

**Lived Experiences of Community Empowerment
Programme Workers Participating in a Community
Empowerment Programme**

by

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Declaration

I declare that this research; lived experiences of community empowerment programme workers participating in a community empowerment programme is my own work.

It is submitted for the Master's degree in Nursing by dissertation at the University of KwaZulu-Natal South Africa. It has never been submitted for any purpose.

All sources of information that have been utilised and quoted have been acknowledged by complete reference.

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Date

Abstract

Nongovernmental organizations (NGOs) and governmental organizations are united in their goal to develop and implement community empowerment programmes (CEPs). The researcher explored the lived experiences of HIV/AIDS Community Empowerment Programme Workers (CEPWs) participating in two CEPs in Ladysmith, Kwazulu-Natal, South Africa, a lower socio-economic area. The researcher further explored recommendations for the development of CEPs based on the lived experience of CEPW's.

Methodologically, data was explored using a qualitative hermeneutic phenomenological approach as described by the phenomenologist Van Manen (1990).

The researcher found that the CEPW participants "gave themselves" by responding to a need with passionate engagement. The successes of the CEP motivated CEPWs to remain involved and encouraged community members to approach the CEPWs for support and assistance.

Community ownership of the CEP; seeing results; careful selection of the volunteers; monitoring and evaluation was viewed as factors contributing to the sustainability of a CEP. Particular emphasis was put on care in selection of volunteers, and there was a range of opinion on the preferred characteristics of a CEPW. Factors mentioned were humility, a caring, disposition, sensitivity and courteousness, commitment to their community, trustworthiness, ability to maintain confidentiality and respect for culture. The ability to read and write English was also seen as an advantage.

Recommendation flowing from the research were that communities must be involved in all aspects of the CEP. Health professionals must respect the community, and their value systems. Upskilling and resource management were cited as important

empowering factors. Participants felt that CEPs must reduce dependency yet still explore governmental and NGO support. Participants had divided views on the contractual engagement of CEPWs. The participants emphasized the importance of financial and resource-management reports and accountability of supervisors and CEP directors.

Health professionals and CEPWs alike need to acknowledge and be prepared to defer to the first-hand knowledge and experience of the community members they serve.

Dedication

This dissertation is dedication to the men and women who dedicated selflessly their services daily to vulnerable community members in need of care.

Acknowledgement

I thank God for awarding me the opportunity to be tutored by the community empowerment programme workers.

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List of abbreviations

The following abbreviations were utilized in the research dissertation.

AHW	Ancillary health worker
AMREF	African Medicine and research foundation
ANC	African National Congress
AIDS	Acquired Immunodeficiency syndrome
ARV	Antiretroviral drug
CCW	Community care worker
CBO	Community base organisation
CD4	Cluster of differentiation 4
CEP	Community empowerment programme
CEPW	Community empowerment programme worker
CHW	Community health worker
DOT	Direct observation treatment
GO	Government organisations
HCBW	Home and community base workers
HIV	Human Immunodeficiency virus
KZN	KwaZulu Natal
LHW	Lay health worker
MDG	Millennium development goals
NGO	Non-governmental organisation
NPO	Non-profitable organization
OVC's	Orphans and Vulnerable children
PHC	Primary health care
PMTCT	Prevention mother-to-child transmission
SAMA	South African medical association
SWAAZ	Society of Women Against AIDS in Zambia
UKZN	University KwaZulu Natal
UNAIDS	United Nations Acquired Immunodeficiency syndrome
WHO	World health organisation

Chapter 1

Introduction

1.1 Background to the study

When the current African National Congress (ANC) government came into power in 1994 the principal focus of health care in South Africa shifted from curative care to preventative care. The new government took guidance from the Alma Ata Declaration drawn up by world leaders on the 12 September 1978 which set targets, that came to be known as the Millennium Development Goals (MDGs), for reducing child mortality, improving maternal health and combating HIV/AIDS, eradicating poverty and hunger, promoting universal primary education, promoting gender equality, and ensuring environmental sustainability (Gavino, 2010). At a global summit in 2000, world leaders re-committed themselves to the MDGs. In 2008, Dr Chan, Director General of the World Health Organisation, described the Alma Ata Declaration and the Millennium Development Goals as an ambitious and enlightened policy that could raise the level of health by putting the emphasis on local ownership (Chan, 2008).

In 2009 the Aids Foundation South Africa News and Events reports (2009) that the shortage of health professionals, resources and infrastructure has had a negative impact on reaching the MDG objectives, making it difficult to sustain optimal health care (Magezi and Aids Foundation of South Africa, 2009). According to a report by Ncayiyana (2010) achieving the targets for preventative care by 2015, as determined by the MDG, hinges on access to primary health (Ncayiyana, 2010).

At a KwaZulu Natal (KZN) provincial consultative health forum in Pietermaritzburg on 6 November 2012 Dr Dhlomo, Member of the Executive Committee (MEC) Health KZN, outlined the revised ten-point National Health plan, according to which the implementation of National Health Insurance will force health services to focus more

on delivering effective and efficient primary health care services. Another point raised in the ten-point plan is mass mobilisation for better health for the population (Dhlomo, 2012).

In the course of the past 15 years, community empowerment has come to be an insistent point of focus in international funding for both government organisations (GOs) and NGOs with the emphasis on community empowerment programmes (CEPs) involving community empowerment programmes workers (CEPWs) and health workers. In developing nations the challenges they will be grappling with will almost inevitably be AIDS, Tuberculosis and malaria and a concomitant poor primary health care infrastructure (Chan, 2008).

Over a period of more than 25 years the researcher had extended contact with primary health care services. As evidence of the key role that community-based nurses and health workers play in community health, the researcher saw how they will commonly be relied on for their special expertise when a community launches and develops a CEP. This is an example of the task shifting discussed by Gavino (2010), who notes how it came to be accepted as a way forward whereby primary health care nurses fulfil roles which traditionally belong to medical officers, thus expanding their supervisory accountability and ethical decision-making responsibilities. Task shifting triggered the expansion of the role of Enrolled Nurses and the CEPWs (Gavino, 2010). The researcher saw how primary health care nurses provide the first line of health care, which puts them in a special and unique relationship with the community. PHC nurses and Enrolled nurses are more accessible to the community and spend more time in the community, augmenting their position of trust.

Nurses take leadership roles in community outreach programmes because it is they who have the most experience in aspects of health care, preventative programmes and community networking. Gavino's (2010) study found likewise that primary health care nurses play a leading role in CEPs.

Chaskin, R., Brown, P., Venkatesh, S., & Vidal, A. (2001) describe participation in community empowerment interventions as capacity building by individuals and organizations according to strategies developed by the leadership (Chaskin et al., 2001). Community empowerment interventions seek to build capacity; community organizing seeks to build connections and thereby increase the capacity of participants. This coincides with the CHANGE approach to capacity-building assistance described by Vega (2009), according to which effective empowerment must be customized, holistic, analytic, network-building, grassroots, and evaluatory.

Vega's model emphasizes community assessment, upskilling, recruitment and retention, programme implementation and evaluation in partnership with the community, policy development, resource development and allocation, and increased networking (Vega, 2009).

The CEP's therefore aims to empower the community; link the community and governmental and/or non-governmental organizations. No specific model guided the implementation of the CEPs described in this study. No specific ground rules, models or recommendations were followed when the CEP's studied were instituted or developed. Sustainability and sound management are crucial both for investors and for the community served but it frequently happens that community members launch a programme having little or no CEP skills and without any detailed understanding of how important it is to determine local factors. A CEP must directly impact the skills and/or standard of living of the members of the community within which it is located. It must address a specific need in the community and the community must therefore be involved in its development and implementation. More broadly, the objective of community empowerment is to expand and strengthen informal ties among community residents and to link community members to supportive individuals, organisations and resources outside the neighbourhood (Kubisch, A. C., Auspos, P., Brown, P., Chaskin, R., Fulbright-Anderson, K., & Hamilton, R. , 2002).

Community empowerment also signifies a holistic approach, building social capital and addressing systemic problems in communities through the development of

partnerships and policies that promote community participation, addressing issues of race and ethnicity, reducing isolation, and strengthening families and neighbourhoods (Minkler et al, 2001). A further dimension of community empowerment is its association with training, which often implies a one-time financial input or short-term external technical assistance. All too often however, efforts to build organisational capacity offer no guarantee of effectiveness or sustainability of institutions or programmes.

Empowerment has been defined as “the process by which people, organizations and communities gain mastery over their lives and the process of increasing personal, interpersonal, or political power. A community empowerment approach involves collaboration between external agents and communities in programme design and implementation as to enhance a community’s capacity to respond to health problems (de Souza, 2007, p6).

This implies that communities take ownership of the community programme, which can raise issues of co-operation. Health workers and participants might feel that a certain aspect should be prioritised while the community regard another aspect as more important to them; sustainability and community support will thus be stronger when the community and the developer of the community empowerment programme are in agreement about approach and priorities (De Souza, 2007).

CEPWs are often deeply integrated in health care provision, both in South Africa and internationally. They are involved in the provision of health education, immunization, early detection and prevention of disease, reducing mother and child mortality as well as combating poverty and illiteracy (Gavino, 2010). African Medicine and research foundation (AMREF) reports (2009) notes that as CEPWs continue to work, as they so often do, under difficult conditions, their confidence and skills grow in concert with the problems they face (John Losikiriati’s story, 2009). AMREF reports (2009) cautions, however, that while CEPWs are motivated and encouraged by the positive changes they bring about in the lives of community members, they are all too often discouraged by non-payment, exposure to severe heat, water shortage,

lack of resources, accessibility to villages, bad roads, travelling long distances and problems of security (Jane Sereu's story, 2009). Research by De Souza, et al. (2007) on NGOs and empowerment in relation to HIV/AIDS in India found that volunteers were dedicated, committed and willing to work incredibly hard for the smallest of gain. As volunteers welcomed the expansion of their roles, the community and traditional leaders showed growing respect for them, raising their levels of recognition (De Souza, 2007).

In regard to educational preparation of community health programme students and CEPWs ahead of their involvement in a CEP, Kautzky and Tollman (2009) advocate a targeted intervention which will provide orientation, training, support and mentorship to nursing students. This must be implemented in conjunction with increased investment in the training of nurses and nurse clinicians, mid-level medical practitioners, community health workers and volunteers. Kautzky and Tollman highlight the importance of innovative models and approach to Primary Health Care (PHC) delivery and that will require a resurgence of inventiveness and experimentation (Kautzky and Tollman, 2008).

In her interaction with the Ladysmith community members, the researcher found that among the numerous CEPs that were launched at various times by government organizations (GOs) and NGOs some were sustainable in the long term, while others lasted only for as long as the original driving force remained a presence in the programme. In none of the programmes had specific recommendations been provided to guide their on-going implementation. For the purpose of this study, the researcher focused on HIV/AIDS CEPs that were sustainable and had the most community involvement.

1.2 CEPs in Ladysmith

Ladysmith, a small, low-income town in the province of KwaZulu-Natal, is situated in a rural area in the Midlands region. A community assessment of the town was completed in 2005 by a steering committee consisting of various role players which revealed a range of critical problems such as poverty, illiteracy and poor health

(Statistics, 2004). In 2005 community members, officials from the Department of Health and members of the Ladysmith Council formed a partnership and launched a variety of community projects to address areas of concern. This was a localized initiative in an attempt to empower the citizens of Ladysmith. These CEPs received undisclosed amounts of funding to address teenage sexual activities, psychosocial services, life skills, values, education, HIV/AIDS care and prevention, nutritional needs, poverty, unemployment, and caring for orphans and vulnerable children. The researcher became aware of the varying approaches – and uneven sustainability – of CEPs when she became involved with outreach to community members neighbouring a military area.

Successes were mixed, but five years from their inception four empowerment projects were demonstrably sustainable. These CEPs continued to expand the services they rendered within the borders of their project location, and seemed likely to offer useful models for emulation. Two programmes concentrated on HIV/AIDS, poverty and unemployment-related aspects. One team, consisting mainly of community volunteers, functioned since 2005 in the Watersmeet/Peace Town area and served mainly the residents of that locality. The other project had its base as from 2007 in Ladysmith and was supported both by professionals such as medical officers, social workers and nurses, and by community volunteers; its services could be accessed by any member of the Ladysmith community.

Both these CEPs are community-driven, and the respective communities accepted full responsibility for all services rendered, for management of resources, and for alterations in the CEP services rendered.

Wishing to understand the dynamics of these two CEPs and the lessons they could provide was what first prompted the research presented in this thesis. There were also unexpected learning curves. The researcher was one of a group of professionals who began their participation in these projects with the assumption that their academic skill and knowledge would benefit the communities in need. Seen in retrospect, it was often the community that tutored the professionals.

1.3 Problem statement

In 1994 South Africa committed itself to a Primary Health Care (PHC) approach in its delivery of health services (Gavino, 2010). Personnel, budget and resources constraints saw NGOs and GOs uniting against HIV/AIDS, unemployment, education, poverty, teenage sexual activities, nutritional needs and shortcomings in services provided by the Departments of Health, Agriculture and Social Services. The Millennium Goal targets could not be reached unless communities, NGOs and GOs came together in setting up CEPs with funds that became available from government and the private sector (Ncayiyana, 2010), but this happened without models that could have helped to shape the formation and functioning of the projects.

Ladysmith health and census statistics were discussed with the Ladysmith community members, community leaders and officials from the three above-mentioned government departments. Community leaders emphasised the importance of community participation and also community ownership of CEPs. A total of ten CEPs were launched with a focus on problem solving, skills development and strengthened social networks. CEPs addressing the particular needs of HIV/AIDS affected and infected members, the youth, the elderly and poverty were given priority. Team leaders all had access to the same resources, support and information.

Of the ten programmes only four were ultimately deemed sustainable by the community committee, although none of the available reports offer any specific reason for this assessment. Reports that do exist address CEP outcomes such the number of patients reached, food parcels delivered, training presented, children enrolled in schools, and social and health status of the community members. A different route to understanding what underpins the relative sustainability of projects such as these would be to seek insight into the programme from within by accessing, if possible, the lived experience of a programme worker, a CEPW, in the course of his or her daily contribution to the work of the programme. None of the available reports say much about the community members participating in the program and

information on the lived experience of any CEPW would have to be sought by other means.

The researcher is interested in what makes the difference between programmes, what sustains certain CEPs and keeps the role players motivated, and whether it is possible that certain methods or implementation steps could improve their success. There is a need for more CEPs, and for the two successful CEPs to be further expanded. Understanding the lived experience of programme participants may be a way to arrive at recommendations to boost retention of individual CEPWs and extend the sustainability of the programme itself.

1.4 Purpose of study

To explore the lived experience of HIV/AIDS CEPWs in Ladysmith, KZN, South Africa, and to develop recommendations for community empowerment based on the lived experience of participants in two CEPs selected for study.

1.5 Objectives of the study

- To explore the lived experience of community programme workers (CEPWs) participating in two HIV community empowerment programmes in Ladysmith.
- To develop CEP recommendations based on the lived experience of participants in the two CEPs studied.

1.6 Research questions

- What were the experiences of the CEPWs working within the community empowerment programmes?
- What aspects contributed towards the sustainability of the two community empowerment programmes in Ladysmith?
- What recommendations for CEPWs could assist community empowerment programme developers, in the development and implementation of CEPs?

1.7 Significance of the study

The 2001 South African Health Review recorded the 'voices' of health care services users, health policy makers, managers and parliamentarians involved in primary health care service. But although the report reflected individual voices and opinions these are by no means representative of the views of South African primary health care facility workers as a whole. Furthermore, these are the voices of professionals in a health care facility rather than participants of a CEP (Leon et al., 2001). Hartwig, K. A., Humphries, D., & Matebeni, Z. (2008) concluded that efforts to build organisational capacity do not guarantee effectiveness or sustainability of institutions or programmes. This brings to mind the following two questions: (i) What will ensure sustainability of a CEP? (ii) What aspects have to be taken into account when developing a CEP? Data captured from answers to these questions could be used by medical personnel, CEP developers, educators tutoring community nurses, and those involved with training CEPWs. Both professionals and volunteers could possibly be exposed to traumatic experiences, and they need to be equipped to deal with them. CEPWs, with no medical knowledge, who enrol to help fellow community members, are vulnerable as they might have to cope with the possibly grave reality of health issues. After five years of operation, the two programmes being researched continued to be sustainable, provided a more expanded set of services than initially envisaged, and included surrounding regions that did not initially fall within their geographical ambit. Available CEP reports that were explored concentrated on the CEP outcome (i.e., the impact it had in the community) and on accounting for the resources received and distributed. No data could be found on lived experiences of CEP participants. The aspects raised in this study could be taken into account when developers implement CEPs and orientate participating CEP workers. Academics and researchers could utilise the information to explore the aspects in further detail and adapt curriculums.

1.8 Operational definitions

1.8.1 Community empowerment

Community empowerment is defined as a process whereby people, organisation and communities gain increased personal, interpersonal or political power enhancing community capacity and the community ability to respond to health problems.

Community participation is a process whereby community members collectively assess their needs and problems. Strategies are devised for implementing, maintaining and monitoring solutions to identified problems (De Souza, et al, 2007). In this study community empowerment refers to community skilling, resource development and management, and CEP ownership.

1.8.2 Community empowerment programme

For the purpose of this research *community empowerment programme* refers to a programme for psychosocial upliftment, economic empowerment, life skill development, educational upliftment and improved standard of living in a given community. In Ladysmith, CEPs were developed to address health issues, psychosocial needs, lack of resources, lack of services, training and educational needs.

