

ANXIETY AND DEPRESSIVE SYMPTOMS AMONGST CAREGIVERS OF CHILDREN WITH MENTAL ILLNESS

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As the candidates supervisor I have/have not approved this thesis for submission.

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Declaration

I, Dr MAYURI RAMDHIAL, declare as follows:

1. That my contribution to the project is as follows, I am the principal investigator and have performed this study in its entirety with supervision by XXXX.
2. That the contributions of others to the project are as follows, contribution with electronic data entry and analysis by Dr Nolene Loubser.
3. The research reported in this dissertation, except where otherwise indicated is my original work.
4. This dissertation has not been submitted for any degree or examination at any other university.
5. This dissertation does not contain other persons' data, pictures, graphs or other information, unless specifically acknowledged as being sourced from other persons.
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PART 1

INTRODUCTION

This chapter provides a background to and discusses the significance of research in caregivers of children with mental health needs. The study reviews the current evidence on caregiver burden and the often neglected mental health needs of caregivers. The chapter also presents the problem statement, the aim and objectives of the study.

1.1 Background and context of the study

Caregiving is a normal part of being the parent of a young child, yet this role takes on a completely new dimension when caring for a mentally ill child with psychological and or functional limitations. The foremost challenge for many parents is managing their child's chronic health problems effectively whilst coping with requirements of everyday life. There have been several studies that have evaluated the burden of care in caregivers of mentally ill children (Anjuman *et al.* 2010, Mendenhall *et al.* 2011, Meltzer *et al.* 2011, Yusuf *et al.* 2013, Nehra 2014), with the vast majority set in developed countries and suggesting high levels of burden and emotional distress of varying severity. However no such study has been conducted in KwaZulu – Natal (KZN), South Africa, a developing world setting with a large population of young people, limited mental health resources and a multicultural population.

Burden of care has been defined as “the presence of problems, difficulties or adverse events which affect the lives of the psychiatric patient's significant others” (Dada *et al.* 2011). This is directly related to the difficulties experienced in the course of caring for the mentally ill child and the chronicity of such care. The impact of living with a mentally ill person is felt across multiple facets of family life, including family interaction, family morale, family routine, family emotional stress and social dysfunction. Amongst the first degree relatives of mentally ill children, more subtle distress is propagated by the associated stigma, feelings of guilt and self-blame creating further stress.

Caregiver strain has two dimensions, objective burden is regarded as the observable disruption of aspects of the caregivers' life (financial strain, interruption of career, interruption of social life), and subjective burden is the extent to which the caregiver perceives care responsibilities to be stressful (anger, sadness, embarrassment, worry, anxiety,

stigma) (Anjuman *et al.* 2010). Subjective burden is an important predictor of health utilisation, as often subjective distress in the parent/caregiver results in more frequent visits to health facilities and caregivers seeking additional treatment for the child. The impact of the caregiver subjective burden, manifested as repeated visits, impacts on health service load without addressing the core problem, caregiver emotional distress.

Caregivers are not necessarily parents, care is generally provided because of emotional bonding, guilt, family duty and lack of alternative community based care resources. As the number of children with mental illness is increasing, the number of children requiring care from relatives is also growing. Consequently, there is an increasing demand to understand the needs of caregivers. Understanding caregiver needs is crucially important for planning interventions and testing the value of programmes to support caregivers. This is critical as parental strain has a detrimental effect on parental health (increased anxiety, depression, physical ill health and increased smoking and drinking) which in turn may negatively impact on the child's mental health. It is therefore important to reduce the caregiver's burden in the interest of the caregiver and child, so that parents can provide sufficient care and maintain their own healthy life (Anjuman *et al.* 2010). This study thus sought to identify caregiver burden and depression and anxiety in caregivers of children with mental health needs.

Study context

The study is set in KZN, one of the most populous provinces in South Africa. It is estimated that 18.5% of South Africans are in the 10-19 year age group. The majority of the population relies on public health services (Statistics South Africa, General Household survey 2014). The province has limited adult and even more limited child mental health services with only two child psychiatrists registered in the public health sector. There are very limited community and psycho-social programs to provide support to children and families with mental health needs. Thus it is hoped that this study provides the incentive and evidence for funding such programs.

1.2 Research Question

Caring for children with mental illness is associated with high levels of emotional distress (depressive and anxiety symptoms) and caregiver burden amongst primary caregivers.

The main purpose of this study is to determine the prevalence of anxiety and depression in caregivers of children and adolescents with mental illness and identify factors associated with

increased risk of emotional distress and burden of care at two psychiatric clinics in Durban, KwaZulu Natal, South Africa.

The research problem may be summarised by the following questions:

1. What is the socio-demographic profile of caregivers and children with mental health needs?
2. What is the prevalence of depression and anxiety in caregivers of children with mental health needs?
3. What is the caregiver burden associated with care of children with mental health needs?

The study objectives include:

- Description of the demographic profile of caregivers of mentally ill children attending psychiatric clinics
- Determine the prevalence of anxiety and depressive symptoms in caregivers of children with mental illness attending psychiatric clinics
- Identify the demographic characteristics of caregivers and children that are associated with anxiety and depression in caregivers and possibly predict for emotional distress
- Identify the clinical variables in the child associated with caregiver anxiety and depression
- Measure the level of burden of care experienced by caregivers

1.3 Critical Literature Review

Approximately 14% of the global burden of disease has been attributed to neuropsychiatric disorders, mainly due to the chronically disabling nature of depression and other common mental disorders, and such estimates have drawn attention to the importance of mental disorders for public health (Prince *et al.* 2007). Anxiety and depressive disorders are the most common disorders in the general population and it is predicted that by 2020 depression will be one of the leading causes of disability globally (Murray *et al.* 1996).

Anxiety and depression in caregivers

The South African Stress and Health Study (SASH) reported high prevalence rates of mental illness amongst adults in the general population, with a 30.3% lifetime prevalence rate for any mental disorder. Eleven percent of respondents had two or more lifetime disorders and 3.5% had three or more lifetime disorders. The most prevalent class of disorders was anxiety disorders (15.8%), followed by substance use disorders (13.3%) and mood disorders (9.8%). The most prevalent individual lifetime disorders were alcohol abuse (11.4%), major depressive disorder (9.8%) and agoraphobia without panic (9.8%). Female gender, 35-49 year age group and marital status of being separated, widowed or divorced demonstrated increased risk for any disorder and increased severity (Herman *et al.* 2009). Another South African rural community prevalence study by Bhagwanjee *et al.* (1998) reported weighted prevalence for generalised anxiety and depressive disorders was 23.9%, with significant associations between diagnoses and age, marital status, employment, income and educational level.

In a more recent South African study that described the burden of mental health disorders among caregivers of young children (4-6years) living in an environment of poverty and high human immunodeficiency virus (HIV) sero-prevalence, 31.3% of caregivers screened positive for at least one psychiatric disorder, with post-traumatic stress disorder being the most common. Caregivers who screened positive for any disorder were more likely to be older, to have no individual source of income and to have less formal education. Known HIV infected caregivers were more likely to have a mood disorder than caregivers who previously tested HIV negative (Chhagan *et al.* 2014). In a study in China, Liu and colleagues found that parents of mentally ill children experienced additional stress in their life, and 97.9% of parents reported increased anxiety (Liu *et al.* 2007).

Considering these findings, the primary caregivers of children with mental illness, in the public health sector, who are often female, single and from poor socioeconomic conditions appear to be at increased risk of mental illness (Anjuman *et al.* 2010, Dada *et al.* 2011, and Ambikile *et al.* 2012). In addition, the vulnerable often do not access appropriate health care due to poor access to care, stigma and the cultural context of experience and expression of psychiatric disorders but rather resort to coping mechanisms such as alcohol and substances to treat their high levels of daily stress (Prince *et al.* 2007).

The significant lack of resources for mental health care in KZN, South Africa places considerable strain on families and caregivers of mentally ill individuals (Burns 2011). The magnitude of the burden of disease related to child and adolescent mental disorders is difficult to quantify. It is important to highlight that worldwide up to 20% of children and adolescents suffer from a disabling mental illness. Disorders identified as priority areas, based on their higher frequency of occurrence, degree of associated impairment, therapeutic interventions and long term consequences, include attention deficit hyperactivity disorder (ADHD), learning disorders, depression, suicide, psychosis, autistic spectrum disorders, anxiety disorders, Tourette's syndrome, conduct and behavioural disorders and substance use disorders (WHO, 2003). Within the South African context, the effects of poverty, the HIV epidemic, poor access to education and underdeveloped rural and community health programmes magnify the effects of mental illness for the patient, carers and the community.

A systematic review that assessed the prevalence of child mental health problems in sub-Saharan Africa reported considerable levels of mental health problems among children and adolescents (Cortina *et al.* 2012). Fourteen percent of children were identified as having psychopathology; 1 in 7 participants experienced significant difficulties and 1 in 10 had a specific psychiatric diagnosis. Evidence supports a multifactorial cause for mental disorders in young people; with poverty and social disadvantage strongly associated with mental disorders (Cortina *et al.* 2012). Longitudinal studies have also shown that factors such as a sense of connection, low levels of conflict and an environment in which the expression of emotions was encouraged protected against the development of behavioural or emotional disorders in children (Patel *et al.* 2007). Studies suggest that consistent and engaging parenting styles, parents and friends who model health behaviour, being in full time education in a school which promotes learning by addressing individual needs, and involvement in community and religious observance are protective (Patel *et al.* 2008). Perhaps the single most important factor for building resilience in youth is to enable parents

to provide adequate psychosocial stimulation during early childhood. A recent report on resilience concluded that “the key to giving young people a good start in life is to help their parents”, because responses to adverse situations are shaped by early life experiences (Patel *et al.* 2007). This clearly highlights the need for a proactive approach to managing child psychiatric problems and focus attention on caregiver wellbeing to optimise child and family outcomes.

Caregiver burden

While caregiving and parenting is a normal part of being the parent of any young child, providing high levels of care often required by children with mental health problems can become burdensome and may impact on the psychological and physical wellbeing of the caregiver.

Previous studies on emotional distress in caregivers of children with mental illness have provided consistent evidence that caregivers of children with chronic mental illness suffer from moderately high levels of caregiver burden which occur as a result of the challenges encountered whilst caring for a mentally ill child (Dada *et al.* 2011; Anjuman *et al.* 2010). Burden of care is predicted by the presence of psychiatric co morbidity in the caregiver, level of functioning of the caregiver, level of functioning of the child, degree of impairment as assessed by the caregiver and educational level of the child. Lower levels of education of children showed significant association and predicted higher burden of care, possibly because those with higher education levels were better able to care for themselves (Dada *et al.* 2011).

Anjuman and colleagues reported that almost half of the caregivers showed high burden of care and the majority experienced mental distress. In their study in Pakistan, 49% of caregivers had high burden of care, 6% suffered from anxiety and insomnia, 52% experienced somatic symptoms and 48% suffered from severe depression (Anjuman *et al.* 2010).

A recent study in Tanzania, Africa, highlighted the social, economic, psychological and emotional challenges experienced by caregivers living with mentally ill children. Three major themes identified in their study with regards economic challenges, included existing poverty, interference with income generating activities and extra expenditure due to illness (Ambikile *et al.* 2012). Psychological and emotional challenges in this third world setting were similar to those described in the first world setting with caregiver worry over long term

consequences for the affected child being a common concern (Meltzer *et al.* 2011). Other key emotional manifestations described by participants were sadness, bitterness, inner pain and difficulty in communicating with their children. The challenges of inadequate social services in Tanzania mirror the South African context and highlighted the dire need for special needs school programs and day care facilities. Importantly, the need for synergy amongst health and social services was raised (Ambikile *et al.* 2012, Meltzer *et al.* 2011).

Moreover, over half of parents in a study in China indicated that their leisure time was significantly decreased, and over a third of parents reported that they were reluctant to invite friends into their house since their child had developed mental problems (Lui *et al.* 2007). Thus parental feelings of burden and stigma seem to be evident across cultures (Aneshensal *et al.* 1995).

A Nigerian study on emotional distress associated with caring for epileptic patients, found similarly high levels of emotional distress amongst caregivers. Emotional distress was significantly related to male gender, providing care for a male patient, siblings as caregivers and residing in a rural area was associated with increased burden (Yusuf *et al.* 2013).

Raina and colleagues reviewed the evidence and explored models for the process of caregiver burden in children with developmental disabilities and described that, for each individual, a number of psychosocial mechanisms may exist that regulate the impact of stress on health and well-being. The characteristics of the caregiver, the recipient of care, the shared history, and the social, economic and cultural contexts within which they find themselves combine to create an infinite variety of circumstances from which stress may originate or be managed. Individuals typically occupy multiple roles in life, such as family and occupational roles. Becoming the caregiver of a child with long term disability introduces an additional role, requiring rearrangement of priorities and redirection of energy. Not only is this likely to produce strain at a personal level but it is also likely to spur a range of reactions (potentially negative) from various people who are interconnected to a person through his or her roles outside the realm of caregiving (Raina *et al.* 2004). Stress is therefore understood to arise at the level of care for the child and in other areas of life.

Raina *et al.* (2004) further explained that the unexpected career of caregiver for children with disability results in a multifaceted, complex and stressful life situation that can have important consequences if not supported by health and psychosocial services. Importantly the caregiving process is a dynamic process, where an individual proceeds through a series of

stages, necessitating considerable transitions and restructuring of responsibility over time. It is important to note that becoming an informal caregiver is not typically chosen or planned, people do not often envision being in a caregiver role when they project themselves into the future. Thus preparation for this role will most often occur only once it is acquired.

The relationship between caregiving and health is described generally in terms of stress. Stressors maybe defined in the context of caregiving as “the problematic conditions and difficult circumstances experienced by caregivers” (Aneshensel *et al.* 1995). Highlighting that stress develops at the intersection between internal states and external demands, especially when external demands collide with and overpowers internal coping mechanisms. This explains why some caregivers are less affected by caregiver stressors and cope well versus those who are significantly affected (Raina *et al.* 2004).

Severe mental illness in children can significantly impact parents who care for these children in both positive and negative ways, with strain and enrichment manifesting in all areas of caregivers’ lives, including work, mental and physical health, social and family relations. Predictors of caregiver strain included severity of the child’s illness and impairment, race and social support (Meddenhall *et al.* 2011). This is supported by a study of caregivers of children with intellectual disability which highlighted that comorbid behavioural problems were found to contribute significantly to caregiver stress (Nehra *et al.* 2014). The indirect costs of caregiving borne by caregivers is significant, however the subjective gains and satisfaction of caregiving are also emphasized by the author. Researchers concluded that as youth’s symptoms improved, caregiver’s symptoms might also benefit from reduced stress associated with a symptomatic child (Nehra *et al.* 2014).

