drinking/eating		
Helping to drink	Not defined	Nursing-type work

Helping to eat	Not defined	Nursing-type work
Helping to drink/eat special food	Not defined	Nursing-type work
Buying special food/drink	Other practical help	Domestic-type work
Preparing special food/drink	Other practical help	Nursing-type work
Movement		
Helping to get in & out of bed	Physical help	Nursing-type work
Helping to turn/move in bed	Physical help	Nursing-type work
Helping to walk inside	Physical help	Nursing-type work
Helping to walk outside	Physical help	Nursing-type work
Helping to get into/out of a chair	Physical help	Nursing-type work
Helping to get on/off a mat	Physical help	Nursing-type work
Laundry		
Putting linen on & taking linen off bed	Practical help	Domestic-type work
Washing linen	Practical help	Domestic-type work
Hanging linen	Practical help	Domestic-type work
Folding/ironing linen	Practical help	Domestic-type work
Washing clothes	Practical help	Domestic-type work
Hanging clothes	Practical help	Domestic-type work
Folding/ironing clothes	Practical help	Domestic-type work
Going with … to health facility		
Travelling to & from & waiting at the hospital with the ill person	Taking the helped person out	Domestic-type work
Travelling to & from & waiting at the clinic with the ill person	Taking the helped person out	Domestic-type work
Travelling to & from & waiting at the private doctor with the ill person	Taking the helped person out	Domestic-type work
Travelling to & from & waiting at the traditional healer with the ill person	Taking the helped person out	Domestic-type work
Going for … to health facility		
Travelling to & from & waiting at the hospital for the ill person	Other practical help	Domestic-type work
Travelling to & from &	Other practical help	Domestic-type work

waiting at the clinic for the ill person		
Travelling to & from & waiting at the private doctor for the ill person	Other practical help	Domestic-type work
Travelling to & from & waiting at the traditional healer for the ill person	Other practical help	Domestic-type work
Obtaining oral medication		
Going to & from & waiting at the pharmacy for oral medication	Other practical help	Domestic-type work
Going to & from & waiting at the supermarket/ spaza for oral medication	Other practical help	Domestic-type work
Going to & from & waiting at the traditional healer for oral medication	Other practical help	Domestic-type work
Going to & from & waiting at the hospital for oral medication	Other practical help	Domestic-type work
Going to & from & waiting at the private doctor for oral medication	Other practical help	Domestic-type work
Going to & from & waiting at the clinic for oral medication	Other practical help	Domestic-type work
Obtaining non-oral medication		
Going to & from & waiting at the pharmacy for non-oral medication	Other practical help	Domestic-type work
Going to & from & waiting at the supermarket/ spaza for non-oral medication	Other practical help	Domestic-type work
Going to & from & waiting at the traditional healer for non-oral medication	Other practical help	Domestic-type work
Going to & from & waiting at the hospital for non-oral medication	Other practical help	Domestic-type work
Going to & from & waiting at the private doctor for non-oral medication	Other practical help	Domestic-type work
Going to & from & waiting at the clinic for non-oral	Other practical help	Domestic-type work

medication		

APPENDIX L – CARE TASK CLASSIFICATION (SPECIALIST METHOD)