1.8.3 Community empowerment programme workers

For the purpose of this research *community empowerment programme worker* refers to any one of a group of people who voluntarily offer their time, skills and resources to the community empowerment programme. Depending on the role they fulfil and the community empowerment programme they joined, some may receive a small remuneration.

1.8.4 Community empowerment programme sustainability

For the purpose of this research *community empowerment programme sustainability* refer to a programme developed and implemented more than 5 years ago delivering the services as outlined by the community empowerment programme goals.

1.9. CONCLUSION

The researcher identified only a limited body of knowledge, nationally or internationally, on the lived experience of CEP participant workers. The study will help to fill this knowledge gap. The lived experience of CEPWs in the two CEPs which is reflected on in this thesis and the recommendations that emerge could assist future community nurses, health professionals, CEP developers and NGOs to boost the sustainability and success of the project and to retain personnel.

Chapter 2

Methodology

2.1 Introduction

Chapter 2 describes the research paradigm; research approach; setting of the study; describing the participants; data collection and data analysis; trustworthiness and ethical considerations. The annexures contain the Interview schedule (Annexure A); participant information sheet (Annexure B); the consent form (Annexure C); ethical clearance form (Annexure D); permission to undertake research (Annexure E) and the transcripts of interviews with participants (Annexure E).

2.2 Research paradigm

Weaver and Olson (2006) describe paradigms as patterns of beliefs and practices providing lenses, frames and processes through which an investigation is accomplished. Nursing practice knowledge may be constructed from multiple modes of inquiry. A positive interpretive approach, adopted in this thesis, sought to articulate the lived experience of the CEPWs whose activities this study considered.

The positivist paradigm, also referred to as the received view, utilizes scientific methods to describe and predict patterns in the physical world. Theory is established deductively in seeking to generalize findings beyond a particular sample (Weaver and Olsen, 2006). A qualitative phenomenological research approach allowed the researcher to analyse the data; identify themes and sub-themes; compare the data with literature and discuss the findings with the participants. This enabled the researcher to arrive at recommendations for the development of a CEP.

The interpretive paradigm emphasizes understanding of the meaning which individuals ascribe to their own actions and to the reactions of others. The phenomena are studied through the eyes of people in their lived situations, seeking

an in-depth description, understanding and explanation as experienced by the participant (Weaver and Olsen, 2006).

An interpretive positivist paradigm approach seeks epistemologically to articulate the lived experience of the CEPW. This is why, no literature study chapter was included in the proposal, other than to indicate some preliminary research in order to explain the phenomenology. Three open-ended questions were put to the participants. Their responses were transcribed and all data was regarded as having equal significance. Interviews were continued until no new themes emerged and data was saturated.

A positivist interpretive approach required a significant paradigm shift on the part of the researcher. With more than 20 years military experience, where the emphasis was on discipline, precise operational planning and acting according to commands the researcher encountered significantly different approaches when she began to engage with CEPs and CEPWs in localities where there was military deployment. Because military nurses have more experience in aspects of health care such as preventative programmes and community networking they tend to take leadership role in these CEPs. The researcher became increasingly interested in CEPs and volunteered free time as a CEPW. It was with this background, and in response to a lack of specific CEP modules, that the researcher undertook this research.

2.3 Research approach

The researcher explored the lived experience of community program workers participating in two CEPs utilizing a qualitative hermeneutic phenomenological approach as described by the phenomenologist Van Manen (Van Manen, 1997a). Hermeneutic phenomenology connects the reader to a phenomenon by means of a text and offers an expression of meaning based on the research outcome and study findings (Van Manen, 1997a). It describes the phenomenon as accurately as possible, refraining from any pre-given framework, but remaining true to the facts. As a research method it is the study of essences, describing the “particular manifestations of the phenomenon” (Van Manen, 1997, p.10 a). This implies that the researcher will attempt to be open-minded and broadminded, free-thinking, and

tolerant, while relating to the subjective understandings and the actions of those being studied.

2.3.1 Qualitative research

The qualitative researcher seeks to understand and relate to the subjective understandings and the actions of those being studied. Qualitative researchers are good listeners, have some flexibility, and are willing to engage in discussion with all the participants in order to understand the reason for the given phenomenon (McBride and Schostak, 2010). Qualitative research as a method will allow the researcher to fully understand the participants' experiences and viewpoints, in contrast to quantitative studies which provide merely statistical data. There are various styles of qualitative research which differ in approach, disciplines and ideologies, and data collection. Qualitative phenomenology will focus on the depth of an experience (Holloway and Todres, 2003).

2.3.2 Phenomenology

Phenomenology seeks to uncover the meanings in our everyday existence, with consciousness of life-force. Phenomenology poetises activities, seeking to voice the views of the participants. It describes the quality and meaning of the lived experience (Van Manen, 1997a). Its description of meaning takes the form of mediated expression with an interpretive direction. Through the use of some type of text or symbolic expression interpretations are made of life experience. Phenomenological text is descriptive and exemplifies the phenomenon which is being studied (Van Manen, 1997a). The initial assumption is that the meaning of lived experience is hidden. As a research method phenomenology discourages predetermined procedures, techniques and concepts (Van Manen, 1997a).

Phenomenological research has three primary components: (1) a stage of gathering life-experience material; (2) a stage of analysis, which consists of focussing on, identifying, and elucidating essential themes within the descriptions gathered in stage one; (3) a stage of practical application, or better, a stage wherein phenomenological research suggests ways to inspire improved praxis. In

phenomenology, personal experience is the starting point. The source of personal experience is a comprehensive description or account of the lived experience, without offering causal explanations or interpretive generalisations (Van Manen, 1997a, p. 54). To produce lived-experience descriptions, Van Manen suggests the following guidelines (which duly guided the present study):

- (1) Avoid casual explanations, generalisations, or abstract interpretations. The study avoided generalised remarks and took care to request each participant to explain his/her opinion in detail.
- (2) The participants describe their feelings, their mood and emotions. The study gave participants adequate time to describe their emotions and feelings, while recording non-verbal behaviour in research field notes.
- (3) Focus on specific events, an adventure, a happening, a particular experience. The study asked participants to explain events and experiences as clearly as they could, which helped her to understand the meaning behind the phenomenon.
- (4) Try to focus on an example which stands out for its vividness, or first-time experience. The researcher asked participants to indicate if the experience they were relating was a once-off incident or whether the specific occurrence had a more frequent or continuous impact on them. (See annexure A)
- (5) Attend to how the body feels, how things smell(ed), how they sound(ed), etc. The study was attentive towards the needs of the participants and made sure that each participant was comfortable during the interview.
- (6) Avoid beautifying your account with conjured phrases or elaborate terminology (Van Manen, 1997a). The textually recorded findings, recommendations and conclusions were presented to the participants without any flowery descriptions or elaborated terminology.

Phenomenological description is less concerned with factual accuracy and focusses more on the person's living sense of the experience – on what it is like to live through a particular experience. Phenomenological literature offers insights into lived experience, but, according to Van Manen, differs from other kinds of descriptive discourse in four ways. Phenomenological literature may contain material which has

already addressed, in a descriptive or an interpretive manner, the very topic or question which occupies us. The work of other phenomenologists turns into a source for us with which to dialogue. Selected phenomenological materials enable us to reflect more deeply on the way we tend to make interpretive sense of lived experience. Phenomenological sources allow us to see our limits and to transcend the limits of our interpretive sensibilities (Van Manen 1997a).

2.3.2.1 Maintaining a strong and oriented relation

Van Manen suggests that modern research suffers from three main problems: (1) confusing pedagogical theories (2) losing touch with the lifeworld of the living; and (3) failing to see the general erosion of pedagogic meaning from the lifeworld" (Van Manen, 1997b, p. 135). Van Manen understands hermeneutic phenomenological research in the human sciences as an interplay of six research activities, which must be taken as linear steps rather than as processes that are interwoven and built upon each other:

- (1) Exploring the lived experience and attempting to make sense of it by examining the data from interviews. In this study the researcher formulated the phenomenological question, familiarised herself with her own assumptions and beliefs (Van Manen, 1997b, p. 151), and, in an attempt to understand the essence of their experience, put three broad, open-ended questions to the participants.
- (2) Reflecting on the emerging themes and sub-themes. Van Manen explains that a rich text with concrete descriptions does not immediately exhaust the meaning of the lived experience and (Van Manen, 1997b, p. 152). In the study the researcher identified themes and sub-themes during the analysis of the data collected and returned to the participant to ensure that the researcher's description accurately reflected the participant's experience.
- (3) Exploring the significance of the experience. The researcher discussed with the participants the themes and sub-themes that emerged and compared the data to other literature. In the course of this third activity Van Manen advises that the researcher must explore the phenomenon to gain a dimension of depth and a fuller understanding of the significance of the study (Van Manen,

1997b, p. 152). In order to achieve this researcher discussed the findings; literature review and recommendations with the participants.

- (4) Describing the phenomenon in writing and bringing speech to the experience. .According to van Manen (1996) an oriented text is one that fully describes the lived experience of CEPWs (van Manen, 1997b, p. 151).
- (5) Tracing *etymological* Sources. The researcher ensured that the words were used in their correct context (Van Manen, 1997b, p. 151). The recommendations were presented to the CEP directors, who confirmed that they were agreement with the written text, after which the data analysis was presented and discussed with the supervisor.
- (6) Obtaining experiential descriptions from participants. The researcher considered the parts and the whole. Data was reviewed in context, thereby achieving a balance. Phenomenological human sciences text needs to be oriented, strong, rich, and deep. Strong text aims to interpret a phenomenon pedagogically (Van Manen, 1997b, p. 151) and the researcher must accordingly attempt to understand the phenomenon in all its ramifications.
- (7) Bracketing. No bracketing was included. Bracketing requires the phenomenologist to bracket their previous understanding, past knowledge and assumption enabling them to focus on the phenomenon studied. Finlay (2008) cautions the novice researcher against misunderstanding bracketing as the first step to subjectivity. Hermeneutic researchers does not encourage the researcher to bracket, arguing against shifting back and forth between personal assumptions and participants experiences (Finlay, 2008)

Hermeneutic phenomenological explores personal thought and the action that flows from it; it is a philosophy of actions in a pedagogic context (Van Manen, 1997b, p. 154). A focus on pedagogy in CEPs research could lead to improved sustainability of CEPs; studying the lived experience of CEP workers could improve retention of participants in these programs and enhance their sustainability.

2.4 Setting of the study

The smallish town of Ladysmith is situated in a socio-economically depressed area of KwaZulu-Natal, South Africa. One of the HIV/AIDS community empowerment

programmes examined in this study ran its project from an office in the centre of the town. This office co-ordinated the services rendered in and around Ladysmith. Although the office was situated in the centre of town, the greater community of Ladysmith and its surrounds was served as the programme was not confined to any one area of the town, The second CEP researched in this study delivered services in the Watersmeet area. This project served mainly people in and around Watersmeet as its limited resources did not allow of wider coverage.

2.5 Participants

In 2004 ten CEPs were launched to address community needs in rural low-income areas in the vicinity of Ladysmith by a steering committee comprising community members, community leaders, religious leaders, representatives from the business chambers, health representatives, education representatives, social department representatives, Department of Home Affairs representatives and agricultural department representatives. Each community program addressed a specific aspect or aspects of need in the particular community. Two of these projects, which concentrated on HIV / AIDS, poverty and unemployment-related concerns, were also those with the biggest community involvement. A third project, supported mostly by a partnership between the Departments of Health and of Social Welfare and the local Council, concentrated on the provision of primary health care and preventative care programmes. A fourth project focussed on care for orphaned children. A team which operated in the Watersmeet/Peace Town area served mainly the residents of that locality.

A locally resident Zulu-speaking research assistant was identified by the CEPWs on the grounds that the assistant would enjoy the trust of the community and understand their traditions, and that this would also help to obviate language barrier problems. The research assistant had to assist the researcher and participant to cross the language barrier. The researcher and the research assistant conducted interviews according to a structured questionnaire in the language of choice with the health professionals and community members in Watersmeet and Central Ladysmith. Participants were also given the option of being interviewed at an

alternative location 20-kilometre radius that would be accessible to both them and the researcher.

2.6 Sampling

The study focussed on the two CEPs that were sustainable since 2007. The CEPs sampled expanded their services over the years serving larger communities than initially. These programmes also offered additional services addressing the additional needs of the community.

A convenience or volunteer sample was used in this study. Boyd (2001) regards two to ten participants or research subjects as sufficient to reach saturation. Creswell (1998) recommends “long interviews with up to ten people” for a phenomenological study. The inclusion criterion for the sample stipulated that only persons who had been involved for at least 6 months in the two programmes being studied could be selected as participants. Accordingly, the project leaders of each of the two programmes were included: project leader x1 of each project = 2; also included were four programme workers located in town (Medical Officer x1, nursing personnel x1, two community programme workers with no medical background); likewise four programme workers located in Watersmeet (Medical Officer x1, nursing personnel x1, two community programme workers with no medical background). The two CEP leaders identified participants who had been involved in the HIV/ AIDS CEPs for more than a year. The researcher explained the objectives of the study (See Annexure B). Participants had an opportunity to included or excluded from the study. The diversity of backgrounds and educational levels among the participants meant that valuable data could be collected from a wide range of perspectives.

2.7 Data collection

The leaders of the two CEPs being studied were approached after ethical approval had been obtained from University of KwaZulu Natal (UKZN) for the researcher to access the research setting. The CEP leaders helped set up opportunities for the researcher to explain the research purpose, objective and data collection process to the parties involved. The researcher and research assistant were introduced, a call

was made for volunteer participants and the inclusion criteria were explained. Individual meetings were then set up with each of the participant project leaders, health professionals and community members, at their convenience and at venues of their choice.

On meeting with each participant for the first time the researcher and research assistant engaged them in informal social conversation to establish rapport until such time as the participant felt comfortable and seemed at ease. The consent agreement was explained to the participant, who was given time and opportunity to peruse it before giving their informed written consent (See annexure C).

A research assistant recruited to conduct interviews in isiZulu was trained to assist with the collection of data. The research assistant had a thorough understanding of research confidentiality and likewise of the ground rules for the interviews – according to which no leading questions could be put to the informants, sufficient must be allowed for them to respond, and responses had to be translated word for word. No time limit was set to an interview. Demographic data was collected, but had no impact on the data analysed. The research assistant verified the accuracy of what he/she had understood by having the participant give confirmation. Body language and mannerisms were observed by the researcher during the conversation and recorded in the field notes. The participant could at any stage choose to be interviewed in isiZulu, even if the interview had been initiated in English.

Audio recordings of the interviews were made with the permission of the participants and these served to verify accuracy of transcriptions (See Annexure F). The isiZulu-speaking research assistant also provided interpretation where necessary during the interviews themselves.

In the transcription stage the interview was transcribed by researcher as guided by the interpreter. In addition a member of the military language department was approached to check transcripts and interpretations to ensure correct transcription and translation from isiZulu to English. Once verbatim transcriptions had been made

of each interview, validity checks were conducted by returning to the informant to determine if the essence of the interview has been correctly captured. None of the participants took issue with deductions or inferences made by the researcher and no further interviews were required.

2.8 Data analysis

The researcher was guided by the phenomenology research steps described by the hermeneutic phenomenologist Van Manen (Van Manen, 1997).

2.8.1 Phenomenological reduction.

The essence of the phenomenon described is explored through the thoughts and actions of the participants (Van Manen, 1997). No position was taken by the researcher either for or against any CEP recommendations suggested. The researcher made sure that questions and responses in the interviews were transcribed word for word as expressed by the participants. A record was also included in the transcriptions of non-verbal behaviour. Respondents participated voluntarily and could withdraw at any stage. Data-collection interviews continued until no new themes emerged and the topic was saturated – the point of saturation having been reached as soon as no new perspectives on the topics are introduced by interviewees. Collected data as perceived by the researcher was validated by the participating respondents.

2.8.2 Delineating units of meaning

This is a critical phase in the explication of the data. Rather than theorising the participant's experience, the researcher, following Van Manen (1997), sought to explore the lived experience as regarded by the participant himself or herself. The researched phenomena were extracted from the statements of the participants, avoiding inappropriate subjective judgements. (Creswell, 1998; Holloway, 1997; Hycner, 1985). The researcher considered the literal content, the number of times a unit of meaning was mentioned (its significance), and also how it was stated (verbally or through paralinguistic cues).

2.8.3 Clustering of units of meaning to form themes

Units of meaning were assembled into clusters within the holistic context, whilst maintaining a strong and oriented pedagogical relation to the phenomenon (Van Manen, 1997). By interrogating the meaning of the cluster, central themes were determined which expressed the essence of the clusters (Hycner , 1985), and in this way the researcher identified significant topics, also called units of significance (Sadala and Ardorno, 2002). In addition emerging themes and sub-themes were compared with other literature. Overlap in clusters was expected, considering the nature of human phenomena.

With the assistance of the research supervisor the researcher compiled a summary that incorporates all the themes elicited from the data to give a holistic context. The researcher conducted a validity check by returning to each informant to determine if the essence of the interview had been correctly captured. Both the researcher and the participant reflected on the conversations (Van Manen, 1997). Themes and sub-themes elicited were supported by extracts from the transcriptions, in which pauses were indicated by extended ellipses (“.....”) and quoted speech was notated in italics. Themes and sub-themes identified were then compared with literature.