In addition to the economic impact of caregiving, caregiver burden impacts on a variety of domains including social functioning and relationships within the family. In a survey by Meltzer *et al.* approximately half the parents of children with conduct disorder reported that they felt restricted in social activities with or without their children, embarrassed about their child’s problems, and that these challenges also made the relationship with their partner more strained. Parents felt embarrassed and stigmatised and therefore hid their feelings, further exacerbating the situation. In this survey the elevated rates for burden of care in parents of children with externalising disorders compared to internalising disorders was explained as being related to more persistent and visible symptomatology in the externalising group and more sympathy for parents of children with internalising disorders versus blame against those

whose children had externalising disorders. Interestingly the study also reported that more parental burden/embarrassment resulted from gender atypical disorders, that is, girls with behavioural problems and boys with emotional problems (Meltzer *et al.* 2011).

This was further explored by Vaughan *et al.* (2013) in an American study which investigated the relationship between child symptoms and caregiver strain among 177 youth and their caregivers in a school based system of care. Youth were grouped by symptom domain into internalising group, externalising group and combined internalising/externalising group. Results revealed significant group differences on measures of caregiver strain and parenting stress. Caregivers of youth with combined symptoms reported the highest levels of strain, with impact on caregiver ability to carry out day to day tasks, form a close relationship with their child, or to cope with negative feelings they had about their child.

The impact of externalising disruptive behaviour on caregiver distress is further supported by a study that examined the impact of young children with externalising behaviours (hyperactive, aggressive behaviours) on their families, which concluded that compared to normally developing children, parents with externalizing children reported more negative impact on social life, more negative and less positive feelings about parenting, and higher child related stress (Donenberg *et al.* 1993). Moreover, parents of externalising children reported high levels of impact and stress similar to those reported by parents of children with autism. The authors highlighted, the impact on families of children with externalising behaviours may be only partly accounted for by the child's behaviours per se. They felt attributions about the child's behaviour and the frequently lacking clear diagnosis may have played a role in increased parental stress in this group. Unlike in the case of children with autism or other handicapping conditions, where the disruptive behaviour is attributed to low intelligence or the disorder, externalising children's disruptive behaviour was often attributed, by parents themselves and others, to the child intentions or child rearing deficiencies (Donenberg *et al.* 1993). Additionally, levels of burden were influenced by services available, with increased specialised and support services reducing caregiver stress, as for the autistic group (Donenberg *et al.* 1993).

Caregiver burden also varies depending on the type of illness or diagnosis in the child. Meeting the high care demands of caring for children with autism spectrum disorders is extremely challenging with many parents reporting considerable problems combining daily activities with care, financial problems or depressive mood (Hoefman *et al.* 2014). A survey

of 219 parents of children with autism, found that more than 80% reported sometimes being stretched beyond their limits, with mothers reporting higher stress levels than fathers (Sharples *et al.* 1997). The three most stressful factors being, “concern over the permanency of the condition, poor acceptance of autistic behaviours by society, and often by other family members and the very low levels of social support received by parents” (Johnson 2016).

Comorbid disorders also increase burden of care. In child psychiatric practice comorbidity may be considered the rule rather than the exception. The parents of children with ADHD and multiple comorbid conditions experienced the highest level of depression, stress and burden of care in a study of the additive effects of care for children with comorbid conditions compared to children with ADHD only (Rokhill *et al.* 2013).

Thus from the available literature we recognise that parents of children with mental illness worry about everything from general physical and mental health, levels of children’s achievements versus parental expectations, family disharmony, from support networks to societal acceptance, parents are stressed and angry, and parents of children with comorbid conditions and externalising behaviours are more stressed and experience higher levels of burden (Donenberg *et al.* 1993, Meltzer *et al.* 2011).

Appreciating caregiver distress is critical as research in high income countries has repeatedly demonstrated the deleterious impact of maternal mental health disorders on growth, development and behaviour of their children, but in low and middle income countries these issues are inadequately studied (Chhagan *et al.* 2014).

Parental influence on the emotional development of children is critical in the case of children with mental illness. The overall development of children is dependent on supportive parenting to foster confidence and growth. Longitudinal attachment studies have shown that children with anxious attachment were more likely to be emotionally disturbed and display low self-esteem (Mattejat *et al.* 2008). Studies have also consistently demonstrated that depressed mothers put a child at risk of developing emotional problems due to greater levels of indifference towards their children, reduced social exposures and stimulation (Adrian 1993, Goodman 1999). Thus screening for mental illness among parent of children with mental health needs is critical to improve quality of life for parents, children and the family.

Finally, in spite of effective interventions for the care of children and adolescents with mental disorders, a huge proportion of these caregivers do not access care for themselves due to

barriers which include a lack of awareness, poor access to resources (financial, human, facilities) and stigma. Stigma is experienced by patients and ironically those providing care for them at all levels of society. Stigma is defined as an actual or inferred attribute that damages the bearers' reputation and degrades him/her to a socially discredited status (Mukolo *et al.* 2011). Stigma has been identified as a likely key factor in mental health services access and utilization, particularly under-utilization of existing services by some segments of society, most notably minority racial/ethnic children. In child mental health services, the role of stigma is presumed to be significant with implications for caregiver strain and burden of care. One way parents/ family caregivers cope with children's mental health problems is to seek mental health services, stigma towards mental health services compounds the burden of care and caregiver help seeking behaviours. Mukolo *et al.* (2011) reported that negative public responses included preference for social distance from the child/family, the distancing of the child from other children, blaming the child's family for the child's problems, and preference for severe treatment modalities for the child including treatment in restrictive settings.

We therefore need to support campaigns to reduce stigma, especially as it impacts entry to care and continuum of care with significant implications to patient and caregivers.

Interventions to reduce barriers to care and therefore caregiver stress need to focus on improving family communication, increasing awareness of and access to psychosocial programmes, promotion of service integration, establishing alliances with religious bodies for appropriate referrals and treatment, utilising scarce resources such as non- governmental organisations (NGO), encouraging development and implementation and monitoring of national policies for child and adolescent mental health services.

Studies collectively demonstrate the significant burden associated with caring for a mentally ill individual. Children are dependent on their caregivers for basic needs, support, protection and love. Mental disorders in childhood are often chronic and disturbing, requiring significant attention and support from caregivers. Caregivers require support services and screening for emotional distress to ensure good outcomes for themselves and their children (Meltzer *et al.* 2011, Mendenhall *et al.* 2011, Ambikile *et al.* 2012).

Research has identified increased caregiver emotional stress and various physical, emotional and psychological, social and economic challenges that contribute to and are predictors of caregiver strain and burden. Child and parental factors such as psychiatric or medical

comorbidities, levels of impairment, levels of education, coping skills, socio-economic status and support structures for either group (Dada *et al.* 2011). Understanding how to manage the negative consequences of caregiving is critical to developing and implementing realistic, appropriate response strategies. Appreciating the scope of the problem locally, will guide interventions for successful management of child mental illness which must incorporate efforts to enhance caregiver strengths and resources and decrease pertinent aspects of caregiver strain, therefore improving the health and functioning of the entire family.

References

- Adrian, C., Hammen, C. (1993). Stress exposure and stress generation in children of depressed mothers. *Journal of consulting and Clinical Psychology*, 61(2), 354-359.
- Ambikile, J. S., Outwater, A. (2012). Challenges of caring for children with mental disorders: Experiences and views of caregivers attending the outpatient clinic at Muhimbili National Hospital, Dar es Salaam – Tanzania. *Child and Adolescent Psychiatry and Mental Health*, 6(16), 1-11.
- Aneshensal, C. S., Pearlin, L. I., Mullan, J. T., Zarit, S. H., Wihitlatch, C. J. (1995). *Profiles in caregiving; the unexpected career*. San Diego Academic Press.
- Anjuman, W., Chaudhry, H. R., Irfan, M. (2010). Burden of Care in caregivers of patients with Schizophrenia and Epilepsy. *Journal of Pakistan Psychiatric Society*, 7(2), 79-83.
- Bhagwanjee, A., Parekh, A., Paruk, Z., Peterson, I., Subedar, H. (1998). Prevalence of minor psychiatric disorders in an adult African rural community in South Africa. *Psychological Medicine*, 28(5), 1137-1147.
- Burns, J. K. (2011). The Mental Health Gap in South Africa – A Human Rights issue. *The Equal Rights Review*, 6, 99-110.
- Chhagan, M. K., Mellins, A. C., Kauchali, S., Craib, M. H., Taylor, M., Kvalsvig, J. D. (2014). Mental health disorders among caregivers of preschool children in the Asenze study in KwaZulu-Natal, South Africa. *Maternal Child Health Journal*, 18(1), 1-15.
- Cortina, A. M., Sodha, A., Fazel, M., Ramchandani, P. G. (2012). Prevalence of Child Mental Health Problems in Sub - Saharan Africa. *Arch Pediatr Adolesc Med*, 166(3), 276-280.
- Dada, M. U., Okewole, N. O., Ogun, C. O., Bello-Mojeeed, M. A. (2011). Factors associated with caregiver burden in a child and adolescent Psychiatric facility in Lagos, Nigeria. *BMC Pediatrics*, 11, 110. doi: 10.1186/1471-2431-11-110.
- Donenberg, G., Baker, B. L. (1993). The Impact of Young Children with Externalising Behaviours on Their Families. *Journal of Abnormal Child Psychology*, 21(2), 179-195.

- Eccleston, C., Palermo, T. M., de C Williams, A. C., Lewendosky, A., Morley, S., Fisher, E. (2012). Psychological interventions for parents of children and adolescents with chronic illness. *Cochrane Database Systematic Reviews* (online) 8. doi.org/10.1002/14651858.
- Goodman, S. H., Sherryl, H., Gotlib, I. H., Ian, H. (1999). Risk for psychopathology in the children of depressed mothers: A developmental model for understanding mechanisms of transmission. *Psychological Review*, 106(3), 458-490.
- Herman, A. A., Stein, J. D., Seedat, S., Heeringa, S. G., Moomal, H., Williams, R. D. (2009). The South African Stress and Health (SASH) study: 12-month and lifetime prevalence of common mental disorders. *South African Medical Journal*, 99, 339-344.
- Hoefman, R., Payakachat, N., Exel, J. V., Kuhlthau, K., Kovacs, E., Pyne, J. (2014). Caring for a Child with Autism Spectrum Disorder and Parents' Quality of Life: Application of the CarerQoL. *J Autism Dev Disord*, 44(8), 1933-1945. doi:10.1007/s10803-014-2066-1.
- Johnson, J. (2016). Parental Stress and Autism Spectrum Disorders. *Autism Research Review International*, 1-4. https://www.autism.com/parent_stress.
- Liu, M., Lambert, C. E., Lambert, V. A., (2007). Caregiver burden and coping patterns of Chinese parents of a child with a mental illness. *International Journal Mental Health Nursing*, 16(2), 86-95.
- Mattejat, F., Remschmidt, H. (2008). The children of mentally ill Parents. *Deutsches Arzteblatt International*, 105(23), 413-418.
- Mendenhall, A. N., Mount, K. (2011). Parents of Children with Mental Illness: Exploring the Caregiver Experience and Caregiver – Focused Interventions. *Families in Society*, 92(2), 183-190.
- Meltzer, H., Ford, T., Goodman, R., Vostanis, P. (2011). The Burden of Caring for Children with Emotional or Conduct Disorders. *International Journal of Family Medicine*, 2011, 8 doi:10.1155/2011/801203.
- Mukolo, A., Heflinger, C. A., Wallstone, K. A. (2010). The stigma of childhood mental disorders: A conceptual framework. *J Am Acad Child Adolesc Psychiatry*, 49(2), 92-198.

- Murray, C. J. L., Lopez, A. D. (1996). The Global Burden of Disease: A comprehensive assessment of Mortality and Disability from Diseases, Injuries and Risk Factors in 1990 and Projected to 2020. Geneva, Switzerland; World Health Organisation.
- Nehra, D. K. (2014). Study of Burden in parents of children with mental retardation. *Journal of Indian Health Psychology*, 8(2), 12-19.
- Patel, V., Flischer, A., Hetrick, S., McGorry, P. (2007). Mental health of young people: a global public-health challenge. *Lancet*, 369, 1302-13.
- Patel, V., Flisher, A. J., Nikapota, A., Malhotra, S. (2008). Promoting child and adolescent mental health in low and middle income countries. *The Journal of Child Psychology and Psychiatry*, 49(3), 313-334.
- Prince, M., Patel, V., Saxena, S., Maj, M., Maselko, J., Philips, M. R. (2007). No health without mental health. *The Lancet*, 370, 859-77. doi: 10.1016/S0140-6736(07)61238-0.
- Raina, P., O'Donnell, M., Schwellnus, H., Rosenbaum, P., King, G. (2004). Caregiving process and caregiver burden: Conceptual models to guide research and practice. *BMC Pediatrics*, 4, 1-13.
- Reinhard, S. C., Given, B., Petlick, N. H., Bemis, A. (2008). *Supporting Family Caregivers in Providing Care. Patient Safety and Quality: An evidence based handbook for Nurses*. Rockville (MD): Agency for Healthcare Research and Quality (US). Chapter 14.
- Rokhill, C., Violette, H., Stoep, A.V., Grover, S., Myers, K. (2013). Caregivers Distress: Youth with Attention-Deficit/Hyperactivity Disorder and Comorbid Disorders Assessed via Telemental Health. *Journal of Child and Adolescent Psychopharmacology*, 23(6), 379-385.
- Saxena, S., Thornicroft, G., Knapp, M., Whiteford, H. (2007). Resources for mental health: scarcity, inequity, and inefficiency. *The Lancet*, 370(9590), 878-889. doi: 10.1016/S0140-6736(07)61239-2.
- Sharpley, C. F., Bitsika, V., Efremidis, B. (1997). Influence of gender, parental health, and perceived expertise of assistance upon stress, anxiety and depression among parents of children with autism. *Journal of Intellectual and Developmental Disability*, 22, 19-28.

Statistics SA, General Household Survey. (2014). www.statsa.gov.za.

Vaughan, E. L., Feinn, R., Bernard, S., Brereton, M., Kaufman, J. S., (2013).

Relationships between child emotional and behavioural symptoms and caregiver strain and parenting stress. *Journal of Family Issues*, 34(4), 534-556.

World Health Organisation. (2003). *Caring for children and adolescents with mental disorders: setting WHO directions*. Geneva.

Yusuf, A. J., Nuhu, F. T., Olisah, V. O. (2013). Emotional Distress amongst caregivers of patients with Epilepsy in Katsina State, Northern Nigeria. *African Journal of Psychiatry*, 16(1), 41 – 44.

CHAPTER 2

Anxiety, depressive symptoms and caregiver burden amongst caregivers of children with mental illness

*The manuscript is prepared according to the instructions for Authors for the Journal of Child
& Adolescent Mental Health (author's guidelines in appendix)*

Abstract

Background: Studies on emotional distress in caregivers of children with mental illness have provided evidence for high levels of anxiety, depression, caregiver burden and emotional distress, which may negatively impact on child care.

Objectives: To investigate the prevalence of anxiety, depression and burden of care in caregivers of children and adolescents with mental illness at two psychiatric clinics.

Methods: A questionnaire study of 121 adult caregivers of children with mental illness was conducted. Assessments included a socio-demographic questionnaire, Patient Health Questionnaire (PHQ-9), Generalised Anxiety Disorder-7 Questionnaire (GAD-7), and the Child and Adolescent Impact Assessment (CAIA).

