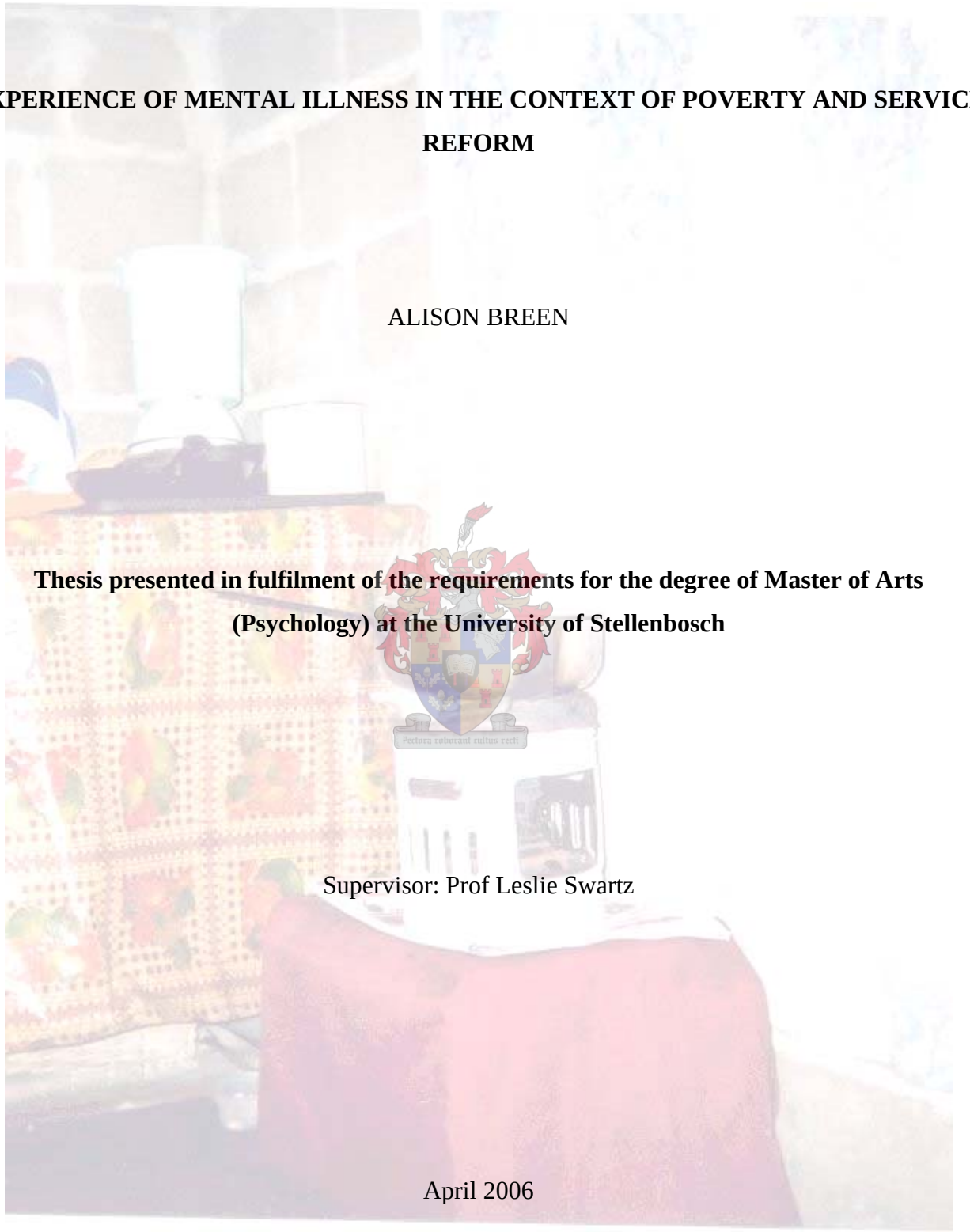
EXPERIENCE OF MENTAL ILLNESS IN THE CONTEXT OF POVERTY AND SERVICE REFORM

ALISON BREEN



Thesis presented in fulfilment of the requirements for the degree of Master of Arts (Psychology) at the University of Stellenbosch

Supervisor: Prof Leslie Swartz

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STATEMENT

I, the undersigned, hereby declare that the work contained in this thesis is my own original work, and that I have not previously in its entirety or in part submitted it at any university for a degree.

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SUMMARY

Many researchers have argued that social factors such as poverty and urbanisation play a role in the experience of and may be risk factors for mental disorders. There is however a paucity of research examining this issue, particularly in developing countries, where the prevalence of mental disorders has been shown to be as high, if not higher than in developing countries.

The present study aimed to begin to address this gap by collecting in depth exploratory data that could inform further study in the field. We conducted ten qualitative case studies consisting of semi structured interviews with family members of households caring for a member with a mental illness. The specific factors of interest were the role of structural factors, namely, municipal and health services in the experience of mental illness. Data were analysed thematically, using an adaptation of Yin's (2003) approach.

The findings indicate that factors associated with service delivery and cost recovery in poor urban contexts may increase stress and burden on households who are caring for a member with a mental illness. This has implications for the course and experience of mental illness and the primary environment in which care is received. These claims are tentative and further research is needed to substantiate them.

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OPSOMMING

Navorsing dui aan dat sosiale faktore soos armoede en verstedeliking ‘n rol speel in die ervaring van geestes-versteurings. Hierdie faktore dien ook as risikofaktore vir geestes-versteurings. Daar is ‘n tekort aan navorsing wat hierdie probleem ondersoek, veral in ontwikkelende lande. Dit bewys dat die voorkoms prevalensie van geestes-versteurings net so hoog, indien dalk niehoër, is as in ontwikkelde lande nie.

Die doel van die studie was om, deur die insameling van exploratiewe kwalitatiewe data, by te dra tot die uitbreiding van kennis in dié navorsingsveld en daardeur verdere studie te beinvloed. Ten einde hierdie doel te bereik is die navorsing op kwalitatiewe gevallestudies van tien huishoudings gebaseer. Semi-gestruktureerde onderhoude is gevoer met familielede wat ‘n geestesiektelyer versorg. Spesifieke faktore wat in hierdie studie ondersoek is, is die rol wat strukturele faktore, naamlik, munisipale en gesondheidsdienste, speel in hoë geestesiektes ervaar word. ‘n Adaptasie van Yin (2003) se benadering is gebruik on die data tematies te analiseer.

Die bevindings van die studie dui daarop dat faktore wat verband hou met dienslewering en kosteherwinning in arm stedelike gebiede, die stres en druk op geaffekteerde huishoudings kan verhoog. Dit hou implikasies in vir die koers en ervaring van geestesiektes, asook die primêre omgewing waarin sorg ontvang word. Die bevindings van die studie is tentatief en verdere, bevestigende navorsing word dus benoding.

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CHAPTER 1: INTRODUCTION AND BACKGROUND TO THE STUDY

The present study formed part of a larger initiative, the Municipal Services Project, that was funded by the International Development Research Council (IDRC). The Municipal Services Project is a multi-partner research, policy and educational initiative, examining the restructuring of municipal services in Southern Africa. The Project's central research interests are the impacts of decentralization, privatization, cost recovery and community participation on the delivery of basic services to the rural and urban poor (Municipal Services Project, 2003). The project's main interest is the impact of these service reforms on public, industrial and mental health.

I formed part of a research team, which consisted of Prof Leslie Swartz (future head of the Psychology Department of Stellenbosch University), Prof Alan Flisher (professor and head of the Division of Child and Adolescent Psychiatry at the University of Cape Town (UCT) and Red Cross War Memorial Children's Hospital and director of the Adolescent Health Research Institute at UCT), Dr John Joska (senior specialist at Lentegeur Hospital and lecturer in the Department of Psychiatry and Mental Health at UCT), Dr Joanne Corrigal (a public health registrar with a special interest in mental health), Lindelwa Plaatjies (an auxillary social worker) and myself. We were commissioned by the Municipal Services Project to conduct a study to explore how issues surrounding services were impacting on the mental health of poor communities.

There is a paucity of research in the area of municipal service reform and mental health. We therefore decided to conduct a review of the literature covering mental disorder and poverty, urbanisation and globalisation. For the purposes of the study, mental disorder was taken to include psychotic and common mental disorders, such as depression and anxiety disorders, but not neuropsychiatric and developmental disorders.

The review revealed that there is evidence that social factors such as poverty play a role in the aetiology of mental disorders (Bahar, Henderson & Mackinnon, 1992; Desjarlais, Eisenberg, Good & Kleinman, 1995; Patel, Araya, de Lima, Ludermir, & Todd, 1999; Patel, Abas, Broadhead, Todd, & Reeler, 2001; Patel & Kleinman, 2003; Patel, Flisher & Cohen, in press; Saraceno & Barbui, 1997). There is, however, a gap in research on the inter-relationship between

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these social factors and mental disorders, particularly with respect to developing countries (Patel & Sumathipala, 2001).

The review also revealed the importance of research in this area as the prevalence of mental disorders in developing countries has been shown to be as high if not higher than in developed countries (Araya, Rojas, Fritsch, Acuna & Lewis, 2001; Bhagwanjee, Parekh, Paruk, Petersen & Subedar, 1998; Cooper et al., 1999; Robertson, Ensink, Parry, Chalton, 2001; Rumble, Swartz, Parry & Zwarenstein, 1996). The review also revealed that although there is evidence of a relationship between poverty and mental disorders, the details and nature of this relationship are in need of investigation. As many developing countries have high levels of poverty, the relationship between poverty and mental ill health is in need of exploration.

In many developing countries there is a rapid increase in urbanisation with an increase in the number of people living in urban poverty (National Academies Press [NAP] 2003). This is a phenomenon of interest in South Africa which is in a period of transition, experiencing rapid urbanisation and population growth, high levels of unemployment and poverty (Thomas, Seager, & Mathee, 2002).

Farmer (2003) speaks of “structural violence”, which comprises forces such as poverty and socio-economic inequality. He illustrates the role that social, political and economic forces play in shaping both the context for risk for developing illness and the context in which health care is provided. Eisenberg (as cited in Rahman & Hussain, 2001) asserts that many social policy decisions have a major impact on family life and argues that explicit attention must be paid to the mental health consequences of such policy decisions.

Given these arguments, the research team felt it was important to examine how factors related to forces such as poverty and socio-economic inequality impact on the experience of mental disorders.

Of particular interest to the research team was the role of various social policies in the experience of mental disorder. These policies, although conceptualised independently by policy makers in different government departments, come together to impact on households and influence the experience of mental disorder.

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The central policies of interest were:

1. the progressive shift towards deinstitutionalisation, and community-based care for mental disorders.
2. the global shift towards privatisation of municipal services and corresponding policies of cost recovery,

The research team decided to explore the experience of mental disorder in poor urban contexts in order to begin to understand the possible impacts of the policies mentioned above as well as the impact of factors related to poverty.

The role of the disability grant in the household economy was also a point of interest. The disability grant is one of a number of social grants available in South Africa aimed at poverty alleviation. These grants include: old age pension, child support grant, care dependency, foster grants and disability grants (Department of Social Services and Poverty Alleviation, 2005). In order to qualify for the grant, the recipient must be 18 years or older and not able to work due to a mental or physical disability. The amount of the grant is R780 per month. In April 2005, the number of disability grants in the Western Cape was for men and 63639 for women 55678 (personal communication[1], November 20, 2005). We chose to focus on the disability grant as all of the households that would participate in the study would have a member with a chronic mental disorder. We would therefore be able explore the role of the disability grant in the experience of mental disorder.

As the study formed part of the Municipal Services Project described above, a major focus was on municipal service delivery. The study was exploratory and aimed to identify themes that would be able to inform further research in the field.

We decided that the ideal method in which to address the research purpose was to conduct a series of 10 case studies of purposively selected households that are caring for a member with a mental disorder and living in poor urban environments. A series of in-depth, semi-structured interviews were conducted with various members of these households. This method allowed for the collection of in-depth exploratory data and for data to be collected in the areas identified

[1] This information came from a member of the South African Regional Poverty Network, who used the SOCPEN database as a source of information.