The researcher was concerned less with factual accuracy and more with the participant’s lived experience (Van Manen, 1997). The concern was not whether the participant’s responses were correct or not but how the participant described his/her lived experience. General and unique themes and sub-themes were extracted from the interview as a whole, and care was taken not to cluster common themes if significant differences were apparent. A watch was kept for unique or minority voices, these being were important counterpoints in the phenomenon researched (Groenewald, 2004, p 21). The researcher analysed the data and then returned it to the participants for validation. The researcher also analysed the literature, compared it with the findings, and once more returned data to the participants for further validation. The analysed data was then presented to the research supervisor, who guided the researcher through the recording of findings.

2.9 Trustworthiness

Trustworthiness determines the quality of research findings. Trustworthiness of the findings was strengthened through member checking; providing a rich description of the methodology. Guba and Lincoln (1994) name four criteria that qualitative researchers must adhere to in pursuit of trustworthiness: credibility, transferability, dependability and confirmability.

2.9.1 Credibility

Credibility is primarily concerned with demonstrating that the research was conducted and analysed in a correct manner. Internal validity seeks to ensure that findings are congruent with reality and here a crucial requirement is that phenomena are recorded accurately. Overall, credibility is achieved by prolonged engagement, persistent observation, checking the validity of the data with the participant, debriefing, and triangulation. According to Guba and Lincoln (1994), prolonged engagement between the participant and the researcher leads to a better understanding and builds a relationship of trust. In this study the researcher gained in-depth understanding by being present during each contact session with each participant; by making persistent observations; by making sure that sufficient time was available for the interview and by building a relationship of trust. Initially participants were asked to set aside an hour when they would be available, following which additional time was agreed to as and when required. In some cases the researcher would spend the whole day accompanying the respondent in the field before working through the research question at the end of the day's tasks. To avoid intimidating participants and put them more at ease the researcher wore civilian clothing without epaulettes..

Data exploring the lived experience of CEPWs involved in a CEP were collected from three different kinds of participants: CEP leaders, health professionals, and CEPWs. Multiple sources ensured that different perspectives were taken into consideration. Data triangulation was provided by comparing the data from these diverse sources, and the data was 'validated' if it yielded similar findings (Arksey & Knight, 1999). Credibility is established when the true value of the argument

emerges from the data, strengthened by triangulation and member checks (Guba and Lincoln, 1994). In the study emerging themes, sub-themes and recommendations were presented to the participants and compared with literature, and debriefing sessions between the researcher and the supervisor served as a valuable sounding board.

2.9.2 Transferability

Transferability is concerned with whether the research findings can be applied to other situations which are deemed similar. Transferability depends on thick description in which the similarities and differences are apparent (Guba and Lincoln, 1994). In the detailed description contained in this study of the research process the researcher has sought to provide a baseline understanding of the phenomena being studied that will aid the reader in deciding where the findings may be applicable to other, similar situations. Since CEP programmes by their nature, involve members of the community in providing self-help health care and with primary health care a key strategic focus in South African government health care provision, the research results which hold good for this study may well be applicable in comparable rural CEPs.

2.9.3 Dependability

Dependency speaks to the consistency of the research (Guba and Lincoln, 1994). The researcher took care to ensure that research process was systematic, rigorous and well documented.

2.9.4 Confirmability

Confirmability offers neutrality through triangulation and alternative explanations (Guba and Lincoln, 1994). In this study a chain of evidence linking conclusions to data collected establishes confirmability to the extent that another researcher examining the raw data would be likely to arrive at a similar set of findings. Detailed methodological description enables the reader to determine if he/she could accept the data, and discussion of the findings by both researcher and participants gave them further opportunity to add data or explain a phenomenon in more detail.

2.10 Ethical considerations

Ethical standards as outlined by Emanuel, Wendler, Killen, and Grady (2004) ban any exploitation of participants, and include fair selection of participants, community participation, consideration of social values, scientific validity and data integrity, positive risk–benefit ratio, independent risk review, informed consent, and on-going respect for the participants. These standards were met in this study.

2.10.1 Selection of participants

The two project leaders identified participants who had been involved in the HIV/AIDS CEPs for more than a year. A convenience sample was used, following Boyd's (2001) assessment that between two and ten participants or research subjects constitutes a sufficient sample.

2.10.2 Community participation

Participants from diverse background and academic levels offered valuable data from different perspectives.

2.10.3 Social value

The research has potential to assist the development and implementation of CEPs. Professionals rendering services in the community will be alerted to issues that strengthen the sustainability of CEPs, and CEPW preparation, training and support will be made more efficient.

2.10.4 Scientific validity and integrity

Transcripts were made of all conversations and will be kept for five years. Subsequent to each interview the researcher recorded secondary data, in the form of field notes, as comprehensively as possible. All data will be destroyed five years after completion of the study by means of incineration or shredding of hard-copy documents. Electronic data on memory sticks will be permanently deleted.

2.10.5 Risk-benefit ratio

No potential risks were foreseen in respect of the studies. Participants chose pseudonyms to ensure that they cannot be identified. Participant's names and identifying data will not be disclosed. The researcher did not fund meetings, provide meals or provide transport fares.

2.10.6 Independent ethics review

The proposal was presented to the University KwaZulu-Natal ethics committee and approval was granted. Consent to conduct the research was requested from the CEP directors, who in turn discussed the research proposal with their funders. The funders were in an agreement that the community would benefit from the knowledge gained and accordingly granted their approval.

2.10.7 Informed consent: respect for recruited participants and study communities.

An explanatory 'Consent agreement' was provided to participants in soliciting their informed consent. Purpose, procedures, risk and benefits of the research were explained, participants were reminded that their participation was voluntary and that they had the right to withdraw from the research at any time. Procedures were followed to protect confidentiality, interviews were conditional on informed agreement by the respondent, and no leading central research questions were put to the participants.

2.11 CONCLUSION

The researcher collected the data and thereafter compared the data with the literature review.

Chapter 3

Literature review

3.1 Introduction

South Africa is making very slow progress towards the health-related targets set out in the Millennium Development Goals (Magezi and Aids Foundation of South Africa, 2009). Attainment of these targets is fundamentally dependent on access to primary health care (PHC) but the *South African Health Review* (2008) report, identifies shortage of health professionals as a major problem in health-service delivery, imposing a huge burden on the health care system. The burden is further compounded by the twin challenges of HIV/AIDS and Tuberculosis (South African Health Review, 2008).

3.2 Community empowerment in South Africa

Communities look to Community Health Workers (CHW's), fulfilling one function or another, to provide a spectrum of community-based care and support in resource-poor settings where formal health care services are not adequate – all this at a very difficult time when poverty is compounded by new threats such the HIV/AIDS epidemic challenge the social fabric (Magezi and Aids Foundation of South Africa, 2009).

According to a research study conducted by De Souza, et al (2007) Non-Government Organizations (NGOs) plays an increasingly important role in the health sector of developing countries to make significant improvements in health. NGOs are considered to provide a relative advantage in the health arena, because they have the size, flexibility and resources to implement community programmes, as well as the ability to impact macro-policy by providing the link between local communities and higher reaches of political power. NGOs are increasingly used as a vehicle for service provision. (De Souza, 2007)

Home care is defined as a preventive, promotive, therapeutic, rehabilitative, long-term maintenance and palliative care service rendered in the home by formal and informal caregivers aspiring to promote, restore and maintain maximum health levels. It plays an integral role in community-based care. Community-based care ensures that the community can access care near to their residence; encourage community participation; responds to community needs; encourages traditional community life and promote ownership (Magezi and Aids Foundation of South Africa, 2009)

3.3 HIV/AIDS in South Africa, KZN and Ladysmith.

As of the end of 2000 an estimated 25.3 million adults and children in sub-Saharan Africa were living with HIV/AIDS (UNAIDS, 2000), and from antenatal survey data it was estimated in 2004 that 32,5 % of infected patients in South Africa were from KwaZulu-Natal (UNAIDS, 2004). HIV/AIDS contributes to escalating orphan hood, and for this reason there is an interest in estimating the magnitude of the orphan rate. One study found that 13% of children aged between 2 and 14 had lost father, mother, or both: 3% of children had lost their mother and 8.4% of children had lost their father (Shisana, 2002). At the end of 2001, UNAIDS estimated that 1.1 million children in South Africa had been orphaned by AIDS (lost at least one parent). To mitigate the present and future societal impact, it is crucial that community capacity sustain and support orphans and vulnerable children (OVCs) be enhanced (UNAIDS, 2004).

3.4 Overview of International CEP

The primary goal of public health is to protect and promote the health of the broad populace. Typically, research, surveillance, policies and programmes in public health focus on patterns and factors that promote understanding and improvement of the health of populations rather than of individuals, with an emphasis on reducing risk factors and strengthening protective factors. Among these factors are social, economic, political and physical environmental conditions covering a wide spectrum

of preventative measures against ill health (physical and mental) and of environmental, social, behavioural, and biological risk factors (Kieffer et al. 2004).

3.5 Approaching community empowerment programmes

Community empowerment seeks to expand and strengthen informal ties among community residents and also to link community members with supportive individuals, organizations, and resources outside the neighborhood (Kubisch et al. 2002). Community empowerment also refers to holistic approaches for building social capital and addressing systemic problems in communities through partnerships and policies that promote community participation, address issues of race and ethnicity, reduce isolation, and strengthen families and neighbourhoods (Blackwell & Colmenar 2000).

3.6 Examples of community empowerment HIV/AIDS Projects South Africa

The AIDS Foundation of South Africa was established as a non-profit organisation in 1988. The Foundation exists to support integrated HIV/AIDS responses in vulnerable communities in South Africa, enabling such communities to implement appropriate and effective interventions to limit new infections and mitigate the impact of the epidemic, resulting in reduced HIV prevalence and amelioration of its effects. The Foundation has strategically positioned itself to work in partnership with community-based organisations (CBOs) in view of their close proximity to vulnerable communities and households. The Foundation equips CBOs with the necessary resources and tools to put into effect relevant and effective HIV/AIDS programmes, develop the skills base within target CBOs to enable them to plan, implement, monitor and evaluate their work effectively, and build the organisational capacity of CBO partners in the interests of good governance and to improve their long-term sustainability (South African Health Review, 2001)

3.7 Impact of CEPs on society

Capacity building has been defined as the process by which people gain knowledge, skills, and confidence to improve their own lives (Gibbon et al, 2002). In the context of poverty alleviation and focusing on those on the margins of society, CEPs are seen as an intervention to improve the lives of intended programme beneficiaries. Capacity building, in this context, is not merely the acquiring of new skills and knowledge; it also involves an adjustment and application of these new insights to the political, social and economic environment (Hawe, 1994). One major issue is the role of indigenous knowledge. Traditionally, capacity building has been seen as training local people to use 'modern' methods and approaches to improve their situation. While recognizing that local people have experience, culture, and traditions that contribute to this process, in practice, it has usually resulted in professionals telling local people what to do and how to do it (Hobart, 1993). Such approaches, it can be argued, are apt to undermine both empowerment and, often by extension, equity. In the field of health, evidence for the value of capacity building exists in a number of areas. On the negative side, data provided by Wallerstein indicates that individuals who feel that they lack capacity and confidence in their own lives have worse outcomes in terms of morbidity and mortality than those who do not feel this way (Wallerstein, 1993). Positive experience, on the other hand, supports linkage between empowerment, equity, and improved health outcomes.

Community and social support group interventions support healthy lifestyles through community awareness, developing resources and social support group activities. The community intervention in Detroit successfully raised community awareness of diabetes through media and other public education activities. One of its major accomplishments is the development of a bilingual website where a community calendar of events links community residents to accurate sources of health information and community assets, thus promoting physical activity and healthy eating. This intervention has created resources that support healthy lifestyles such as salsa and hustle aerobics classes and Healthy Latino and Healthy Soul Food cooking demonstrations. It has also led to the development of a training programme that equips community fitness instructors to with the necessary skills to address the

needs of community residents with, or at risk for, diabetes. The Social Support Group Intervention has successfully trained community residents to organise and lead activities such as walking groups and diabetes support groups. (Kieffer et al. 2004)

3.8 Health system interventions

Health system intervention aims to improve quality and access in service by health care providers working with REACH participants diagnosed with diabetes. Following activities such as continuing education, sessions focussing on cultural competence are conducted jointly with Family Health Advocates and participants with diabetes. REACH participants report greater confidence in their ability to communicate with their physicians. (Kieffer et al. 2004)

3.9 Family interventions

While most of the REACH interventions are aimed at building community capacity, family intervention aims to change individual behaviour and ultimately health outcomes. While it is too soon to expect changes in long-term outcomes such as reductions in diabetes complications, changes have been noted in intermediate behavioural risk factors and biological markers of risk for diabetes complications. After receiving social support and the “Journey to Health” curriculum from community-resident Family Health Advocates, REACH participants with diabetes have shown increased levels of physical activity and fruit and vegetable consumption, as well as an improvement in several physiological measures of health, including lower levels of blood glucose, triglyceride and blood pressure (Kieffer et al. 2004).

Capacity building that leads to new or greater organizational skills may be necessary to launch and maintain public health programmes. Community-building strategies should also result in strengthened organizational capacity and skills within community-based organizations. The level of capacity building improves the position of community organizations in applying for, receiving and managing funds, and in maintaining and sustaining a public health improvement initiative. Similarly,

capacities to attract, hire, train, and retain community resident staff and manage personnel activities raises the possibility of successful and sustainable programmes (Braithwaite & Lythcott 1998).

The strong coalition that developed through these strategies has survived and thrived. While the initial area of concern was prevention of drug abuse, the coalition widened the scope of its activities to include new public health issues such as diabetes. This coalition was also able to apply successfully for tax-exempt status as a non-profit organisation. A number of other successful coalitions have since come into being modelled on the strategies of the Detroit project (Kieffer et al. 2004).

3.10 The example of Society of Women Against AIDS in Zambia

The Society of Women against AIDS in Zambia (SWAAZ) was set up in 1989 to deal mainly with issues relating to women, and subsequently extending to problems of adolescents and orphans. SWAAZ began by conducting educational workshops and in the process came to realise that out-of-school youth were beset by lack of skills and inability to find gainful employment. Two programmes have evolved as a result of these early experiences: Tasintha and Kuasha Mukwea.

Tasintha is a programme that targets girls in the sex trade and assists them in skills training and building self-esteem (Nduati et al, 2007). The second programme, Kuasha Mukweu, seeks to support widows and orphans. SWAAZ has thus far bought four houses in the low-income areas of Lusaka and hopes to increase this to six in the future. The houses function as family support units. Activities include some provision of health care. Women of the community have been trained to take blood spots for syphilis testing and it is hoped that this service will expand to target adolescents. The houses provide services to orphans and to families caring for the orphaned children. It is better for orphaned children to remain in the community, among their own people where they are known. Income-generating projects linked to these houses support these activities and the families they render services to with basics such as food, uniforms and health needs. (Nduati et al, 2007)

Corrupt or self-serving leadership, dysfunctional organisational structures, forced or artificial collaborations, lack of reciprocity or trust among partners, and avoidance of confrontation may compromise the success of community-building and/or public health initiatives. Additionally, and importantly, community-building efforts may be undermined if some participants in the process accrue or hold onto power or expertise and fail to release control of resources in step with expanded community capacity. This is especially likely if true power in the initiative remains with outside experts who are involved in the community-building process. It may also occur when community leaders or organisations gradually (and perhaps even unintentionally or subconsciously) become more self-serving or begin to pursue their own interests at the expense of community (Nduati et al, 2007).

It is difficult to find empirical evidence to confirm the impact of community-building strategies on public health outcomes (Roussos & Fawcett 2000). In many cases, such strategies are part of broader public health interventions and the specific role and effect of community-building strategies and activities are not often explicitly or adequately measured (Minkler et al. 2001). Community-building activities may be seen as useful methods, but not as critical outcomes. In other cases, public health outcomes may be influenced positively by community-building initiatives, but they are not detectable because their measurement was not included in the evaluation of the initiative, or the link was assumed, but not well measured. The major constraint facing SWAAZ is the high cost of programmes that include a home-care component. Zambia is a large country and the distances have made it difficult for SWAAZ to have wider national coverage. Most of the resources received by SWAAZ have been allocated to the beneficiaries, leaving very little for human resources and operational cost. A different constraint is deeply-rooted cultural beliefs, which influence women's self-perception and create a dependency syndrome (Nduati et al, 2007).

3.11 Impact on volunteers: South Africa

3.11.1 The ‘voices’ of health care services users, health policy makers, managers and parliamentarians

In 2001 the *South African Health Review* recorded the ‘voices’ of health care services users, health policy makers, managers and parliamentarians. Health care service users complained of problems such as overcrowding, long waiting times and limited hours of service, which are symptomatic of under-resourcing. Similarly, facility managers voiced both job satisfaction and frustrations. Job satisfaction was associated with factors such as team work, good staff relationships, accessible management, recognition and affirmation of effort and peer support, while frustrations were caused by understaffing, heavy workload, limited physical space, poor remuneration, inadequate support from their respective districts and ‘summons to meetings’ (South African Health Review, 2001).

The ‘Voices’ of Primary Health Care Facility Workers, focus on day-to-day concerns that impinge on the interviewees’ performance. They provide a platform from which further investigations can be made of supporting or hindering factors for health care delivery at PHC facilities in the country and appropriate interventions sought. (Leon et al, 2001). The experiences of PHC facility health workers are summarized under the following themes. The key themes relate to issues of:

- Basic training, in-service training and utilisation of skills
- The working environment
- Facilities, Infrastructure and Resources
- HIV/AIDS.