Results: The caregivers were predominantly female (n=96, 79.5%), married (n=72, 59.5%) and had completed secondary education (n=71, 58.7%). 54 (44%) participants reported depression with a mean PHQ9 score of 5.75 and 65 (54 %) reported anxiety symptoms with the mean GAD7 score of 5.71. Caregiver burden was predominantly reported in the domains of restrictions in activities (n=40, 32.8%), feelings of personal well-being (n=37, 30.7%) and economic impact (n=21, 17.4%). The caregivers of children with attention deficit hyperactivity disorder (ADHD) reported higher anxiety levels ($p=0.023$) than for autistic children. A diagnosis of autistic spectrum disorder was associated with higher income impact ($p=0.004$) and restrictions impact ($p=0.001$) than for children with ADHD diagnosis in terms of perceived caregiver burden.

Conclusion: The high levels of depression and anxiety symptoms amongst caregivers suggests the need for better screening and psychosocial support programs that focus on impact of caregiving on mental health, income and social restrictions.

Keywords: caregivers, children with mental illness, caregiver burden, anxiety, depression, South Africa

Introduction

Caregiving is a normal part of being the parent of a young child, yet this role takes on a completely new dimension when caring for a mentally ill child with psychological or functional limitations. The foremost challenge for many parents is managing their child's chronic health problems effectively whilst coping with routines and requirements of everyday life. This may result in increased mental health problems and caregiver burden.

In a South African study that described the burden of mental health disorders among caregivers of young children (4-6years) living in an environment of poverty and high human immunodeficiency virus (HIV) sero-prevalence, 31.3% of caregivers screened positive for at least one psychiatric disorder, with post-traumatic stress disorder being the most common. Caregivers who screened positive for any disorder were more likely to be older, to have no individual source of income and to have less formal education. Known HIV infected caregivers were more likely to have a mood disorder than caregivers who previously tested HIV negative (Chhagan *et al.* 2014). In a study in China, Liu and colleagues found that parents of mentally ill children experienced additional stress in their life, and 97.9% of them reported increased anxiety (Lui *et al.* 2007).

Burden of care has been defined as “the presence of problems, difficulties or adverse events which affect the lives of the psychiatric patients’ significant others” (Dada *et al.* 2011). This burden is directly related to difficulties experienced in the course of caring for the mentally ill child and the chronicity of such care. The impact of living with a mentally ill person is felt across multiple facets of family life, including family interaction, family morale, family routine, family emotional stress and social dysfunction. Amongst first degree relatives of mentally ill children, more subtle distress is propagated by the associated stigma, feelings of guilt and self-blame (Mendenhall, 2011).

Previous studies on emotional distress in caregivers of children with mental illness have provided consistent evidence that caregivers suffer from moderately high levels of caregiver burden secondary to challenges encountered whilst caring for a mentally ill child. In a study by Angold *et al.* (1998), 16.8% of caregivers reported burden of care and similarly more recently 25% of caregivers of patients with epilepsy reported moderate to severe burden of care in Nigeria (Dada *et al.* 2011).

Emotional distress/mental health problems and caregiver burden is influenced by several factors including parental, child and environmental variables (*Liu et al.* 2007, *Dada et al.* 2011 and *Vaughn et al.* 2013). Environmental factors associated with increased caregiver burden include residing in rural areas with limited access to health care facilities, lack of support structures, family dysfunction, living under poor socio-economic conditions and stigma (*Raina et al.* 2004, *Caqueo-Urizar et al.* 2009, *Yusuf et al.* 2013). Stigma has been identified as a likely factor in mental health service under- utilisation, especially for minority ethnic/racial groups, with resulting implications for caregiver strain and burden of care (*Mukolo et al.* 2011). Socioeconomic variables have emerged as key correlates of exposure to care related stressors, and socioeconomic resources may help to contain the extent to which a patient's condition becomes burdensome (*Raina et al.* 2004). Evidence from numerous studies on parental/caregiver factors, suggest male caregiver gender, single mothers, younger age, lower levels of caregiver education, presence of parental psychopathology, low level of functioning and low self - esteem were significantly associated with increased experience of caregiver stress and burden (*Cook et al.* 1994, *Raina et al.* 2004, *Dada et al.* 2011).

Studies have evaluated ethnic/racial differences in relation to caregiver strain; findings indicate that White parents report substantially more burden than Black parents, with differences remaining after controlling for income, gender, age, diagnosis and perceived stigma (*Horwitz et al.* 1995, *Kang et al.* 2005).

Child factors include male gender, type of behaviour, diagnosis, severity of mental illness, the presence of emotional or physical comorbidities and level of education (*Houtrow et al.* 2011, *Dada et al.* 2011 and *Yusuf et al.* 2013). Houtrow and colleagues found among families of children with mental health problems, 28% reported family burden, and the experience of burden was more frequently reported in children with moderate to severe mental health problems compared to those with mild mental health problems (*Houtrow et al.* 2011). African and international studies have found lower child educational level and severity of child problems to be a consistent and significant predictor of caregiver burden (*Brannan et al.* 2006, *Liu et al.* 2007 and *Dada et al.* 2011).

Thus the better understanding of emotional distress and caregiver burden amongst caregivers of children with mental health needs will improve health outcomes for families and the paediatric patient.

Aims

This study therefore aims to describe the prevalence of anxiety and depressive symptoms in caregivers and the socio-demographic and clinical characteristics that are associated with anxiety and depression in caregivers. This research also sought to measure the level of burden of care experienced by caregivers.

Method

A cross-sectional questionnaire study was conducted among consecutive adult caregivers of children attending psychiatric services at 2 hospitals. Both facilities are situated in Durban, Kwa Zulu-Natal, South Africa and are the only units that offer specialist child psychiatric services with a child psychiatrist managing services. Data were collected over a 4 month period from November 2014 to February 2015.

Participants

121 adult caregivers of children aged 1-18 years with mental illness attending a psychiatric service were recruited. Caregivers had to be living with the child and be responsible for the child's care, literate and able to speak English. Exclusion criteria included caregiver mental illness prior to child's mental illness, caregiver history of general medical illness that may contribute to mental illness, or history of recent bereavement. Caregivers of children with a current significant general medical illness that required additional care were not included.

Instruments

Brief case finding instruments used included:

A structured socio-demographic questionnaire for socio-demographic data of caregiver, child and clinical information.

The Patient Health Questionnaire (PHQ-9) by Spitzer *et al.* 2006: The PHQ-9 is a multipurpose instrument for screening, diagnosing, monitoring and measuring the severity of

depression. It is suitable for use in screening for depression among parents of children with severe disabilities (Blucker *et al.* 2011). Scores between 0 and 4 indicate no depression, 5–9 indicate mild depression, 10–14 indicate moderate depression, 15–19 indicate moderately severe depression, and 20/more indicate severe depression.

The Generalised Anxiety Disorder-7 Questionnaire (GAD-7) by Spitzer *et al.* 2006: It is a self-report questionnaire for detecting common anxiety disorders independently and when they are comorbid with depressive disorders. Scores range from 0–21. Scores ranging from 5–9 indicate mild, 10–14 indicate moderate and 15–21 indicate severe anxiety symptoms.

Child and Adolescent Impact Assessment (CAIA) (Angold *et al.* 1998): The CAIA measures family burden associated with childhood psychiatric disorders and is designed for use as a research instrument. The instrument measures 6 domains of burden; economic impact, impact on family relationships, impact on other relations, restrictions in activities, responsibility for problems and impact on the feelings of personal well-being.

Statistical Analysis

The data was analysed using the Statistical Package for Social Sciences (SPSS version 23). Descriptive statistics involved frequency counts for demographic data. As all the instruments yielded ordinal data, statistical computations then used non-parametric techniques. The Mann-Whitney U-test was used for all two-group comparisons, and the Kruskal-Wallis test was used for comparisons involving three or more groups. The Spearman Rank Order

Correlation was used for analysing potential relationships between the dependent measures. The level of significance was set at an alpha level of 0.05.

Our sample consisted largely of children with Attention deficit hyperactivity disorder and Autism spectrum disorders, given that there are differences in the clinical presentation, treatment modalities, prognosis and social perceptions about these disorders, the impact of the individual disorders on parental well-being and burden of care was further explored in this study.

Ethical considerations

The study was approved by the University of KwaZulu-Natal's Biomedical Research Ethics Committee (Ref BE285/14). Permission was also obtained from the department of health.

Results

One hundred and twenty one adult caregivers were included.

Demographic profile of caregivers:

The caregivers were predominantly female with a mean age of 34.99 years [SD 10.38 median 31 years] and 74% were mothers. Table 1 summarises the socio-demographic profile of the caregivers.

Prevalence of Anxiety and Depression, and Caregiver Burden:

Fifty four (44%) caregivers reported scores of greater than 4 on the PHQ9 suggesting the presence of depression. Of these 33(27%) caregivers scored 5-9 (mild depressive symptoms), 10(8%) scored 10-14 (moderate symptoms), 6(5%) scored 15-19 (moderately severe symptoms) and 5(4%) scored 20 or more (severe depression). Sixty seven (56 %) scored 4 or less for depressive symptoms. The mean PHQ 9 score was 5.75 (SD 5.98) (mild depression) amongst all the caregivers.

Sixty five (54%) of caregivers reported anxiety symptoms, with mild anxiety reported among 45(44.1%), moderate anxiety in 11(10.8%) and severe anxiety in 9(8.8%) caregivers. The mean GAD7 score was 5.71, (SD 5.03) (mild anxiety) for the entire group.

Caregiver burden was predominantly reported in the domains of restrictions in activities (n=40, 32.8%), feelings on personal well-being (n=37, 30.7%) and economic impact (n=21, 17.4%). The reported caregiver burden in each domain was: restrictions in activities (mean score on CAIA 1.97; SD 2.05), feelings on personal well-being (mean score on CAIA 4.60; SD 2.89) and economic impact (mean score on CAIA 1.40; SD 1.68), whilst there were minimal reports of impact on income loss (mean 0.74; SD 1.65), stigma (mean 0.14; SD 0.47) and health impact (mean 0.47; SD 1.22).

Caregiver demographic variables with anxiety, depression and caregiver burden:

Gender

Female gender of caregiver was significantly associated with increased reports of burden of care in the domain of feelings of personal well-being on the CAIA (mean 4.88; SD 2.736;

$p=0.027$) compared to male gender (mean 3.71; SD 2.199). There were no other significant gender differences in caregiver burden domains or emotional distress measured by anxiety and distress.

Marital Status

The marital status of married was only associated with higher burden on the domain of health impact (mean 0.41; SD 0.957; $p=0.024$) than single caregivers (mean 0.00, SD 0.00). There were no other significant associations with marital status.

Race

White caregivers scored higher depression (mean 10.36; SD 7.298; $p=0.005$) and anxiety scores (mean 9.27; SD 7.976; $p=0.006$) compared with other race groups (Black African, Coloured and Indian). White caregivers also reported greater impact on feelings of personal well-being (mean 6.45; SD 3.012; $p=0.003$) and health impact on the CAIA (mean 0.91; SD 1.044; $p=0.003$), while Indian caregivers reported significantly higher stigma (mean 0.15, SD 0.534; $p=0.033$). No other significant associations for race and other caregiver domains. Table 2.

Educational level

The significant associations were that caregivers with a lower educational level (incomplete secondary schooling) reported significantly higher anxiety (mean 8.50; SD 5.803; $p=0.017$) and a primary school education was associated with higher scores on economic impact (mean 4.25; SD 2.363; $p=0.001$) than incomplete secondary schooling (mean 0.94; SD 0.938) or complete secondary schooling (mean 1.10; SD 1.24). The presence or absence of tertiary education yielded no significant differences for depression, anxiety or on caregiver burden domains ($p>0.05$).

Relationship of Caregiver to child

Mothers showed significantly higher levels of anxiety (mean 5.87; SD 5.294; $p=0.045$), and experienced higher impact on feelings of personal well-being on the CAIA (mean 4.89; SD 2.652; $p=0.004$) in comparison to fathers with anxiety scores of (mean 3.43; SD 2.760) and \

feelings of personal wellbeing scores of (mean 3.14; SD 1.574). There were no associations for depression or other caregiver domains.

Stigma

Fifteen (12.3%) caregivers reported stigma. The significant association for caregivers who reported stigma was on economic impact (mean 2.50; SD 2.380; $p=0.001$) only when compared to those who did not report experience of stigma (mean 1.17; SD 1.367).

Demographic and clinical of the children with mental illness:

The demographic and clinical profile of the children is described in Table 2. There was a predominance of boys with a 1:4 ratio of girls to boys. The most common diagnoses in the children was attention deficit hyperactivity disorder ($n=fifty\ six, 59.6\%$) and autism spectrum disorder ($n= twenty\ two, 23.4\%$).

Child demographic and clinical variables and caregiver anxiety, depression and care burden:

The caregivers of boys scored significantly higher on the restrictions impact (mean 2.27; SD 2.195; $p=0.13$) compared to caregivers of girls (mean 1.67; SD 2.017).

Caregivers of children in mainstream education reported lower restriction impact score (mean 1.42; SD 1.918; $p=0.002$) than children with special schooling needs (mean 2.32; SD 2.033).

The number of children receiving treatment in the family did not yield any significant differences for emotional distress or caregiver burden ($p>0.05$). Family history of mental illness and the duration of treatment were also not associated with depression, anxiety or caregiver burden impact ($p>0.05$).

Finally, caregivers of the children with a diagnosis of either ADHD or autistic spectrum disorder (ASD) were compared for emotional distress and burden of care (Table 3). The caregivers of children with ADHD showed significantly higher anxiety (mean 5.89; SD 4.648; $p=0.023$). A diagnosis of autistic spectrum disorder was associated with higher impact on caregiver income generation (mean 1.17; SD 2.036; $p=0.004$) and restrictions in caregiver activities (mean 2.72; SD 2.109; $p=0.001$) than for children with ADHD diagnosis in terms of perceived caregiver burden.

Support Structures

The support structures used by the caregivers for assistance included single and multiple structures. Eighty five (70.24%) respondents used multiple structures, with family being the most common source of support (27.6%), followed by friends (20.4%), school structures (18.8%), psychologists (9.2%), social workers (6.6%) and religious structures (5.3%).

Perception of cause of condition:

The caregivers' perception of aetiology for the child's condition is reported in Table 4. 32.2% of caregivers attributed causality of illness to religious belief whilst 31% of caregivers perceived causality of illness to be genetically based.

Discussion

The key findings of this study were that there were significant levels of anxiety and depression and burden of care particularly relating to feelings of personal well-being and restriction on personal and social activities reported by the caregivers. Female gender, race, educational level and marital status were associated with aspects of emotional distress and burden of care. Male gender, psychiatric diagnosis and type of schooling needs of the child were associated were also associated with caregiver burden.

Depressive & Anxiety symptoms

The finding of increased prevalence of anxiety and depressive symptoms amongst caregivers of mentally ill children in this study is consistent with the literature on caregiver emotional distress (Angold *et al.* 1998; Anjuman *et al.* 2010 and Yusuf *et al.* 2013). Anjuman and colleagues reported that 49% of the caregivers showed high burden of care, 56% of caregivers suffered from anxiety and insomnia, 48% suffered from severe depression and 52% experienced somatic symptoms (Anjuman *et al.* 2010). In a study in China, parents of mentally ill children reported additional stress in their life (Liu *et al.* 2007).