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from the review of the literature; but also allowed for themes to emerge that had not been previously identified.

A point that needs to be clarified is the use of the term urban in the present study. The areas from which the households were selected are referred to as peri-urban areas. However, both areas fall under the jurisdiction of the City of Cape Town and are therefore provided with services. The interest of the study was the impact of services and as these areas are provided with services they will be referred to as urban.

Therefore the purpose of the present study was to provide exploratory and in-depth data in a field that has been sparsely researched. We further attempted to identify themes that could inform further study in order to begin to understand the social context of mental disorder in poor urban environments and how social factors such as poverty impact on this experience.

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CHAPTER 2: REVIEW OF THE LITERATURE

The broad aim of the study was to explore the experience of mental disorders in the context of urban poverty. Although the main emphasis was the relationship with poverty, other social factors such as urbanisation and globalisation may also influence the experience in the particular context of interest. Rapid urbanisation in many developing countries is leading to an increase of people living in urban poverty and therefore the literature covering factors associated with urbanisation and mental health in developing countries was included. Globalisation in many cases has an influence on policies and impacts on the understanding and experience of mental disorders. We therefore decided to conduct a review of the literature covering the areas of poverty, urbanisation and globalisation and mental health, with particular emphasis on developing countries.

We also reviewed the literature relevant to the South African context in order to understand the context of the study. We were particularly interested in the influence of policies, namely deinstitutionalisation and cost recovery for basic services. A point of central interest in the study was that of services (mental and municipal), and therefore a review of literature (peer-reviewed and grey literature were included) was also conducted, in relation to municipal and mental health service delivery. No literature was identified on the mental health impacts of municipal service delivery, and therefore the review included the impact on social, behavioural and physical health.

Academic literature was identified through searches of international databases including PubMed, PsychInfo, Medline and Science Direct, as well as local databases such as Sabinet. Grey literature included reports from human rights and anti-privatisations organisations and university theses.

INTRODUCTION TO THE LITERATURE REVIEWED

Mental disorders are increasingly recognised as a significant contributor to the global burden of disease and disability (Patel et al., in press; World Health Organisation [WHO], 2001). It is now widely accepted that most mental disorders are multi-factorial in origin as well as the importance of considering the role of social and cultural factors (Patel et al., in press). The economic and social burden of mental disorders impacts not only on the individuals, but also on their families and communities (Funk, Saraceno, Drew, Lund, & Grigg, 2004). The economic burden includes

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the cost of treatment as well as indirect cost associated with unemployment and lost productivity. The social burden experienced by individuals with mental disorders and their families include stigma, discrimination and violation of human rights (WHO, 2004).

Recently, there is increasing evidence of a significant burden attributable to mental disorders in developing countries, in spite of the co-existing burden of infectious and other non-communicable diseases (Becker, 2004; Harpham, Snoxell & Rodriguez, 2005; Lovisi, Mann, Coutinho & Morgado, 2003; Patel et al., 2001; Patel et al., in press; Rahman & Hussain, 2001; WHO, 2001). Many studies have indicated that the prevalence of mental disorders in developing countries is as high if not higher than in developed countries (Araya et al., 2001; Bhagwanjee et al., 1998; Cooper et al., 1999; Robertson et al., 2001; Rumble et al., 1996). However, developing countries often do not have the resources to combat these mental health problems (McKenzie, Patel & Araya, 2004).

Mental health to a large extent has been neglected in developing countries and more pressing demands such as poverty and basic health care have placed a considerable burden on governments. Government agendas have also prioritized the 'big killers' such as HIV/AIDS, malaria and other infectious diseases, which place a great burden on health systems (Blue & Harpham, 1996). HIV/AIDS in particular has been shown to have massive implications for mental health (Freeman, 2004). However, reports of the significant contribution of mental disorders in the global burden of disease has led to an increase in the understanding of the importance of prioritizing mental health (Desjarlais et al., 1995; WHO, 2001).

The issue of human rights is an important aspect to consider when examining the impact of social conditions such as poverty on mental health. From this framework it is important to understand the mechanisms by which social processes are translated into personal distress and become embodied as individual experience (Farmer, 2003). This emphasizes understanding the context in which mental disorders occurs, as in many cases the risk for disorders is structured by political and economic forces. Farmer (2003) speaks of “structural violence” which comprises of forces such as poverty and socio-economic inequality and discrimination. These forces impact on people’s health, and human rights violations occur as inequalities in power impact on access to resources and opportunities essential for realizing basic rights. For example, he has used the concept of structural violence to examine the spread of HIV/AIDS in Haiti, and the role that

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social, political and economic forces play in shaping both the context for risk for developing the disorder and the context in which health care is provided (Kelly, 2005).

Kelly (2005) demonstrates the relevance of this concept in the context of schizophrenia, and emphasises the strong need to explore the role of socio-environmental and socio-political factors in the clinical presentation and outcome of schizophrenia. Sen (2003) argues that the best way in which to examine the impact of structural violence is through "real life" examples that examine the experiences of affected individuals. Interventions informed by a structural violence approach would therefore be informed by broader social, political and economic factors.

Many countries in the developing world are experiencing rapid urbanisation and an increase in people living in urban poverty (NAP, 2003). Globally, mental health is a question of economic and political welfare, as generally enduring political and economic structures contribute to the perpetuation of poverty, hunger and despair (Desjarlais et al., 1995). Mental health problems associated with urbanisation, environmental scarcities and physical illness generally take a greater toll on the poor due to lack of access to services to lessen their impact.

It is now well established that there is an enormous gap between mental health research in wealthier countries and that being conducted in poorer countries (Patel & Sumathipala, 2001). This has been referred to as the 90/10 gap, where 10% of the research and funding takes place in developing countries which experience 90% of the global burden. Recent reports have stressed the importance of research to inform policy and practice for mental health, in particular in developing countries where the unmet need is the greatest (Maj, 2005; Patel & Sumathipala, 2001).

Therefore we now know that there is a high prevalence of mental disorders in developing countries, that social factors may be associated with mental ill health and that there is scarce research in this area in developing countries. I will now review the research examining the relationship between social forces in developing countries, namely poverty, urbanisation and globalisation and mental health.

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POVERTY

An epidemiological understanding of poverty refers to low socio-economic status, unemployment and low levels of education (Saraceno & Barbui, 1997). Taken in broader terms, this also refers to having insufficient means, which may include lack of social or educational resources (WHO, 2001).

A distinction is often made between different dimensions of poverty, in particular between absolute and relative poverty (Richter, 1994). Absolute poverty focuses on households, and whether the income for the household is sufficient to meet the basic costs necessary for survival and decency. Absolute poverty also refers to the resources available to the household. Relative poverty essentially refers to the concept of inequality, with respect to access to educational and employment opportunities. It also refers to social and economic stratification within societies as a result of inequalities. This is an important dimension, as given the social and economic changes occurring in many societies in developing countries, social and economic inequality is increasing (Patel, 2001). In this understanding, poverty not only refers to deprivation in terms of material possessions, but also to inequalities of opportunity and power (Yang, 2004). The distinction between the different dimensions needs to be understood, as the stressors associated with absolute poverty may be different from those of relative poverty (Patel et al., 1999).

Is there a relationship?

There is evidence to show that there is a greater prevalence of common mental disorders among the poor than the rich (Patel et al., 1999; WHO, 2001).

The majority of research has been conducted in developed countries (Costello, Compton, Keeler & Angold, 2003; Weich & Lewis, 1998), however there is increasing evidence confirming a relationship between poverty and both common and severe mental disorders (such as psychosis) in developing countries (Bahar et al., 1992; Patel et al., 1999; Patel et al., 2001; Patel & Kleinman, 2003; Saraceno & Barbui., 1997). This literature has tended to focus on the impact of stressors associated with poverty on common mental disorders such as anxiety and depressive disorders (Patel et al., 1999; Patel & Kleinman., 2003) and epidemiological studies in this field have tended to focus more on prevalence rates rather than an investigation of risk factors (Patel et al., 1999).

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There are many challenges and clichés which surround understandings of the relationship between poverty and mental health in developing countries (Patel, 2001), which lead to challenges when attempting to place mental health on global agendas. “The relationship between poverty and mental health is a topic which, at best, inspires cautious scepticism, and at worst, dismissal from public health practitioners in developing countries” (Patel, 2001, p. 247). In the past, mental disorders have been seen to be a phenomenon that applies only to the middle class, however mental health is becoming increasingly seen to be a central component of health problems stemming from inequality as well as playing a role in perpetuating inequality in developing countries (Patel, 2001).

In order to test the hypothesis that poverty is associated with common mental disorders in developing countries, the data from five studies in four countries in differing stages of economic development were analysed (Patel et al., 1999). Low-income groups were found to be more vulnerable to suffer common mental disorders, regardless of the stage of development of the country.

There is increasing evidence of a high degree of co-morbidity between physical illness and mental disorder, and people living in conditions of poverty are at greater risk for physical health problems (Patel, 2001; Patel et al., in press).

Figure 1 on page 10 provides a model illustrating an explanation of the association and mediating factors between poverty and common mental disorders in developing countries (Patel et al., 1999).

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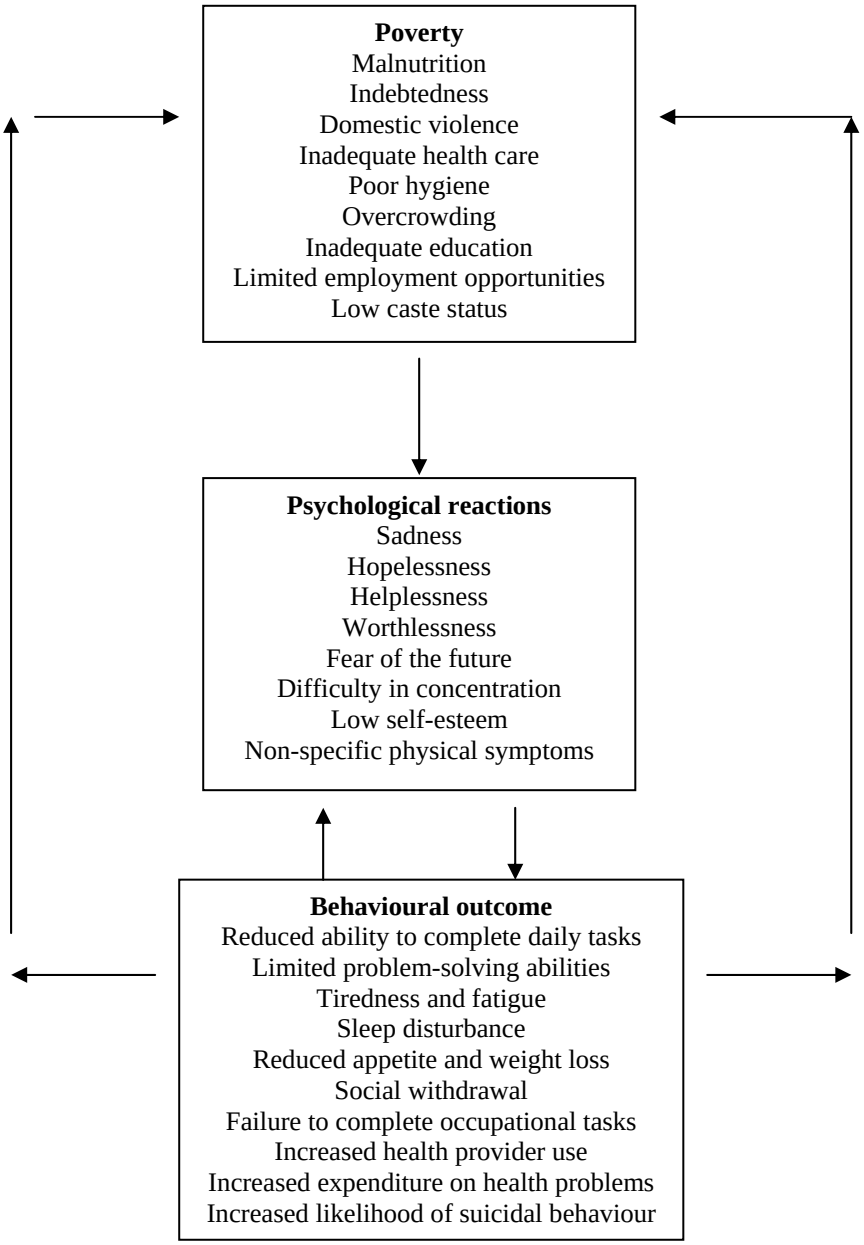

Figure 1. A model to explain the relationship between poverty and common mental disorder (Patel et al., 1999)

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What is the relationship?