Basic training, in-service training and utilization of skills for provision of quality PHC service hinges on the quality of training for providers and requires multi-skilled workers who are prepared and have time to upgrade their competencies regularly.

The competencies needed by PHC staff are well articulated in ‘*The primary Health Care Package for South Africa – A set of norms and standards*’ (South African

Health Review, 2001). The initial training of a PHC health worker, particularly the nurse, was and still is to a large extent urban-hospital / academic-institution based. Often it does not address the real day-to-day competency needs and challenges of a PHC health worker such as cultural diversity, community mobilization and participation, community data-collection analysis, interpretation and utilization, problem solving, integration of PHC services, inter-sectoral collaboration, coordination (Strasser and Gwele, 1998). Issues commonly raised included access to and impact of training, and the differing expectations and conditions of service that may be encountered. Lack of resources, heavy workload and poor facilities cause frequent frustration in denying many health workers the opportunity to use all their skills. Many health workers experience stress because they feel that their training has not equipped them to perform the tasks that their jobs entail. A heavy workload also makes it impossible for health workers to participate in training opportunities. Some nurses feel that although investment of their time in further training has not added value to the quality of care they provide to their patients (South African Health Review, 2001).

3.11.2 The working environment

The 1997 White Paper for the *Transformation of the Health System in South Africa* provided a framework for addressing inequalities (Republic of South Africa. 1997). A few nurses discussed transformation and its impact on their work. Some recognize that change always brings resistance but recommended that transformation processes should be supported realistically. Environmental health practitioners (EHPs) seem to be especially affected by the redefining of the role of Local Government in providing health care. (South African Health Review, 2001)

3.11.3 Roles of the Health Care workers

In the absence of other health professionals at many PHC facilities, the nurse is expected by management, supervisors, patients and the community to perform multiple roles. She is in turn a social worker, pharmacist, physiotherapist and nurse. Changes in PHC services now require clinic-based staff to combine preventive and promotive care with a wide variety of curative services (Strasser et al.1998). They are expected to provide care for chronic diseases such as hypertension and

diabetes, as well as manage tuberculosis, sexually transmitted infections, and HIV/AIDS counselling and care. Some nurses have tried to take up this challenge but others are still grappling. Similarly, a nurse may spend considerable time on minor duties instead of concentrating on her/his primary roles. Nurses said that they were used to being a jack-of-all-trades (Leon et al. 2001)

The message delivered by South African Minister of Health to developed countries at the 2002 World Summit for Sustainable Development in Johannesburg. was “Stop poaching our health care professionals” (Lauring, 2002). The brain drain, although a worldwide phenomenon, it is becoming a major problem for the African continent. The South African Medical Association (SAMA) estimated that five thousand doctors have left South Africa for western countries. Pharmacists, dentists and other health professionals are migrating to the private sector, where pay and working conditions are better. Many PHC facilities in under-served communities remain without adequate doctors’ services. A typical rural South African clinic is staffed by two or three professional nurses (PNs), two or three enrolled nurses and one or two nursing assistants (Reid, 2002), with irregular support and supervision from the Primary Health Care (PHC) Coordinator – who may not be trained for the job but is responsible for all PHC services in a given area (Lehmann et al. 2002). A common consequence of unmanageable workload is stress, which manifests itself as ‘low morale, rapid turnover of staff and detrimental effects on service delivery as well as interpersonal relationships which impact negatively on service delivery and interpersonal relations’. Ancillary workers experiences an undue workload when their colleagues are on leave or absent. “There are supposed to be four staff, and that’s including the supervisor. Most of the time they are only three – either one is off sick, or on leave, or they have to relieve somewhere else” (South African Health Review, 2001)

3.11.4 Coping with workload

A heavy workload clearly has the potential to impact negatively on quality of care – cutting out community outreach services. Participants commented that although a PHC facility **is supposed** to offer preventative health care, “they don’t do much preventative health care, it’s mostly curative”. The problem of overtime can be

especially acute for doctors. The pharmacists also feel overworked and this led to stress associated illness in at least one facility (South African Health Review, 2001).

3.11.5 Health care workers overwhelmed by workload

Pharmacists said that they were exhausted and frustrated because they were overloaded. Pharmacists interviewed were of the opinion that without community service pharmacists pharmaceutical services in the whole country, would have collapsed. Pharmacists attribute the poor recruitment into public pharmacies to poor remuneration in particular, and to conditions of service in general. They are convinced that unless without drastic changes there is little likelihood of filling the pharmacists posts (South African Health Review, 2001).

3.11.6 Health care workers' relationships with Management

Enabling managers are those who recognise a responsibility to provide leadership and supervision that enhance staff morale and motivation; who likewise recognise a responsibility to address and fix problems and grievances related to procedures and workplace dynamics. Supportive supervision requires thorough planning with clear objectives, effective communication skills (McMahon et al, 1992). In the South African public health context, studies have shown that many facility managers/supervisors have had no proper training in leadership, management or supervision. Moreover, those who work in isolated areas are faced with the additional difficulty of running a facility and supervising staff in the most trying of circumstances (poor infrastructure, a poorly equipped facility, inadequate funding, too few – and overworked - staff (Strasser et al. 1998; Reid, 2002; McMahon et al. 1992).

Poor interdepartmental relationships are also blamed for poor communication. Frustrations are experienced when other departments are not able to solve problems as they do not have their house in order (South African Health Review 2001)

3.11.7 Relationship with patients and communities

Social scientists have helped to develop an understanding of the provider-patient interaction, recognizing the influence of provider behavior and the existence of biases and cultural misalignments between patients and health care workers. Good interaction between health care workers and their patients/communities heighten user satisfaction and improve patient cooperation and compliance. For their part, the health workers' morale was boosted by appreciation, recognition and affirmation from the communities and patients they served. Many health workers gained satisfaction and pride from their relationship with their patients/clients or communities (South African Health Review, 2001).

3.11.8 Relationship with colleagues

In their study on 'Management of district hospitals' Couper discuss the importance of creating teamwork as a basis for a 'functioning' district hospital (Couper, 2002). When people work as a team they build good relationships, individuals respect one another, become accountable to each other, and they share information. They have a common vision, which guides their actions and contributes – to effective service delivery. Similarly, effective PHC service delivery depends on how well the PHC teams are operating (South African Health Review, 2001).

3.11.9 Security

The incidence of violence in the South African health sector is among the highest in the world. Recent research has indicated that 61% of the surveyed health sector personnel in South Africa had experienced at least one incident of physical or psychological violence in the year prior to the study (World Health Organization, 2002). Women are especially vulnerable. While ambulance staff are reported to be at greatest risk, nurses are three times more likely on average to experience violence in the workplace than other occupational groups (Department of Health Annual Report, 2000). Health workers need to feel secure when at work, but at times are threatened by patients they are supposed to serve. There were also complaints that the facilities were not well guarded particularly at night.

3.11.10 Facilities, Infrastructure and Resources

Since 1994, South Africa has made remarkable strides in building PHC facilities, particularly in the previously under-served communities. The number of clinics in the public sector stands at approximately 3 500 and more than 500 were built in the five years prior to the Department of Health's Annual Report of 2000. The 2000 National PHC Facilities survey recorded an overall improvement in the provision of infrastructure for fixed clinics. These improvements are however undermined by the frequent breakdown of, for example, telephones and radiophones and by electricity interruptions. So constraints of various kinds persist, and some clinics are still operating without adequate sanitation and water provision, particularly in the Eastern Cape, Limpopo and North West provinces (Department of Health Annual Report, 2000).

Lack of transport was by far the most common constraint mentioned by interviewees. The 2000 Facilities Survey reported that of the 92 mobile clinics included in the survey, the vehicles belonging to 24 (26.1%) were out of order for one or more days in the month preceding the survey. In Mpumalanga and Limpopo provinces, some vehicles were out of order for 14 days (South African Health Review, 2001).

3.11.11 Experiences of PHC facility health workers in HIV/AIDS

Many PHC workers, particularly nurses, were silent on the issue of HIV/AIDS. This was unexpected given the gravity of the epidemic in the country. It may be that feelings of helplessness, hopelessness, lack of skills in counselling and palliative care, and burn-out as a result of having encountered too much suffering, stigma and discrimination prevented health workers from openly discussing HIV/AIDS. There is an urgent need to equip PHC workers with appropriate knowledge and skills regarding the management of HIV/AIDS, and this was borne out in a recent study of the pilot Prevention Mother to Child Therapy (PMTCT) sites, which indicated that many staff at the 18 national PMTCT locations did not have a strong foundation of knowledge and skills in HIV/AIDS management and care (McCoy et al.2002). Concerns about confidentiality and feelings of guilt were voiced by participants in the case of someone known to them as HIV-positive going out with persons who could

not be alerted to that status because of confidentiality obligations. Some even considered such conduct to be criminal and asked themselves whether it should be reported to the police. Patients they had counselled appear to have understood the implications of their status but still behaved in the same old way (South African Health Review, 2001).

Despite a host of negative experiences, there are some positive experiences and there are dedicated staff doing their best in a working environment marked by continual challenges and changes. The efforts of these staff need to be identified and affirmed. Some of the perceived problems may be ameliorated by managers and supervisors finding ways to strengthen the PHC team. The views expressed by the interviewed health workers had a personal focus but also give a broader indication of the problems that beset service delivery at public health care facilities. Nor are these challenges new, although their persistence indicates the scale of PHC capacity that is needed to deal with the rising numbers of AIDS-related cases (South African Health Review, 2001).

3.12 Impact on volunteers: international

Strategies suggested for the development of an AIDS-competent community were (1) Building knowledge; (2) Creating safe social spaces for dialogue; (3) Promoting ownership and responsibility; (4) Building confidence in local strengths and agency to mobilise these; (5) Building solidarity ('bonding' relationships); (6) Building partnership ('bridging' relationships). Volunteers valued the counselling training as it gave them skills and confidence. Research by De Souza, found that it was a myth to regard the mobilisation of grassroots community participation as a cheap way of service delivery: initiating and sustaining programmes designed to address social problems in deprived communities is extremely resource-intensive (de Souza, 2007).

Successful project implementation that results in actual changes in community conditions or behaviours can create readiness for additional change. Schulz, Krieger and Galea have emphasised that "interventions at the local level that have tangible and immediate benefits for local residents are an essential part of building trust and strengthening the social relationships between members of the partnership. Building

strong partnerships is a first step toward building capacity to work for macro-level change” (Schulz et al.2002). In many communities, the driver of change may be a desire to reduce the causes or impact of a particular health condition. For example, in the REACH Detroit Partnership, the community’s initial reason for working together was to counter the spread of diabetes and its complications among community residents. In other communities, the chief motive may be a desire to strengthen the ability of the community to work together on other important issues. Where the process begins, and which strategy is chosen, will vary from case to case, depending on the point of reference or perspectives of the participants (e.g., citizen, health care worker, policy maker, institution, etc.) (Nduati et al, 2007).

3.13 Specific programmes / interventions

Community building aims to expand and strengthen informal ties among community residents and to link community members to supportive individuals, organisations, and resources outside the neighbourhood through partnerships, coalitions, and networks. Community building is widely believed to contribute to a variety of outcomes important to the community such as improved economic opportunity, housing, safety, health status, physical infrastructure, and strengthened social relationships that provide mutual support. Community-building efforts have largely been supported by the non-profit sector and various government initiatives. Community-building strategies include leadership development programmes aimed at identifying current and potential community leaders and strengthening their capabilities through training, mentoring, and peer support in such areas as effective communication, mobilisation of residents, planning, administration, programme evaluation, budget and human resource development and management, and conflict resolution (Blackwell & Colmenar, 2000).

The primary goal of public health care is to protect and promote the health of the general populace. Typically, research, surveillance, policies and programmes in public health focus on patterns and factors affecting the health of populations (rather than of individuals), including reduction of risk factors and strengthening of protective factors. These are factors which extend beyond immediate issues of health care to

include social, economic, political and physical environmental conditions that affect people's health. The field of public health began emphasizing community participation in health-related planning in the 1960s, particularly after the development of the neighbourhood health centre movement in 1965 as part of the War on Poverty (Minkler et al, 2001). These federally qualified centers provided (and continue to provide) preventive and primary health care to medically under-served communities throughout the United States, under the direction of community boards.

The growing emphasis on community-based participation in planning and implementing initiatives promoting public health continued during the 1970s and 1980s. In 1986, the World Health Organization (WHO) adopted an approach to health promotion that emphasized the importance of people's control over the determinants of health, public participation and inter-sectoral cooperation. Beginning in the 1980s, community organization strategies were adopted as part of efforts to combat the growing AIDS epidemic (South African Health Review, 2001).

The picture that emerges from a study in India is that most programmes in that country continue to neglect rural areas. Low HIV awareness and high stigma, fuelled by low literacy, seasonal migration, gender inequity, spatial dispersion and cultural taboos, pose extra challenges to effective implementation of much-needed HIV education programmes in rural areas. Using established networks (such as community based-organizations already working on empowerment of women) and training women's self-help leaders, and also hairdressers, as peer educators was found to be an effective and culturally appropriate way to disseminate comprehensive information on HIV/AIDS to low literacy communities. Similar models for reaching and empowering vulnerable populations should be expanded to other rural areas (Van Rompay et al.2008).

The extension of free primary health care to all South Africans has improved access to health care. PHC services, providers and facilities carry a heavy burden of responsibility for the provision of health care in South Africa and even though the implementation of this policy has removed cost barriers, major challenges still remain such as inappropriate training of primary health care nurses and other PHC facility

health workers, multiplication of roles, heavy workload, infrequent and inadequate supervision, inequitable distribution of resources, poor facilities, poor infrastructure and transport. There is no doubt that the escalating twin epidemic of HIV/AIDS and TB is placing huge demands on PHC workers. Steinberg and others (2002) contend that there is high utilization of public clinics by AIDS patients, and McCoy et al. point out the challenges of deploying adequate and appropriate human resources at pilot sites for the prevention of mother-to-child transmission (PMTCT) (Steinberg et al.2002).

Although South Africa has the rich potential of a new democracy committed to people centered development, the unwelcome reality is that global and national macroeconomic systems often threaten rather than strengthen programmes that target the two-headed 'monster' of poverty and HIV/AIDS. All the more crucial, then, is the role of community-based health workers in continuing to span the fields of health promotion, prevention, care, rehabilitation and palliation (South African Health Review, 2001).

3.14 Project limitations

Despite reluctance to shift views about healthcare, there is growing evidence to support the more radical PHC approach. Two publications have made major contributions in this regard. Although neither focuses directly on the impact upon health outcomes of the relationship between equity and empowerment, they provide the wider context that is suggestive of such a link. The first document is the World Bank's World Development Report 2000/2001 titled "Attacking Poverty", which pulls together data describing the situation of the poor worldwide and identifies three areas for policy action by national governments. One of them is empowerment (the other two being opportunities for improvement and security). The second document, written by Nobel Laureate Amartya Sen, is titled "Development as Freedom". In it Sen gathers data to show the link between equity and empowerment and argues that the oppression and deprivation of the disempowered result from constraints upon their opportunities to realise their potential by developing individual capacity. The

lack of freedom limits the options people have to act in their own best interests and those of the society (Sen, 2001).

The major reason why this potential is limited, at the present time, is inequity in distribution of resources and opportunity, and weakness or absence of mechanisms to allow people to engage actively in decisions about resource allocation and insure that consensual decisions are transparent and carried out. (Rifkin, 2003)

3.15 CEP Ladysmith

The CEPs in Ladysmith, KwaZulu-Natal, which are being researched in this study came into being in 2004, KZN. Prior to their launch, issues and concerns were discussed with community members, community leaders, and representatives from the Departments of Health, Social Welfare and Agriculture in relation to HIV/AIDS, unemployment, education, poverty, teenage sexual activities, nutritional needs and shortcomings in service provision by the three named Departments. The Ladysmith community and community leaders identified a need to participate and take ownership of community projects. The projects being launched were aimed at problem solving, skills development and strengthening of social networks. The goals of these projects were to promote community and organizational participation in project planning, resource development and allocation. CEP leaders were identified among the community program workers and representatives from the Departments of Health, Social Welfare, Agriculture and the local Council to form a steering committee that met monthly to discuss each project's planning, achievements and difficulties. Community program workers joined the project of their choice. A partnership was formed between community members, representatives from the Department of Health and members of the Ladysmith Council.

3.16 CONCLUSION

The data explored in the literature review was compared with the data obtained via the interviews. The researcher discusses in chapter 4 the findings.

Chapter 4

Findings and discussions

4.1 Introduction

Chapter 4 describes the data collection process; description of the participants; and discussion of findings.

4.2 Data collection process

The CEP leaders were approached at the central offices from which they function in Watersmeet and in central Ladysmith. Interviews were conducted at venues such as community centres and meeting venues accessible to the participants and researcher. The interviews were tape-recorded with the permission of the participants. The participants evidently felt at ease in sharing their experiences and the stories and experiences they related were rich in knowledge which they generously and enthusiastically shared with the researcher. The participants welcomed the researcher into their community and gave the researcher full access to their daily activities. In the interest of the research, the researcher joined the participants in some of the CEPs, encountering both the generosity and the thoughtfulness which they showed towards the fellow community members they had undertaken to help, together with the firm understanding they evidently had (without necessarily realising it) of CEP fundamentals. This was a powerful and enriching experience for the researcher, as the participants had much to offer and demonstrated commendable passion, dedication and ability to serve. These were also rich lessons and insights that regrettably fell beyond what could be captured and conveyed in this thesis. The participants were contacted after the interviews to determine if the essence of the interview had been correctly captured.