In this current study, being unemployed and female was associated with anxiety and depression which is consistent with general population studies (Stein *et al.* 2008) and studies on caregiver burden (Johnson 2016, Sharply *et al.* 1997). The results from this study are also consistent with other literature on caregivers.

Caregiver factors associated with increased emotional distress include being female, lower level of education, lower income group and Caucasian race (Houtrow *et al.* 2011, Chhagan *et al.* 2014). Mothers were found to display significantly higher levels of anxiety and burden of care similar to findings in African and international studies (Raina *et al.* 2005, Dada *et al.* 2011 and Horowitz *et al.* 2011).

Multiple factors may be associated with milder anxiety and depression symptom severity in this study compared to the literature (Liu *et al.* 2007 and Ambikile *et al.* 2012). Possible explanations include, caregivers were screened at specialist level of care, with access to a wider range of specialist and allied services, hence improved patient outcomes. Attendance at specialist clinics also exposes caregivers to others with similar challenges; allowing for support groups, information sharing and acquisition of improved coping strategies.

Additionally, during the early period of patient care there are often uncertainties relating to diagnosis, treatment side effects, prognosis and patient symptoms are often more severe as treatment may not be optimised. These factors contribute to increased anxiety and depressive symptoms amongst caregivers. In our study children had already received a diagnosis and were on treatment with the majority on treatment for more than 2 years and this may account for better adjustment to the caregiving role. The results of this study will require further research to establish possible protective factors.

Other protective factors for emotional distress in this study may include low report of perception of stigma, understanding and acceptance of genetic attributions and cultural explanations for illness, access to support structures such as family and the use of multiple support structures. Thus local socio-cultural factors may play an important role in stress adaptation and needs to be further explored. However, in contrast to other studies, marital status was not found to be protective, rather single status was associated with reduced impact on emotional distress and caregiver burden (Houtrow *et al.* 2011). This finding is however considered with caution due to the small sample size.

The findings of this study for child correlates associated with caregiver burden and distress are also in keeping with the literature. Male gender, children with poorer academic achievement, severity of illness and externalising symptoms place higher demands for care on caregivers (Dada *et al.* 2011, Houtrow *et al.* 2011 and Yusuf *et al.* 2013).

Burden of Care

The findings of impact on social restrictions, personal wellbeing and economic burden are similar to a study in Tanzania which highlighted the social, economic, psychological and emotional challenges experienced by caregivers living with mentally ill children (Ambikile & Outwater, 2012). The finding of high impact on social restrictions appears to also be consistent with research in other settings as Liu *et al.* (2007), reported that over half of parents indicated that their leisure time was significantly decreased, and over a third of parents reported that they were reluctant to invite friends into their house since their child had developed problems (Liu *et al.* 2007).

Child factors associated with burden of care in this study included having a male child on treatment and remedial schooling. Emotional distress among caregivers in a Nigerian study was significantly associated with male gender (Yusuf *et al.* 2013). Studies have consistently established that a lower level of education and function of patient predicts a higher level of burden (Liu *et al.* 2007, Dada *et al.* 2011, Yusuf *et al.* 2013). It is likely that those in remedial schooling have more severe illness and impairment resulting in greater caregiver strain.

Caregiver factors associated with increased burden of care in the literature include female gender and unemployment and are consistent with this study. Caregivers were predominantly females who reported significantly greater impact on feelings of personal well-being on the CAIA. Mothers are more likely to miss work and make personal sacrifices to care for sick children as fathers are generally the primary breadwinners in our local context. Mothers are also more likely to be at the frontline in engaging and accessing treatment and managing the child's behavioural, social and schooling issues (Raina *et al.* 2004 Anjuman *et al.* 2010, Dada *et al.* 2011, Yusuf *et al.* 2013).

Childhood mental health problems are common and disproportionately affect children with fewer family and health care resources. The role of stigma is presumed to be significant in this regard, the experience of stigma and correlation with higher levels of caregiver burden in this study are in keeping with the literature (Mukolo *et al.* 2010).

Autism Spectrum Disorders (ASD) versus Attention Deficit Hyperactivity Disorder (ADHD) group

There are many challenges that are associated with raising children with ADHD and/or autism spectrum disorders. In this study caregivers of ADHD children reported higher anxiety levels whilst caregivers of children with autism reported greater impact on burden of care in the income impact and social restrictions domain. The differences reported should be considered in planning appropriate caregiver interventions for each group.

Donenberg and Baker (1993) evaluated the impact of young children with externalizing behaviours such as ADHD on their families. They found that compared to parents with normally developing children, parents with externalizing children reported more negative impact and less positive feelings about parenting, and higher child related stress (Donenberg & Baker, 1993).

In ADHD, the lack of impulse control is perhaps the most difficult symptom to manage socially, as children are often defiant, argumentative, overstimulated and situations can quickly escalate to problems. Social interactions remove structure and boundaries which are crucial for ADHD sufferers, predisposing them to disorganisation and distractibility (Rokhill *et al.* 2013). The unpredictability of their behaviours is likely therefore associated with greater anxiety in caregivers and supported by this study.

Children with autism spectrum disorders are often unable to communicate their needs effectively, may not understand what's happening around them and may become easily angry and frustrated. The need for predictable environments in these children restricts social activities for their caregivers.

A lack of adequate social, educational and care facilities for patients with autism who are unable to attend mainstream schools results in caregivers having to assume full day responsibilities for these patients possibly accounting for greater economic impact. Hoefman *et al.* (2014) described the considerable problems experienced by the parents of children with autistic spectrum disorders and these included difficulties with managing multiple roles, financial problems and depressive symptoms. Importantly the higher impact of caring was associated with higher subjective burden of care and lower family quality of life (Hoefman *et al.* 2014). Thus the prevalence of anxiety, depression and caregiver burden appears to be mediated by several factors.

Study Limitations

This study has several limitations. The limitations included the cross-sectional design, hospital setting, limited sample size, self-report from a heterogeneous group of caregivers and children with varying types of mental illness. The urban setting limits generalisability as rural community samples are not adequately represented in this study and caregivers in these communities often faces greater challenges in accessing multidisciplinary care, remedial schooling and support structures.

Children in the pre-diagnosis & pre-treatment phases of care were not included in the study, and the symptomatic untreated child is often more problematic and these caregivers experience substantial stress. The use of screening tools and not a diagnostic interview also limited findings and the results need to be explored further in a larger study.

The study also only included English speaking caregivers only; who were more likely to have had access to education which was found to be protective against emotional distress and we acknowledge this as a further significant limitation.

Conclusion

This study suggests that caregivers experience increased levels of anxiety and depressive symptoms and reported caregiver burden particularly in domains of social restrictions and feelings of personal well-being.

The study reinforces the need to screen all caregivers at all points of child contact with health services, to ensure optimal outcomes for themselves and their children. Further research is required to establish the risk and protective factors in our local context.

References

- Aloba, O., Fatoye, O., Mapayi, B. (2013). A review of quality of life studies in Nigerian Patients with Psychiatric Disorders. *African Journal of Psychiatry*, 16(5), 333-337.
- Ambikile, J. S., Outwater, A. (2012). Challenges of caring for children with mental disorders: Experiences and views of caregivers attending the outpatient clinic at Muhimbili National Hospital, Dar es Salaam – Tanzania. *Child and Adolescent Psychiatry and Mental Health*, 6(16), 1-11.
- Angold, A., Messer, S. C., Stangl, D. (1998). Perceived Parental Burden and Service Use for Child and Adolescent Psychiatric Disorders. *American Journal of Public Health*, 88 (1), 75-80.
- Anjuman, W., Chaudhry, H. R., Irfan, M. (2010). Burden of Care in caregivers of patients with Schizophrenia and Epilepsy. *Journal of Pakistan Psychiatric Society*, 7(2), 79-83.
- Blucker, R. T., Elliot, T. R., Warren, R. H., Warren, A. M. (2011). Psychological adjustment of family caregivers of children who have severe neurodisabilities that require chronic respiratory management. *Families, Systems & Health*, 29(3), 215-231.
- Botha, M. (2011). Validation of the Patient Health Questionnaire (PHQ-9) in an African Context. *Institutional Repository/North West University*.
- Brannan, A. M., Heflinger, C. A. (2006). Caregiver, Child, Family and Service System contributors to caregiver strain in two child mental health systems. *The Journal of Behavioural Health Services & Research*, 33(4), 408-422.
- Caqueo-Urizar, A., Gutierrez-Maldonado, J., Miranda-Castillo, C. (2009). Quality of life in caregivers of patients with schizophrenia: a literature review. *Health Quality Life Outcomes*, 11(7), 1-5. doi:10.1186/1477-7525-7-84.
- Chhagan, M. K., Mellins, A. C., Kauchali, S., Craib, M. H., Taylor, M., Kvalsvig, J. D. (2014). Mental health disorders among caregivers of preschool children in the Asenze study in KwaZulu-Natal, South Africa. *Maternal Child Health Journal*, 18(1), 1-15.

- Cook, J. A., Lefley, H. P., Pickett, S. A., Cohler, B. J. (1994). Age and family burden amongst parents of offspring with severe mental illness. *American Journal of Orthopsychiatry*, 64(3), 435-447.
- Dada, M. U., Okewole, N. O., Ogun, C. O., Bello-Mojeeed, M. A. (2011). Factors associated with caregiver burden in a child and adolescent Psychiatric facility in Lagos, Nigeria. *BMC Pediatrics*, 11, 110. doi: 10.1186/1471-2431-11-110.
- Donenberg, G., Baker, B. L. (1993). The Impact of Young Children with Externalising Behaviours on Their Families. *Journal of Abnormal Child Psychology*, 21(2), 179-195.
- Hoefman, R., Payakachat, N., Exel, J. V., Kuhlthau, K., Kovacs, E., Pyne, J. (2014). Caring for a Child with Autism Spectrum Disorder and Parents' Quality of Life: Application of the CarerQoL. *J Autism Dev Disord*, 44(8), 1933-1945. doi:10.1007/s10803-014-2066-1.
- Horowitz, A. V., Reinhard, S. C. (1995). Ethnic differences in caregiving duties and burdens among parents and siblings of persons with severe mental illness. *Journal of Health and Social Behaviour*, 36(2), 138-150.
- Houtrow, A. J., Okumura, M. J. (2011). Pediatric Mental Health Problems and Associated Burden on Families. *Vulnerable Child Youth Stud*, 6(3), 222-233.
- Johnson, J. (2016). Parental Stress and Autism Spectrum Disorders. *Autism Research Review International*, 1-4. https://www.autism.com/parent_stress.
- Kang, E., Brannan, A. M., Heflinger, A. C. (2005). Racial differences in response to the Caregiver Strain Questionnaire. *Journal of Child and Family Studies*, 14(1), 43-56.
- Kroenke, K., Spitzer, R., Williams, W. (2001). The PHQ-9: Validity of a brief depression severity measure. *J Gen Intern Med*, 16, 606-616.
- Liu, M., Lambert, C. E., Lambert, V. A., (2007). Caregiver burden and coping patterns of Chinese parents of a child with a mental illness. *International Journal Mental Health Nursing*, 16(2), 86-95.

- Mendenhall, A. N., Mount, K. (2011). Parents of Children with Mental Illness: Exploring the Caregiver Experience and Caregiver – Focused Interventions. *Families in Society*, 92(2), 183-190.
- Meltzer, H., Ford, T., Goodman, R., Vostanis, P. (2011). The Burden of Caring for Children with Emotional or Conduct Disorders. *International Journal of Family Medicine*, 2011, 8.doi:10.1155/2011/801203.
- Messer, S. C., Angold, A., Costello, E. J. (1996). The Child and Adolescent Burden Assessment (CABA): Measuring the family impact of behavioural and emotional problems. *International Journal of Methods in psychiatric research*, 6(4), 261-284.
- Monahan, P. O., Shacham, E., Reece, M. (2009). Validity/Reliability of PHQ-9 and PHQ-2 Depression Scales among Adults Living with HIV/AIDS in Western Kenya. *J Gen Intern Med*, 24(2), 189-197.
- Mukolo, A., Heflinger, C. A., Wallstone, K. A. (2010). The stigma of childhood mental disorders: A conceptual framework. *J Am Acad Child Adolescent Psychiatry*, 49(2), 92-198.
- Nehra, D. K. (2014). Study of Burden in parents of children with mental retardation. *Journal of Indian Health Psychology*, 8(2), 12-19.
- Raina, P., O'Donnell, M., Schwellnus, H., Rosenbaum, P., King, G. (2004). Caregiving process and caregiver burden: Conceptual models to guide research and practice. *BMC Pediatrics*, 4, 1-13.
- Raina, P., O'Donnell, M., Rosenbaum, P., et al. (2005). The Health and Wellbeing of caregivers of children with Cerebral Palsy. *Paediatrics*, 115(6), 626-36.
- Resch, J. A., Elliott, T. R., & Benz, M. R. (2012). Depression among Parents of Children with Disabilities. *Families, Systems, & Health*, 30(4), 291-301. doi: 10.1037/a0030366.
- Rokhill, C., Violette, H., Stoep, A.V., Grover, S., Myers, K. (2013). Caregivers Distress: Youth with Attention-Deficit/Hyperactivity Disorder and Comorbid Disorders Assessed via Telemental Health. *Journal of Child and Adolescent Psychopharmacology*, 23(6), 379-385.

- Sharpley, C. F., Bitsika, V., Efremidis, B. (1997). Influence of gender, parental health, and perceived expertise of assistance upon stress, anxiety and depression among parents of children with autism. *Journal of Intellectual and Developmental Disability*, 22, 19-28.
- Sidik, S. M., Arroll, B., Goodyear-Smith, F. (2012). Validation of the GAD-7(Malay version) among women attending a primary care clinic in Malaysia. *Journal of Primary Health Care*, 4(1), 5-11.
- Spitzer, R. L., Kroenke, K., Williams, J. B., et al. (2006). A brief measure for assessing generalised anxiety disorder: the GAD-7. *Arch Intern Med*, 166, 1092-7.
- Stein, DJ., Seedat, S., Herman, A., Moomal, H., Heeringa S. G., Kessler R. C., Williams, D. R. (2008). Lifetime prevalence of psychiatric disorders in South Africa. *The British Journal of Psychiatry*, 192, 112-117.
- Swaroop, N., Ravi, S., Goud, B. R., et al. (2013). Burden among Caregivers of Mentally- Ill patients: A Rural Community Based Study, *Int J Res Dev Health*, 1(2), 29-34.
- Tomlinson, M., Grimsrud, A.T., Stein, DJ., Williams, DR., Myer, L. (2009). The epidemiology of major depression in South Africa: Results from the South African Stress and Health study. *South African Medical Journal*, 99(5), 368-373.
- Vaughan, E. L., Feinn, R., Bernard, S., Brereton, M., Kaufman, J. S., (2013). Relationships between child emotional and behavioural symptoms and caregiver strain and parenting stress. *Journal of Family Issues*, 34(4), 534-556.
- World Health Organisation. (2003). Caring for children and adolescents with mental disorders: setting WHO directions. Geneva.
- Yusuf, A. J., Nuhu, F. T., Olisah, V. O. (2013). Emotional Distress amongst caregivers of patients with Epilepsy in Katsina State, Northern Nigeria. *African Journal of Psychiatry*, 16(1), 41 – 44. doi: <http://dx.doi.org/10.4314/ajpsy.v16i1.7>.