It is obvious that poverty in itself does not cause mental disorders just as poverty does not cause physical illness such as tuberculosis. However, we could agree that the poor as more likely to suffer from tuberculosis as factors associated with poverty, such as overcrowding and inadequate access to health care, lead to increased risk for the spread of tuberculosis (Patel, 2001). Poverty in developing countries is associated with many stressors and both absolute and relative poverty can have consequences for mental health (Patel, 2001).

There is an obvious association between poverty and lack of opportunity (Patel, 2001). A strong predictor of mental disorder has been shown to be lack of education (NAP, 2001) and the poor are less likely to have access to adequate education. Huge income inequality, unemployment or under employment and no social welfare provision can lead to anger, hopelessness and despair (Patel, 2001). The poor are also more likely to have inadequate access to health care and therefore poor people with mental health problems may not receive the necessary care.

The relationship between poverty and mental health is complex and multi-dimensional as illustrated in Figure 2.

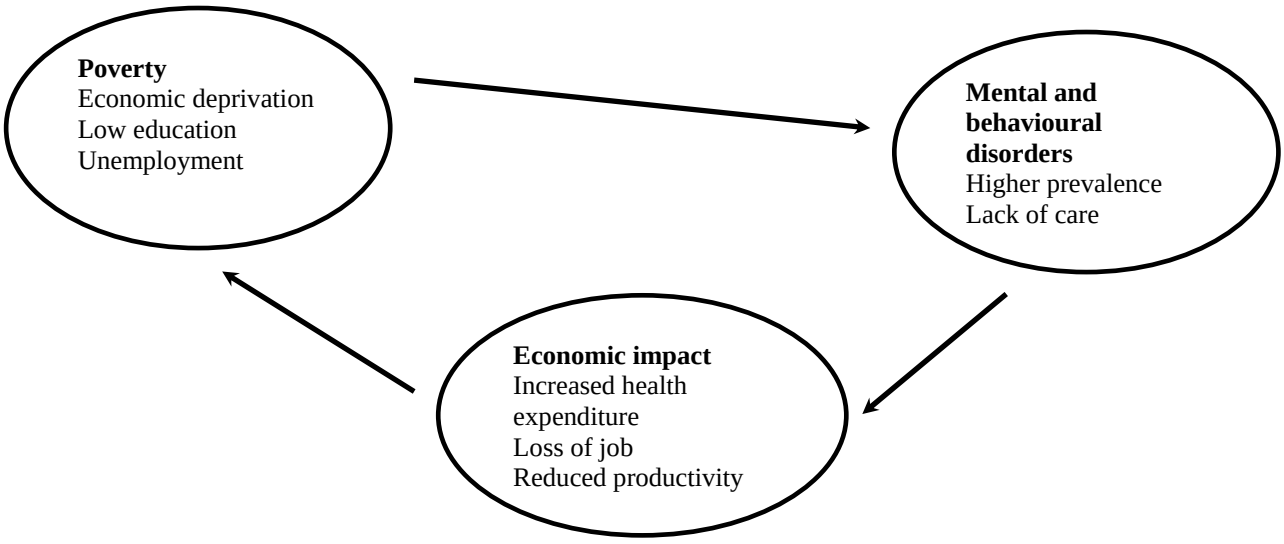

Figure 2. The cycles of poverty and mental disorders (Patel, 2001)

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Poverty has been hypothesized to be a risk factor for mental disorder in that it may lead to circumstances of increased life event stressors, scarce social resources and inadequate health care (Saraceno & Barbui, 1997). There is much debate in the literature about whether the stressors associated with poverty may be implicated in the causation of mental disorder, or whether these stressors may prolong the disorder once it is already being experienced. Another issue of much contention is the direction of the relationship between poverty and mental disorder; whether poverty can be said to cause mental disorder (so called social causation theory) or whether people experiencing mental disorder are more likely to unemployed and suffer similar social ills (social selection theory) (Saraceno & Barbui, 1997; WHO, 2001).

The rationale for the social causation theory is that poverty is likely to lead to increased life event stressors, poor quality of maternal obstetric care and scarce social resources, thus leading to higher risk for mental ill health (Saraceno & Barbui, 1997). Evidence for the selection theory comes from two major mechanisms (Patel, 2001). Firstly, there is evidence that mental disorders lead to social and occupational disability (Patel et al., 1997) and therefore people with mental disorders are unable to be economically productive to their full potential. The impact of severe mental disorders may be even greater as on top of the social and occupational disability as these people may also experience stigmatization which may also impact on their ability to find a job. Secondly, there is evidence that people with mental disorders have increased expenditure on health care. The care may also be inadequate and therefore they remain unwell for longer and continue to have increased expenditure.

The causal theory may be more valid for anxiety and depressive disorders, while the selection theory may account for the higher prevalence of psychotic and substance abuse disorders amongst the poor (WHO, 2001). Regardless of the social causation-selection debate, the idea that the stressors associated with poverty lead to psychological distress has been established in both the developing and developed world.

There is also evidence that poverty may act as a prognostic factor for mental disorder outcomes, as regardless of whether poverty can be seen to cause mental disorder or not, most people with mental disorder experience the consequences of the environment of poverty (Saraceno & Barbui, 1997). It is therefore important to assess whether this status affects the long-term course and outcome of mental disorders.

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In a study of depression in Zimbabwe, Patel et al. (1997) found that economic stressors such as having experienced hunger in the past month was associated both with the onset of an episode of depression and the persistence of an existing episode. People presenting with common mental disorders were also more likely to be under acute economic stress. Depressed people have increased use of health services and therefore higher financial costs. They found evidence for a vicious cycle of poverty: depression, illness, disability, increased health costs, inadequate health care and further impoverishment (as illustrated in Figure 2 on page 11).

The effects of poverty on mental health are usually explained in terms of individual level factors, such as psychological variables and demographic characteristics (Ruback & Pandey, 2002). A large amount of the research has examined the effect of gender on how people respond to stressors (Patel et al., 1999). Previous research has indicated different patterns of psychological distress among women compared to men (Desjarlais et al., 1995). When examining women's position in society and the multiple roles they are increasingly fulfilling, it becomes clear that women's mental health must be understood in the context of political, social and economic issues (Patel et al., 1999). The multiple roles, such as child-rearing, caring for sick relatives and earning an income, are thought to be placing increased burden and stress on women. This, together with gender dynamics and power relations leading to unequal status for women in a variety of situations, all lead to enormous social, physical and economic stress on women (WHO, 2001). Violence against women, in particular domestic violence, is an increasingly important issue contributing significantly to women's stress and mental health (Bowman, 2003; Ceballo, Ramirez, Castillo, Caballero, & Lozoff, 2004; Jewkes, Levin, & Penn-Kekana, 2002). Physical health problems also place a great burden on women with respect to their role as carer. This is of great importance in the context of HIV/AIDS where women may have to cope not only with their families' ill health, but their own failing health as well (Patel et al., 1999).

The association between factors associated with poverty and mental ill health may be mediated by individual psychological factors, such as low self esteem and frustration, as well as the breakdown in structural factors in the community, such as social cohesion and infrastructure (Patel et al., in press).

The role of psychological variables is thought to involve increased reporting of mental distress symptoms in people who experience stressful life events and who have lower perceived control over their environment. The idea is that people living in poverty are more likely to experience

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major life event stressors, have less perceived control over their environment, less social support and less access to quality health care (Patel, 2001).

There is increasing evidence from the developing world of the impact of stressors associated with poverty on mental health. The research to date has focussed on prevalence and individual characteristics in the development of mental disorders. What has been lacking in the literature is more focus on the role of contextual factors such as environmental stressors on mental health. The research linking life events and mental disorder has tended to comprehensive summaries of all possible environmental stressors that may impact on mental health. There is a gap in the literature regarding more focused studies examining specific stressors and the associated impact.

URBANISATION

Urbanisation is occurring at a rapid rate in many developing countries, resulting in dramatic environmental, social and economic changes (Harpham & Blue, 1997). It has been predicted that by 2020, the developing world is likely to be more urban than rural (NAP, 2003). Almost all of the world's population growth is predicted to occur in cities and towns in Africa, Asia and Latin America (NAP, 2003). To date the research conducted in developing countries has paid little attention to the implications of the urban context for well-being (NAP, 2003). The complex societal changes accompanying urbanisation are associated with both beneficial and detrimental effects on the health of communities (Vorster et al., 2000; Yach, Mathews, & Buch, 1990).

In developing countries, urbanisation often occurs independently of a surge in industrialization and thus is not associated with improved economic circumstances, but can often lead to urban poverty and increased behaviours that leave people more vulnerable to risk for chronic lifestyle diseases as well as risk for infectious diseases (von Schirnding & Yach, 1991). There is a massive increase in urban poverty with manifestations such as overcrowding, inadequate housing, pollution, insufficient access to clean water sanitation and other social services (NAP, 2003). It is therefore recognised that the urban poor in developing countries are most at risk for severe adverse health effects. Box 1 on page 15 outlines the multiple dimensions of urban poverty. Although patterns of urbanisation vary in different countries and regions, some generalisations can be made.

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Box 1. The multiple dimensions of urban poverty (NAP, 2003).

Income and consumption Poverty is conventionally defined in terms of income that is inadequate to permit the purchase of necessities, including food and safe water in sufficient quantities. Because income can be transitory and is difficult to measure, levels of consumption are often used as indicators of the longer-term component of income.

Assets The nature of household assets also bears on the longer-terms aspects of poverty and the degree to which households are shielded from risk. A household's assets may be inadequate, unstable, difficult to convert to monetized form, or subject to economic, weather-related or political risks; access to credit may be restricted or loans only available at high rates of interest. For many of the urban poor, significant proportions of debt go to repay debt.

Time costs Conventional poverty lines do not directly incorporate the time needed for low-income households to travel to work or undertake other significant task. Such households often try to reduce their monetary expenditures on travel by walking or enduring long commutes.

Shelter Shelter may be of poor quality, overcrowded, or insecure

Public infrastructure Inadequate provision of public infrastructure (piped water, sanitation, drainage etc.) can increase health concerns, as well as the time and money costs of employment

Other basic services There can be inadequate provision of such services as health care, emergency services, law enforcement, schools, day care, vocational training, and communication.

Safety nets There may be no social safety net to secure consumption, access to shelter and health care when incomes fall.

Protection of rights The rights of poor groups may be inadequately protected, there being a lack of effective laws regarding civil and political rights, occupational health and safety, pollution control, environmental health, violence and crime, discrimination, and exploitation.

Political voice The poor's lack of voice and their powerlessness within political and bureaucratic systems may leave them with little likelihood of receiving entitlements and little prospect that organising and making demands on the public sector will produce a fair response. The lack of voice also refers to an absence of means to ensure accountability from public, private and nongovernmental agencies.

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There are many benefits associated with urban living. These may include improved access to employment and education, access to health care and other basic services (von Schirnding & Yach, 1991; Yach et al., 1990). These benefits are, however often only experienced by the wealthy minority (Blue & Harpham, 1996). Rapid urbanisation is often accompanied by housing problems, poverty, crime, unemployment, and separation from extended families (Flisher & Chalton, 2001). Many people experience a range of problems including lack of access to education, health and other basic services, hazardous environmental conditions and social instability.