Activity	**South African Standard Classification of Occupations code**
Personal care	
Bathing/washing	Nursing and midwifery professionals (2230)
Dressing	Nursing and midwifery professionals (2230)
Undressing	Nursing and midwifery professionals (2230)
Toileting	
Helping to go to toilet	Nursing and midwifery professionals (2230)
Helping to get to toilet	Nursing and midwifery professionals (2230)
Helping to get back from toilet	Nursing and midwifery professionals (2230)
Helping to use bucket/bedpan etc.	Nursing and midwifery professionals (2230)
Emptying bucket/bedpan etc.	Nursing and midwifery professionals (2230)
Wetting/soiling	
Putting on & taking off nappies	Nursing and midwifery professionals (2230)
Buying nappies	Buyers (3416)
Putting on & taking off linen savers	Nursing and midwifery professionals (2230)
Buying linen savers	Buyers (3416)
Putting on & taking off plastic (sheeting)	Nursing and midwifery professionals (2230)
Buying plastic sheeting	Buyers (3416)
Medication/rubbing/applying dressings	
Giving medication	Nursing and midwifery professionals (2230)
Obtaining/buying medication	Buyers (3416)
Rubbing/massaging	Nursing and midwifery professionals (2230)
Obtaining/buying ointment	Buyers (3416)
Applying dressings	Nursing and midwifery professionals (2230)
Obtaining/buying dressings	Buyers (3416)
Drinking/eating	
Preparing drink & helping ill person to drink	Nursing and midwifery professionals (2230)
Preparing drink & giving drink to ill person	Nursing and midwifery professionals (2230)
Preparing drink, giving drink to ill person & watching ill person drink	Nursing and midwifery professionals (2230)
Preparing food & helping ill person to eat	Nursing and midwifery professionals (2230)
Preparing food & giving food to ill person	Nursing and midwifery professionals (2230)
Preparing food, giving food to ill	Nursing and midwifery professionals (2230)

person & watching ill person eat	
Buying special food/drink	Buyers (3416)
Preparing special food/drink	Cooks (5122)
Movement	
Helping to get in & out of bed	Nursing and midwifery professionals (2230)
Helping to turn/move in bed	Nursing and midwifery professionals (2230)
Helping to walk inside	Nursing and midwifery professionals (2230)
Helping to walk outside	Nursing and midwifery professionals (2230)
Helping to get into/out of a chair	Nursing and midwifery professionals (2230)
Helping to get on/off a mat	Nursing and midwifery professionals (2230)
Laundry	
Putting linen on & taking linen off bed	Hand launderers and pressers (9133)
Washing linen	Hand launderers and pressers (9133)
Hanging linen	Hand launderers and pressers (9133)
Folding/ironing linen	Hand launderers and pressers (9133)
Washing clothes	Hand launderers and pressers (9133)
Hanging clothes	Hand launderers and pressers (9133)
Folding/ironing clothes	Hand launderers and pressers (9133)
Going with … to health facility	
Travelling to & from & waiting at hospital	Messengers, package and luggage porters and deliverers (9151)
Travelling to & from & waiting at clinic	Messengers, package and luggage porters and deliverers (9151)
Travelling to & from & waiting at private doctor	Messengers, package and luggage porters and deliverers (9151)
Travelling to & from & waiting at traditional healer	Messengers, package and luggage porters and deliverers (9151)
Going for … to health facility	
Travelling to & from & waiting at hospital	Messengers, package and luggage porters and deliverers (9151)
Travelling to & from & waiting at clinic	Messengers, package and luggage porters and deliverers (9151)
Travelling to & from & waiting at private doctor	Messengers, package and luggage porters and deliverers (9151)
Travelling to & from & waiting at traditional healer	Messengers, package and luggage porters and deliverers (9151)
Obtaining oral medication	
Going to & from & waiting at pharmacy	Messengers, package and luggage porters and deliverers (9151)
Going to & from & waiting at supermarket/spaza	Messengers, package and luggage porters and deliverers (9151)
Going to & from & waiting at	Messengers, package and luggage porters and

traditional healer	deliverers (9151)
Going to & from & waiting at hospital	Messengers, package and luggage porters and deliverers (9151)
Going to & from & waiting at private doctor	Messengers, package and luggage porters and deliverers (9151)
Going to & from & waiting at clinic	Messengers, package and luggage porters and deliverers (9151)
Obtaining non-oral medication	
Going to & from & waiting at pharmacy	Messengers, package and luggage porters and deliverers (9151)
Going to & from & waiting at supermarket/spaza	Messengers, package and luggage porters and deliverers (9151)
Going to & from & waiting at traditional healer	Messengers, package and luggage porters and deliverers (9151)
Going to & from & waiting at hospital	Messengers, package and luggage porters and deliverers (9151)
Going to & from & waiting at private doctor	Messengers, package and luggage porters and deliverers (9151)
Going to & from & waiting at clinic	Messengers, package and luggage porters and deliverers (9151)