Tables

Table 1: Socio-Demographic profile of caregivers (N=121)

		Caregivers N (121)	Caregivers %
Gender			
	Female	96	79.5
Marital status			
	Divorced	12	9.9
	Married	72	59.5
	Single	30	24.8
	Widowed	7	5.8
Occupational status			
	Employed	46	38.0
	Unemployed	75	62.0
Race			
	Black	43	35.5
	Coloured	10	8.3
	Indian	41	33.9
	White	27	22.3
Caregiver educational level			
	Primary School	8	6.6
	Some Secondary	38	31.4
	Grade 12	71	58.7
	Unknown	4	3.3
Tertiary Education			
	Yes	44	36.4
	No	72	59.5
	Unknown	5	4.1
Household Monthly Income			
	Under R1000	3	2.5
	R1000-R2500	24	19.8
	R5000 – R10000	60	49.6
	Over R10000	27	22.3
	Unknown	7	5.8
Relationship of caregiver to child			
	Mother	90	74.4
	Father	15	12.4
	Both parents	1	0.8
	Grandparent	11	9.1
	Other	4	3.3
Stigma experienced			
	No	103	85.1
	Yes	15	12.4
	Unknown	3	2.5

Table 2: Demographic profile of child and adolescent mental health care users

		Children with mental illness N=121		%	
Gender of child					
	Female	26		20.5	
	Male	101		79.5	
Age of child					
	Under 5	1		0.8	
	5-7	9		7.4	
	7-9	27		22.3	
	9-12	32		26.4	
	Over 12	52		43.0	
Number of children in family receiving treatment					
	One	113		93.4	
	Two or more	7		5.8	
	Unknown	1		0.8	
Child education					
	No school	13		10.7	
	Remedial	49		40.5	
	Mainstream	58		47.9	
	Unknown	1		0.8	
Number of Diagnosis in child					
	One disorder	94		77.7	
	Two disorders	22		18.2	
	3 or more disorders	5		4.1	
Duration of treatment in child					
	Less than two years	32		26.4	
	More than two years	88		72.7	
	Unknown	1		0.8	
Diagnosis in Child					
		Children with Single diagnosis (N=94)		Children with Comorbid disorders (N=27)	
		N	%	N	%
	Psychotic disorders	2	2.1	3	4.5
	Bipolar Mood disorders	2	2.1	5	7.5
	Depressive disorders	1	1.1	6	9.0
	Anxiety disorders	0	0.0	7	10.4
	ADHD	56	59.6	19	28.4
	Disruptive behaviour disorders	2	2.1	8	11.8
	Autism Spectrum disorder	22	23.4	5	7.5
	Other	9	9.5	14	20.9

Table 3: Reports from caregivers of children with ADHD (n= 56) & ASD (n= 22)

Caregiver Scores	Mean Score	SD	Median	P Value
Anxiety (GAD 7)				
ADHD	5.89	4.648	5.00	0.023
ASD	4.00	4.814	2.50	
Depression(PHQ 9)				
ADHD	5.57	4.83	4	0.136
ASD	4.14	4.99	3	
Income impact (CAIA)				
ADHD	0.20	0.842	0.00	
ASD	1.17	2.036	0.00	0.004
Restrictions impact (CAIA)				
ADHD	1.40	1.912	0.00	
ASD	2.72	2.109	4.00	0.001

Table 4: Caregiver perception of cause for child's condition

	Caregiver perception N=121 (Percentage)
God's will	32.2
Genetics	31.1
Self	12.9
Child's other parent	10.5
Physical injury / disability	9.4
Previous traumatic experience	4.1
Partner	2.8
Satan	1.9
Chance or bad luck	1.4
Another family member	1.1
Child	0.8
School	0.8
Other	0.8
Child's friends / peers	0.0
Neighbourhood/ community	0.0

NB: respondents were allowed multiple options

APPENDICES

Appendix 1: Protocol

Research protocol:

Anxiety and Depressive symptoms amongst Caregivers of Children with Mental Illness

Aim of the study

Determine the prevalence of anxiety and depression in caregivers of children and adolescents with mental illness and identify factors associated with increased risk of emotional distress and burden of care at two psychiatric clinics in Durban, KwaZulu Natal, South Africa.

Background

Caregiving is a normal part of being the parent of a young child, yet this role takes on a completely new dimension when caring for a mentally ill child with psychological and or functional limitations. The foremost challenge for many parents is managing their child's chronic health problems effectively whilst coping with routines and requirements of everyday life.

Burden of Care has been defined as “the presence of problems, difficulties or adverse events which affect the lives of the psychiatric patients significant others”.¹ This is directly related to the difficulties experienced in the course of caring for the mentally ill child and the chronicity of such care. The impact of living with a mentally ill person is felt across multiple facets of family life, including family interaction, family morale, family routine, family emotional stress and social dysfunction. Amongst first degree relatives of mentally ill children, more subtle distress is propagated by the associated stigma, feelings of guilt and self-blame creating further distress.

Caregiver strain has 2 dimensions, objective burden is regarded as the observable disruption of aspects of the caregivers life (financial strain, interruption at work, interruption of social life), whereas subjective burden is the extent to which the caregiver perceives care responsibilities to be stressful (anger, sadness, embarrassment, worry, anxiety, stigma).² Subjective burden is an important predictor of visits to health facilities, as often subjective distress in the parent results in more frequent visits to health facilities and caregivers seeking

additional treatment for the child. The impact of the caregiver subjective burden manifested as repeated visits impacts on health service load without addressing the core problem, caregiver emotional distress.

Caregivers are not necessarily parents, care is generally provided because of emotional bonding, guilt, family duty and lack of alternative community based care resources.

As the number of children with mental illness is increasing, the numbers of children requiring care from relatives is also growing. Consequently there is an increasing demand to understand the needs of caregivers. Understanding their needs is crucially important for planning interventions and testing the value of programmes to support caregivers.² Since parental strain has a detrimental effect on parental health (more worry, depression, physical ill health, and increased smoking and drinking) which in turn may negatively impact on the child's mental health, it is important to reduce the caregivers' burden, so that parents can provide sufficient care and maintain their own healthy life.²

Objectives

1. Describe the demographic profile of caregivers of mentally ill children attending psychiatric clinics.
2. Prevalence of anxiety and depressive symptoms in caregivers of children with mental illness attending at a psychiatric clinic
3. Determine the demographic characteristics of caregivers and children that are associated with anxiety and depression in caregivers and possibly predict for emotional distress.
4. Identify the clinical factors which are associated with caregiver anxiety and depression
5. Measure the level of burden experienced by caregivers on account of their child's mental health problems.
6. Evaluate the impact of a child's mental illness on different domains of family function and relations.

Hypothesis

A high Level of emotional Distress (depressive and anxiety symptoms) amongst primary caregivers is associated with caring for children and adolescents with mental illness.

Literature Review

Previous studies on the on emotional distress in caregivers of children with mental illness have provided consistent evidence that caregivers of children with chronic mental illness suffer from moderately high levels of caregiver burden which occur as a result of the challenges encountered whilst caring for a mentally ill child. Burden is predicted by the presence of psychiatric co morbidity in the caregiver, level of functioning of the caregiver, level of functioning of the child, degree of impairment as assessed by the caregiver and educational level of the child. Lower levels of education of patients showed significant association and predicated higher burden of care, possibly because those with higher education levels were better able to care for themselves¹.

Anjuman and colleagues noted in a study on caregiver burden that almost half of the caregivers showed high burden of care and majority experienced mental distress. 49% of caregivers had high burden of care. 56% of caregivers suffered from anxiety and insomnia, 52% experienced somatic symptoms and 48% suffered from severe depression².

A recent Tanzanian study highlighted the social, economic, psychological and emotional challenges experienced by caregivers living with mentally ill children. Three major themes emerged in this study with regards economic challenges, including existing poverty, interference with income generating activities and extra expenditure due to illness. Psychological and emotional challenges in this third world setting were similar to those described in 1st world setting with caregiver worry over long term consequences for the affected child. Other key emotional manifestations in this group were sadness, bitterness, inner pain and difficulty in communicating with their children. Challenges of inadequate social services mirror the South African context and highlighted the dire need for special needs school programs and day care facilities. Importantly, the need for synergy amongst health and social services is raised³

In a study in China, Liu and colleagues (2007) found that most parents of mentally ill children experienced pressure in their life, and 97.9% of them had increased anxiety.⁴ Moreover, over half of parents in their study indicated that their leisure time significantly decreased, and over a third of them reported that they were reluctant to invite friends into

their house since their child had developed their problems. Parental feelings of burden and stigma seem to be evident across cultures⁴.

In a study in Nigeria on emotional distress associated with caring for epileptic patients, found high levels of emotional distress amongst caregivers. Emotional distress in the study is significantly related to male gender, providing care for a male patient, siblings as caregivers also experienced higher levels of distress and residing in a rural area is associated with increased burden ⁵.

Studies collectively demonstrate the significant burden associated with caring for a mentally ill individual. Children are dependent on their caregivers for basic needs support, protection and love. Mental disorders in childhood are often chronic and disturbing, requiring significant attention and support from caregivers. Caregivers require support services and screening for emotional distress to ensure good outcomes for themselves and their children.

Methods

Study Design

A prospective study design is planned. Data will be collected via interviews with caregivers of children and adolescents attending psychiatric clinics using structured data collection questionnaires and screening tools.

Study Sites

This study will be conducted at King Dinuzulu Hospital and King Edward VIII Hospital; both facilities are situated in Durban, Kwa Zulu-Natal, South Africa. Psychiatric services are offered at a regional level at King Edward VIII Hospital. King Dinuzulu Hospital has an established child psychiatry unit and child clinics. The 2 hospitals were selected as they are the only 2 units in Durban with child psychiatrists.

Study Period

Data will be collected over a 12- 18 month period

Study population

The sample will comprise caregivers accompanying a child for consecutive visits to the outpatient child psychiatry clinic. A diverse population accesses care at both facilities.

-) The population comprises individuals living in urban and peri-urban settings.
-) The socioeconomic status of the sample is variable.

Sampling strategy

All consecutive caregivers accompanying children to the child psychiatry outpatient clinics will be considered.

Inclusion Criteria

-) Adult Caregiver (greater than 18 years) – male or female
-) Child/children (age 1-18 years) on treatment for mental illness.
-) Caregiver must live with the child and be responsible for monitoring treatment in the child.
-) Caregiver willingness to participate in study
-) Able to communicate in English.

Exclusion Criteria

-) Caregivers on treatment for a mental illness, prior to child receiving psychiatric treatment
-) Mental Retardation in the child
-) Current significant general medical illness in the child that requires additional care, e.g. Human Immunodeficiency Virus or Epilepsy
-) History of recent bereavement in caregiver
-) History of general medical illness in caregiver that may contribute to mental illness in caregiver

Sample size

120 Participants- The sample size was discussed with the statistician. The sample size represents more than 30% of the clinic population.

Data Collection methods and tools

The child and adolescent clinics at which this study will be conducted are busy and poorly staffed, resulting in time constraint being a major problem. Brief case finding instruments with proven diagnostic accuracy have therefore been selected for use in this study.

The participants will be interviewed using the following instruments:

1. A socio-demographic Questionnaire [APPENDIX A]
2. The Patient Health Questionnaire (PHQ-9) [APPENDIX B]
3. The Generalised Anxiety Disorder-7 Questionnaire (GAD-7) [APPENDIX C]
4. Child And Adolescent Impact Assessment (CAIA) [APPENDIX D]

The Patient Health Questionnaire (PHQ-9)

The PHQ-9 is a multipurpose instrument for screening, diagnosing, monitoring and measuring the severity of depression; it incorporates DSM-1V diagnostic criteria with other leading major depressive symptoms into a brief self-report tool. It is also suitable for use in screening for depression among parents of children with severe disabilities (Blucker, Elliott, Warren, & Warren, 2011).

The PHQ9 was designed for use in clinical and medical settings, and uses a four-point Likert scale (0 not at all, 1 = several days, 2 = more than half the days, 3 = nearly every day) to gauge responses to questions asking about the respondents mental/emotional health over the previous 2-week period.

Scores on the PHQ9 can range from 0–27; scores between 0 and 4 indicate no depression, 5–9 indicate mild depression, 10–14 indicate moderate depression, 15–19 indicate moderately severe depression, and 20/more indicate severe depression.¹¹ Reliability and validity studies of the PHQ9 have yielded results indicating sound psychometric properties.

The diagnostic validity of the PHQ-9 was established in studies and internal consistency of the PHQ9 has been shown to be high. A study involving two different patient populations and 6000 total participants produced Cronbach's alpha of .86 and .89. Additionally, test–retest reliability had a high correlation at $r = .84$ and discriminant validity was established via a ROC analysis that produced an area under the curve for the PHQ9 of .95 when diagnosing depression (11). Moreover, criterion validity was demonstrated by both high sensitivity and specificity for the PHQ9.

In addition, among the 6000 participants who completed the PHQ9, 580 were interviewed by mental health professionals, and results demonstrated strong agreement between diagnoses made by the PHQ9 and by the mental health professionals.¹¹

The Generalised Anxiety Disorder-7 Questionnaire (GAD-7)

The seven item Generalised Anxiety disorder scale has been developed for use in primary care settings. It is a self-reported questionnaire with demonstrated good reliability, with sensitivity for diagnosing anxiety (cut point 8) of 92% and specificity of 76%.

The GAD-7 has been found to be a good case-finding instrument for GAD, panic disorder, social anxiety disorder and post-traumatic stress disorder (PTSD), and is the most appropriate for use in primary care settings. The GAD-7 presents a rapid, efficient, reliable and valid method for detecting the presence of common anxiety disorders independently and when they are comorbid with Depressive Disorders.⁸

The GAD-7 scale description: patients rate answers (0=not at all, 1=several days, 2=more than half the days, 3=nearly every day) to 7 anxiety related questions; how often in the past 2 weeks they felt (1) nervous, anxious, or on edge; (2) easily annoyed or irritable; (3) afraid as if something awful might happen; (4) worried about different things; (5) restless and unable to sit still; (6) unable to stop or control worrying; or (7) had trouble relaxing. Score ranges are from 0–15; with 0–5 mild, 6–10 moderate, 11–15 severe.