The numerous health problems faced by the urban poor are hypothesized to have three main sources (Harpham et al., 1998 as cited in Helman, 2000). Firstly, problems may be experienced as a direct result of poverty, which may include unemployment, low income and limited education. When considering the context of urban poverty, it is important to consider the social and economic conditions as well as the physical elements of the environment in understanding how health is affected (Stephens, 1995). Secondly, environmental problems may occur in many countries as the rapid rate of urbanisation often outstrips the city's ability to provide infrastructure and basic services. This places strain on the city's resources, leading to a range of problems such as poor housing, overcrowding, inadequate water and sanitation supply, inadequate access to health care and education (Ruel, Haddard & Garrett, 1999).

Social changes resulting from breakdown in the traditional structure and role of the family and lack of social support as well as economic changes resulting from unemployment or employment insecurity are also often experienced within this process (Harpham & Blue, 1997; Rahman & Hussain, 2001). These adverse social circumstances often lead to behavioural changes, which in turn impact on well-being (Flisher & Chalton, 2001). These changes may often result in risk behaviour, which is behaviour that exposes one to the risk of adverse psychological, social and physical outcomes. Risk behaviour is therefore an important consideration in the context of rapid urbanisation (Flisher & Chalton, 2001; Wild, Flisher, Bhana, & Lombard, 2004).

The idea that the process of urbanisation may have detrimental health consequences is an area that has been subject to a large amount of research (Blue & Harpham, 1996). Studies initially focused on physical health problems traditionally associated with developing countries. For example, infectious and parasitic diseases such as diarrhoea, resulting from poor water and sanitation supply, and acute respiratory infections associated with crowded conditions and air

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pollution from domestic fuel use coal and wood fires, paraffin and cigarette smoke (von Schirnding & Yach, 1991). More recently, however, there is increasing evidence of an association between poor mental health and urbanisation in developing countries (Blue & Harpham, 1996; Gillis, Welman, Koch, & Joyi, 1991; Harpham, 1994; Harpham & Molyneux, 2001; Ludermir & Harpham, 1998).

The idea that urban living is detrimental to mental health is a notion that has received a fair amount of attention, however similar to the poverty literature, most of the research has been conducted in developed countries. More recently, there is increasing evidence of an association between poor mental health and urbanisation in developing countries (Gillis et al., 1991; Harpham, 1994; Harpham & Molyneux, 2001; Ludermir & Harpham, 1998). It is now more understood that urban areas in the developing world are associated with poor social conditions and high levels of stress and mental disorder (Desjarlais et al., 1995).

The urban environment has now been recognized as significant in the onset of mental disorders (Blue & Harpham, 1996). However, there remains a gap in the literature regarding specific stressors associated with urbanisation and the impact on mental health.

A conceptual framework of the social factors associated with urbanisation in developing countries, that could be linked to mental health, has been developed (Harpham, 1994, 1997). The framework is based on the hypothesis that urbanisation may increase stressors (long term stressors and life events) and reduce social support. Both of these may be mediating factors in the association with mental health (see Figure 3 on page 18). Daily and long-term stressors may include factors such as poor physical environment and inadequate basic services leading to increased burden on families. Life events may involve loss of employment or migration. The concept of life events has been important in understanding the development of common mental disorders such as depression and anxiety (Lewis & Araya, 2002). The importance of the life events literature is that it takes the context into account. The stress associated with migration has also been indicated as a risk factor for mental disorders (Bhugra, 2004) and will be discussed in more detail later in the review. Reduced social support may occur due to reduction of the extended family or an increase in single parent households.

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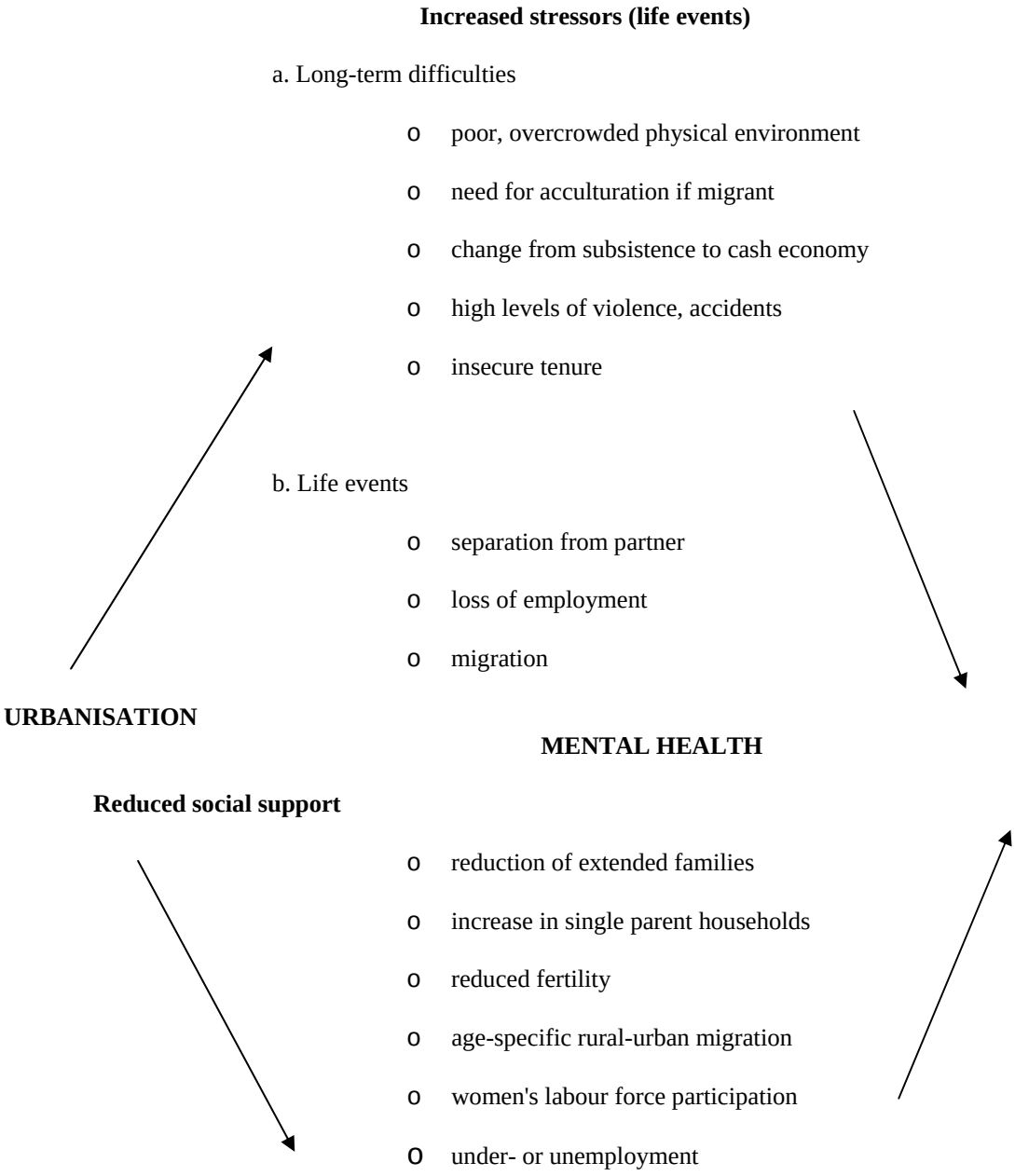

Figure 3. A model of social factors of urbanisation in developing countries associated with mental health (Harpham, 1994)

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Risk factors for mental ill health have also been hypothesized be associated with rural to urban migration, modernization and economic displacement (Ludermir & Harpham, 1998). In many cases deteriorating economic conditions in rural areas is leading to an increase in rural to urban migration (von Schirnding & Yach, 1991).

There are three models present in the literature, which explain the association between migration and mental health (Ludermir & Harpham, 1998). Firstly, the social and cultural change resulting from migrating from a traditional rural setting to a modern urban industrial society is highly stressful. This may involve a change from community life to one of capitalist consumerism. Secondly, city life itself is assumed to produce stress and thus impact on mental health. This is based on the assumption that traditional village life is essentially healthy and city life is not. This may also include a negative response to migrants from the community. Lastly, migration is seen to lead to increased stress due to changes in the economic system, with high levels of unemployment and financial insecurity (Mumford, Minhas, Akhtar, Akhter, & Mubbashar, 2000). Although levels of absolute poverty may not change in the urban environment, relative poverty may increase as a result of the increased cost of living and the change in norms to compare and aspire to.

A study investigating the role of the environmental and social context in shaping local experience of mental ill health in the urban poor, identified many afflictions that impacted on mental health (Parkar, Fernandes & Weis, 2003). These included access to health care and sanitation, addictions, criminality, domestic violence and the burden of paying for electricity and water. Parkar et al. (2003) also raised the point that although mental health services are vital in treating psychiatric disorders, they cannot affect the environmental conditions that impact on mental health.

Urban environments with high levels of poverty are often associated with high levels of violence and crime. Exposure to violence and trauma has been indicated as a risk factors for mental ill health (Seedat, Nyamai, Njenga, Vythilingum, & Stein, 2004; Stein, Seedat, & Emsley, 2002; Ward, Flisher, Zissis, Muller & Lombard, 2001; Rosenthal & Wilson, 2003).

In many cases urban living places greater burden on women due to greater participation in the workforce and an increase in female-headed households. This may lead to an increase in stress

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and burden placed on women in the juggle between fulfilling productive and reproductive roles (Ruel et al., 1999).

The studies reiterate the importance of contextual factors on a level beyond individual control that contribute to stress and mental health and well-being (Blue & Harpham, 1996).

The literature regarding the stressors associated with urbanisation has tended to provide summaries of all possible environmental stressors when considering the impact on mental health. What is needed is more in depth focus on one specific area of environmental stress in order to understand the mechanisms involved in the development of mental ill health. Urbanisation literature has also been critisised in that it focuses too much on a search for single risk factors rather than taking the social structural context into account (Ludermir & Harpham, 1998).

GLOBALISATION

The world is in a period characterised by economic restructuring, driven by globalisation and the revolution in information and communication technology (NAP, 2003). Countries are in the process of linking themselves to the international market which increasingly exposes residents to the risks and benefits of participating in these world networks of finance, information and production (NAP, 2003).

There are many different understandings of the term globalisation. This depends on the context in which it is referred to; whether in economic spheres, communications or cultural domains (Lee, 2000). There are also varying opinions and polarized views as to the impacts of globalisation on societies and individuals. Generally, globalisation refers to the process by which traditional boundaries between cultures and societies begin to dissipate and is associated with factors such as economic liberalization, media influences, political changes which in turn lead to environmental changes (Bhugra & Mastrogianni, 2004; Mastrogianni & Bhugra, 2003). Globalisation also involves the removal of trade barriers and implies a capitalist agenda (Lewis & Araya, 2002). This is advocated by international organizations such as the World Bank and the International Monetary Fund, as a tool to combat poverty. These international organisations also advocate an ideology of neo-liberalism, which advocates the dominance of a competition-driven market model (Farmer, 2003).

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The impact of these macro forces on social, cultural, economic and political inequality, and how these are used to legitimatize further inequality, is an area of great interest in the globalisation debate (Kalb, Pansters, & Siebers, 2004). Another issue of central importance is the changing role of the state (Kalb et al., 2004). The nature of governance and management of cities is undergoing a fundamental change in the form of decentralisation of service delivery (NAP, 2003). Neo-liberalism advocates curtailing the role of the state in society and economy in favour of the involvement of the private sector, which raises issues of state accountability, authority and competence.

There is increasing concern that the competitiveness inspired by globalisation is leading to more individualistic societies (Kalb et al., 2004). Critics believe modern forms of globalisation lead to increasing inequality and social polarisation (NAP, 2003). There have also been arguments that globalisation leads to strong developed nations having advantages over the poorer developing countries in the economic market (Lewis & Araya, 2002). From this view, globalisation will lead to further poverty, inequality and social injustice (Kelly, 2003).