APPENDIX M – DETAILED COSTED UNPAID CARE PROVISION INFORMATION

Table V: Costed unpaid care provision – average earnings method (employed) (Rands)

Ill person	Cost of UCP time	Financial cost	Total daily cost	Total monthly cost
Yengwa	65.32	32.55	97.87	2,993.83
Sibiyo	35.72	36.25	71.97	2,201.68
Khubona	17.13	14.12	31.25	955.89
Luthuli	16.70	13.48	30.18	923.28
Mfeka	21.98	25.96	47.94	1,466.61
Mncube	25.65	23.36	49.01	1,499.15
Thwala	64.12	14.28	78.40	2,398.26
Cibane	49.92	6.99	56.91	1,740.94
Mngadi	52.21	78.16	130.37	3,988.08
Mbongeni	118.16	63.47	181.63	5,556.18
Ngidi-S	55.42	13.48	68.90	2,107.59
Ngidi-Z	39.39	2.74	42.13	1,288.70
Ndaba	109.16	20.54	129.70	3,967.66
Madondo	57.21	15.04	72.25	2,210.25
Shibe	14.66	2.57	17.23	526.94
Tembe	38.47	11.69	50.16	1,534.46
Dladla	32.52	14.22	46.74	1,429.72

Table VI: Costed unpaid care provision – average earnings method (self-employed) (Rands)

Ill person	Cost of UCP time	Financial cost	Total daily cost	Total monthly cost
Yengwa	49.20	32.55	81.75	2,500.66
Sibiyo	26.75	36.25	63.00	1,927.29
Khubona	12.89	14.12	27.01	826.24
Luthuli	12.65	13.48	26.13	799.31
Mfeka	16.46	25.96	42.42	1,297.75
Mncube	19.21	23.36	42.57	1,302.16
Thwala	48.02	14.28	62.30	1,905.76
Cibane	37.39	6.99	44.38	1,357.49
Mngadi	39.10	78.16	117.26	3,587.04
Mbongeni	88.49	63.47	151.96	4,648.58
Ngidi-S	41.50	13.48	54.98	1,681.93
Ngidi-Z	29.50	2.74	32.24	986.16
Ndaba	82.25	20.54	102.79	3,144.20
Madondo	43.08	15.04	58.12	1,777.93
Shibe	10.98	2.57	13.55	414.37
Tembe	28.81	11.69	40.50	1,238.96
Dladla	24.35	14.22	38.57	1,179.95

Table VII: Costed unpaid care provision – opportunity cost method (education) (Rands)

Ill person	Cost of UCP time	Financial cost	Total cost (daily)	Total cost (monthly)
Yengwa	329.23	32.55	361.78	11,066.86
Sibiyo	602.94	36.25	639.19	19,552.82
Khubona	31.56	14.12	45.68	1,397.43
Luthuli	14.04	13.48	27.52	841.85
Mfeka	218.24	25.96	244.20	7,470.04
Mncube	60.37	23.36	83.73	2,561.24
Thwala	184.68	14.28	198.96	6,086.31
Cibane	112.38	6.99	119.37	3,651.50
Mngadi	962.30	78.16	1040.46	31,827.79
Mbongeni	580.01	63.47	643.48	19,684.05
Ngidi-S	39.93	13.48	53.41	1,633.81
Ngidi-Z	28.38	2.74	31.12	951.96
Ndaba	432.71	20.54	453.25	13,864.86
Madondo	116.45	15.04	131.49	4,022.27
Shibe	125.25	2.57	127.82	3,909.95
Tembe	82.15	11.69	93.84	2,870.63
Dladla	69.44	14.22	83.66	2,559.10

Table VIII: Costed unpaid care provision – opportunity cost method (employment) (Rands)