Child and Adolescent Impact Assessment [Previously known as The Child and Adolescent Burden Assessment]

The CAIA is an instrument for the measurement of family burden associated with childhood psychiatric disorders, designed for use as a research instrument; it has been used in clinical research studies, such as the ACC Study. The instrument adopts a multidimensional view, assessing both subjective and objective aspects of burden. It measures burden, specifically for difficulties and adversities experienced by a family because of a child's mental illness.¹²

Psychometric properties of the CAIA have been examined in general population and clinical samples. Factor analysis demonstrated robust general burden construct in community and clinical samples. The internal consistency reliability estimates were high (coefficient alpha > .80), test retest stability was adequate, criterion related validity was supported in comparisons of mean burden levels between clinical [Assessing coordinated care, ACC, Burns et al] and community samples [Great Smokey Mountains Study, Costello et al 1996].¹²

The CAIA requires approximately 10 minutes for completion. Parents are questioned about 20 potential perceived burdens in relation to their child's mental illness. The following domains are covered, Economic impact, impact over family relations, impact over other relations, restrictions in activities, responsibility for problems and impact on feelings of

personal well-being. Items are scored on a scale from 0 to 3 with the exception of substance use which is scored 0 to 2. The highest total possible score is 59.¹³

Data Analysis

The data collected will be captured and subsequently analysed using the Statistical Package for Social Sciences (SPSS version 21). Descriptive statistics such as frequencies, percentages, mean and standard deviation will be used to summarize results. Pie chart and bar graphs will be used to present results. Mann-Whitney test will be used to test if there is any relationship between depression levels and employment status of the caregiver. Kruskal-Wallis will be used to test if there depression and anxiety levels are similar across all categories of marital status. Kruskal-Wallis test will also be used to test if there is a relationship between depression levels and income levels. Level of significance will be set at 0.05.

Limitations

1. The study is urban based and hospital based, therefore findings may not necessarily reflect trends in the other settings, this work may lack generalizability to people living in the community who are not actively seeking or receiving mental health services.
2. Caregivers may be genetically predisposed to mental illness; this may be viewed as a confounding factor despite controlling for parents with confirmed mental illnesses.

Ethical Considerations

Data will be collected by the researcher and strict confidentiality will be maintained.

Data collection sheets will be coded to maintain confidentiality and PI will not have patient identifiers on data sheets

Ethical approval will be obtained from the KwaZulu-Natal Biomedical Research Ethics Committee (BREC).

Approval for the study will also be obtained from the management of the two health establishments and Department of Health.

This study will be a questionnaire interview with written informed consent (information document and consent sheet attached). There is no risk to participants except possible discomfort associated answering distressing questions. Participants have the option of not answering any question that they find distressing.

The study will not impact on level of care patients receive irrespective of their participation

The participants will not receive any incentive for participation in the study.

Participants with elevated scores or in distress will be referred to the general psychiatry doctor at the hospital for further assessment and management.

The records will be kept in rooms with limited access to medical staff only. The results of the study will be made available to the hospital and department to enhance patient management and will assist in future programs in this field.

The hospital will not bear any costs associated with the study. All study related costs will be borne by the PI.

Study Timeline

Prospective review and proposed time frame for study:

Post graduate office submission	April 2014
Ethics submission	May 2014
Data Collection	August 2014
Data Analysis	November 2014
Publication	March 2015

Budget

Photocopying	1500 Pages x 0.8 = R 1200
Transport costs for data collection	No additional cost to PI

Statistician Fee	Free
Total Costs	R 1200

References

1. Dada M U, Niran O Okewole, Oluyemi C Ogun et al. Factors associated with caregiver burden in a child and adolescent Psychiatric facility in Lagos, Nigeria. BMC Pediatrics 2011, 11:110.
2. Wahida Anjuman, Haroon Rashid Chaudhry, Muhammad Irfan. Burden of Care in caregivers of patients with Schizophrenia and Epilepsy. Journal of Pakistan Psychiatric Society, July-December 2010, Volume 7, No2, page 79.
3. Howard Meltzer, Tamsin Ford, Robert Goodman et al. The Burden of Caring for Children with Emotional or Conduct Disorders. International Journal of Family Medicine, Volume 2011, article id 801203.
4. AJ Yusuf, FT Nuhu, VO Olisah. Emotional Distress amongst caregivers of patients with Epilepsy in Katsina State, Northern Nigeria. African Journal of Psychiatry, January 2013.
5. M Liu, CE Lambert, VA Lambert. Caregiver burden and coping patterns of Chinese parents of a child with a mental illness. International Journal Mental Health Nursing, 2007, April 16(2): page86-95.
6. Joel S Ambikile and Anne Outwater. Challenges of caring for children with mental disorders: Experiences and views of caregivers attending the outpatient clinic at Muhimbili National Hospital, Dar es Salaam-Tanzania. Child and Adolescent Psychiatry and Mental Health 2012, 6:16.
7. P Raina, M O'Donnell, P Rosenbaum et al. The Health and Wellbeing of caregivers of children with Cerebral Palsy. Paediatrics. 2005 June, 115(6).
8. RL Spitzer, K Kroenke, JB Williams, et al. A brief measure for assessing generalised anxiety disorder: the GAD-7. Arch Intern Med 2006, 166: 1092-7.

9. SM Sidik, B Arroll, F Goodyear-Smith. Validation of the GAD-7(Malay version) among women attending a primary care clinic in Malaysia. *Journal of Primary Health Care*, vol 4, nos 1, March 2012.
10. Resch, J. A., Elliott, T. R., & Benz, M. R. (2012, November 12). Depression Among Parents of Children With Disabilities. *Families, Systems, & Health*. Advance online publication. doi: 10.1037/a0030366.
11. K Kroenke, R Spitzer, W Williams. The PHQ-9: Validity of a brief depression severity measure. *JGIM*, 2001, 16: 606-616.
12. S C Messer, A Angold, E J Costello. The Child and Adolescent Burden Assessment (CABA): Measuring the family impact of behavioural and emotional problems. *International Journal of Methods in psychiatric research*, vol6, July 1996.
13. A Angold, S C Messer, D Stangl. Perceived Parental Burden and Service Use for Child and Adolescent Psychiatric Disorders. *American Journal of Public Health*, Vol. 88, No 1, January 1998.
14. O Aloba, O Fatoye, B Mapayi. A review of quality of life studies in Nigerian Patients with Psychiatric Disorders. *African Journal of Psychiatry*, vol. 16, nos 5, September 2013.
15. P O Monahan, E Shacham, M Reece, et al. Validity/Reliability of PHQ-9 and PHQ-2 Depression Scales among Adults Living with HIV/AIDS in Western Kenya. *J Gen Intern Med*. 2009 February; 24(2): 189-197
16. M Botha, Validation of the Patient Health Questionnaire (PHQ-9) in an African Context. Institutional Repository/North West University, 2011.

Appendix 2: Authors Instructions; Journal of Child & Adolescent Mental Health

Instructions to authors

The *Journal of Child & Adolescent Mental Health* welcomes papers from all disciplines addressing child and adolescent mental health including specific focus areas such as epidemiology, mental health prevention and promotion, community-based interventions, psychotherapy, pharmacotherapy, policy and risk behaviour. Sections of the journal include: Original research papers (<4 000 words); brief reports (<2 000 words); systematic reviews (<4 000 words unless by special arrangement); clinical perspectives; case series (<2 500 words) book reviews; editorials; and letters to the editor.

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Format

Title: This should be brief, sufficiently informative for retrieval by automatic searching techniques and should contain important keywords (preferably <10 words).

Author(s) and address(es) of author(s): The corresponding author must be indicated and an email address and telephone number provided. The authors' respective addresses where the work was done must be indicated.

Abstract: For data-based contributions, the abstract should be structured as follows: Objective — the primary purpose of the paper; Method — data source, subjects, design, measurements, data analysis; Results — key findings; and Conclusions — implications, future directions. For all other contributions (except editorials, letters and book reviews) the abstract must be a concise statement of the content of the paper not exceeding 200 words. It should summarise the information presented in the paper but should not include references.

Referencing

The Journal uses the APA (6th ed.) author-date system. Every source cited in text must appear in the reference list, and each entry in the reference list must be cited in text. References should be cited as per these examples:

Book

Winnicott, D. W. (1977). *The Piggle: An account of the psychoanalytic treatment of a little girl*. London: Hogarth Press.

Chapter in edited book

Lee, A. C. (2009). Psychoanalytic play therapy. In K. J. O'Connor & L. D. Braverman (Eds.), *Play therapy theory and practice: Comparing theories and techniques* (2nd ed., pp. 1–58). London: Wiley.

Journal article

Newman, L., & Stevenson, S. (2005). Parenting and borderline personality disorder: Ghosts in the nursery. *Clinical Child Psychology and Psychiatry*, 10(3), 385–394. doi: 10.1177/1359104505053756

Lein, E. S., Hawrylycz, M. J., Ao, N., Ayres, M., Bensinger, A., Bernard, A., ... Jones, A. R. (2007). Genome-wide atlas of gene expression in the adult mouse brain. *Nature*, 445 (7124), 168–176. doi: 10.1038/nature05453

Technical and research reports

U. S. Department of Health and Human Services, Office of the Surgeon General. (2010). *How tobacco smoke causes disease: The biology and behavioral basis for smoking-attributable disease*. Retrieved from http://www.surgeongeneral.gov/library/tobaccosmoke/full_report.pdf

Tests and scales

Pozanski, E. O., & Mokros, H. B. (1996). *Children's Depression Rating Scale, revised (CDRS-R)*. Los Angeles, CA: Western Psychological Services.

Conference presentation

Ammon, R. L., & Vellacher, R. R. (2006, May). Go ahead and lie to me: Self-coherence interactions with interpersonal preference. Poster presented at the meeting of the Association for Psychological Science, New York.

Tables and figures: Each table and figure must be numbered with Arabic numerals and must be accompanied by an appropriate stand-alone caption. Figures must not repeat data presented in the text or tables. Authors must ensure that their figures conform to the style of the journal. Pay particular attention to line thickness, font and figure proportions, taking into account the journal's printed page size (140 mm wide x 256 mm high). Costs of redrawing figures may be charged. For digital photographs or scanned images the resolution should be at least 300 dpi for colour or greyscale artwork and a minimum of 600 dpi for black line drawings. These can be saved (in order of preference) in PSD, JPEG, PDF or EPS format. Graphs, charts or maps can be saved in AI, PDF or EPS format. MS Office files (Word, Powerpoint, Excel) are also acceptable but DO NOT EMBED Excel graphs or Powerpoint slides in a MS Word document, rather send the original Excel or Powerpoint files. More detailed technical information is given in *Figure Guidelines for Authors*.*

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Appendix 3: Socio-demographic Questionnaire

Participant Study Number:

Site:

Section 1: Caregiver demographics

1.1 Caregiver Age:

18- 30 yrs.	
31 - 40	
41 - 50	
51 - 60	
>60	

1.2 Participant Gender:

Male	
Female	

1.3 Marital Status:

Single	
Married	
Divorced	
Widowed	

1.4 Occupational Status:

Employed	
Unemployed	

1.5 Race:

Black	
White	
Indian	
Coloured	
Other	

1.6. Caregiver Educational Level:

Grade _____

Tertiary Education

Yes	
No	

1.7. Household Income:

< R1000	
R1000 – R2500	
R2500 – R5000	
>R5000	
>R10 000	

1.8. Number of children:

1.9. Relationship of Caregiver to Child:

Mother	
Father	
Sibling	
Grandparent	
Other Specify:	

Section 2: Child/ clinical factors

2.1. Number of children receiving treatment:

One	
Two	
>Two	

2.2. Age of child receiving treatment:

2.3. Gender of child:

Male	
Female	

2.4. Childs Age & Current Level of Education

< 5yrs	
--------	--

5 – 7yrs	
7-9yrs	
9-12yrs	
>12yrs	

No School	
Remedial school	
Mainstream: Grade	

2.5. Diagnosis in Child

Psychotic Disorder	
Bipolar Mood Disorder	
Depressive Disorder	
Anxiety Disorder	
Seizure Disorder	
Attention Deficit Hyperactivity Disorder	
Disruptive Behaviour Disorder	
Autism Spectrum	
Other and specify	

2.6. Duration of Illness in Child

< 2 Years	
>2 Years	

2.7. HIV Status of Child

Positive	
Negative	
Unknown	

2.8. HIV Status of Caregiver

Positive	
Negative	
Unknown	

SECTION 3: Other factors influencing emotional distress

3.1. Child Family History of Mental Illness

Yes		Parent	
No		Sibling	
		Grandparent	
		Other	

3.2. Stigma experienced by Caregiver / Family

Yes	
No	

3.3. Satisfaction with Treatment

Yes	
No	

3.4. Support Systems:

Psychologist	
Social Worker	
School	
Family	
Friends	
Religious Organisations	
Other / Specify	

3.5 History of Recent Bereavement

Yes	
No	

Appendix 4: Patient Health Questionnaire 9 (PHQ-9)

Patient Health Questionnaire (PHQ-9)

Patient name: _____ Date: _____

1. Over the last 2 weeks, how often have you been bothered by any of the following problems?

	Not at all (0)	Several days (1)	More than half the days (2)	Nearly every day (3)
a. Little interest or pleasure in doing things.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Feeling down, depressed, or hopeless.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Trouble falling/staying asleep, sleeping too much.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Feeling tired or having little energy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Poor appetite or overeating.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Feeling bad about yourself, or that you are a failure, or have let yourself or your family down.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Trouble concentrating on things, such as reading the newspaper or watching TV.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Moving or speaking so slowly that other people could have noticed. Or the opposite; being so fidgety or restless that you have been moving around more than usual.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Thoughts that you would be better off dead or of hurting yourself in some way.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. If you checked off any problem on this questionnaire so far, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

☐ Not difficult at all ☐ Somewhat difficult ☐ Very difficult ☐ Extremely difficult

TOTAL SCORE _____

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Appendix 5: Anxiety Disorder 7 Questionnaire (GAD-7)

GAD-7 Anxiety

Over the <u>last two weeks</u> , how often have you been bothered by the following problems?	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious, or on edge	0	1	2	3
2. Not being able to sleep or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it is hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid, as if something awful might happen	0	1	2	3

Column totals _____ + _____ + _____ + _____ =

Total score _____

If you checked any problems, how difficult have they made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all

☐

Somewhat difficult

☐

Very difficult

☐

Extremely difficult

☐

Source: Primary Care Evaluation of Mental Disorders Patient Health Questionnaire (PRIME-MD-PHQ). The PHQ was developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke, and colleagues. For research information, contact Dr. Spitzer at rls8@columbia.edu. PRIME-MD® is a trademark of Pfizer Inc. Copyright© 1999 Pfizer Inc. All rights reserved. Reproduced with permission

Scoring GAD-7 Anxiety Severity

This is calculated by assigning scores of 0, 1, 2, and 3 to the response categories, respectively, of "not at all," "several days," "more than half the days," and "nearly every day." GAD-7 total score for the seven items ranges from 0 to 21.

0–4: minimal anxiety

5–9: mild anxiety

10–14: moderate anxiety

15–21: severe anxiety

Appendix 6: Child and Adolescent Impact Assessment (CAIA)

CHILD AND ADOLESCENT IMPACT ASSESSMENT

ECONOMIC BURDEN

IF SERVICES RECEIVED IN THE LAST 3 MONTHS, ASK EXPENSES. OTHERWISE, SKIP TO "LOSS OF INCOME" (PAGE 2).



EXPENSES

The monetary expenses associated with getting services for child's emotional or behavioral problems. Include costs of medication.