Lee (2000) examined some key features of globalisation, whereby change is seen to be occurring on three dimensions. Firstly, the spatial dimension refers to how we think of and perceive physical space. Increased travel, communication, trade and other shared experiences all play a role in the growing sense of the world as a single place. The temporal dimension refers to changes in the actual and perceived time in which human interaction occurs. Technological advancements lead to a speeding up of timeframes as well as an increase in frequency of human interactions. Lastly, the cognitive dimension refers to how we think about and perceive the world. Globalising forces affect a variety of processes - the creation and exchange of scientific knowledge, ideas, norms, beliefs, values and cultural identities.

The economic and social changes associated with globalisation have been linked with mental disorders in developed and to a lesser extent in developing countries (Bhugra & Mastrogianni, 2004; Chan, Hung, & Yip, 2001; Dech, Ndetei, & Machleidt, 2003; Lewis & Araya, 2002; Mastrogianni & Bhugra, 2003; Swartz, 2005; Yang, 2004). The hypothesis is that globalisation is likely to influence both idioms of distress and pathways to care (Bhugra, 2004).

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The social change associated with globalisation can affect mental health in the following ways (Swartz, 2005):

- Increase in rural to urban migration has occurred as a result of globalisation, with the rural poor migrating to the cities in search of work and asylum. This leads to a reduction in support for mothers as the traditional family structure is disrupted, as fathers and other family members migrate to cities in search of work. This also affects the elderly and mentally ill who are less likely to be cared for. Social networks and community cohesiveness are also disrupted as whole families migrate in search of work.
- Women in low-income countries often disproportionately bear the burden of the effects of globalisation. The increased position of women in the work place but often with lower status and wages increases their burden. They now have to fulfil multiple roles including that of the family provider and caregiver. Thus the globalisation of the economic market has lead to increase in inequalities in income and the differences in the social roles occupied by men and women.
- Increases in suicide by men who have lost their livelihoods, often due to their employer's inability to compete in the global market.

Globalisation also affects the way people understand and experience mental disorders, as people in developing countries adopt Western understanding and labels as well as treatments (Swartz, 2005).

The literature reviewed above has focused on the impact of stressors associated with social factors such as poverty, urbanisation and globalisation on mental health in a broad manner, in many cases providing multi-factorial models hypothesizing the mechanisms to mental ill health. What is evident from the literature is the need to take these models a step further and examine specific aspects of environments and social forces and how these impact on mental health. Studies in disciplines such as urban studies, anthropology and sociology have to a greater extent examined the impact of specific stressors on health but have focussed on the impact on physical health.

What is needed is more detailed study of specific stressors together with specifics of lived experience within a specific context in the mental health realm. To elaborate on what is meant by the specifics of lived experience: how do people live their lives everyday? What do they do and

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what would they like to be doing? What are the barriers that prevent them from achieving this? These barriers may be located on a number of levels including personal, social and environmental (Dexter, 2004).

A useful framework for examining these issues is the emerging discipline of occupational science which is based in the field of occupational therapy. This discipline suggests that in order to explore the issues above, it may be useful to ask questions about what has been termed as doing (how people are constantly engaged in purposeful doing even when free from obligation or necessity), being (encapsulates such notions as existing, living, nature and essence) and becoming (about fulfilling and achieving human development, growth and potential) (Wilcock, 1999). A dynamic balance between being and doing is central to healthy living and becoming is dependent on both (Wilcock, 1999).

Occupation, when used within this discipline is much broader than the conventional understanding of occupation as formal work but rather to the ordinary things people do every day to meet their needs (Dexter, 2004). Occupational behaviour is profoundly influenced by poverty and the disadvantages associated with disability (Watson, 2004).

This may provide a useful framework in examining how factors associated with poverty, urbanisation and globalisation may act as barriers for people to fulfil their potential and engage in activities they would chose to engage in and what implications this has for mental health.

I will now review some of literature relevant to South Africa in order to provide a context for the study.

THE SOUTH AFRICAN CONTEXT

Until recently, in the mental health field as in all others, South Africa expended resources on health and mental health unequally across races and provinces (Thom, 2004). Mental health services have historically provided care to a small percentage of the population that needs care. Issues regarding poor care and even abuse of human rights of people with psychiatric disorders remain (Thom, 2004). Screening for and identification of mental disorders has been and continues to be inadequate.

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Previous research (Joska & Flisher, 2005) indicates that there is a great need for mental health services in South Africa. There are a number of contributors to this need, which I will now discuss.

Presence of risk factors

The social factors discussed earlier in the paper, such as poverty and urbanisation, have been identified as factors which increase the risk for mental disorders (WHO, 2004). South Africa is a country in a period of transition, experiencing rapid urbanisation and population growth and high levels of unemployment and poverty (Thomas et al., 2002). Other risk factors identified by the World Health Organisation (2004) as associated with mental ill health such as violence, (Govender & Killian, 2001; Hirschowitz & Orkin, 1997; Kaminer, Seedat, Lockhat & Stein, 2000) unequal gender relationships and substance use (Bhana et al., 2002; Flisher, Parry, Evans, Muller, Lombard, 2003) are all issues which impact on mental health in South Africa.

The high burden of physical illness present in South Africa such as HIV/AIDS and tuberculosis also has implications as many people with mental disorders have significant physical co-morbidity (NAP, 2001; Patel, 2001). The HIV/AIDS pandemic also has massive implications for mental health in South Africa both in terms of emotional impact of the epidemic, psychiatric side effects of medication and more directly, as a proportion of people with AIDS will develop brain disorders (Freeman, 2004). Psychiatric co-morbidity has been demonstrated to be common in people with HIV/AIDS in South Africa (Els et al., 1999).

Prevalence of mental disorders

Although no national data exist on the prevalence of mental disorders in South Africa (Seedat et al., 2004), prevalence studies that have been conducted in specific regions of South Africa (Bhagwanjee et al., 1998; Cooper et al., 1999; Robertson et al., 2001; Rumble et al., 1996) suggest a prevalence at least as high as and possibly higher than internationally.

A study investigating the prevalence of post-partum depression in Khayelitsha, found a prevalence of major depression of 34.7%, a rate 3 times that found in British samples (Cooper et al., 1999). Another community-based epidemiological study in KwaZulu-Natal found a population prevalence for generalised anxiety and depressive disorders of 23.9% (Bhagwanjee et

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al., 1998). Rumble et al. (1996) found a community prevalence of psychiatric morbidity of 27.1% in a village in the Western Cape Province. Finally, an investigation of the prevalence of psychiatric disorders among children and adolescents attending a primary health clinic also in the Western Cape found 15.3% met the DISC-2.3 criteria for psychiatric disorder with impairment (Robertson et al., 2001).

A major epidemiological survey of mental disorders in South Africa is underway which will attempt to give an indication of the extent of mental disorder in South Africa (Williams et al., 2004).

As mentioned earlier, South Africa is in a period of social change, with high levels of poverty and inequality and urbanisation. Policies in areas of service provision are being developed and implemented in line with international influences.

The two main policies of interest were:

1. the progressive shift towards deinstitutionalisation, and community-based care for mental disorders.
2. the global shift towards privatisation of municipal services and corresponding policies of cost recovery,

These policies are conceptualised independently by policy makers in different government departments, but come together to impact on households. Therefore it is of importance to investigate how these policies are impacting on families.

Policies of interest

Mental health care for chronic mental disorders

The first policy of interest relates to changes in mental health policy and the integration of mental health services into the Primary Health Care System.

In the context of political transformation in South Africa during the past decade, mental health and substance abuse have been prioritised on government agendas. The new legislation on mental health care (Mental Health Care Act 17 of 2002) aims to redress many of the inadequacies in the mental health care system, as well as focussing strongly on human rights in

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order to address problems surrounding abuse of rights of people with mental disorders (Freeman, 2002; Thom, 2004). The legislation emphasises a community-based rehabilitative model of mental health care within a comprehensive integrated health service. This policy to deinstitutionalise mental health care is in line with international trends, and focuses on developing comprehensive and integrated community-based services (Thom, 2004). The objective is to integrate mental health services into primary health care services, and thus make mental health an issue not separate from other health issues, in an attempt to destigmatise and normalise mental disorder (Freeman, 2000). This is important as previous studies have indicated that stigma and misinformation surrounding mental disorders exist, which influence treatment seeking behaviour (Hugo, Boschoff, Traunt, Zungu-Dirwayi & Stein, 2003).

These progressive policies aim to redress previous inequalities in mental health care and abuse of human rights of people with mental disorders. There is, however, concern as to how effectively these policies are being implemented, given the under-resourced and under-developed services (Lazarus, 2005; Thom, 2004). Research has played a vital role in the process of identifying problems but has lacked clear organised collection of findings and analysis of relevance or the impact of this information on the policy-implementation process (Thom, 2003).

A review of mental health literature, with particular emphasis on mental health services, was conducted by the Health Systems Trust (Thom, 2003). Problems associated with implementation of policies were found to include shortages and inequitable distribution of mental health personnel relative to international settings (Freeman, 2000; Lund & Flisher, 2002). Other challenges to implementation included limited resources and budget cuts, ineffective management of these resources and a lack of a broader mental health care approach due to a scarcity of human resources in general. This scarcity of human resources was found to lead to a lack of time to provide more than basic medical and nursing care. Stigmatization of mental disorders, as well as competing priorities on an already overburdened health care system also was found to have implications for implementation (Lazarus, 2005).

In particular, concerns were raised regarding the process of deinstitutionalisation, as government policy has attempted to decrease reliance on long term institutional care for people with severe and chronic mental disorders, in favour of the promotion of community care (Dartnall, Porteus, Modiba, & Schneider, 2000; Lazarus, 2005). Concerns raised echo those that have been raised internationally in response to deinstitutionalisation (Lovisi et al., 2003).

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These concerns include (Lazarus, 2005):

- That pressure to reduce hospital beds may result in indiscriminate discharges without careful consideration of readiness for discharge.
- Inadequate family and community preparation and support – issues of obtaining chronic medication, disability grants, emergency assistance.
- Inadequate community resources, critical in reducing the burden of care for families caring for a member with a mental disorder.
- Inadequate continuity of mental health care leading to increased chances of relapse.
- Revolving doors where patients are neither adequately treated in hospital nor effectively integrated into the community.
- Neglect and abuse within families and other placement options, abuse of disability grant.
- Homelessness, as the housing problems many South Africans face, people with chronic mental disorders are even more likely to be ejected or unable to access even the more basic shelters.

In particular, the concern of the burden of families due to lack of adequate services and support has been investigated (Freeman, Lee & Vivian, 1999; Hamber, 1997 as cited in Thom, 2003). This burden has been reported as including financial strain, in some cases with a family member having to leave employment to care for the member with the mental disorder, impact on social relationships with family members and friends (Freeman, Lee & Vivian, 1999). Consequently, the task of care may be a particularly difficult one in households that are increasingly held responsible for monitoring the welfare of a psychiatrically impaired member, due to the policy of brief hospitalization and rapid deinstitutionalisation.

Studies from other developing countries raise concerns. In the 1970s, Brazil shifted its mental health policy emphasis from hospital-based to community-based care for mental disorders; however the implementation of community-based services was slow to develop. Patients were discharged from hospitals before adequate care was in place. A recent study in Brazil showed a high prevalence of mental disorders among the homeless as well as history of previous hospitalisation for a mental disorder (Lovisi et al., 2003). Although this cannot provide evidence for causation, it does provide food for thought.

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This progressive mental health policy, and the challenges associated with implementation, may have implications for households that now have to take care of family members with mental disorders.

A second policy of interest in the present study has also been implicated to place increased burden on poor households. This policy involves the shift towards privatisation and cost recovery for municipal services.