Average	Cost of UCP time	Financial cost	Total cost (daily)	Total cost (monthly)
Yengwa	33.53	32.55	66.08	2,021.33
Sibiyo	99.66	36.25	135.91	4,157.49
Mncube	10.25	23.36	33.61	1,028.07
Mngadi	12.95	78.16	91.11	2,787.18
Mbongeni	49.29	63.47	112.76	3,449.33
Ngidi-S	38.48	13.48	51.96	1,589.40
Ngidi-Z	27.35	2.74	30.09	920.39
Ndaba	36.57	20.54	57.11	1,746.99
Shibe	5.86	2.57	8.43	257.75

Table IX: Costed unpaid care provision – generalist method (proportionate approach) (Rands)

Ill person	Financial cost	Cost of UCP time (proportionate)	Total cost (proportionate) (daily)	Total cost (proportionate) (monthly)
Yengwa	32.55	91.07	123.62	3,781.54
Sibiyo	36.25	52.93	89.18	2,728.02
Khubona	14.12	19.02	33.14	1,013.75
Luthuli	13.48	15.58	29.06	888.95
Mfeka	25.96	29.45	55.41	1,694.99
Mncube	23.36	33.92	57.28	1,752.20
Thwala	14.28	99.12	113.40	3,468.91
Cibane	6.99	59.64	66.63	2,038.21
Mngadi	78.16	74.34	152.50	4,664.98
Mbongeni	63.47	185.60	249.07	7,619.05
Ndw-Za	13.48	79.50	92.98	2,844.26
Ndw-Zi	2.74	57.33	60.07	1,837.54
Ndaba	20.54	158.19	178.73	5,467.35
Madondo	15.04	80.37	95.41	2,918.59
Shibe	2.57	16.56	19.13	585.19
Tembe	11.69	59.49	71.18	2,177.40
Dladla	14.22	46.27	60.49	1,850.39

Table X: Costed unpaid care provision – specialist method (Rands)

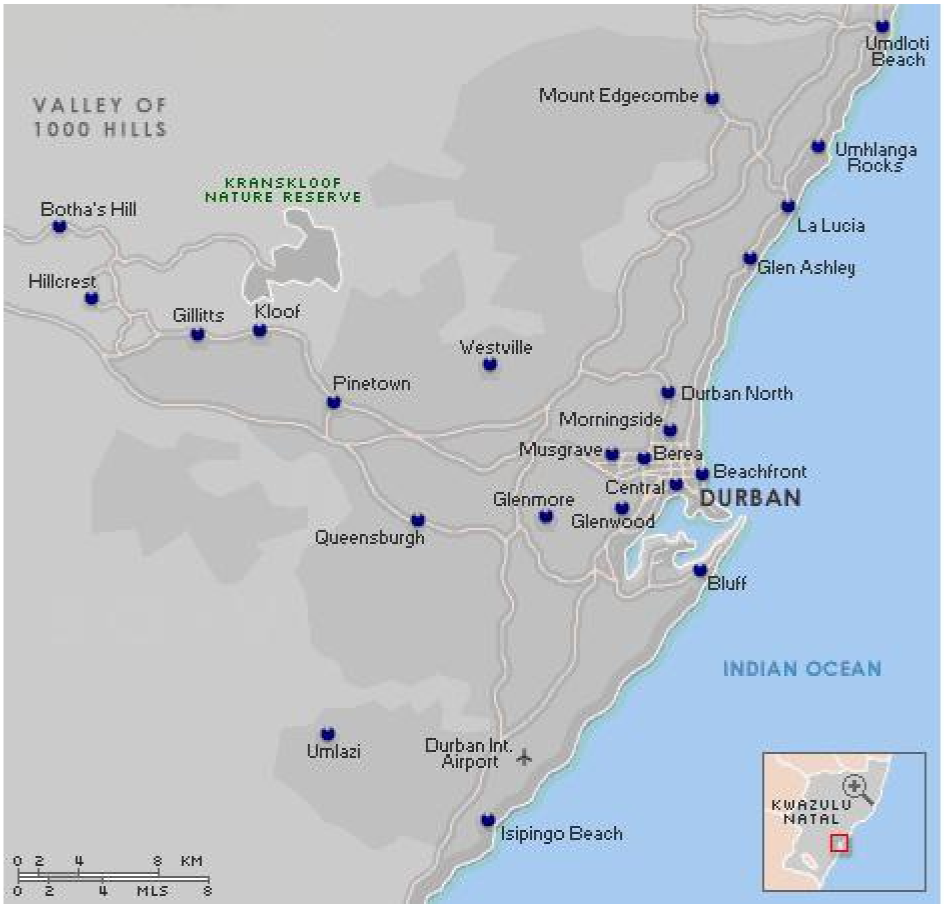
Ill person	Financial cost	Cost of UCP time	Total cost (daily)	Total cost (monthly)
Yengwa	32.55	292.29	324.84	9,936.86
Sibiyo	36.25	162.45	198.70	6,078.23
Khubona	14.12	51.25	65.37	1,999.67
Luthuli	13.48	34.87	48.35	1,479.03
Mfeka	25.96	94.96	120.92	3,698.94
Mncube	23.36	96.89	120.25	3,678.45
Thwala	14.28	315.53	329.81	10,088.89
Cibane	6.99	163.37	170.36	5,211.31
Mngadi	78.16	236.69	314.85	9,631.26
Mbongeni	63.47	627.15	690.62	21,126.07
Ngidi-S	13.48	259.87	273.35	8,361.78
Ngidi-Z	2.74	189.10	191.84	5,868.39
Ndaba	20.54	543.19	563.73	17,244.50
Madondo	15.04	208.46	223.50	6,836.87
Shibe	2.57	47.91	50.48	1,544.18
Tembe	11.69	200.72	212.41	6,497.62
Dladla	14.22	151.02	165.24	5,054.69