Do not include income lost because of child's problems, which is coded under "Loss of Income".

Have there been ANY expenses associated with getting help for your child?

IF ANY EXPENSES, CONTINUE.

Have the costs of getting help for your child's problems had an impact on family budget for other things?

Do you have savings to cover them?

Have you had to cut back on other things to pay for it?

Are they causing any restrictions elsewhere?

Have you had to work extra hours?

Have you or anyone else had to take an additional job?

Have you gone into debt to cover these expenses?

Are you concerned about being able to pay back these expenses?

EXPENSES

0 = No expenses.

1 = Expenses but affordable.

2 = Expenses causing effects on other areas of family budget.

PTA0101

Intensity

IMPACT ON EXPENSES

0 = Absent

1 = Using savings.

2 = Necessitate cutting back on other expenditures.

3 = Necessitate working additional hours/jobs.

PTA0102

DEBTS

0 = Absent

2 = Incurred debts but envision no serious problems with payback.

3 = Incurred debts and envision will have problems with payback.

PTA0103

LOSS OF INCOME

Loss of income that results from the need to get professional services for child's emotional or behavioral problems or from the need to provide an increased level of care at home, or from other things directly associated with the child's problems.

Do not include actual expenditures incurred for the child's problems, which are coded under "Expenses".

Have your child's problems affected your family's income?

DO NOT INCLUDE ACTUAL EXPENSES INCURRED.

IF PRESENT, CONTINUE.

*Have your child's problems affected your paid work?
Have you lost any time at work because of it?
Or have you had to cut down to part-time work?
Or have you been unable to work at all?
Or lost your job?*

Has "Parent #2's" paid work been affected at all?

*Has s/he lost any time at work because of it?
Or had to cut down to part-time work?
Or been unable to work at all?
Or lost his/her job?*

*Has any other family member's work been affected?
Have they lost any time at work because of it?
Or have they had to cut down to part-time work?
Or been unable to work at all?
Or lost their job?*

**IF THERE ARE 2 PARENTS IN THE HOUSEHOLD, CONTINUE.
OTHERWISE SKIP TO NEGATIVE IMPACT ON PARENT'S
PREVIOUS RELATIONSHIP (PAGE 3).**

LOSS OF INCOME

0 = Absent

2 = Present

PTA1190

Intensity

PARENT #1

0 = No income lost.

2 = Time lost at work or hours reduced.

3 = Unable to work or lost job.

PTA1101

PARENT #2

0 = No income lost.

2 = Time lost at work or hours reduced.

3 = Unable to work or lost job.

PTA1102

OTHER FAMILY MEMBER

0 = No income lost.

2 = Time lost at work or hours reduced.

3 = Unable to work or lost job.

PTA1104

IMPACT ON FAMILY RELATIONSHIPS

NEGATIVE IMPACT ON PARENT'S CURRENT PARTNERSHIP

The impact of the child's emotional or behavioral problems on the parent's "marital relationship".

Have your child's problems had a NEGATIVE impact on your relationship with "Parent #2"?

*Has your child's problems strained the relationship at all?
How much of a strain has it been?*

NEGATIVE/NEUTRAL IMPACT ON CURRENT RELATIONSHIP

0 = No negative effects.

1 = Some negative effects,
but relationship essentially
satisfactory.

2 = Severe negative effects
on quality of relationship
attributed to the child's
problems.

3 = Child's problems
contributed to marital
breakdown.

PTA2I01
Intensity

POSITIVE IMPACT ON PARENT'S CURRENT PARTNERSHIP

The impact of the child's emotional or behavioral problems on the parent's "marital relationship".

Have your child's problems had a POSITIVE impact on your relationship with your "Parent #2"?

*Has having to deal with these problems strengthened that
relationship at all?*

POSITIVE IMPACT ON CURRENT RELATIONSHIP

0 = No positive effects.

2 = Relationship has been
strengthened.

PTA2I02
Intensity

**IF OTHER PARENT (OP1) CONTINUE, OTHERWISE SKIP TO
NEGATIVE IMPACT ON PARENT'S PREVIOUS
RELATIONSHIP (PAGE 4)**

NEGATIVE IMPACT ON PARENT'S PREVIOUS RELATIONSHIP

The impact of the child's emotional or behavioral problems on the parent's relationship with the child's "Other Parent" who no longer lives in the home. "Other Parent" may be either a biological parent who lives elsewhere or another person who lives elsewhere that has played a significant part in raising the child.

Did your child's problems contribute to the breakdown of the relationship between you and "Other Parent"?

Were your child's problems responsible for the breakdown of the relationship?

*Did your child's problems strain the relationship at all?
How much of a strain was it?*

NEGATIVE/NEUTRAL IMPACT ON BREAKDOWN OF PREVIOUS PARTNERSHIP

0 = No negative effect.

1 = Some negative effects, but breakdown of marital relationship not influenced by child's problems.

2 = Child's problems seen as contributing to breakdown of marital relationship.

3 = Child's problems seen as most important reason for breakdown of marital relationship.

PTA3I01
Intensity

IMPACT ON PARENT'S CURRENT RELATIONSHIP WITH OTHER PARENT

The impact of the child's emotional or behavioral problems on the parent's relationship with the child's "Other Parent" who no longer lives in the home. "Other Parent" may be either a biological parent who lives elsewhere or another person who lives elsewhere that has played a significant part in raising the child.

Has your child's problems affected your current relationship with "Other Parent"?

Have your child's problems had any NEGATIVE impact on your current relationship with "Other Parent"?

*Has your child's problems strained your current relationship with "Other Parent"?
How much of a strain has it been?*

NEGATIVE/NEUTRAL IMPACT ON CURRENT RELATIONSHIP WITH PREVIOUS PARTNER

0 = No negative effect.

1 = Some negative effects, but the quality of current relationship not influenced by child's problems.

2 = Child's problems seen as contributing to difficulties in current relationship.

3 = Child's problems seen as most important reason for difficulties in current relationship.

PTA3I02
Intensity

IF EXCLUSIVE PARTNER OR BOY/GIRL FRIEND, CONTINUE. OTHERWISE, SKIP TO "IMPACT ON PARENT'S RELATIONSHIP WITH OTHER CHILD(REN) IN THE HOUSE", (PAGE 51).

NEGATIVE IMPACT ON PARENT'S NON-RESIDENTIAL BOYFRIEND/GIRLFRIEND

The impact of the child's emotional or behavioral problems on the parent's relationship with his/her steady, but non-residential, boyfriend/girlfriend.

Have your child's problems had any NEGATIVE impact on your relationship with your "boyfriend/girlfriend"?

*Has your child's problems strained the relationship at all?
How much of a strain has it been?*

NEGATIVE/NEUTRAL IMPACT ON CURRENT RELATIONSHIP

0 = No negative effects.

1 = Some negative effects, but relationship is essentially satisfactory.

2 = Severe negative effects on quality of relationship attributed to the child's problems.

3 = Child's problems contributed to breakdown of relationship.

PTC0101
Intensity

POSITIVE IMPACT ON PARENT'S NON-RESIDENTIAL BOYFRIEND/GIRLFRIEND

The impact of the child's emotional or behavioral problems on the parent's relationship with his/her steady, but non-residential, boyfriend/girlfriend.

Have your child's problems had a POSITIVE impact on your relationship with your "boyfriend/girlfriend"?

Has having to deal with these problems strengthened that relationship at all?

POSITIVE IMPACT ON CURRENT RELATIONSHIP WITH BOYFRIEND/GIRLFRIEND

0 = No positive effects.

2 = Relationship has been strengthened.

PTC0102
Intensity

IF OTHER CHILDREN IN THE HOME, CONTINUE. OTHERWISE, SKIP TO "IMPACT ON RELATIONSHIPS WITH OTHER FAMILY MEMBERS", (PAGE 61).

IMPACT ON PARENT'S RELATIONSHIP WITH OTHER CHILD(REN) IN THE HOUSE

The impact of the child's emotional or behavioral problems on the parent's relationship with other child(ren).

Have your child's problems affected your relationships with your other child(ren)?

In what way?

Have your child's problems had a NEGATIVE impact on your relationship with the other child(ren)?

Have your child's problems taken time away from your contact with the other child(ren)?

Have the problems made it more difficult for you to deal with the other child(ren)?

IMPACT ON PARENT'S RELATIONSHIP WITH OTHER CHILD(REN)

0 = Neutral or positive effect.

2 = Subject child's problems leave parent less time for other child(ren), but not otherwise affected.

3 = Subject child's problems have led to a worsening of the relationship between parent and other child(ren).

PTA4I01
Intensity

IMPACT ON RELATIONSHIPS BETWEEN OTHER CHILD(REN) IN THE HOUSEHOLD

The impact of child's emotional or behavioral problems on the relationships between children.

Include both relationships with the index child and between other children.

Have your child's problems affected his/her relationship the other children?

In what way?

Have these problems led to conflicts between the children?

Have these problems led to worsening relationships between the children?

IMPACT ON RELATIONSHIPS BETWEEN OTHER CHILDREN

0 = Neutral or positive effect on relationship.

2 = Subject child's problems have led to some conflicts between children.

3 = Subject child's problems have led to major disruption of previous relationship.

PTA5I01
Intensity

IMPACT ON THE BEHAVIOR OF OTHER CHILD(REN) IN THE HOUSEHOLD

The impact of child's emotional or behavioral problems on the other children's behavior.

Include both relationships with the index child and between other children.

Has your child's problems affected the behavior of the other children at home?

Are the other children getting in more trouble at HOME because they are acting like him/her?

Are the other children getting in trouble at SCHOOL because they are acting like him/her?

Are they getting in trouble ELSEWHERE, like at grandma's house or the store, because they are acting like him/her?

Tell me about the last time.

IMPACT ON OTHER CHILDREN'S BEHAVIOR

0 = Neutral or positive effect on other children's behavior.

2 = Subject child's problems have led other children to have some behavior problems and to get into trouble at home.

3 = Subject child's problems have led other children to have some behavior problems and to get into trouble at school or elsewhere.

PTA5I02
Intensity

IMPACT ON OTHER RELATIONSHIPS

IMPACT ON RELATIONSHIPS WITH OTHER FAMILY MEMBERS

Impact on the child's emotional or behavioral problems on the parent's relationships with other family members.

Have your child's problems had a NEGATIVE impact on your relationship with other members of your family?

Tell me what they are like?

Has your relationship with family members gotten worse because of his/her problems?

Has having to deal with these problems strained your relationship with your parents?

Your brothers or sisters?

Other close relatives?

How much worse have the relationships gotten?

RELATIONSHIPS WITH OTHER FAMILY MEMBERS

0 = Positive or neutral effect.

1 = Some negative effects, but relationships essentially unchanged.

2 = Worsening of relationships attributable to the child's problems.

3 = Child's problems have resulted in breakdown of relationships.

PTA6I01
Intensity

IMPACT ON RELATIONSHIPS WITH FRIENDS

The impact of the child's emotional or behavioral problems on the parent's relationships with friends.

Have your child's problems had a NEGATIVE impact on your relationship with your friends?

Tell me what they are like?

Has your relationship with friends gotten worse because of his/her problems?

Has having to deal with these problems put a strain on your friendships?

How much worse have the relationships gotten?

RELATIONSHIPS WITH FRIENDS

0 = Positive or neutral effect.

1 = Some negative effects, but relationships essentially unchanged.

2 = Worsening of relationships attributable to the child's problems.

3 = Child's problems have resulted in breakdown of relationships.

PTA7I01
Intensity

RESTRICTIONS ON ACTIVITIES

RESTRICTIONS ON FAMILY'S SOCIAL ACTIVITIES

Restrictions on family's social life that result from the child's problems.

Have these problems kept you from doing things socially with your child?

Are you embarrassed to do things with him/her because of his/her problems?

Are there places that are harder to go because of these problems?

Or places that you can't go?

Do you not go out because you are concerned about what others will think?

RESTRICTED SOCIAL ACTIVITIES FOR FAMILY

0 = No effect of family's social life.

2 = Some disruption, such as family can no longer go some places because of child's problems.

3 = Most or all social activities restricted or disrupted because of child's problems.

PTA9I01
Intensity

RESTRICTIONS ON PARENT'S PERSONAL ACTIVITIES

Restrictions on parent's personal life and activities that have resulted from the child's problems. Do not include changes in employment coded under "Expenses" and "Loss of Income" or changes in family social structure coded under "Restrictions on Family Social Activities".

Have your own activities been affected because of his/her problems?

Have your child's problems changed your social life?

In what way?

Are there things that you haven't done because of your child's needs?

Like hobbies?

Or other activities?

RESTRICTED PERSONAL ACTIVITIES

0 = Little effect on personal activities.

2 = Some disruption of personal leisure activities due to child's problems, such as cutting down on activities or hobbies.

3 = Most or all personal leisure activities restricted or disrupted because of child's problems.

PTA8I01
Intensity

STIGMA

Child's problems have resulted in parent's feeling that others disapprove or blame him/herself and/or his/her partner.

Are you embarrassed about your child's problems?

Have you felt that others disapprove of you or the way you handle things?

Do you think others blame you for what has happened to him/her?

Or avoid you because of your child's problems?

Who is that disapproves of the way you handle your child's problems?

STIGMA

0 = No stigma perceived.

1 = Embarrassed but does not feel disapproval or blame directed at him/herself.

2 = Parent feels stigmatized in the eyes of at least some people.

3 = Parent feels stigmatized by almost anyone who knows about child's problems.

PTB0I01
Intensity

RESPONSIBILITY FOR PROBLEMS

ATTRIBUTION OF CAUSE OF PROBLEMS

Parent's view of what has caused the child's problems, including attribution to various causes or individuals. Include self-blame by parent who feels responsible for having caused the child's problems, or for the child's lack of progress in dealing with the problems.

I want to ask you what you think are the causes for these issues.

I want you to tell me if these things "MAYBE," "PARTIALLY," or are "COMPLETELY" responsible for your child's issues.

Do you think that your child was born with these problems?

GENETICS

PTB1101

0 = Absent

1 = Vague or indefinite attribution.

2 = Partially responsible for child's problems.

3 = Completely or almost completely responsible for child's problems.

☐

Is a physical injury or disability to blame?

PHYSICAL INJURY/DISABILITY

PTB1102

0 = Absent

1 = Vague or indefinite attribution.

2 = Partially responsible for child's problems.

3 = Completely or almost completely responsible for child's problems.

☐

Or does s/he have problems because something really bad happened to him/her?

PREVIOUS TRAUMATIC EXPERIENCE

PTB1103

0 = Absent

1 = Vague or indefinite attribution.

2 = Partially responsible for child's problems.

3 = Completely or almost completely responsible for child's problems.

☐

Do you think your child is responsible for what has happened?

CHILD

PTB1104

0 = Absent

1 = Vague or indefinite attribution.

2 = Partially responsible for child's problems.

3 = Completely or almost completely responsible for child's problems.

☐

Do you blame yourself for any of what has happened?

Do you feel responsible for the problems that your child has?

Do you think that your "current partner" is responsible?

Or child's "other parent"?

Or other members of your family?

Or you child's friends and/or peers?

SELF

0 = Absent

1 = Vague or indefinite attribution.