Privatisation of Municipal Services

Following the 1994 democratic elections, the Reconstruction and Development Programme (RDP) was adopted by the African National Congress (ANC) government, which focused on providing free basic services to the poor and marginalized, in an attempt to address the issues surrounding socio-economic rights (Mwebe, 2004). However, this strategy was subsequently replaced by the Growth, Employment and Redistribution strategy (GEAR), which incorporated policies of cost recovery, payment for services and encouraged private sector involvement in the delivery of services, in line with the global shift in focus driven by the World Bank and International Monetary Fund (Hemson & Owusu-Ampomah, 2005; Tsheola, 2002). This shift in strategy, together with the globalisation inspired drive towards privatisation, has implications in a context where high levels of poverty may lead to an inability to afford basic services that are recognized as rights, such as health care and water (Mwebe, 2004).

Access to basic services such as sufficient water is defined as a right in the South African Constitution (section 27 (1)), progressively realised for adults and immediately for children. Policies of cost recovery lead to access based on ability to pay, which is in conflict with the definition of access as a human right (McDonald, 2002). In an attempt to address this and following the cholera outbreak in KwaZulu-Natal, the free basic services policy was developed, which stated that every household was entitled to 6 *kl* of water per month or 25 *l* per person per day; and 50 free kWh of electricity per household per month (Hemson & Owusu-Ampoah, 2005; McDonald, 2002). Many low-income households use more than this due to high number of occupants and old infrastructure leading to leaks. Therefore how this policy is being implemented in terms of service delivery and how families are accessing water and electricity is in need of investigation.

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This trend towards increasing privatization where publicly owned and operated water systems are managed like private businesses advocate policies of cost recovery leading to water cut offs, housing repossession, drip valves that restrict water supply (McDonald & Ruiters, 2005). This policy of cost recovery has led to large-scale disconnections of water and electricity for non-payment of services by the municipalities (Ruiters, 2002).

Previous research by the Municipal Services Project (MSP) and others has shown how changing modes of service delivery of services such as water and electricity affects the livelihoods and wellbeing of poor families in South Africa and elsewhere (McDonald, 2002; Xali, 2002). Behaviours are modified in the climate of paying for basic services. Studies, conducted both internationally and locally, investigating the impacts of modes of service delivery (e.g. prepaid meters) and cut-offs (inadequate water facilities) have focused on the public health, behavioural, environmental and social impacts of these changes (Allison & Harpham, 2002; Deedat & Cottle, 2002; Xali, 2002).

Studies conducted in areas in South Africa where prepaid water meters have been installed as experimental pilot projects and other cost recovery measures implemented have described the stress and burden these measures have placed on households (Deedat & Cottle, 2002; The Coalition Against Water Privatisation, 2004; The Coalition Against Water Privatisation, The Anti-Privatisation Forum, & The Phiri Concerned Residents Forum, 2004; Xali, 2002).

Prepaid water meters are seen as a solution to problems experienced by the municipalities with collecting fees for services, within the context of cost recovery policies (Ruiters, 2002). With prepaid meters, basic services are paid for before they are received. In the past inability to pay for service bills led to services being cut off by municipalities, however with prepaid meter, households would in essence “self-disconnect” when they are unable to pay for water and electricity. Thus the responsibility is shifted from the municipalities to the households for accessing basic services.

As households are often unable to pay, they have to find other ways to access water. The pilot projects so far have indicated many practical problems associated with prepaid meters (Deedat & Cottle, 2002; The Coalition Against Water Privatisation, 2004; The Coalition Against Water Privatisation, The Anti-Privatisation Forum, & Public Citizen, 2004). The meters in many cases were found to be faulty, often not recognizing cards, and breaking down. The responsibility was

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then on the household to have the meters fixed, and having to seek an alternative water source in the meantime. The stores where cards could be purchased were only open during certain hours and were often located far away from the homes.

As the free basic water provided was in most cases far from sufficient for most households, residents were found to modify their behaviour in order to cut down on water usage, using the amount they could afford rather than what they needed. Behaviour changes were found to include decrease in hygiene behaviour such as bathing and hand washing as well as cleaning in food preparation. This has important health implications as this creates an ideal environment for the spread of infectious diseases. Women and children would also walk far distances to find free sources of water. This also has serious implications as women and children walking long distances, sometimes at night, are vulnerable to attacks.

The social impact of the prepaid meters was also described. Social relations between neighbours were placed under increased strain, as sharing water resources are no longer possible, thus creating an individualized relationship with water. Households were often forced to beg for water and situations where people would increasingly steal from each other were described. Traditional and cultural practices eroded as communal celebrations and mourning that have previously involved large amounts of water were no longer possible.

Many of the households were previously able to survive on low incomes as they were able to grow their own food. Problems affording sufficient water were found to have detrimental effects on their ability to provide for the household's nutritional needs.

Although the focus in the above studies was on the water prepaid meters, it is also important to note that paying for electricity was also a problem and cheaper alternatives such as candles and paraffin were often used, which have negative health consequences and increase the risk of fires dramatically.

The findings from the studies above show that policies of cost recovery have serious implications for poor households. Access to clean water is determined by ability to pay and water consumption was determined not by needs but by affordability. Cost recovery also appeared to have implications in contributing to the perpetuation of social inequality.

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CONCLUSION OF FINDINGS FROM REVIEW

The review of the literature presented above indicates that there is a great need for research in developing countries. Social factors such as poverty, urbanisation and globalisation appear to play a role in the experience of mental disorders however there is a paucity of research, particularly in developing countries examining this relationship.

The literature reviewed indicates a need for a new field of study to be opened up. Studies investigating the impact of stressors associated with poverty, urbanisation and globalisation on mental health have in many cases provided broad multi-factorial models in understanding the impact on health. These models now need to be taken a step further and specific stressors investigated in order to understand the impact on mental health more comprehensively. Studies that have examined the impact of specific stressors have focussed on physical health outcomes, such as cost recovery measures described above on physical health. What is now needed is a pairing of the two streams of study. This literature review forms part of a study that aims to contribute to an area lacking in the literature, addressing the impact of specific stressors on mental health by examining the impact of cost recovery measures on service delivery and how this in turn impacts on mental health.

In South Africa the deinstitutionalisation of psychiatric patients and greater emphasis on family- and community-based care, is resulting in families having to take a greater responsibility for their family members who suffer from mental disorders. At the same time, cut-offs and new modes of service delivery are thought to be putting greater strain on families. The question arises as to how families are responding to these two demands, which were conceptualized independently but are experienced together within the family context.

In the next chapter I discuss the research design and methodology we selected as appropriate in addressing the research purpose.

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CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY

Research design addresses the planning of scientific inquiry (Babbie, 1998; Babbie & Mouton, 2001); the blueprint of how research will be conducted. There are two major aspects of research design; firstly clearly conceptualising what it is one wishes to study, and secondly determining the best way in which to do it (Babbie, 1998).

I begin this chapter by defining the research problem and purpose and then move on to discuss the research design we selected as most appropriate in addressing the research purpose. I discuss the strengths and possible limitations of the design and explore measures taken to minimise these limitations. Finally, I outline the methods followed during sampling, data collection and analysis.

RESEARCH PROBLEM

A well-formulated research problem contains two elements; namely a clear conceptualisation of the research purpose and a clear specification of the object of study or the unit of analysis (Babbie & Mouton, 2001).

Purpose

Three of the most common and useful purposes of social research are exploration, description and explanation (Babbie & Mouton, 2001).

The literature reviewed in the previous section shows that we know relatively little about the inter-relations between social factors such as poverty and the experience of mental disorder in urban contexts. As discussed earlier in the introduction and illustrated in the review of the literature, this is a new area of study which has been sparsely researched and is of great importance and relevance particularly in the South African context.

Babbie (1998) states that exploratory studies are essential when research is breaking new ground. He feels that the merit of these studies is that they can yield new insights into a topic for research.

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The present study aimed to do just this; provide new insights and information in an area that has been sparsely researched and has great need for further investigation. More specifically, the purpose of the study was to generate rich, in-depth, descriptive and exploratory data in order to identify themes that would be useful in informing further research.

The purpose of the study was not to provide explanations or illustrate causal relationships nor did it attempt to assess a prevalence of phenomenon or develop theories from the data that can be generalised to a larger population.

In most cases, exploratory studies are thought to lead to insight and comprehension as opposed to the collection of detailed, accurate, and replicable data, and therefore are most likely to involve the use of in-depth interviews and the analysis of case studies (Babbie & Mouton, 2001). The most important considerations in exploratory studies include the need to follow an open and flexible research design. These considerations also include the use of methods such as literature reviews, interviews, case studies and informants which may lead to insight and comprehension.

Unit of analysis (object of study)

In the present study the research team defined the unit of analysis as the household with a member with a mental disorder. The concept of a household is one that is difficult to define and there are many different classifications as to what defines a household (United Nations, 2003). For the purposes of this research, a household was defined as including all individuals sharing the same physical space, income and resources. This definition does not include the necessity of being related by blood to one another. This definition was selected as one of the areas to explore as an important focus was that of municipal service provision. Thus, all members sharing the same space and resources would be impacted by the service provision. In the same light, all individuals sharing the same space would be to some extent affected by the member with the mental disorder.

Although the unit of analysis was the household, there were also sub-units of analysis which consisted of the individual household members. The sub-units of interest were the household as a whole and the member with the mental disorder.

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Once the research problem and the unit of analysis had been clearly conceptualised, the most appropriate research design to address the problem could be chosen.

RESEARCH DESIGN CONSIDERATIONS

Research design and research methodology are two different dimensions of research and are often confused (Babbie & Mouton, 2001).As mentioned at the beginning of the chapter, the research design is the plan or blueprint of how the research will be conducted and research methodology is the execution of the research design (Babbie & Mouton, 2001). Different types of research design attempt to answer different research questions or problems and therefore employ different methods and procedures.

Babbie and Mouton (2001) suggest that all social research should conform to a standard logic and should consist of four elements, namely a research problem, a research design, empirical evidence and conclusions.

As mentioned previously, the research question was exploratory in nature. The research team decided that a series of 10 qualitative case studies would be the most appropriate method to address the research question and purpose. This method was selected as appropriate as it would allow flexibility to explore and uncover themes and issues related to the research question in depth and from multiple perspectives.

Babbie & Mouton (2001) suggest that qualitative research designs share the following features:

- A detailed engagement/encounter with the object of study
- Selecting a small number of cases to be studied
- An openness to multiple sources of data
- Flexible design features that allow the researcher to adapt and make changes to the study when and where necessary.

As the research design chosen for the present study was a series of case studies, some case study design considerations will now be discussed.

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Case study design considerations

Case study methodology is utilised when the aim of the research is to provide an in-depth description of a small number (less than 50) of cases and the key research questions are exploratory or descriptive in nature (Mouton, 2001). The conceptualisation is inductive in that no hypothesis is formulated, although in some cases general ideas or expectations may act to guide the research.

In qualitative case study we seek a greater understanding of the case (Stake, 1995). We want to appreciate the uniqueness and complexity of the case, its embeddedness and interaction with its context. “We are interested in them [the cases] for both their uniqueness and their commonality. We seek to understand them. We would like to hear their stories” (Stake, 1995, p. 1).

There is some debate about case studies and whether they are in themselves a valid research design or not. Case study design has been criticised and called a weak method for having insufficient precision, objectivity and rigour (Yin, 2003). Another criticism is that the method provides little basis for scientific generalisability (Mouton, 2001; Yin, 2003).

Yin (2003) asserts that the case study method is a valid design in itself, provided rigorous procedures are followed throughout the process. These procedures must be followed from conceptualisation of the idea to reporting of the findings, in order to combat the above criticisms and minimise potential sources of error.

Stake (2005, p.443) refers to the use of case studies as “not a methodological choice but a choice of what is to be studied”. His view is that the case study should be used when the purposes of the research is to determine what can be learned from the case as opposed to generalising beyond it.

The reason for the selection of case study strategy over other possible strategies was that case studies allow the collection of in-depth descriptive and exploratory data. This strategy also allows for flexibility in that theoretical propositions and hypotheses are developed at the beginning of the study to guide data collection and analysis, but the method also allows themes and areas to emerge that did not form part of the original propositions (Yin, 2003).