APPENDIX N – ECONOMIC COSTS FOR KWA ST VINCENT (2007/2008)

CAPITAL COSTS	**Specific cost**	**Total cost**
Vehicles		**0**
Electronic equipment		**0**
Non-electronic equipment		**3,083**
Built-in cupboards	1,542	
Curtain rail	514	
Fridge	127	
Television	386	
Washing machine	514	
Training, non-recurrent		**0**
Social mobilisation, non-recurrent		**0**
Total capital costs		**3,083**
RECURRENT COSTS		
Personnel		**84,158**
Jean's salary	34,493	
Doris' salary	49,665	
Vehicles operation and maintenance		**0**
Vehicle costs-Recurrent	0	
Buildings operation and maintenance		**16,745**
Curtain hooks	100	
Food-garden maintenance	7,020	
Labour-garden maintenance	2,520	
Labour-installing tiles	667	
Labour-painting	1,800	
Labour-putting up curtain rails	2,500	
Labour-sewing curtains	405	
Paint & polyfilla costs	400	
Tiles	1,333	
Training, recurrent		**0**
Training-Recurrent	0	

Social mobilisation, recurrent		**0**
Social mobilisation, recurrent	0	
Medical supplies		**1,550**
Pharmacy costs (Lions)	300	
Pharmacy donations	1,250	
Food & other supplies		**4,945**
Cost per patient items	2,200	
Food-Winnie and patients	2,515	
Toilet rolls	230	
Other operating inputs		**26,774**
Electricity	1,000	
Fire extinguisher	100	
Gas bottle	711	
Kettle	33	
Rental	24,000	
Shower curtain	100	
Water	800	
Winnie uniform	30	
Total recurrent costs		**60,738**
Total costs		**63,821**
Cost per patient per day (2007/08)		**788**
Cost per patient per day (2004)		**662**

APPENDIX O – MAP OF GREATER DURBAN



Source: http://www.sa-venues.com

APPENDIX P – ECONOMIC COSTS FOR HIGHWAY HOSPICE (2006)