2 = Partially responsible for child's problems.

3 = Completely or almost completely responsible for child's problems.

PARTNER

0 = Absent

1 = Vague or indefinite attribution.

2 = Partially responsible for child's problems.

3 = Completely or almost completely responsible for child's problems.

CHILD'S OTHER PARENT

0 = Absent

1 = Vague or indefinite attribution.

2 = Partially responsible for child's problems.

3 = Completely or almost completely responsible for child's problems.

OTHER FAMILY MEMBER

0 = Absent

1 = Vague or indefinite attribution.

2 = Partially responsible for child's problems.

3 = Completely or almost completely responsible for child's problems.

CHILD'S FRIENDS/PEERS

0 = Absent

1 = Vague or indefinite attribution.

2 = Partially responsible for child's problems.

3 = Completely or almost completely responsible for child's problems.

PTB1105

PTB1106

PTB1107

PTB1108

PTB1109

Or the school?

SCHOOL

PTB1110

0 = Absent

1 = Vague or indefinite attribution.

2 = Partially responsible for child's problems.

3 = Completely or almost completely responsible for child's problems.

Or neighborhood and community?

NEIGHBORHOOD/COMMUNITY

PTB1111

0 = Absent

1 = Vague or indefinite attribution.

2 = Partially responsible for child's problems.

3 = Completely or almost completely responsible for child's problems.

Do you think these problems are the result of bad luck?

CHANCE/BAD LUCK

PTB1112

0 = Absent

1 = Vague or indefinite attribution.

2 = Partially responsible for child's problems.

3 = Completely or almost completely responsible for child's problems.

Or God's will?

GOD'S WILL

PTB1113

0 = Absent

1 = Vague or indefinite attribution.

2 = Partially responsible for child's problems.

3 = Completely or almost completely responsible for child's problems.

Or the work of Satan?

SATAN

PTB1114

0 = Absent

1 = Vague or indefinite attribution.

2 = Partially responsible for child's problems.

3 = Completely or almost completely responsible for child's problems.

Do you think anything else has been responsible?

OTHER

PTB1115

0 = Absent

1 = Vague or indefinite attribution.

2 = Partially responsible for
child's problems.

3 = Completely or almost
completely responsible for child's
problems.

Specify

IMPACT OF FEELINGS OF PERSONAL WELL-BEING

PSYCHOLOGICAL ADJUSTMENT

Parent's psychological adjustment to child's problems.

I want to ask you how you have been feeling.

Have you been depressed because of his/her problems?

Have you felt discouraged about his/her situation?

Has that affected your ability to function?

Have you been worried about what was happening with your child?

Has that affected your ability to function?

Have you been feeling tired?

Has that affected your ability to function?

Have your child's problems made you irritable or quick to get angry about things?

Has that affected your ability to function?

Have your child's problems affected your health at all?

In terms of mental or emotional health?

In what way?

Has that affected your ability to function?

DEPRESSION

PTB3101

0 = No increase in depressive feelings attributed to child's problems.

2 = Yes, some depression related to child's condition.

3 = Depression related to child's condition affecting ability to function normally.

WORRIES

PTB3102

0 = No increase in worries attributed to child's problems.

2 = Yes, some worries related to child's condition.

3 = Worries affecting ability to function normally.

TIREDNESS OR ANERGIA

PTB3103

0 = No tiredness attributed to child's problems.

2 = Yes, some tiredness related to child's condition.

3 = Tiredness affecting ability to function normally.

IRRITABILITY

PTB3105

0 = No irritability attributed to child's problems.

2 = Yes, some irritability related to child's condition.

3 = Irritability affecting ability to function normally.

OTHER MENTAL HEALTH PROBLEMS

PTB3106

0 = No other mental health problems attributed to child's problems.

2 = Yes, other mental health problems related to child's condition.

3 = Other mental health problems affecting ability to function normally.

Specify

What about in terms of physical health?

How?

Has that affected your ability to function?

OTHER PHYSICAL HEALTH PROBLEMS

PTB3107

0 = No other physical health problems attributed to child's problems.

2 = Yes, some other physical health problems related to child's condition.

3 = Other physical health problems affecting ability to function normally.

Specify

Have you taken any medication to make yourself feel better?

ASSISTANCE WITH PROBLEMS: MEDICATION

PTB4101

0 = No medication for parent's problems related to child's condition.

2 = Medication being taken.

Have your child's problems led you to use alcohol or drugs?

ASSISTANCE WITH PROBLEMS: SUBSTANCE USE

PTB4102

0 = No increase or change in pattern of usage because of child's problems.

2 = Child's problems have led to increase in usage of alcohol and/or drugs.

Have you sought help from anyone to assist you in dealing with the strain?

ASSISTANCE WITH PROBLEMS: SUPPORT NETWORK

PTB4103

0 = Family and/or friends have been of assistance to parent in dealing with the stress of the problems.

2 = Limited assistance.

3 = No assistance.

4 = Parent has not sought help.

From family or friends?

Have you sought help from anyone?

Were they helpful?

Have you gotten any professional help to assist you in dealing with the strain?

ASSISTANCE WITH PROBLEMS: PROFESSIONAL HELP

PTB4104

0 = No help sought.

2 = Parent has sought help from a professional for own problems related to child's condition.

Have you sought help from anyone?

Do you feel you have the energy to handle your child's problems?

Do you feel you know what to do about them?

**FEELINGS OF
COMPETENCE**

PTB4105

0 = Absent

2 = Feels some doubts about own ability to handle all or most child's problems adequately.

3 = Feels incompetent to deal with all or most of child's problems.

Appendix 7: Patient Consent Form

Information Sheet and Consent to Participate in MMED Research Project

Dear Caregiver

Good day

My name is Dr. Mayuri Ramdhial; a Registrar in the Department of Psychiatry at the University of Kwa Zulu Natal and currently employed by the Kwa Zulu Natal Department of Health.

The family and caregiver are an important support system in the care of a child or teenager. Caregiving is a normal part of being the parent of a young child, yet this role takes on additional responsibility when caring for a mentally ill child.

You are invited to consider taking part in a study that involves research to identify stressors related to caring for a child with mental illness and the impact of such stressors on caregiver emotional states and quality of life.

This study aims to

- ✓ Determine the presence of anxiety and depression in caregivers of children and adolescents with mental illness.
- ✓ Identify factors associated with increased risk of emotional problems in caregivers.
- ✓ Identify factors which are associated with a negative impact on the quality of life for the caregiver/family of the patient.

This study is being conducted at King Dinuzulu Hospital and King Edward VIII Hospital and is expected to enroll 120 caregivers.

It will involve an Interview with the Principle Investigator [Dr M Ramdhial] during which time 4 Questionnaires will be administered. The questionnaires are about depressive and anxiety symptoms and how looking after a child with mental illness impacts on your life..

It is not experimental and does not include invasive procedures and administration of any treatment. If your answers suggest you need assessment for any anxiety or depression, then we will refer you to the adult clinic.

The study interview is expected to be approximately 120 minutes. The study is funded by the principle investigator toward a MMed Degree.

RISKS

Risks of being in the study are possible inconvenience or distress at having to answer questions. You do not have to answer a question if you feel unable to.

There is no additional cost to you.

POTENTIAL BENEFITS

Whilst the study holds no direct immediate benefit to you or the patient; we hope that this study may contribute to improve knowledge on stress in caregivers.

Participation is entirely voluntary and refusal to participate will not affect your child's care and treatment. Your decision will not affect your/ your child's further treatment or your relationship with those treating your child in the hospital.

You may stop participation at any time without penalty or loss of benefits to which your child is otherwise entitled.

Appendix 8: BREC Approval letter



25 September 2014

Dr Mayuri Ramdhial
PO Box 65625
Reservoir Hills
4090
mramdhial@yahoo.com

Dear Dr Ramdhial

PROTOCOL: Anxiety and depressive symptoms amongst caregivers of children with mental illness;
Degree Purpose: (MMed). **BREC REF:** BE285/14.

EXPEDITED APPLICATION

A sub-committee of the Biomedical Research Ethics Committee has considered and noted your application received on 04 June 2014.

The study was provisionally approved pending appropriate responses to queries raised. Your responses received on 22 September 2014 to queries raised on 18 September 2014 have been noted by a sub-committee of the Biomedical Research Ethics Committee. The conditions have now been met and the study is given full ethics approval and may begin as from 25 September 2014.

This approval is valid for one year from **25 September 2014**. To ensure uninterrupted approval of this study beyond the approval expiry date, an application for recertification must be submitted to BREC on the appropriate BREC form 2-3 months before the expiry date.

Any amendments to this study, unless urgently required to ensure safety of participants, must be approved by BREC prior to implementation.

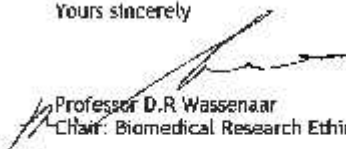
Your acceptance of this approval denotes your compliance with South African National Research Ethics Guidelines (2004), South African National Good Clinical Practice Guidelines (2006) (if applicable) and with UKZN BREC ethics requirements as contained in the UKZN BREC Terms of Reference and Standard Operating Procedures, all available at <http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx>.

BREC is registered with the South African National Health Research Ethics Council (REC-290408-009). BREC has US Office for Human Research Protections (OHRP) Federal-wide Assurance (FWA 678).



The sub-committee's decision will be **RATIFIED** by a full Committee at its meeting taking place on **14 October 2014**.






We wish you well with this study. We would appreciate receiving copies of all publications arising out of this study.

Yours sincerely


Professor D.R. Wassenaar
Chair: Biomedical Research Ethics Committee

Biomedical Research Ethics Committee
Professor D.R. Wassenaar (Chair)
Westville Campus, Govan Mbeki Building
Postal Address: Private Bag X54001, Durban 4000
Telephone: +27 (0) 31 260 2400 Facsimile: +27 (0) 31 260 4003 Email: prof@ukzn.ac.za
Website: <http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx>

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Appendix 9: Department of Health Approval letters



health

Department:
Health
PROVINCE OF KWAZULU-NATAL

Health Research & Knowledge Management sub-component
10 – 102 Natalia Building, 330 Langalibalele Street
Private Bag x9051
Pietermaritzburg
3200
Tel.: 033 – 3953189
Fax.: 033 – 394 3762
Email.: hrkm@kznhealth.gov.za
www.kznhealth.gov.za

Reference : HRKM236/14
Enquiries: Mrs G Khumalo
Telephone : 033 – 395 3189

Dear Dr M Ramdhial

Subject: Approval of a Research Proposal

1. The research proposal titled '**Anxiety and depressive symptoms amongst caregivers of children with mental illness**' was reviewed by the KwaZulu Natal Department of Health (KZN-DoH).

The proposal is hereby **approved** for research to be undertaken at King Edward VIII & King Dinuzulu Complex Hospitals.

2. You are requested to take note of the following:
 - a. Make the necessary arrangement with the identified facility before commencing with your research project.
 - b. Provide an interim progress report and final report (electronic and hard copies) when your research is complete.
3. Your final report must be posted to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to hrkm@kznhealth.gov.za

For any additional information please contact: Mrs G Khumalo on 033-395 3189.

Yours Sincerely

Dr. E Lutge

Chairperson, KwaZulu-Natal Health Research Committee

Date: 29/07/14

uMnyangc Wezemphilo. Departement van Gesondheid

Fighting Disease. Fighting Poverty. Giving Hope



health

Department:
Health
PROVINCE OF KWAZULU-NATAL

OFFICE OF THE HOSPITAL CEO

KING EDWARD VIII REGIONAL HOSPITAL
Private Bag X02, CONGOILIA, 4013
Corner of Rick Turner & Sydney Road
Tel: 031-3303853/3015; Fax: 031-2061457
Email: rejolcc.khuzwayo@kznhealth.gov.za
www.kznhealth.gov.za

Ref.: KE 2/7/1/ (33/2014)
Enq.: Mrs. R. Sibuya
Research Programming

14 August 2014

Dr. M. Ramdhial
P.O. Box 85625
Reservoir Hills
4020

Dear Dr. Ramdhial

Protocol: Anxiety and depressive symptoms amongst caregivers of children with mental illness: Degree Purposes (MMed). BREC REF: BE285/14

Permission to conduct research at King Edward VIII Hospital is provisionally granted, pending approval by the Provincial Health Research Committee, KZN Department of Health.


Kindly note the following:-

- The research will only commence once confirmation from the Provincial Health Research Committee in the KZN Department of Health has been received.
- Signing of an indemnity form at Room 8, CEO Complex before commencement with your study.
- King Edward VIII Hospital received full acknowledgment in the study on all publications and reports and also kindly present a copy of the publication or report on completion.

The Management of King Edward VIII Hospital reserves the right to terminate the permission for the study should circumstances so dictate.

Yours faithfully

SUPPORTED / NOT SUPPORTED


DR. OSIBALO
ACTING CHIEF EXECUTIVE OFFICER


DATE

uMnyango Wezemphelo . Departement van Gesondheid

Fighting Disease, Fighting Poverty, Giving Hope



**DEPARTMENT OF HEALTH
PROVINCE OF KWAZULU-NATAL**

KING DINUZULU HOSPITAL COMPLEX

**PO DORMERTON, 4015
75 Dr R D NAIDU DRIVE, SYDENHAM, DURBAN 4015**

Enquiries : Mr S B Maharaj	Telephone Number : (031) 2426000 Extender : 2711	Fax Number : (031) 2095588
E-mail : shanin.maharaj@kznhealth.gov.za	Your Reference : _____	Date : 20 August 2014

Dr M Ramdhial
Department of Psychiatry
UKZN
Durban

Dear M Ramdhial

**REQUEST FOR PERMISSION - TO CONDUCT RESEARCH ENTITLED 'ANXIETY AND
DEPRESSIVE SYMPTOMS AMONGST CAREGIVERS OF CHILDREN WITH MENTAL
ILLNESS'**

1. Your letter dated 25/7/2014 refers.
2. Permission is granted for the above mentioned purpose, provided you obtain BREC approval. You will have to obtain informed consent from the caregivers prior to them completing the non-interventional questionnaire.
3. Your attention is once again drawn to the maintenance of confidentiality as discussed.
4. Arrangements should be made for you to work with the staff and patients files in the Psychiatry Department.

Yours sincerely,

S B Maharaj
Dr S B Maharaj
Medical Manager KDHC



**DEPARTMENT OF HEALTH
PROVINCE OF KWAZULU-NATAL**

KING DINUZULU HOSPITAL COMPLEX

**PO DORMERTON, 4015
75 Dr R D NAIDU DRIVE, SYDENHAM, DURBAN 4015**

Enquiries	Dr S B Maharaj	Telephone Number	(031) 2428600	Fax Number	(031) 2095588
		Extensor	6711		
Email	shamir.maharaj@kznhealth.gov.za	Your Reference		Date	20 August 2014

Dr M Ramdhial
Department of Psychiatry
UKZN
Durban

Dear M Ramdhial

**REQUEST FOR PERMISSION - TO CONDUCT RESEARCH ENTITLED 'ANXIETY AND
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Yours sincerely,

S B Maharaj
Dr S B Maharaj
Medical Manager KDHC