4.3 Description of the participants

Data was collected from ten participants involved in two CEPs. All the participants identified by the CEP leader agreed to participate. Table 4-1 below contains a short description of the participants.

Table 4-1 Description of participants

Participant pseudonym	Age	Gender	Description
Pat	50's	F	Pat is a health professional with prior experience in community services.
Thabani	30's	M	Thabani is a volunteer who has been involved in the CEP since 2008.
Neliswa	20's	F	Neliswa enrolled in the CEP in 2008. She has a specific interest in community projects that address the needs of orphans and children.
Joanne	50's	F	Joanne is a health professional with prior experience in mobile clinic services.
Themba	50's	M	Themba was recruited in 2003 as a volunteer.
Lindiwe	40's	F	Lindiwe has a special interest in orphan care and was recruited in 2008 as a volunteer.
Swenkie	60's etc.	M	Swenkie was recruited in 2006 and entered as a volunteer addressing the needs of the elderly.
William	60	M	William was recruited 4 to 5 years ago. He approached the programme director and volunteered his services.
Norah	70	F	Norah was recruited as a volunteer approximately

Participant pseudonym	Age	Gender	Description
			8 years ago. She entered the programme via the elderly craft programme.
Ntombifuthi	30	F	Ntombifuthi was recruited as a volunteer in 2007. She entered the programme via the Care giver programme.

4.4 Discussion of findings

Themes and sub-themes are set out in Table 4-2.

Table 4-2 Themes and sub-themes

Themes	Sub-themes
Giving of yourself	Responding to a need
	Passionate engagement
Maintaining the sustainability	Community ownership
	Seeing the results
	Careful selection of volunteers
	Monitoring and evaluation
Assisting the CEPs and CEPWs	Respect and trust
	Upskilling
	Community independency

4.4.1.1 Experiences of CEPWs within a CEP

The participants described their experiences within the community empowerment programme as “giving of yourself”. This theme was subdivided into two sub-themes, namely responding to a need and passionate engagement.

4.4.1.2 Responding to a need

The participants explained to the researcher how they noticed a need and chose to become involved. The participants mentioned that attending to the social, emotional, spiritual and psychosocial needs of families was important for them.

Speaking humbly yet passionately, Pat explained that she could not ignore what was happening around her and needed to get involved, she said:

I was doing [a] community programme, so I used to visit households in community vehicles from which we were seeing patients. One day when a child was looking for food and asked its ailing mother to prepare food [it] really made me decide that people need support closer to them.

Initially getting involved was not an easy task, as she explained:

I experienced a lot of stigma [and] they [HIV positive people] were scared to come forward and test and say “I am positive”. And even at home people were really isolated. I remember in one home, one person was put in a tin house where food would be pushed to him, because people were scared they would infect them. The communities were really not informed, so with the start of this programme. The volunteers targeted those people and encouraged them and motivated them to declare [their HIV status].

William and Swenkie had similar views and William said:

We realised that there were a lot of patients not receiving any care. We got together and decided to help them, assessed the clientele, .assessed the amount of members that must be taken to the clinic, got a taxi. [We] compiled a data base, received their medication, made porridge and administered the medication. It was difficult here. We were

using wheelbarrows to get water. We applied for funds [and] thereafter we started with gardens.

Swenkie said

I was trying to help the other peoples but I couldn't make it, because there are lots of peoples here who are vulnerable, peoples who need to [be] rescue[d].

Various participants focused on the needs of vulnerable children in the community. Neliswa described herself as having a passion for children and said she got involved in the programme to attend to social, emotional, spiritual and psychosocial needs of families. The programme empowered her to understand children's needs and their responsibility, as she explained:

It has been so hard to see children experiencing this life, like when you grow up and you don't have any one around you to guide you, to feed you, even to dress you, anyone to go to take you to school. It is sad. Although they don't have parents but if they are given a chance to go to school. We [volunteers] bought them new uniform. We got centres where they got food and when the school close we bought them food parcels and delivered those food.

Lindiwe shared this need to help vulnerable children which had been started by her mother and wanted to spend more time with them. She wanted to open her own orphan care centre and was assisted by Social Development. She said

My neighbours are orphans [and] no one cares for them, so my mother chose to help the orphans by giving money to buy food and cook breakfast, dinner and supper. So I was serving them for a long time then I decided on how can I help this children, .because at school they were being chased. They don't have school fees and books. I went to the social workers [and] spoke to them. They said that I must gather all the orphans, their surname and first names, then bring them to them to see how many they are and how they can help them. My mother decided to talk with the director and the director phoned schools and confirmed that the children were about to be chased away from schools due to non-payment and no books.

According to an AIDS foundation report, government and non-state actors have turned to community volunteers to serve as community health workers (CHWs), addressing health challenges and reducing the strain on the formal health care system. DOT Supporters, have been widely recognized as having a vital role in complementing existing primary health care services and improving their quality and outreach (Magezi and Aids Foundation of South Africa, 2009).

Community-based health workers fulfil a wide variety of roles, and few communities are entirely without them. They work in rural, urban, peri-urban and farm settings, among some of the country's most under-served communities. They have played a significant role in reducing child morbidity and mortality by promoting nutrition, growth monitoring, breastfeeding, immunization, contraception and oral re-hydration (South African Health Review, 2001). According to De Souza (2007), volunteers welcomed the possibility of expanding their role, on condition that the appropriate training and support was provided. The training they received positively assisted them their overall tasks of promoting each of the six components of AIDS competence (de Souza et al, 2007).

4.4.1.3 Passionate engagement

The participants showed total commitment and involvement in the community need and often persevered and continued to help and be involved even under very difficult circumstances.

Several responses conveyed a sense of passionate engagement, linked to emotional rewards that CEPWs had experienced – often unexpectedly. Respondents displayed total commitment and involvement in the CEPs, persevering despite difficulties. Initially stigma had been intense and affected community members were scared to come forward and be tested. Poverty and physical access created further difficulties.

William explained:

Initially it was very bad. I found that the community was very sick. It was difficult to get transport to go to clinics. They wanted the person [patients] to come to them [mobile service points]. You find others that

are sick, they cannot even stand, others they are on the bed [bedridden]. We used wheelbarrows.

Joanne, a primary health care nurse, enjoyed getting to know her patients and providing them with psychosocial support. Her experience in the mobile clinic had been that her interaction with the patients went no further than simply providing them with consultation. Paying tribute to the work done by the CEPWs, she said:

Volunteers took food from their households and give to whomever. They [patients] don't have food [and] can't take medication on an empty stomach.

The researcher observed this delivery of food at first hand while she was accompanying CEPWs in their day-to-day activities. On a day when the mobile clinic was visiting the area the CEPWs wanted to make sure that certain patients reached the service point at a particular time. At sunrise, she and the CEPWs set out on foot to collect the patients, but first the CEPWs provided a dish of porridge so that the patient didn't leave home on an empty stomach. For patients too weak to walk the only way to get them to the clinic was sometimes in a wheelbarrow. At the clinic a registered nurse consulted briefly with each patient and provided the necessary treatment and counselling. Taking over once more, the CEPWs not only got each patient home again but also stayed on to make sure that the patient had a cooked meal and that there was also appropriate counselling for the family.

AMREF reports (2009) indicate that CEPWs often persevere under difficult circumstances, and participation in these programmes serves to increase their confidence and skills (John Losikiriat's story, 2009). However, while they are motivated and encouraged by the positive changes they have brought about in the lives of community members, they become discouraged by non-payment, exposure to severe heat, water shortages and lack of resources, accessibility to villages, bad roads, traveling long distances and security aspects (Jane Sereu's story, 2009). De Souza (2007), found that volunteers were remarkably dedicated and committed, and that they welcomed the possibility of expanding their role (De Souza, 2007).

4.4.2 Maintaining the sustainability

According to the CEPWs, community ownership, seeing results, careful selection of CEPWs and monitoring and evaluation all strengthen the sustainability of the CEP.

4.4.2.1 Community ownership

The participants said that it was extremely important for the community to take ownership of the CEP. Steps singled out by participants included initial mobilization of the community, identifying the hierarchy of community leadership and the key community members, finding out what CEPs are already in place that could be strengthened (which could include social activities), and determining the needs, challenges, resources and disease profile of the community. The participants stressed that hierarchy, traditions and culture must be acknowledged and taken into account.

Thabani:

Within themselves there should be some sort of hierarchy, some sort organisation or leadership. So whatever you [do] should be addressed to proper channels. [Find] out who is in charge of that community, approach also the leaders and [gain] first consent. You can't just go around the community [without gaining] consent [from] the indunas or the counsellors. You have to follow each and every channel that is within that community. If the leaders even don't know who's working in their community they will [view it as] scams.

CEP issues, including expectations and funding, were discussed with the community; the CEP adapted to the community's changing needs and the community reshaped the CEP according to their needs. Having begun as an HIV-support CEP, the programme now also addresses PMTCT, Tuberculosis and cancer, reaching out to all the households within the community. CEPWs were trained and received certificates in HIV and TB management and home-based care and special attention was paid to vulnerable community members such as older people, children and low-income groups.

Pat explained how communities can gain community ownership. She remarked that all existing programmes must be acknowledged, whatever their impact. This includes social church activities and community activities. She also advised:

If you want to establish a committee for the community find [a] leader who they think should be there and then make suggestions. You won't have everyone but try to have almost everybody represented

She noted in addition that the CEP was well supported by the professionals in and around Ladysmith, and by community members, community leaders and other leaders.

Joanne confirmed Pat's observations:

The most important thing is to find as much out from them [the community] as possible. Give them time to voice whatever, but yet keep control because you again can't meet the whole community, you meet the representatives. If you meet the whole community you won't get anything. You can't go and call everybody there, but you look for the leaders, the councillors, people that are representing the community.

Joanne's saw CEPs as a valuable extension of government programmes where inability to travel to clinics or be at the specific mobile health service point at a specific time may otherwise prevent patients from accessing treatment:

Making a related point Thabani commented that

You do a like community profiling, because you cannot just come with what you're going to be doing, First hear from them, find out exactly what are their needs, so that whatever you be bringing to them will be relevant to that community.

In recent years, public health practitioners and researchers have increasingly recognized that many of the social and physical environmental determinants of health require that public health expand its conceptualization of mission and scope of activity to include non-traditional partnerships with professionals, community organisations and residents concerned with such areas as housing, transportation, economic development, architecture, recreation and others (Kieffer et al., 2004).

Although the generic term community health worker embraces a wide range of personnel and very uneven levels of competence, the National Minister of Health and the Department are vigorously encouraging provincial departments to establish CHW programmes as quickly as possible in disadvantaged communities throughout the country. From 2004 both the National Department and at least three other provinces have had formal CHW policies (Magezi and Aids Foundation of South Africa, 2009).

Among the possible community empowerment strategies noted by Blackwell and Colmenar (2000) are strengthening people's capabilities through training, mentoring, and peer support in areas such as effective communication; mobilizing residents; planning, administering, and evaluating programmes; developing and managing budgets and human resources; and conflict resolution. (Blackwell & Colmenar 2000). Broadening of leadership capacity (with multiple people at various levels of leadership, refreshed by regular addition of more individuals) is important since each person has their own sphere of influence (organization, church, neighborhood, family, etc.) with its own web of connections.

Cheadle, Senter, Solomon, Beery and Schwartz (2005) note that broad-based community partnerships are seen as an effective way of addressing many community health issues, although the partnership approach has had relatively limited success in producing measurable improvements in long-term health outcomes. One potential reason, among many, for this lack of success is a mismatch between the goals of the partnership and its structure/membership (Cheade et al, 2005).

4.4.2.2 Seeing results

The positive outcomes motivated volunteers to remain involved in the CEP and encouraged community members to approach the CEPWs.

Themba described how services rendered impact on the community:

Maybe they coming from hospital, they heard that now he have got HIV, then he [patient] is crying. We [volunteer] just talk with him. If they just

come here out, they must laugh, they [are] happy. They know this is not the last road; the road is still going on with love.

Themba explained that recovering patients reclaiming their position as breadwinner encouraged community members to approach the CEPWs:

Then he goes to his boss [and say] I am coming back. I am alright now [and] they [patients] start working. They feed their family.

Pat, Nombithi and Lindiwe shared a similar experience, described by Pat:

They [volunteers] were consistent in providing services. People saw results. Patients who were not able to walk at the start on treatment, because of their low CD4 count. Now they [patients] are standing up walking, gaining weight and being prepared to lead and talk about it. They are sharing [talking to community member] listen you saw me I was smelling, I was this and that and nobody wanted to be next to me, guys come there in there is life in accessing treatment.

Lindiwe commented that

The project is very special because children attend school and receive food. They received breakfast, .lunch box for supper. There are children that don't get food at home. This programme works a lot for the orphans. Others are in universities.

The training in HIV/AIDS, Tuberculosis and cancer counselling and in resource management empowerment had given the participants increased confidence, enabling them to use the resources provided by the CEP to address community needs and improve community wellbeing.

Mentioned in particular was empowerment given them by the CEP to *act as councillors; solve problems; share knowledge*, understand *children's needs*. With the training he had been given, Swenkie *felt like a doctor*, and comments such as those given above by Joanne and Lindiwe illustrate a sense of renewed or reinvigorated commitment to community service.

Joanne said,

It was exciting to come and work here because I am community-based person, but what I found out is that where we were working at the health department we don't really get to know the people that you serve. As much as I was working in the community mobile, .you can only see them at the point [at a particular] time at the community clinic, but working here [community programme] has made me able to go into their households, see the real person that I am serving and see their real problems.

John Losikiriat's story indicates that CEPWs, who often keep working under difficult conditions, derive motivation and encouragement from the positive changes they have brought about in the lives of community members (John Losikiriat's story, 2009). De Souza, et al. (2007), studying HIV/AIDS projects in India, found that volunteers were willing to work incredibly hard for the smallest of gains.

4.4.2.3 Careful selection of volunteers

CEPWs in this study had been selected from the local area and this was important as it increased support for them from the community. Initially participants avoided dangerous areas, but as Thabani explained,

When you are dealing with areas that are little bit rough, whenever [you feel] threatened, [I] would you suggest if you are not able to provide them with security [to] avoid some areas. Because if you tell them to work in groups, four people are doing the job that can be done by one. [This implies that] four people did five households [instead of] twenty people [covering] twenty households. You are not going anywhere; rather spread them. You are understaffing yourself.

Initially Pat grouped CEPWs together and assisted them to obtain an NPO (Non-profit Organization) number which allowed them to seek funding. Committed, caring, non-judgmental and sensitive CEPWs were selected who respect the community and don't give up, despite challenges. Confidentiality is maintained at all times. The CEP was not politically obvious and the health of all was addressed. Pat explained:

It is it is better if they [CEPWs] are nominated by the community, they will tell you the characters. You are looking for a person who is

confidential. You say your standards of education, the qualities of a volunteer [you are looking for] somebody caring, somebody humble. You say to them [that] if you want proper service for your community, nominate people who will who have these characters because they will be serving your community. Everybody must be comfortable, happy working with them, because people will provide proper service for you.

Norah agreed with Pat, commenting that

First you would contact people that you trust and can work with, .like on a committee .Identify the right people, also identify the untrustworthy and bad ones, .like us now. We know who to approach [who] we don't want , [who] is disrespectful [who] must not be assigned to people. You have to be patient when working with people, greet them even if they don't want to greet back, be courteous, be patient, dress appropriately, .walk and be humble. Don't fight with them[patients] , because you are here to help.

Participants advised that key community leaders should be requested to assist with the selection of CEPWs. Norah emphasized the importance of considering age and gender appropriate volunteers, she said

The young ones will go to their girlfriends and the old men are naughty, .even us as the old people, we've got a lot of things that trouble us.

Norah explained further that in her opinion older CEPWs remained strongly committed as they were passionate about the suffering of community members. Unlike some of the younger CEPWs, they did not demand a salary of R1000 per month or more. Initially they received an allowance of R70 per month, which had recently been increased to R77 per month. With strongly dedicated CEPWs their motivation in offering their services is fundamentally spiritual. CEPWs increasingly reported that they could see the success of the CEP, and patients increasingly reported that they had positive experiences.

Joanne supported Norah's observation:

The younger female, they can just start something, less than in the thirties. They are still looking for greener pastures. So yes they can come with their standard tens but they leave the position for more

fruitful, you can't stop them, but while they are there in the community, they can do something.

Joanne also commented that

You have to standardise your selection and you need plan it thoroughly before you enter any community. I will need such and such people, females only or males and females [and] what message you will spread.

Participants emphasised that CEPWs must display leadership skills and commitment and also certain characteristics, such as humility, caring, sensitivity, courtesy, and confidentiality. Kieffer et al. emphasis the correct selection of volunteers. The literature also indicates that gender and age criteria might differ from culture to culture. (Kieffer et al. 2004).

The Departments of Social Development and Home Affairs, fellow health professionals in and around Ladysmith, community members, community leaders, and other leaders support the volunteers. They see CEPs as extending government programmes which have hitherto been inaccessible to patients unable to travel to clinics or be at a specific mobile health service point at a specific time. At one stage some of the CEPWs were given contracts, which was an added motivation for them.