CAPITAL COSTS	**Specific cost**	**Total cost**
Vehicles		**0**
Electronic equipment		**0**
Non-electronic equipment		**1,281**
Equipment costs	1,281	
Training, non-recurrent		**10,255**
Palliative care 2004	1,541	
Orientation 2005	138	
Palliative care 2005	1,976	
Social mobilisation, non-recurrent		**0**
Total capital costs		**11,536**
RECURRENT COSTS		
Personnel		**2,086,071**
Gross salaries proportionately allocated	2,086,071	
Vehicles operation and maintenance	0	**0**
Buildings operation and maintenance		**100,980**
Repairs & maintenance	100,980	
Training, recurrent		**6,600**
Orientation 2006	1,400	
Palliative care 2006	5,200	
Social mobilisation, recurrent		**0**
Medical supplies		**181,643**
Surgical & medical supplies & infection	126,649	

control		
Prescription drugs	54,994	
Food & other supplies		**93,075**
Meals	93,075	
Other operating inputs		**991,641**
Cellphone	0	
Christmas party	550	
Cleaning supplies	8,988	
Conferences & seminars	2,527	
Electricity & water	103,049	
Equipment repairs & maintenance	690	
Fire extinguisher & detectors	2,949	
Insurance	2,197	
M-Net	3,860	
Medical waste removal	375	
Pest control	2,022	
Photocopy	420	
Rental	704,820	
Security alarm/panic	3,538	
Security guard night & day	107,525	
Stationery	283	
Sundries & miscellaneous	16,972	
Telephones	25,402	
Transportation of patients	3,159	
TV licences	2,315	
Total recurrent costs		**3,460,010**
TOTAL COSTS		**3,471,546**
Cost per patient per day (2006)		**1,524**
Cost per patient per day (2004)		**1,397**

APPENDIX Q – ECONOMIC COSTS FOR ISANDLA HOME CARE (2008)

Capital costs

Isandla owns no vehicles, electronic equipment or non-electronic equipment. The training received took place more than three years ago and has therefore exceeded its 'lifespan'. There are no social mobilisation costs.

Recurrent costs

Personnel
Seven volunteer caregivers, none of whom receive any form of compensation work about three hours per week. As of 1 July 2007 the government's starting salary for a junior enrolled nursing assistant is R49,665 per annum. Therefore each hour of volunteer caregiving time is worth R25.87 if this salary is used (7 X 3 X R25.87=R543.27).

Vehicle and building operation and maintenance
No costs.

Training, recurrent
No costs.

Social mobilisation, recurrent
No costs.

Medical, food and other supplies
No costs.

Other operating inputs
Mrs Chonco has a cellphone and she uses about R15.63 per week to make calls.

Total economic costs

For the week of 11 to 15 August 2008 the total cost per contact hour comes to R186.30. This is calculated by adding the cell phone calls per week (R15.63) to the cost of the caregivers' time (R543.27). The total of R558.90 is divided by three hours to arrive at the cost per contact hour.

APPENDIX R – ECONOMIC COSTS FOR KHANYA HOSPICE (2007/08)

CAPITAL COSTS	**Specific cost**	**Total cost**
Vehicles		**132,853**
Ford Ranger double cab, diesel 2005	38,432	
Hyundai Getz 1.4 manual 2006	21,080	
Hyundai Getz 1.4 manual 2006	21,080	
Isuzu KB 220 LE DC 2004	28,535	
Nissan 1400+aircon 2003	9,512	
Thule trailer & tow bar 2006	2,390	
VW Chico 1.4 2003	11,825	
Electronic equipment		**29,054**
Computer A	1,738	
Computer B	3,384	
Computer C	1,806	
Computer D	1,806	
Computer E	2,527	
Colour laser printer	992	
Computer upgrade	808	
Data projector	8,023	
Fax	434	
Laptop	3,846	
Security system upgrade	903	
TV with VCR & DVD	2,786	
Non-electronic equipment		**9,339**
Chairs	316	
Desks	964	
Office furniture	2,299	
Office furniture/fittings	1,338	
Table & chairs for training room	4,422	
Training, non-recurrent		**10,352**
Palliative care 2006	9,324	
Social mobilisation, non-recurrent		**0**
Total capital costs		**181,597**
RECURRENT COSTS		