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Yin (2003, p.1) states that, “case studies are the preferred strategy when ‘how’ or ‘why’ questions are being posed, when the investigator has little control over events, and when the focus is on contemporary phenomenon within some real life context”. Case study designs are more commonly used when the unit of analysis is a more clearly defined entity, for instance in the case of specific households, families, organisations etc. (Babbie & Mouton, 2001) These explanations of when case studies should be utilised apply to the present study.

Case study design also offers a great scope in methods of data collection and analysis. As mentioned above, the focus is on what can be learned from the individual case or cases. Yin (2003) gives the following definition of the scope of a case study:

> A case study is an empirical inquiry that
>
> - investigates a contemporary phenomenon within its real-life context, especially when
> - the boundaries between phenomenon and context are not clearly evident.

Although Yin (2003) believes that the findings from case studies may be generalised in certain circumstances, this was not the purpose of the present study but rather, as Stake (2005) asserts, to discover what can be learned from particular cases. Therefore, for the purposes of this research, the idea that the case study is a valid design when systematic procedure are utilised was adopted. The guidelines of Yin (2003) were followed in the case study design, methods of data collection and adapted in analysis. The findings were reported with the view of learning what was specific to the cases and identifying themes as opposed to making an attempt to generalise from them.

Strengths of the case study design include high construct validity, the possibility for in-depth insights and the establishing rapport with participants, and flexibility as the design may be modified to suit the needs of the research (Mouton, 2001).

Limitations of the design may include a lack of generalisability of the results, non-standardisation of measurement and data collection and analysis can be time consuming. Main sources of error include potential bias of researcher and lack of rigour in analysis (Mouton, 2001).

The uses of the case study design presented above indicate that it was an appropriate design for the present study. Case study design allowed for flexibility, by giving space for themes to

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emerge as well as for exploring themes that had been identified. It also allowed for 'thick descriptions' to be developed as multiple perspectives to be obtained.

ISSUES OF RELIABILITY AND VALIDITY

In general qualitative researchers accept the principles of reliability and validity but may apply them differently from quantitative researchers in practice (Neuman, 2003).

Reliability

Reliability (Babbie, 1998; Neuman, 2003) is a matter of dependability or consistency. Qualitative researchers use a number of techniques in order to ensure that they record their observations consistently. However, it is also acknowledged that in many instances the processes they observe are not stable over time, as well as the value of the changing nature of the relationship between the researcher and that which is studied. Researchers should consider a range of data sources and employ multiple methods (i.e. triangulation of methods, which will be discussed later in the chapter).

Validity

Babbie (1998) describes validity as whether measurements actually measure what they are supposed to measure as opposed to measuring something else. Validity means truthful, and refers to the extent to which the data captures the truth of the situation. Qualitative researchers are in many cases more interested in authenticity, that is giving a fair, honest and balanced account of the data, than validity in an abstract sense (Neuman, 2003). A researcher's claim has increased validity when it is supported by other data.

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Objectivity

Smaling (cited by Babbie & Mouton, 2001) developed a conceptualization of objectivity that has relevance to qualitative research; this objectivity is described as doing justice to the object of study.

The following concepts and strategies are of importance in enhancing reliability, validity and objectivity in the qualitative paradigm (Babbie & Mouton, 2001). How these strategies were put into practice in the study is presented in Table 1 on page 41.

Triangulation

Triangulation is generally considered to be one of the best ways in which to enhance validity and reliability in qualitative research (Babbie & Mouton, 2001). In order to increase the accuracy of reporting and reduce the likelihood of misinterpretation and misunderstanding, various procedures may be employed (Stake, 1995, 2005). These procedures are generally called triangulation, which is a process of using multiple perceptions to clarify meaning, verifying the repeatability of an observation or interpretation. Triangulation serves to clarify meaning by identifying the different ways in which the case can be seen and identifying different realities.

There are various types of triangulation (Babbie & Mouton, 2001; Neuman, 2003; Patton, 1990):

- The most common is data triangulation where a variety of data sources are used.
- Another type is triangulation of observers, as a single observer means the limitations of the one observer become the limitations of the study. Multiple observers add alternative perspectives and reduce limitations leading to a more complete picture.
- Triangulation of theory occurs when multiple theoretical perspectives are used in the planning of the research or interpretation of the data.
- Triangulation of method means mixing different methods, e.g. quantitative and qualitative forms of method.

Extensive field notes

Babbie and Mouton (2001) suggest that the researcher keep two sets of notes, one describing the environment in which the study takes place and another containing theoretical memoranda.

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These notes will allow the researcher to adjust the research design if necessary as the research progresses.

Member checks

Member checks refers to the process where transcripts and analysed texts are taken back to the respondents in order to clarify whether what they have said has been accurately captured.

Peer review

During this process two or more researchers debate about various issues in the research and come to a consensus regarding these issues.

Audit trail

This involves making all aspects of the research available to an independent examiner in order to point out biases and flaws and any other problems with the study.

Trustworthiness

Another approach to clarifying the notion of objectivity, namely trustworthiness, can be found in the work of Lincoln and Guba (as cited in Babbie & Mouton, 2001). Qualitative researchers emphasise trustworthiness, ensuring that the research activities are dependable and credible, as a parallel idea to the objective standards in quantitative research design (Neuman, 2003). Trustworthiness helps to ensure that research accurately reflects the evidence.

There are four aspects of trustworthiness, namely credibility, transferability, dependability and confirmability. The procedures used to address these aspects of trustworthiness in the study are presented in Table 1 on page 41.

Credibility

Credibility involves the sense of whether the data ‘rings true’.
Credibility is said to be achieved through the following procedures (Babbie & Mouton, 2001):

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- *Prolonged engagement* – staying in the field until data saturation occurs
- *Persistent observation* – consistently pursuing alternative interpretations and looking for multiple influences
- *Triangulation* – collecting information from different points of view in an attempt to obtain the many different constructions of reality within the context of the study
- *Referential adequacy* – involves the adequacy of the materials available to document findings
- *Peer debriefing* – occurs when a peer questions the research hypotheses, insights, analyses etc. and assists in decisions regarding next steps etc.
- *Member checks* – as described earlier, this involves going to the source of the information and checking whether the information has been accurately captured and interpreted in order to correct obvious errors

Some of the procedures discussed above are also strategies to increase objectivity.

Transferability

Transferability refers to the extent to which the finding can be applied to other contexts or with other respondents (Babbie & Mouton, 2001). All observations are defined by the specific contexts in which they occur, and therefore knowledge that is gained in one context will not necessarily have relevance for another context or for the same context at a different period in time.

Guba and Lincoln (as cited in Babbie & Mouton, 2001) suggest the following procedures when enhancing transferability:

- *Thick description* – the researcher needs to collect detailed and in-depth data and report with sufficient detail and precision in order to allow the reader to make judgements about transferability
- *Purposive sampling* – in contrast to quantitative research that makes use of random sampling, qualitative studies aim to maximise the range of specific information that can be obtained about and from the context, by purposively selecting informants and locations that will achieve this.

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Dependability

Dependability refers to the concept that if the inquiry were to be repeated with the same or similar respondents in the same or similar context, the findings would be similar (Babbie & Mouton, 2001). According to Guba and Lincoln, (as cited in Babbie & Mouton, 2001), similarly to the idea that there can been no validity without reliability, there can be no credibility without dependability. Thus, if an enquiry has been shown to have sufficient credibility it should follow that the study has sufficient dependability. A strategy to assess dependability may involve conducting an audit trial, which has been discussed earlier.

Confirmability

This refers to the degree to which the findings are the product of the focus of the inquiry and not a product of the biases of the researcher. Once again a strategy to increase confirmability of a study is to conduct an audit trail.

All of the strategies discussed in the section above ensure increased reliability and validity of the research. How these strategies were put into practice in the study is presented in Table 1 on page 41.

Table 1

How Strategies to Increase Reliability and Validity were Addressed

Strategy	Concept	Strategy addressed
Triangulation	Objectivity, trustworthiness (credibility)	• Measures: by interviewing different members of the household we were able to obtain different perspectives and views of the experience. • Observers: having 2 interviewers gave the possibility of obtaining multiple perspectives. The interviewers discussed impressions and conclusions and analysed the data independently. • Attempted to confirm information with more than one source e.g. on service rates and billing methods etc.

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Extensive field notes	Objectivity	Detailed notes were kept on observations and other details of field work, questions to be asked, how interview format could be modified etc.
Member checks	Objectivity, trustworthiness (credibility)	Member checks were not performed due to time and budget constraints.
Peer review	Objectivity, trustworthiness (credibility),	The research team discussed and debated all issues related to the research process.
Peer debriefing		Aspects of the research process were discussed with colleagues.
Audit trail	Objectivity, dependability, confirmability	Supervisor and research team fulfilled this role.
Prolonged engagement	Trustworthiness (credibility)	Multiple interviews on different occasions were conducted to ensure data saturation.
Persistent observation	Trustworthiness (credibility)	The interviewers constantly discussed the data and explored alternatives
Referential adequacy	Trustworthiness (credibility)	A digital recorder was used to record the interviews. It was small and unobtrusive and had good recording range and could therefore be placed on a table or floor and participant did not have to talk directly into it.
Thick description	Trustworthiness (transferability)	Detailed and in depth information was obtained from and reported by the participants regarding their experiences. Detailed information regarding the context was also obtained and reported.
Purposive sampling	Trustworthiness (transferability)	Cases were selected if they fulfilled specific criteria that spoke to the purpose of the study.

ISSUES OF MEASUREMENT

Once a research method has been chosen, the measurement techniques need to be chosen (Babbie, 1998).

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In order to explore households' experiences of mental disorder, the research team decided to conduct semi-structured interviews with various household members. This allowed flexibility, yet ensured that the interviewers covered the areas that had been determined as relevant from the review of the literature. Interviewing different household members also contributed to a multi-dimensional understanding of the household's experience.

The data were collected by means of a series of semi-structured interviews which consisted of open-ended questions in order to obtain a large amount of in-depth data from each household. The open-ended questions also gave the opportunity for responses to arise that were unexpected and did not form part of the original propositions. This methodology also gave the interviewers the freedom to explore views and opinions in more depth if appropriate. Yin (2003) states that during an interview, the researcher will pursue a consistent line of enquiry but the actual questions are more fluid than rigid. The purpose of the research was to identify as many themes as possible in relation to the topic at hand and therefore this methodology seemed the most appropriate in addressing this purpose.

Yin (2003) identified strengths and limitations of using interviews as a research methodology. Strengths were that interviews were targeted in that they could be focussed directly on the research topic and insightful and could provide perceived causal inferences.

Weaknesses that were associated with interviews included:

- bias due to poorly constructed questions
- response bias
- inaccuracies due to poor recall
- and reflexivity in that the interviewee may give what the interviewer wants to hear

How these possible limitations were addressed in this study is discussed in Table 2 on page 44.

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Table 2

How Measurement Concerns were Addressed

Concern	Concern addressed
Bias due to poorly constructed questions	Great care was taken to avoid poorly constructed questions. The questions were developed following a comprehensive review of the relevant literature. Consultation and suggestions from other researchers in the area was also received. Once a preliminary interview format was developed, this format was piloted (see p. 47) and changes were made where necessary.
Response bias	No leading questions were asked during interviews to ensure that the responses were the participant's own.
Inaccuracies due to poor recall	All interviews were digitally recorded and then transcribed. The procedures were also documented carefully throughout the process. Inaccuracies in participant recall of facts could have occurred but in general questions pertained to present experiences and therefore poor recall was not as much a concern.
Reflexivity	There is a possibility that this could occur despite strategies to minimise this. One strategy was that the households had an in-depth relationship with one of the interviewers that were based on trust. One of the interviewers knew the families well and they would therefore not easily be able to make up responses in order to give what they thought we wanted to hear.