According to an International Research Centre report (2007) leadership development is a primary component of capacity building. It can also be the precursor to interventions focusing on community awareness and outreach activities. In order for these activities to succeed the leaders' skills must be sufficiently developed and recognized within the community (Nduati et al. 2007).

Community-building initiatives can provide important support for the development of the formal leadership skills of such individuals. Kieffer et al. (2004) address the issue of leadership in a CEP. Leadership may be conceptualized in a traditional way, such as organizational, political or church leadership, but also in less formal ways, such as

natural leaders in a neighbourhood (who will often be women). Leaders “make things happen” because they have the necessary ability and the necessary respect from others. They can galvanize public opinion and organize resources needed to address public health problems.

4.4.2.4 Monitoring and evaluation

Participants in the study underlined the need for systematic monitoring and evaluation. Pat explained that supervisors must be carefully selected:

They [supervisor] will report every week and express their concerns, talk about challenges, advice, capture the data and [forward] to whatever office. It can be a community member that select for that particular programme, because they need to give their view of how they see the programme going. [The committee will meet] like on a monthly basis with the programme director, perhaps on weekly basis meet with the field workers , recording all the information will help you in future [on] what you need to improve.

The supervisor must monitor services rendered, advise and support CEPWs, conduct spot checks and deliver a weekly report at a committee meeting. This report must address the services rendered, challenges experienced, resources utilized and additional resources required. These reports must then be forwarded to a CEP director who remains responsible for services delivered, resource management and financial management. Reports and financial and resource management documents guide CEP improvements and community members who might have to take over responsibilities if the current leaders withdraw from the programme.

Visitation points must be defined clearly. It would also be useful to create a map indicating the visitation points. Thabani explained how practical applied monitoring and evaluation undertakings contributed to sustainability:

Plan the day, like their map, so leave it at where they [CEPWs] supposed to be and where they supposed to signing in the morning, where you going to find them, then you will know same time what he is doing, because if she just submits whatever then goes back to sleep.

Carry some sort of a book, write whatever they [volunteer] did particular for the day.

The Detroit REACH community programme emphasizes community organizing, conducting community meetings and group education, peer leadership, recommendations of evaluation, use of computers for data collection and management, use of the internet to gain access to health information and other resources, advocacy, resource development, case management, and planning and implementing community health awareness events and media campaigns (Kieffer et al. 2004). Themba put a similar emphasis on meticulous procurement processes so that funds are utilized for what it is intended, reaching out to all the households within the community, and gaining the trust of donors and community members:

They have got the one who looking after the budget, I mean for finance. The main thing is money on a project [and] how to use it. When we want to procure an item we make some quotation first, choosing the low price.

4.4.3. Assisting CEPs and CEPWs

Recommendations were developed for CEPs and CEPWs based on the lived experience of programme participants and in line with the researcher's own first-hand experiences of day-to-day practices within the CEPs. These experiences were integrated with the data collected during interviews. Recommendations offered by the participants emphasised respect for community, thoughtful conduct on the part of volunteers, upskilling, and community independency.

4.4.3.1. Respect and trust

CEPWs must be seen to be honest, thereby gaining the trust of the community. CEPWs were advised to introduce their CEP and be very clear about what they can offer. Key community members needed to be involved in the planning phases to secure their support. Pat responded as follows:

The powerful part is the respect when you respect a person the person begins to trust you then they can give you all the information you want give you all the support you need and you must also be honest with them.

You have been trained, you are knowledgeable, you have the skills but she knows her community better. So when they bring their problems please listen to them and give them advice. I am not saying accept everything they are saying but show respect, because you don't just walk in someone's land without letting with them know it is for this reason.

In many communities there is disconnection between perceived concerns of the community and funding available for community planning as imposed externally. If the community does not see the importance of planning for prevention and control, set against an epidemic of community violence, a real community response is unlikely to emerge despite the availability of funding. Community awareness and readiness to change may be enhanced by participation in community planning processes. Community awareness and readiness to change may be stimulated by community participation in identifying and understanding community health issues and their context. This involvement is regarded as essential to the success of public health initiatives, since an otherwise well-designed programme or policy may fail without a basis in community realities, and community agreement regarding the programme's importance and activities (Nduati et al, 2007).

4.4.3.2. Upskilling

CEPWs must not only be trained appropriately, but also upskilled. They must attend refresher courses and be informed of new developments. Participants drew attention to training in home-based care, HIV, Tuberculosis and counselling. Swenkie, an older male, explained how he gained the respect of the community:

It is very important in disease that you know about it, because like myself I am like a doctor. They say to me, come here we only manage to sweep the house, but it stinks. The gogo has messed herself, but we need someone to go there. I go in there like a doctor. I can take off the dresses put it in the bath, clean her perfectly, put all those things back to normal, then clean the bed, start feeding her without troubles, because of that training.

Refresher courses play an important role. Participants pointed out that at times their knowledge are tested by members of the community. Community members lose confidence in the event that CEPW's knowledge is not current. Thabani responded

They [CEPWs] will always be updated, whatever is happening so if they do go to the community some of the people in the community they are updated and they will try to test them, how much they know. So you will end up little bit like a changer [and end up] going to someone who knows his story well, not just somebody who's trying to take chance.

Kieffer et al. (2004) warn against focusing development efforts solely on one person, or just a few people, whose possible departure could then undermine the whole initiative. Community empowerment implies holistic approaches to building social capital and addressing systemic problems in communities, through developing partnerships and policies that promote community participation, addressing issues of race and ethnicity, reducing isolation, and strengthening families and neighborhoods (Blackwell & Colmenar 2000).

De Souza, found that CEPWs valued the counselling training because it gave them skills and confidence and heightened their sense of personal motivation and credibility. Traditional and community leaders showed more respect towards them and they met with heightened recognition of the contribution they were making (De Souza,2007). Gibbon found that for community members capacity building through community empowerment means gaining knowledge, skills, and confidence to improve their own lives (Gibbon et al. 2002).

4.4.3.3. Community independence

Participants suggested various avenues that CEPWs should explore for possible additional support, both governmental (including the Departments of Education, Home Affairs and Social Development) and nongovernmental (such as local organizations within the community and local shop owners). Establishing food gardens was another way to reduce dependency on government.

Pat:

You can negotiate and you can say I understand what you want but here is what I am offering you and this is how far I can go.

Swenkie:

It is to teach the peoples to feed themselves, work for themselves

Thabani:

We not like always depend on receiving. We do not only depend on people to give us money, especially like the funders.

A point made by Blackwell and Colmenar which was endorsed by the participants was the desirability of reducing dependency on government resources (Blackwell and Colemanar, 2000). Broadly defined leadership development protects against loss of community capacity. For example, the connections between a leader who is not indigenous or committed to the community may be fragile. If leadership development focuses solely on this person, or a few people, then the results of the development efforts may disappear if the person exits the CEP (Kieffer et al. 2004).

Leadership must have the ability to gain the respect from others which is needed to “make things happen.” Leaders can galvanize public opinion and organize resources needed for public health problems. Community-building initiatives may provide important support for the development of the formal leadership skills of such individuals. (Kieffer et al. 2004)

Rather than being strictly linear (i.e., community-building outcomes leading to improved public health outcomes), the relationship is often more dynamic, with one result building on another. The entry point may vary depending on the capacity and readiness of the community, its organizations and various leaders. Further, when improvements occur with one set of strategies, additional receptivity to other strategies may be created. Thus, improved public health outcomes may actually provide readiness for more and greater community-building outcomes that in turn speed the implementation of sustainable public health programmes and policies (International Development Research Centre, 2007). Hartwig et al. (2008) caution

against underestimating the time required to establish (i) a consortium; (ii) systems and procedures for working together and (iii) trust (Hartwig et al, 2008).

4.5. CONCLUSION

Chapter 4 outlined the data collection process; described the participants; and discussed the findings. Literature were reviewed and compared with the findings. The researcher made recommendations based on the data explored.

CHAPTER 5

Summary and recommendations

5.1. Introduction

The researcher explored the lived experience of HIV/AIDS Community Empowerment-Programme Workers (CEPWs) in Ladysmith, KwaZulu-Natal, and sought to discover which aspects, as perceived by the CEPWs, contributed towards the sustainability of two Community-Empowerment Programmes (CEPs) in Ladysmith. The study aims to formulate recommendations for CEPs and CEPWs, based on the lived experience and testimony of participants in the two CEPs studied, with a view to assisting nursing and other educators to train and prepare CEPWs for their tasks.

5.2. Experiences of CEPW's within a CEP

The volunteers involved in the two CEPs “gave themselves” to the community. They saw a need and most of them chose to respond to it with passionate engagement. Certainly, the participants in this enquiry did so.

5.2.1. Responding to a need

Participants addressed the social, emotional, spiritual and psycho-social needs of their community as they could no longer ignore what was going on around them. Participants' responses give an indication of the level of dedication called for in implementing a CEP. This comes through in details such as having to use wheelbarrows to transport water, planting food gardens, providing home-based care, accessing funds, enduring stigma, and maintaining political impartiality. Participants indicated that they chose to focus on the needs of specific groups - for example, vulnerable children, teenagers, elderly citizens, and individuals infected with HIV and AIDS. From reports and evaluations of numerous CEPs in different parts of the country, it is clear that many have achieved some astonishing feats over the past decade (South African Health Review, 2001).

5.2.2. Passionate engagement

Speaking humbly and yet passionately, participants explained that attending to the social, emotional, spiritual and psycho-social needs of families in the community was important to them. They displayed total commitment to, and involvement in, the CEPs. They often persevered and continued to be involved under difficult circumstances: poverty, the dearth of health services, stigma, a lack of academic training. Some participants indicated that their commitment rested on a spiritual and religious base. AMREF reports (2009) offered similar findings. John Losikiriati's story noted the determination to persevere under difficult circumstances (John Losikiriati's story, 2009). Jane Sereu's story (2009) reported that volunteers drew encouragement from witnessing the positive changes they had brought about in the lives of community members, and this spurred them to carry on, despite non-payment, exposure to severe heat, water shortages, lack of resources, bad roads, long distances, limited accessibility to villages, and security problems (Jane Sereu's story, 2009).

5.3. Factors in sustainability of a CEP

The participants explained that it was important that the community took ownership of the CEP. Achieving positive results motivated CEPWs to stay with the CEP and also encouraged community members to approach the CEPWs for advice or assistance. CEPWs were appointed after a careful selection process. The CEP director remained responsible, and accountable, for all services rendered by the programme, and also for financial and resource management. Supervisors monitored services rendered by CEPWs. A record was kept of CEP activities which served as a baseline for expanding and adapting them.

5.3.1. Community ownership

Participants explained how community ownership was achieved: a community meeting was requested at which the activities and funding of the proposed CEP were fully discussed. The CEP Director was clear about what was on offer and no false expectations were created. It was made clear that the CEP intended to address the needs of the community as understood and prioritized by the community itself, and to

adapt its activities to changing community needs. It was seen as crucial to involve the community in the CEP's planning processes, from the compilation of a community disease profile to ideas for marketing the CEP, such as sports events or giving out CEP caps and T-shirts. Remaining politically neutral, the CEP would reach out to all households within the community. It would ensure equity in the distribution of resources and opportunity and would put in place mechanisms to allow people to engage actively in decisions about resource allocation. Decision-making would as far as possible be consensual and transparent and decisions would be carried out.

Participants stressed the importance of identifying and co-opting key members of the community. Recognizing that community members had first-hand knowledge of their own situation, CEPWs, in engaging with them, should refrain from assuming a superior, 'know-it-all' attitude based on academic qualifications or status. Adopting a posture of deference, they should display honesty, show consideration (keeping appointments, for example), and maintain transparency. They should be at pains to respect the community's culture, traditions and dress codes, striving to build a relationship of trust, which is so important for the long-term sustainability of any public health endeavour.

In the day-to-day work of the CEP it was important to plan the allocation of CEPWs for maximized coverage of the community by the available personnel. Coverage would be reduced if CEPWs went about the community in groups, even if this might sometimes have seemed advisable for reasons of security. A map of the community indicated visitation points, and localities that could be dangerous were initially avoided. CEPWs were nominated for supervisory and support roles so that co-workers would not neglect their duties. These supervisors provided weekly feedback to the CEP director, passing on concerns noted by the CEPWs. A secretary and treasurer were selected who serve on a day-to-day committee, thus ensuring that resources are utilized for the purpose intended.

5.3.2. Seeing results

The successes of the CEP motivated CEPWs to remain involved in its endeavours, while encouraging community members to approach them for assistance and advice. With observable progress came a sense of renewed and reinvigorated commitment to community service, and participants' responses reflected this.

5.3.3. Careful selection of volunteers

Participants underlined the importance of community leaders assisting with the selection of CEPWs in terms of agreed-upon criteria, one of which would often be ability to read and write English. CEPWs selected should be made known to community leaders, as well as to the community at large (by wearing uniforms, T-shirts or nametags). Qualities of character and temperament seen as important in the selection process included: commitment, 'caringness', sensitivity, respect for the community, scrupulousness in maintaining confidentiality, a willingness to be non-judgmental and to persevere in the face of challenges (including bad weather. A further reason for exercising care in the selection of volunteers stemmed from a desire to avoid a situation in which older men interacted too much with young girls. It transpired, as expected, that offering volunteers a contract led to increased motivation. There was a sense that while older volunteers stayed in the CEP because of a deeply-rooted impulse to relieve the suffering of community members, some younger ones were inclined to leave for greener pastures elsewhere.

5.3.4. Monitoring and evaluation

Systematic monitoring and evaluation of services rendered, difficulties encountered, and resources used and/or requested by volunteers, was done by supervisors who compiled weekly reports under those heads. These reports were available for public viewing.

5.4. Assisting the CEPs and CEPWs

5.4.1. Respect and trust

The importance of good community relations emerged strongly from a number of the responses, with an emphasis on respect and deference towards the community

itself, and recognizing the value of community members own first-hand knowledge. Equally CEPW's were advised to "be very clear about what you can offer", involving key community members in the planning phases to secure their support but also making sure there were no unrealistic expectations..

5.4.2. Skilling

CEPWs were trained and certificated in HIV and TB management and home-based care, with particular attention being paid to vulnerable community members such as the elderly, children, and people with very low incomes. Participants emphasized the need for accredited training opportunities supplemented by refresher courses, as these enhanced both skills and credibility. They affirmed that the skills they had acquired had given them confidence and a sense of empowerment, boosting their personal motivation.

5.4.3. Community dependency

The participants viewed the reduction of community dependency as an important goal and correctly saw their own skills development as contributing to the this objective – as too did fund-raising events, effective marketing of the CEP's services, creation of support groups within the community, cultivation of food gardens, and the establishment of a community care centre. Dependence on outside funding could also be reduced through savings: for example, by not confining the procurement of goods to a single supplier. The truth was, however, that dependence on external funding – though perhaps at a reduced level – was certain to continue for the foreseeable future, and while that was the case it was important to adhere to the policies and guidelines laid down by funders and donors.

5.5. Recommendations for development of CEPs

The researcher noted recommendations for the development of CEPs offered by participants in her research study. These were the fruit equally of lived experience and serious reflection.

5.5.1. Recommendations for developing a CEP

The implementation of National Health Insurance will force health-care bodies to pay a lot more attention to delivering effective and efficient primary health care services. Among other things, the revised ten-point plan calls for the mass mobilization of the population towards better health. In the view of the researcher, this more than ever before will spur communities to 'buy into' programmes concerned with their health.

5.5.2. Background to the development of the CEP recommendations.

The data gathered by the researcher, consisting of transcriptions of audio-taped interviews and some field notes, were analyzed, and themes and sub-themes identified, these being submitted to the scrutiny of the interviewees for validation (or non-validation). Validated data were then projected against the backdrop of comparable investigations conducted internationally, and from this fruitful juxtaposition recommendations emerged.

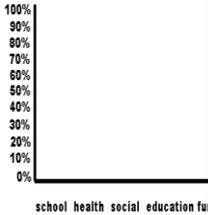
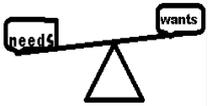
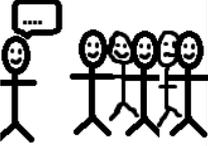
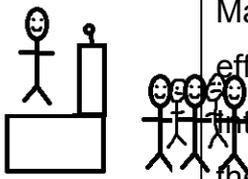
5.5.3. Recommendations for developing a CEP

Identify and approach key members within the community, including the community leaders and traditional leaders. In cooperation with the community, complete a community profile that takes into account at least the following concerns: the public health situation, level and quality of education. social activities. current community programmes, traditional values and norms, available government resources, available non-governmental resources, opportunities, as perceived by the community. Compile a priorities list of the challenges the community faces and of the resources needed to address them. With key individuals in the community discuss the benefits and opportunities that it would derive from a CEP. Be clear about what a CEP can offer the community: what resources it could provide and how it would empower community members. Take care not to raise false hopes or expectations. Assuming the community 'buys into' the idea of a CEP, it should play a role in the selection, preferably from among its own members, of the CEPWs who must be chosen with care and foresight. The criteria for the selection of CEPWs must be congruent with the specific concerns of the community, as reflected in the community profile. The CEPWs must receive sound training and preparation at an accredited training facility and should periodically attend refresher courses ('upskilling') so as to

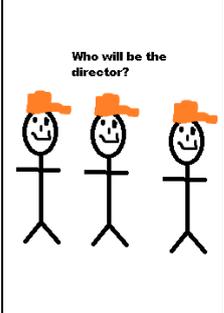
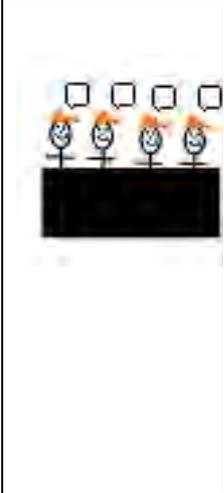
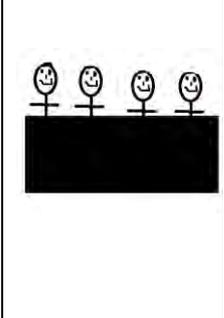
keep their knowledge current, thereby maintaining their credibility in the community's eyes and preserving its confidence in them. The CEP must be effectively marketed, its staff made known to the community, and their duties clearly explained. The supervisor, appointed per area from among the CEPWs, must monitor and evaluate the services they render, offer them support and advice, without delay report problems/challenges to the programme director and/or the appropriate authorities, and submit a weekly written report to the CEP director who will have been appointed from among the supervisors. The CEP director will in turn support and advise his team of supervisors. Depending on the need, the director should meet weekly, or monthly, with governmental and non-governmental funders and should regularly update key members of the community, keeping abreast of its changing needs so that CEP policy can be timeously adapted to address them. He/she must keep a careful record all CEP activities, and must account for all resources utilized. Record-keeping must be comprehensive and accurate, in particular where budget and resource management are concerned. A map of the visitation points must be drawn up and distributed. Support groups should be established within the community. For the convenience of CEP personnel (in particular those working in the field of public health), the researcher has reconfigured the above recommendations into an easy-to-use check list that also serves as a step-by-step guide.