Personnel		**1,615,007**
Board members' time	135,625	
Director's remuneration	158,985	
DIY volunteer's time	4,800	
Replacements	15,974	
Salaries	1,417,505	
Staff support	4,262	
UIF employer	18,281	
Volunteer caregivers' time	2,484	
Vehicles - operation and maintenance		**167,566**
Travel & warehouse costs	167,566	
Buildings - operation and maintenance		**105,400**
Cleaning	4,755	
Electricity	4,057	
Rental	85,500	
Repairs & maintenance	86,791	
Security	5,508	
Water	4,289	
Training, recurrent		**4,046**
Education and training	4,046	
Palliative care 2007	1,027	
Social mobilisation, recurrent		**0**
Medical supplies		**6,424**
Donated bactrum tablets X10	672	
Medical equipment	40	
Nursing supplies	5,634	
Food and other supplies		**47,204**
Donated food items	43,522	
Groceries	2,932	
Nutritional support	750	
Other operating inputs		**197,935**
Audit & secretarial fees	12,106	
Bank charges	902	
Cellphone costs	28,345	

Functions	1,979	
Hospice Palliative Care Association Annual General Meeting expenses	7,512	
Insurance	68,433	
Loose tools and equipment	3,326	
Phone system costs	2,734	
Photocopy costs	9,270	
Postage	1,563	
Poverty alleviation	3,330	
Printing,stationery&computer expenses	25,834	
Professional fees	8,530	
Subscriptions & fees	2,455	
Telephone	21,391	
TV licence	225	
Total recurrent costs		**2,143,582**
Total costs		**2,325,180**
Cost per contact hour (2007/08)		**903**
Cost per contact hour (2004)		**807**

APPENDIX S – SPECIFIC ASPECTS OF THE 2004 KIDS QUALITATIVE STUDY TO BE AMENDED

To start, the analysis of the KIDS quantitative data set would have been enhanced by an age range for ill people of over 20 and under 50, instead of an age range of over 10 and under 60. This age range means that the possibility of including HIV/AIDS ill and dying people is greater. The age range that was used is not likely to have impacted dramatically upon the likelihood of finding HIV/AIDS ill and dying people in this study though, as the criteria for selection were quite focussed on including these people.

In addition, the amendments applied to the illness periods (see section 6.3.3) should be constructed into a model or design for further work.

It has already been noted, in the previous section, that information on two types of care activities (that is 'keeping an eye' and 'keeping company') should be obtained using a 24-hour diary, since stylized questions did not get at this information well.

With regard to the stylized questions, a survey format was limiting when asking questions. What would be better is a free flowing way of asking and recording information, but with guidelines or something of a checklist. Moreover, there are specific aspects of the stylized questions that should be changed and these are reflected below.

Two personal care tasks appear in the United Kingdom's typology but were not enquired about in the KZN study, namely shaving and cutting nails. Some additional tasks not enquired about are mentioned by Folbre (2006): the time spent cutting the ill person's hair and washing and grooming their hair, as well as time spent cleaning their room. All of these tasks should be included in a typology of care activities for the sake of being comprehensive. Moreover, in future questions on taking the person out for social reasons should also be asked, since this could be undertaken for those being cared for who are not extremely ill.

Finally, some changes could be made to the classification of care activities to bring it in line with the United Kingdom's typology, for comparative purposes. With regard to 'preparing food/drink' and 'helping the person to eat/drink', Parker and Lawton (1990, as cited in G. Parker, 1992, p. 10) classify the former as 'practical help' and the latter as 'personal care'. However, in the qualitative study time spent 'making food/drink' and 'helping the person eat/drink' was recorded together where the food or drink was very simple and quick to prepare. For instance, mixing some juice or pouring water in a glass or mixing porridge mixture with water. Preparation of 'special' food or drink was recorded separately. This classification could be brought in line with that of the United Kingdom's typology if the aim is to compare care activities across countries.