Table 0-1 Check list: Recommendations for developing a CEP

Activity	Descriptive notes	Responsible person	Complete	
			Yes	No
Identify and approach the key members within the community	 <p>approach the community</p> <p>Include the community leaders and traditional leaders.</p>			
Complete a community profile in co-operation with the community	<p>Pay attention to health status, educational level, social activities, current community programmes.</p> <p>Take into account</p>			

Activity	Descriptive notes	Responsible person	Complete	
			Yes	No
		traditional values and norms, government resources, non-governmental resources, opportunities as identified by the community.		
		Prioritise the challenges that the community faces and the resources that will be required to address them.		
Developing a CEP		Discuss with key community members the opportunities and benefits that a CEP can offer the community.		
		Be clear about what a CEP can – and cannot – offer the community: how does it propose to empower the community? What resources will it be able to provide?		
		Market the CEP effectively. Introduce the CEPWs to the community.		
CEPWs must		Establish the criteria for		

Activity		Descriptive notes	Responsible person	Complete	
				Yes	No
be selected with care		<p>the selection of CEPWs, bearing in mind the community's values and norms, the particular challenges facing it, and also other concerns identified during the community profiling exercise.</p> <p>The CEPWs preferably should be recruited from within the community.</p>			
		<p>CEPWs should be easily identifiable by means of a nametag, T-shirt or cap.</p>			
Skilling and upskilling		<p>Train the CEPWs at an accredited training facility</p> <p>Keep records of all training sessions attended.</p>			
		<p>Upskill CEPWs regularly, ensure that their knowledge remains current, thereby maintaining their credibility in the community's eyes.</p>			

Activity	Descriptive notes	Responsible person	Complete	
			Yes	No
	<p>The CEP director to be appointed from among the supervisors whom he/she will support/advise.</p>			
	<p>The CEP director to meet weekly or monthly, depending on the need, with governmental and non-governmental funders; to record all CEP activities; to account for all resources utilised.</p>			
	<p>The CEP director to update regularly key members of the community, and to stay alert to its changing needs.</p>			

5.6. Implications of the study for nursing

The researcher has noted a number of implications for nursing practice and nursing education.

5.6.1. Implications for nursing practice

The selfless dedication of the volunteers prompted many reflections about one's understanding of one's role as a health professional: how often do we know where our patients live, and under what circumstances? Do they have the required

resources, food and shelter? Do we take a moment to find out who cares for them in the community? Do we give much thought to the place of community concerns and community involvement in relation to health issues? For community-empowerment programme workers, those would be obvious considerations to start from. And it would be no bad thing for nursing practice if a good deal more attention were paid to them than is the case at present. To begin with, health professionals should be sensitized to the circumstances and challenges their patients will face once they leave the consulting room.

5.6.2. Implications for nursing education

Traditionally, capacity building has been seen as training local people to use 'modern' methods and approaches to improve their situation. While in theory making room for local traditions and culture and acknowledging that local people know the local situation best, in practice, capacity building often ends up with professionals telling local people what to do and how to do it, and this undermines empowerment and, by extension, equity. Health professionals need to acquaint themselves with the traditions and culture of local communities, be respectful of them, and refrain from adopting a superior 'know-it-all' attitude.

5.7. Recommendation for further research

Selection criteria for volunteers (about which participants made suggestions) are an area that would bear further investigation. Issues that could come into play, and need further consideration, are gender and academic skills, cultural beliefs, value systems and community hierarchy. Other aspects that require further exploration are whether or not volunteers should be appointed contractually and whether or not he should be remunerated. Respondents expressed contradictory views on both these points.

5.8. Limitations of the study

It was feared initially that CEPWs, as well as those senior to them in the hierarchy, might feel threatened by the researcher. Was she spying on them? Given that the programme was in receipt of international funding, this was an understandable worry

which, however, was soon dissolved as researcher and volunteers won each other's trust. A more serious challenge was posed by the language barrier: the initial interpreter had to be replaced as she was prone to mistranslating the researcher's questions and the participants' responses. When translating from English into isiZulu, she experienced difficulty in conveying the import of certain key words and concepts, for example, "sustainability" and "empowerment". These lapses were not altogether unexpected, as it has been shown that there is no such thing as a one-to-one correspondence between words, concepts and idioms across cultures and languages (Birbili, 2000). On top of the difficulties hampering translation from English into isiZulu (and the reverse) is the fact that English is the researcher's second language, and this imposed additional strain on the data-collection process.

5.9. Researcher's reflections

The past five years have been an enriching experience. As a military nurse with 20 years of experience, I had to make a whole paradigm shift whilst engaged with the persons and communities that were to become the subject of my research project. What made things particularly difficult was that during the period of my interaction with those persons and communities I was still employed full time in the military and therefore had continually to shuttle between opposing paradigms. In my official world I am involved in strategic planning and providing guidance and direction. When I was with the community in Ladysmith, there occurred a reversal of roles which was not easy to manage: instead of providing guidance and direction, I received them; instead of other people having to listen to me, I had to listen in silence to other people's viewpoints, had to observe how they functioned and consciously had to keep myself from adopting an 'I-know-what-is-best-for-you' attitude. The phenomenological approach shaping my research methodology landed me in similar difficulties: the scrupulous, drawn-out, at times tedious, writing practices dictated by this approach in its pursuit of the 'truth', the 'essence', of the subjects' lived experience was at odds with the curt, 'command' style of writing that I had become accustomed to in the military setting of my official life.

The time spent with the participants who feature in this study, and with the communities they came from, was precious and humbling. At the beginning I felt confident that well-trained, caring health professionals, were in the best position to empower the community. As time went along, I came to see that the CEPWs had much to offer and were well placed to teach the health professionals a thing or two and, indeed, empower them. The dedication and commitment of the CEPWs motivated me to continue with my research despite the challenge of balancing it against family and employment obligations. They served as an inspiration and, by dint of some nagging, encouraged me to complete this research project, viewing it as a resource for empowering health professionals, and in that way helping other communities to develop Community Empowerment Programmes and implement them effectively.

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ANNEXURE A: Interview schedule

5.9.1.1. DEMOGRAPHIC INFORMATION

5.9.1.2. PSEUDONYMS _____

DATE INTERVIEW _____

PLACE INTERVIEW _____

TIME INTERVIEW COMMENCED _____

TIME INTERVIEW COMPLETED _____

INTERVIEW CONDUCTED BY _____

AND _____ **(RESEARCH ASSISTANT)**

RESEARCH QUESTIONS

- What was your experience within the community empowerment programme?
- What aspects contributed towards the sustainability of the community empowerment programme in Ladysmith?
- What recommendations could aid community empowerment programme developers to develop and implement community empowerment programmes?

ANNEXURE B: Participant information sheet

PROJECT INVOLVED IN	
MPHILONHLE PROJECT	WATERSMEET PROJECT
PERIOD INVOLVED IN THE PROJECT	FROM: _____ (DATE)
HIGHEST ACADEMIC QUALIFICATION	
AGE	
MALE/ FEMALE	
CURRENT EMPLOYMENT	
LANGUAGE PREFERRED	
AREA RESIDING AT	
HOW DID YOU ACCESS THE PROGRAM	

ANNEXURE C: Consent Form

INFORMATION SHEET PHENOMENOLOGY DATA COLLECTION

(This information sheet will be provided to the participant before obtaining their written consent to participate in the study)

Title: LIVED EXPERIENCES OF COMMUNITY EMPOWERMENT PROGRAMME WORKERS PARTICIPATING IN A COMMUNITY EMPOWERMENT PROJECT

Researcher: Ms Deidre Horn
Tel: 031-4511070
Email: hornjd@mtn.blackberry.com

University of KwaZulu-Natal Faculty of Health Science Ethics Representative:
Professor Petra Brysiewics
Tel: 031-2601111
Email: brysiewiczp@ukzn.ac.za

RE: Request for participation in above research

I am a student at the University of KwaZulu-Natal, exploring the lived experience of the community empowerment programme workers involved in the HIV/AIDS programmes. The researcher is of the opinion that the information gained could be useful in the development and implementation of new programmes as well as training of community programme workers. The researcher observed that some community programmes are developed and implemented, yet cease to exist or reach their objectives and targets set. You have been approached to participate in the research as your experience could offer an explanation for the phenomenon observed. In order to ensure sufficient exposure to community empowerment programmes, you must be involved in the researched programmes more than a year.

A time and place for the initial interview, where after meetings will be set up at a place and time you are comfortable with. The researcher will pose four questions to you. The conversations will be recorded with your permission. Audio recordings of interviews will be utilised to verify that it was correctly transcribed. You may request an interpreter at any stage

during an interview. Your response will be written and themes will be identified. The researcher will contact on completion of the transcribing. You will have the opportunity to verify that the researcher interpreted and understood the data collected during your interview correct. Should you not agree with the researcher, you could offer alternative interpretations, which will be verified with you again until no new data emerge.

Your identity will be treated as confidential. Anonymity will be ensured as you will select pseudonyms. There will be no risk for you as a participant. Participation is voluntary. You may withdraw at any stage without penalty.

My contact number 031-4511970, 0836554459 (CELL) , hornjd@mtn.blackberry.com.

Your contribution is highly appreciated. Thank you for participating.

Deidre Horn

INFORMED CONSENT FORM

I _____(PSEUDONYMS) freely and voluntary consent to the lived experiences of community empowerment programme workers participating in a community empowerment project.

I understand that the information gained will assist in the developing and implementation of community empowerment programmes. It will also assist in the training of community programme workers.

I understand that I am free to participate or refuse to participate at any stage without the risk of a penalty. I have been informed that the study bear no risk for me as a participant. I will have the right to read the transcribed interview and make the necessary changes should I not agree with the interpretation of the interviewer.

I have read the contents of this document and understand the content thereof. I sign this document knowingly and consciously.

Signed _____ date _____ place _____
(Participant)

Signed _____ date _____ place _____

ANNEXURE D: Ethical approval form

ANNEXURE E: Permission to undertake research

ANNEXURE F: Interview with participants

INTERVIEW WITH JOAN

Date 13 December 2011 at 09h37 to 10h05

Location Central Ladysmith office

Interview First interview in English

INTERVIEW 1

Joanne tell me just as a start and that I can get to know you ...how you got involved in this . Since when have you been involved in Mpihlonhle?

Since 2005

2005. ..So you have been long here. What is your qualification, your background?

Nursing

Nursing..PHC.... Community nursing ?

Both

Your age if I may ask?

You may ask. ...Golden 55

You're currently employed here?

Hmmm

Are you.... are you ok with the English at this stage?

Jaa

Thanks a lot

And do you stay in Ladysmith?

Mmm...

How did you access ... how did you get involve in the community project?

Here... I was working as at the mobile.. eh.. clinic

Ok

I love community work.... Since I qualified as a nurse I never liked being in the hospital ... so I... I kept on worrying ...wanting to come and work here ...until a post was available and I applied and I got the job

Wonderful.... I just want to get the time. Joanne what has your experience been in the project so far... how did you experience the project... you said to me you came

in uhm 2005... what is your experiences.... if you have to explain to me how it is to be part of this... how did you experience this?

Uhhmm... It was exciting to be... to come and work here because I am community based personI love working with the community...but what I found out is that.... where we were working at the health department we don't really get to know the people that you serve... as much as I was working in the community.. the mobile.

Ja

You can only see them at the point ..a time... like at the community clinic...you just see the patient coming into your room.. but working here has made me able to go into their households... to see the real person that I am serving and see their real problems.

Ok

And .their life.. the challenges that they face... you know when a person will take treatment ...and you can look and see that there is no... nothing that.. there's no food... .. there is nobody working.... when you talk to them.... there is no income in this home and maybe my first day.. should I go on?...

Yes please.... this free.... Continue if comfortable

My first day was...because we were working with the HIV stricken people.... There was this was where there was a mother and a daughter who were both infected... the mother was old.. and I don't know wheter the mother got it while nursing..there was no food... there was this fireplace... with a black pot and there was no.. nothing in the pot...it was cold in that house...remember there was no fire... no no movement..no cooking what what...the house becomes so cold... I was ...woo I was crying ...It was terrible.. no one was getting any income here... so here at Mphlonhle...we used to have food parcels.. so I came back to the office and said yeah... you know what I saw.. then they just give me food parcel that's got everything in..then we had it and I will put it into my car and give it .. and said here...then you will find that the people don't even have fuel now...to cook this food...you know they can't go to the forest and look for wood,, they can't buy paraffin.. you know they don't have electricity..you know those kinds of things..so it was like that when I came..

So to you .. if I hear you correctly when you are at the clinic you basically see the patient treated and they go .. where this gave you an opportunity to personally meet people.. and their real..real life

It was like that and then... I saw many many more such cases .. you know the... what I ...my experience with this kind of work the people that are severely sick .. they are hungry...you find that they don't have food... and sometimes they don't even have someone to support them...you know someone to speak to you and visit you .. you know that kind of thing... even the volunteers they usedto used to go from house to house...those volunteers could.. sometimes they took food from their households and go and give to whoever....to their patients that they found .. their suffering.. they don't have food... so you can't take medication on an empty stomach

What would you say makes this programme so successful? Why is Mphlonhle going from strength to strength?

Why ? because there's many other programmes that also want to help those in need, but they fail. What are you doing differently?

I wouldn't say this is the thing ... but my observation is that.... an organization needs finances ...to work .. so BMS has been our pillar

Ok

Because when you get paid you can go in the morning and work...The second thing is the commitment of the staff .. here we work like a..a family... that I should say... because we help each other you know.. and the commitment to go and help the people...and the oomph in each and every one that came to work and help the people we talking about motivated people.. what I observed here at Mphilonle ... I don't know whether God selects this people workpeople have got that personal commitment in whatever they are doing out in the community and the other thing that motivates us .. you must write a report

Ok

Every month of what you have done... then we also have weekly meetings here at the office where each and every one say's this week I did that that that ... I got challenges here and there..

So you get support in these meetings?

Yes

Ok

We've got staff meetings every Friday that is where you.. you... tell what you have been doing .. where and why and how...then in those meetings then .. if you experienced challenges then it is solved there and then... management will say do this or that.. and then the monthly reporting... You need to give a report... you know..a real report.. so that also motivates us... what can you report if you don't do anything..

That true

Ah ha ... so that is that... but mainly we need.. because we the organization needs petrol .. needs vehicles... needs repairing of vehicles...needs to pay these people that are here.. so funding

So the resources must be there?

The resources must be there... if there are no resources .. how can a NGO run..

Ok

And once the resources are there ... those people that are acting as a resource... they need to give and account of everything...you know.. be accountable

Ok

Don't just take anyone .. you don't take the organization's car and do your own thing....you know you must think

If we want to go to for example Timbaktou. There is nothing going on...there nothing. You come across this community and there's nothing going on... no one has started..What advise would you give somebody?

No one been there

Yes . Now I want to go into the community... there's nothing...there is no structures... I want to start something. What advise would you give me?

Uhhh the first thing you need to ... go and meet the key people there.... the leaders

Yes

And find out find out from them... what are their problems.... you know.. you can't just go and say I going to give you whatever.... when they want..... they want something else...we were taught that when we were doing primary health care you know...you need to go and sit down...speak to the people... find out from them... what ever ... just brainstorm and talk to them .. you know

And from there... lets say we have identified the ...

You can't just say you're all alone .. you will work with them... you plan with them...every step of the way they are involved..

Is there anything during the involvement of the community that you would say is important?

During the involvement of the community... it is important to.. eh.. don't impose your views onto them but guide them... once they identified their need.. then they all agree .. yes this is what we want here... work with them.

Ok

And give advise, maybe they do want that but they don't know how to do it... look at all the people always and use other resources too .. don't be the only one who just say everything..

Ok

Involve as many people as you can and do your research in whatever you are venturing into... but always work with them..

Always....Is there anything that you would say is important?