Specific aspects of the stylized questions that should be changed:

- With regard to movement (in and out of bed, onto/off a mat, for example) and going to the toilet and back, including two 'actions' in one was not the best approach since it is far more difficult to estimate time taken for two movements than for one. It is preferable to estimate one 'action' and then double it up.

- Similarly, instead of asking how long it takes to take linen off and put it back on the bed, taking linen off the bed should be asked separately from putting the linen back on the bed.

- In the survey questions a distinction was made between linen and clothes laundry but it is not certain to what extent this is applicable in most of the study households. Because respondents were asked to distinguish between linen and clothes laundry, they could have tried to supply answers to fit in with the study question if they were doing both together. Where the frequency of washing differs for clothes and linen laundry (eg. one is 'every week' the other 'every second week') it could be assumed that they are washed separately. If the frequency is the same (eg. both washed every week) then it could be assumed that they are washed together. In future linen and clothes laundry should be inquired about together, instead of assuming they are separate.

- The time taken to prepare food/drink and the time taken to feed the person should not be recorded together, and rather the two activities should be recorded and counted separately.

- With regard to getting to and from health facilities, information not asked about was the time taken from when the transport to the health facility terminates to getting to the health facility and finding the correct place to wait. Information was also not obtained on the time taken to get from the health facility back to where the transport back home begins. Respondents were asked how long they waited at the health facility. In future this information should be inquired about.

- The question asked about 'laundry washed together' in which was meant 'is the person's laundry washed together with the laundry of other household members' can be (and was in some cases) interpreted to mean clothes and linen laundry being done together. Although this meaning was explained to fieldworkers in the training sessions, it seems there was simply too much information for fieldworkers to remember for the study. In future, the scale of such a study should be limited in order for fieldworkers to be able to focus on getting indepth study data on one theme only but in a thorough fashion.

- As noted in section 6.3.2, the frequency and duration of each care activity was multiplied by the number of people who provided that care activity, and then, if the care activity had not occurred daily, this amount was divided by the relevant unit (e.g. days in the month if it occurred only on one day a month), in order to obtain time spent on that care activity per day. In retrospect it would have been better to calculate this per caregiver as each caregiver would have had different frequency and durations for particular activities. Then a proportionate rate per average day based on the frequency with which it was done could be calculated.

- In section 6.3.5 it was noted that in the Ntini household, some medication was given to Siyanda two times a day, and other medication was given three times a day. Therefore the estimate was taken as the average of the two, that is, 2.5 times a day. In retrospect, there could be different time estimates given for the two different medicines, which was not enquired about. Also, the different medicine applications per day should have been added and not averaged.

- In section 6.3.5 it was noted that where there were inconsistencies an attempt was made to find an average estimate. For example, for the Mbongeni household it says that the ill person was dressed twice a day and undressed 3.5 times a day. The number of times the person was dressed and undressed should be the same as it is only possible to undress and dress one after the other. In this example the average of the two figures was taken, that is, the person was undressed and dressed 2.8 times a day. However, it now seems that one could dress by putting three (for instance) layers on a person, and then undress layer by layer, counting each as a separate undressing, and therefore these dressings and undressings should have been asked about and counted, instead of averaging as was done in this study.

- With regard to counting the time spent doing washing for the ill person, he or she would also have had laundry before being ill, so it probably should not have been calculated at all. In terms of what was counted, it was noted that the average of the time estimates for laundry washing for ill people that was estimated was calculated and added to the time spent caring in households in which the ill person’s washing was done together with the washing of other household members. In retrospect it seems that this should not have been done as the full additional time was not spent.

- Some of the caregiving activities were consistently answered as not having been undertaken and these should probably be excluded from a similar future study in KwaZulu-Natal: using nappies; helping to use a commode; helping to use a urine bottle; applying dressings; helping with policies/membership of an organization; fetching a social grant; visiting the local municipality/traditional authority/church for or with a person.

- The time taken to get to the taxi rank with ill person and the time taken to get to the taxi rank without the ill person should have been included as questions in the care survey.

- Finally, the care survey should be expanded to include additional activities suggested by respondents that were not included in the survey (see section 6.3.4)