Uhhh...Yeah...I don't have anything

Is this kind of structure of importance like in you have in Mphilonhle? Would that be important?

Very important... It is very important.. I don't know if I am getting you question right.. but important ...but reports are the main thing... you can't survive having ... you have to ... lets say you are the director...you are leading the venture ... what ever work that you are doing .. reports are very important..and meetings

What would you discuss during the meeting.....when we meet with the community...what is the kind of things we will talk to them about...or meet with the volunteers.. whoever... what kind of things are important you'd say

The most important thing is to find as much out from them as possible.. let them talk.. do talking...give them time to voice whatever..but yet keep control because ... you again can't meet the whole community.. you meet the representatives.. because if you meet the whole community .. you won't get anything...you need to... lets say you are going to meet with steadville people...you can't go and call everybody there...but you look for the leaders there... the councellors you know... you look for the few people that are representing the community

Ok. Is there anything else that you would think that we must remember being an old community nurse now ... in a community that you would say to us that is important to teach the ...community workers or to equip them

The community workers usually are trained in a lot of work.. they are trained in diseases and... what ... what... .. how to enter a house .. how to handle people.. but they are not well monitored..Hiv work is very important.. whatever work is been done.. having meetings and writing reports is a way of monitoring your work.. it is monitoring.. how people are working.. to have someone always watching .. that what they need

Jaa Jaa

The kind of monitoring is not easy..

Jaa , because during the monitoring it would .. if I understand you correct .. then you can see what is their challenges..

Ahh

And what they still need

Yes

Am I understanding correct if I say that...you can see what has been done and what needs to be done..

And then they also need you know...when you are starting a new community programme they will also need guidance..say...how to write a report

Ja...

How do you want it to be..

Ok

They must have some or other right way ... they write whatever...the interactions they have done ... they collect this into a formal report that you have designed.. which you say I need this... maybe you want it statistics... or past statistics..

Can I ask you something else now... It is just out of interest. With the illiteracy level...that we do have .. there are many people that cannot write.. What will happen... will you just have them at the meeting and you would write and they give you the information

It also depends on what standard....

Or would you bring in a programme that you will teach them to write for example?

Jaa but then again when you need people with you.. you must specific...you need people that can read and write and understand english

Ok

So that they can understand... It is how it is done... Yeh.. You don't just take anyone to work.....so I would say

So you select your NGO's

It is like your staff that .. that will work with you...They are selected.. at least a standard nine person... that can understand...read and write ..

Ok

English... when... when you ...youcompile your report... you won't want someone to always read and interpret .. from Zulu to English..

Ok

The English is the standard that is used in the Africa community...because we are different languages...

Ok. ...because you get the swaili ...

Yes.. you have to standarise your selection And you need plan it thoroughly before you enter any community .. that I will need such and such people.. when they want females only or males and females... ... what message you will spread..females are betterI am not saying .. I am been biased here.... but from experience it is better to work with females....but working with the youngest ones.. they always leave the programme for better.. this is just my observation

Yes Yes that is fine

But the younger females .. they can just start something ...less than the thirtees.. they are still looking for greener pastures..so yes they can come with their standard tens and what.. what... but they leave... leave the position for more fruitful .. you can't stop them.. but while they are there in the community , they can do something...

So.. if I understand you correct.. sometimes they are involved because they are there at that stage

At that stage

But they can move on at any stage..

Yes... as much.. what I have observed in the department of health.. they are working on contract which is reviewed every year..

Ja

So they are working on contract help. ..because they are free to move when the contract is reviewed.....

Ja That is important isn't it?

I don't know.. I think it is... just say it.. there is a lot involved when working with the community...

I think that is very very important ...what you are saying is...makes sense... it really makes sense what you are say

And you can't stop them from going forward ... because they also need to better their lives...

Yes...Because you are empowering them at this stage. Ok...Madam that is lovely... thanks a lot for the information..

As long as you are happy

I think you were a lot of help. What is going to happen now with that is that a typist is going to type it. I am going to bring the interview ... I am going to conNcayiyanat you....bring the interview back to you and say .. did she type her own words... or did she type the correct words in as we spoke and then we will capture out of what you have said.. because you have had a lot of valuable points...and then say ..is this correct... did we really understand correct ... at what we must look at...ok.. uhm do you have a conNcayiyanat number where I can phone you

..... but maybe with the NGO our main worry its funding

Funding?

Because we need to be motivated as we love working in the community ... it is though .. but we also need to live.. ... you knowto be able to get some pay to live... you know some NGO's can't make it because they don't have vehicles.... Sorry for this ...they don't have the source for this... because you will get even the old teacher

Alright

Yet it is also ...we do a whole lot of work in the community to help the government ... sometimes you do such and such ... when the funding ends , then it ends..the government won't take over and won't even help..yet the funder from outside has set the standard and then it is not continuing...and then you find that the patients suffers... starts suffering

So the funding they seeking... let say external...the funding is finished and then the programmes stop.

Yes it happens likes this..

Because nobody takes over

Nobody is doing whatever.. so that how some NGO's seem as if they are failing.... It is not that I say you must depend on the international funder....but the government needs to have the NGO's..because they are an extended hand for them... I just wanted..I am not speaking for them..I just wanted to say.. we are currently helping them ...the mobiles by going out to give injections to the patients that can't go to the mobile point.....

Ok

or those who can't leave their houses and go to the nearest clinics around town... so we help those patients... Help the clinics and the mobiles.. but you will find that once you run out of petrol to go there ... because we use our vehicles that are on funding and the funding that was given to us ... we won't be ale to help them .. you really find that the patients do suffer .. they can't get their streptomycin or carbamycin or whatever...or you know... but they do try to go.. but what I am saying is that they are an extended hand for the government to help those clients not to default TB treatment because ... we are getting more MDR's now..more now than before and because.... this is of the defaultingyou know...not been able to reach their clinics as much as they especially those co-infected patients that have that has TB plus HIV... those that can't walk .. to the nearest town.. mobile.. clinic... no matter how near the clinic is...they just lay in their houses .. sick.. that is too much...for .. the mobile clinics... because they have to be at their mobile points... so when they start to the patient they come late to the community to help... do you understand what I am saying...I just saying this as an additional

Yes

I just want to explain

Yes I understand that is rural and there is not even roads always

And even the location, the roads.. the roads are not so good...but we try

Ok wow I think what you say now is very very important and I will soon get back to you

Oraait

INTERVIEW WITH PAT

Date 13 December 2011 at 11h25 to 11h45

Location Central Ladysmith office

Interview First interview in English

How long have you been involved with Mphilonhle?

I think it is 11 years now... we started from scratch...we started in 2000

Since 2000...and your qualification?

I have general nursing and midwifery...psychiatry and primary health care and B Care

So that is general nursing , midwifery, PHC

Psych

Psychiatry

And B Care

BCare...

B C...U...R

Ah B Cur I et A ok...and your age if I may ask...

My age ... what is this year...2011...I am 53

And are you currently employed here?

Ja... I am the project director here...

Are you comfortable with the English

Uh hum

And do you stay in Ladysmith?

Yes

How did you access the programme...how did you get involved in the programme?

I actually found itbecause of the work I was doing...I was doing community programme ...so I used to visit households in community vehicles from which we were seeing patients ...it is just one day when a child was looking for food and asked its ailing mother to prepare food...that...that is the one that really made me decide... that people need support closer to them because I was co-coordinating community programmes for the department of health....

So then you founded...how did you start off?

I was visiting groups of volunteers...so when they all they need was support and training and motivation to continue offering their services... I grouped all the volunteers according to their area of residence and asked them to form structures like....

Ahh

Like a community with a chairperson ...you know the community structure ...and then have a name for their organization...and then I started then helping them to department of social development ...so that they have MPO's certificates and then when we accessed funding through .. from crystal masseup...this pharmaceutical company...they were all then receiving... even like starting small...like R 100..but at least they started receiving something...so they ... they group together as decided to open their bank account... so they were a community based organization with a bank account...in the process of registering ... so that is how Mphilonhle started ...so in 2000 ... 3 november ...that crystal masseup started funding us in order to mobilize communities about ARV treatment services in Ladysmith because they were not there

Yes

So that people could come out test and be started on treatment ... so at that time the stigma was high... they were scared to come forward as say...and test... and say I am positive...and even at home...people were really isolated...I remember in one home ...one person was put in a tin house where food would be pushed to him , because people were scared they would infect them and then the communities were really... really ...not informed then...so with the start of this programme...people were ...the volunteers targeted those people and encouraged them and motivated them to ...to declare

Ok

I am positive...and then they were referred to hospital

Ok

When the treatment was initiated in...in May 2005 ...only 5 people were eager to start treatment...

Mmm

Only 5... because of the status of the stigma...but later as they saw...they were informed they were encouraged...especially our volunteers from Mphilonhle

encouraging them to go ...to go a and access treatment...now in there are about 8000 plus people on treatment

Mphilonhle...does the word ... does it have a specific meaning

Mphilonhle... means holistic health

Holistic health...ok ...so why do you think this programme just grew from that little group of volunteers to the size of now ... what would you say was the reason for that?

I would attribute our success we had to the support we had from US because we know without funds we would not be able to do anything

Ok

And then also the support from the professionals...in Ladysmith and in the surrounding clinics...and then the commitment of the volunteers...they were really committed and they showed care to the patient and also I would also like to mention that they have been very carefull about confidentiality...nobody spoke about anybody 's condition...and ...I think what also...and the staff also...at Mphilonhle has been very committed and I think ...the results ...we never stopped even if we had challenges...the staff never stopped...they continued to function...and they were consistent in providing services...and when people saw results...because who were having patients who were not able to walk at the start on treatment because of their low CD4 count and their condition , but when they saw people standing up walking , gaining weight and being prepared to lead and talk about it ... sharing..listen you saw me I was smelling...I was this and that and nobody wanted to be next to me , but Mphilonhle wanted to be next to me and look at me now...guys come there in there is life in accessing treatment...anduhmm in the in the organization here...we have been really professional and honest ...we never fittated with funds...we never eh misused funds ... funds were used for what they were offered for ...

Ja

Even our financial records...we have never been doubted any month ...our main funder been ... they've been very supportive also ...coming seeing how we were doing and training us where necessary...really the support of the community leaders around here ...uhmm ...they've been very supportive of our programme...

So the community leaders play a role

Mmm ...they do...they do...because if you... you feel like having an event... and awareness event ...if there is a community leader there and he is given the opportunity to talk ... and he speaks positively about the programme and the organization .. that actually say's to people you can access this service...it working... its here you know

Ok ...

So if you really want to be successful ...involve community leaders. .. involve traditional leaders ...involve...do not be so obvious it politics...everyone must be welcome to you...we were saying to people we know that there is the rivals here ...especially the time that we started here ...there was this fight between Inkhata and the ANC but we were saying guys we are here... everyone in this organization is welcome.. and all we are concerned about is the health of our people...come lets be healthy... lets have more time to stay and live with our children

Mmm If we for example now have to prepare our community workers more properly for our programmes differently...what would you say...what must we do differently....as we prepare our workers...how can we prepare them properly

I think t is very important to respect your community... respect your community...don't come and think that you are learned you are better than that women who has always been there...who knows her community better than you...

Ja

And who knows the problems...the uhmm successes ...what makes people happy better than you ... yes you have been trained....you are knowledgably, you have the skills but she knows her community better...so when they bring their problems please listen to them and give them advise... I am not saying accept everything they are saying but show respect ...it is very important and involve everyone , every structure in the community like I was mentioning...the leaders...because you don't just walk in someones ...eh... land without letting with them know it is for this reason and it is clear you know

Mmm

It is really important...I have notice that people when they are trained they just think they just are going to go impose

Mmm

And tell people what to do...it is better to go there and learn from the people first and ask from them and if ...the powerful part is the respect when you respect a person the person begins to trust you then they can give you all the information you want give you all the support you need.. and you must also be honest with them and commit to your appointments...if you are no longer going to be able to meet the..phone, because of 1—2—3 I said I was going to have a meeting with you ...I cant make... it tell them they are not fools

Jaa

They've uhm have decided to leave whatever they were going to do and they are waiting for you ..now if you decide ...who are they what are I am going to do... tell them

Ja

Tell them and they and then be prepared them ...let them grow on you ...be humble...if you are wrong be prepared to say look I think I was wrong here I apologize...that is what people want and I do understand that everything is not about education ... it is really not about education...it is very important ...that is not what I am saying... its not...it is your pillar of strength in these days but yes even if they're not educated they are still important...and they still mean a lot to their families...so I really would like to emphasize involvement ...transparency ...eh...commitment honesty respect.. and don't judge people...no judgment... just be unconditional to people .. don't judge and say jaa its because of this ..that's why you are like this ...people are very sensitive to...people are human... they are human ...they need to be treated like a human being

And with regard to support to the community to prepare them for what they are going to encounter is there anything that one can prepare them or are you never prepared for what is coming?

I think they must be ready for anything they might face some negativity people just been negative...it will be hard to keep on convincing them ...they must be patient ...they must be patient and carefull what you say ... be carefull what you say...say what is necessary and what you don't have to say...don't say it ...it helps

Why do say it is important...have you had experiences like that

Uhm... ..

I am just trying to understand how that

I am just going to make you an example of the politicians...if you are going to speak negatively about another political organization ... you have already started building yourself a block ..just be general... when you...I was making an example I was ...everyone's health is important... not ANC's health is only important IFP also...you know

Ok

Everyone's health is important ...young, old or middle age...so when I say be carefull what you say...don't say things that might make people sensitive and make them believe you are here on a specific mission not for everyone...

Mmm

You know ..

Ok wow ...Is there anything in the programme design ... you know when you decide ...I am going into this area and nothing is happening there...there's nothing going on that is important for me to know...there is nothing going on ...it is a new place...no one's been there...is there anything else that is important if I take these guidelines that you have given me already...that you would say step by step that you would advise me to do..

I would recommend that your entry point is the community leaders and find out from them what is...because would be something even if it is small...it might be unknown...but definitely there will be something...just find out from them in your whatever related programme...what is happening here ..say oh..around here...they will tell you something...if there are deaths if there are anything they will tell you ...what is happening around social care they will tell you find out from them what is happening ...what has been tried... which one was successful which ones was not succesfullnow if were to sit with me what would you think where do you think we should start what do you want to see happening....and then you talk and then you can negotiate and you can say I understand what you want but here is what I am offering you and this is how far I can go ...you know so that you walk with them all the way from the scratch so that nobody can say I was left out and don't know anything about that and it is not going to happen here...so that you know ...when you walk with everyone will understandso I am saying if...if you ... if you want to establish a committee for the community find this leader who they think should be there and then make suggestions if you think there is a gap they do it ...we took it

there and then that you have all the representatives of the community so that information disseminates down... you won't have everyone but try a much as possible to have almost everybody represented...so with the help of the community leader of the area so that if you really don't involve them they feel like an opposition who have come to promote someone else you know

Mmm

Maybe their rival so it will help you to to start from scratch with them

And the preparing of the volunteers as such what would you advise

It is important also that they are ...they are... it is better if they are nominated by the communitybecause they will know the people and they will tell you the characters looking for....they will tell you the characters you are looking for a person perhaps who is confidential you say your standards of education...you know you.... know you say all the qualities of a volunteer somebody caring ...somebody humble somebody...you know you say to them... if you want proper service for your community nominate people who will who have these characters because they will be serving your community everybody must be comfortable working with them ...happy working with them ...because people will provide proper service for you... it helps

So you select your volunteers very carefully

Mmm

Now if the volunteers are already selected and they are in front of me...what now

Then you now have the characteristics...you train them about these things that we have been talking about so that they know how to provide a service ...the importance of respecting everybody ...all these things and then the skills on how to provide the care

Ok and then how what further they are trained now we are going to send them into the community or what

First introduce them to the leaders as well and you introduce them to community leaders... if the community leaders are willing to accept them...they must call a meeting and introduce them so that they know who they are

Ok

Some communities even prepare them that they have nametags so that they know this one is from this organization he is going to be helping with this this this and

that.... when they've been introduced they can go there to the households and educate and provide care whatever you want to do give the committee

And then basically they are now there on their own or how?

It is better to work with someone supervising them because they need guidance

Whoa I am feeling so hot I don't know if it is flushes or what

Shame

Someone who they will go and give a report every week and perhaps express their concerns you know talk about challenges and then someone who's going to give them advice and who will also going to capture the data and send to whatever office t...they will definitely have someone who will be supervising it can be a community member or a member from the community that you are going to select for that particular programme

And then uhhh supervisor meet with the programme leader or director

Yes because they need to give their view of how they see the programme going ...like on a monthly basis they will meet with the programme director perhaps the supervisor and all of them and perhaps on weekly basis just meet with the field workers

Is there anything else that you would say that is very important ...we must never loose out of the eye and never forget about

It is eh...it is eh... recording all the information that you get because it will help you in future and what you need to improvethere is need for that very important to record your information.... it is basically what I can think of so far but basically if I think of something else I will let you know

Thanx...basically what is going to happen now is the typist is going to transcribe this and then the prof and I will go through it we will take the essence out of it we will come back to you and say is this...did we capture this correctly... is this what you mean will you support us suggestion for a community programme.... is there anything in there still that we missed... in that second interview you can say you know what there is something I remember

Ok

You are welcome to phone me in the mean time as well you can put it on as well and uhm are we correct are we capturing it correct are there where we need to be I just need to take your telephone number

My cell number

Any number

.....

And then we can take it from there.