A detailed framework of questions was developed, following a comprehensive literature review which covered risk factors for mental disorder in the context of poverty, urbanisation and globalisation as well as stressors associated with municipal and mental health services. This format consisted of opened ended questions. This was also chosen in order to ensure that specific areas of interest were covered but also allowed for themes to arise that had not been anticipated. Therefore the content of the interview schedule was based on what had arisen from the literature, but also included ideas and thoughts the researcher thought would be worth exploring.

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Interview questions covered the following areas:

- Household's experience of municipal and mental health service provision
- Household's experience of mental disorder including
    - Household's reasons for disorder and relapse
    - Patients reason for disorder and relapse
    - Experience of mental health services
    - Impact of mental disorder on household
    - Experience of stigma
- General household stressors
- General patient stressors
- Support systems

CASE SELECTION

Determining the unit of analysis of a case study involves defining what the "case" is (Yin, 2003). In the present study the case and therefore the unit of analysis as mentioned earlier was defined as the household with a member with a mental disorder.

Sampling method

"Case study research is not sampling research" (Stake, 1995, p. 4). Given the research purpose, the researcher needs to decide which cases are likely to lead to understanding in order to maximise what can be learned.

The aim of the study was to explore the experiences of households with specific characteristics and therefore purposive sampling was used in the selection of the cases, i.e. cases were selected based on the purpose of the study (Stake, 2005). Purposive sampling is a type of non-probability sampling (Babbie, 1998) in which cases are selected on the basis that they fulfil certain characteristics or in some instances to obtain maximum variation (Gobo, 2004). This strategy of sampling was appropriate in the study as the sample size was too small to warrant random sampling (Stake, 2005). It was also appropriate as the objectives of the study was not to provide generalisable data, but rather to gain in-depth insight into families' experiences of mental disorder in the context of urban poverty. The cases were selected in such as way as to build in some variety to the sample and give the opportunity for intensive study (Stake, 2005).

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Inclusion criteria

In total 10 families were selected to participate on the basis that they fulfilled the following inclusion criteria:

1. have a combined household income of less than R3500
2. be caring for a member with known psychiatric disorder (for the purpose of the study we decided that mental disorder be schizophrenia as we had access to members with schizophrenia in Khayelitsha through one of the interviewers).
3. have access to water and electricity on their plots
4. be living in low cost/RDP type housing

These inclusion criteria were chosen in order to select a sample that would be appropriate to the research question.

DATA COLLECTION METHODS

In order to explore different experiences in different geographical areas, sampling occurred in two locations; namely in Klipheuwel, a peri-urban community 20km from Durbanville and in different areas in Khayelitsha (Makhaza, Harare and Site B). Both of these sites are in the greater Cape Town area. The first area was chosen as it is the only area where households access their water and electricity via prepaid meters and therefore are forced to pay for services. At the time the research was conducted, the author was informed that prepaid water meters were going to be progressively implemented throughout the Western Cape (personal communication, February 10, 2005). This has since changed (Smith, 2005). However at the time of the interviews we decided that it would be important to explore the impact of pre-paying for services on low income households.

In Klipheuwel, households were identified through patient files. Households that were identified as having a member with schizophrenia were asked if they would like to participate in the study. If they agreed a time was arranged that was suitable. As none of the households had access to telephones, all the interviews were set up by means of home visits. As Klipheuwel is approximately 20km from the nearest town, all participants elected to have the interviews take place in their homes. This was useful as it gave the interviewers an opportunity to observe the house.

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Three households were selected from Klipheuwel as only three patients were identified from clinic files. For this reason a decision was made to include all 3 households even if the household income was slightly higher than the cut-off amount originally set out in the inclusion criteria. This decision was made as we felt that it was important to include as many households as possible from the area given the type of water provision.

The first household identified in Klipheuwel served as a pilot study. The author (2nd language Afrikaans) and a co-interviewer (1st language Xhosa, 3rd language Afrikaans) visited the household on four occasions and conducted interviews in Afrikaans (the household's first language). The interviews varied from ½ hour to approximately 1 hour. Following this pilot case study, any changes to the interview format that had been identified were made.

The remaining households in Klipheuwel were interviewed on a number of occasions ranging from 3– 4 visits per household. In all cases it was ensured that information was obtained from the household head and the member with the mental disorder. Other family member's contribution was also valued.

The second area from which cases were selected was Khayelitsha. Households were selected from three areas within Khayelitsha; namely Harare, Makhaza and Site B. Households in Khayelitsha were identified as in all cases the member with the mental disorder had been part of a support group which had been run by one of the interviewers.

Once again, households were asked if they would like to participate and if they agreed an interview was set up at a venue of their choice. Similar to Klipheuwel, in all cases households chose for the interviews to be conducted at their homes.

DATA CAPTURING AND EDITING

During the interviews the data were captured using a digital recorder. Observations were recorded using carefully dated and thorough field notes. The interviews were transcribed from the recorded voice files. Ideally we would have liked to have transcribed the interviews in Xhosa and then translate back into English but this was not done due to budget constraints. Certain measures were taken to minimise error. The co-interviewer, whose first language is Xhosa, listened to the audio files and looked at the transcripts so as to make sure they matched.

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In the case of the Afrikaans interviews, the interviewer for whom Afrikaans was her second language listened to the files and looked at the transcripts to make sure they matched.

DATA ANALYSIS

Merriam (as cited in Cresswell, 1998) asserts that there is no standard format for reporting case study research.

Stake (1995) views qualitative case study analysis as a matter of giving meaning to first impressions as well as to final compilations and feels that there is no particular moment when analysis begins. Analysis involves taking things apart; impressions and observations, and making sense and meaning of data.

Babbie and Mouton (2001) suggest that analysis of case study data involves organisation of findings and decisions regarding whether generalisations and theory development are appropriate.

The aim in the present study was not to generalise findings to a larger population nor to develop theories and provide explanations. We analysed and made sense of the data by identifying themes that arose during the case study interviews. We were not attempting to understand the experiences of the case as a whole but rather to identify a range of possible experiences and perspectives of households in similar circumstances.

The interview transcripts were coded using a qualitative software package, Atlas ti. We first developed clear conceptual categories for the data. Following that, inductive (categories arising from the text) and deductive (predetermined) coding categories were created. Once the codes had been created and the text coded accordingly, we were able to identify themes and patterns that emerged. These themes and patterns could then be matched with patterns that were expected or unexpected from the theory and literature.

I have discussed the methodology that we selected as most appropriate in addressing the research purpose as well as possible limitations of the design and the methods we took in addressing these possible limitations. In the next chapter I discuss the themes that were identified from the case study interviews.

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ETHICAL CONSIDERATIONS

Ethical approval for the study was granted by the Human Sciences Research Council's ethics committee provided that the following criteria were adhered to:

- Written informed consent to be interviewed and photographed was obtained from all participants
- The aims and objectives were explained in the participant's home language and appeared on the consent forms
- Anonymity of participants was ensured by the use of pseudonyms
- Photographs would be digitally disguised to ensure anonymity
- Should the interviewers discover a person with serious mental disorder that had not been diagnosed, it was the responsibility of the interviewers to give information regarding pathways to care.

Permission to conduct the interviews in the Klipheuwel area and access the files at the Durbanville Clinic was granted by the Manager of Quality Assurance and Specialised Services at the City of Cape Town Health Head Office, on condition that the report was made available to the department and that patient confidentiality was maintained and that written conformed consent was obtained.

Permission to conduct the interviews in Khayelitsha was obtained from the Regional Director of the District Health Services, once again on condition that patient confidentiality was respected.

The documentation relating to ethical considerations appears in Appendix 1.

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CHAPTER 4: RESULTS

This section covers the themes which emerged from the analysis of the case study interviews. Quotations from the interviews are used to illustrate themes and photographs to provide visual details. The themes are presented in sections, the first are themes relating to factors associated with municipal service delivery, the second, factors relating to mental health services and lastly, to the households' overall experience of the mental disorder.

DESCRIPTION OF AREAS

Klipheuwel is a low socio-economic area that consists of two types of housing. The two housing types are separated by a railway line. The one side consists of 141 formal houses fitted with pre-paid water and electricity meters (Smith, 2005) and the other of informal housing. The majority of people living in the area are either current of ex employees of farms in the area.

Khayelitsha is settlement located 30km from central business district of Cape Town. Population estimates range from 350 000 to 900 000 (Dyantyi & Frater as cited in Tomlinson, Swartz, Cooper & Molteno, 2004). The vast majority are migrants from the Transkei and Ciskei. The area consists of a mixture of housing types, including low cost housing and shacks (Xali, 2002).

SAMPLE CHARACTERISTICS (see Table 3)

The sample consisted of 10 households, varying in size from 3 to 8 members. The total sample size including all household members was 55. The 3 households from Klipheuwel were Afrikaans speaking and the 7 households from Khayelitsha were Xhosa speaking. Household income varied from R780/month to R4100/month with an average household income of R2000/month. Of the 10 households, 6 had members who were employed. Only members whose salaries contributed to the total household economy were included. Salaries of those employed varied from R850/month to R2200. Some members had casual jobs where they would be paid R50 for the day. This income was affected by season as they were not able to work when it was raining. Of the 10 households 7 were receiving social grants, with 5 receiving only disability grants (one of these households had two members receiving disability grants), and 2 more received a disability grant and a pension.

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Table 3

Sample Characteristics

Household	No. in household	Home language	Household income per month	No. employed	Social grant
1	3	Afrikaans	R780	0	1DG
2	3	Afrikaans	R4100	2	0
3	7	Afrikaans	R3800	2	0
4	7	Xhosa	R1400	1	1DG
5	5	Xhosa	R780	0	1DG
6	6	Xhosa	R1860	1	1DG
7	5	Xhosa	R3360	1	2 DG
8	4	Xhosa	R1560	0	1DG; 1OAP
9	4	Xhosa	R800	1	0
10	8	Xhosa	R1560	0	1DG; 1OAP

* DG = Disability grant (R780)

** OAP = Old age pension (R780)

MUNICIPAL SERVICES

Type of service provision

All households in Klipheuwel (N=3) had piped water in their homes and access via prepaid water meters. Of the 7 households in Khayelitsha, 6 had piped water in their homes and 1 had piped water on the site. All the households in Khayelitsha had water monitored through credit meters.

All of the households in the sample, both in Klipheuwel and Khayelitsha had access to electricity via prepaid meters. All 3 households in Klipheuwel had flush toilets in their homes. In Khayelitsha, 1 had a flush toilet in the house while the other 6 had flush toilets on their site.

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Arrears owed to municipalities for services provision

The amount of arrears owed to municipalities is presented in Table 4.

Table 4

Household Arrears for Municipal Services

Household	Arrears
1	R198
2	N/A
3	R394
4	R13000
5	R16000
6	R9100
7	N/A
8	R1067
9	R4200
10	R18200

In discussions of arrears a distinction will be made between the two areas from which the sample was drawn. In the case of Klipheuwel, residents prepay for water and electricity and these are therefore not included in their monthly bill. They report that they do not receive a monthly bill that includes the rates for waste removal and arrears. In Khayelitsha residents prepay for electricity but receive a monthly bill that includes their water, sewerage and waste removal rates and any arrears they may have accumulated. As this occurs as one bill, the monthly service bill will be discussed together with the arrears in terms of payment and impact.

Payment of arrears and service bills

Although the 3 households in Klipheuwel do appear to have arrears (this was confirmed by looking at household bills), only 1 reported that they pay anything towards this bill. This was the husbands account.

> I'm buying water – but I still have to pay off the water as well……I pay something every month……. When it comes like this, I pay the whole amount. Let's say that it's three or four hundred, and then I pay it like that.

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The wife's account, however, was slightly different.

> No, we're not paying for that any more. No, because we have the little box we are no longer paying for the water. We also don't pay for the refuse removal. We really only pay for the electricity.

The other 2 households seem to be under the impression that their arrears have been written off and that they are not expected to pay off their arrears now that they prepay for their water and electricity.

With the exception of 1 household, none of the households (N=6) in Khayelitsha are paying anything towards their monthly service bill and arrears. This household had made an arrangement with the council that they would pay R20 per month towards their service bill, although they did report struggling to make these payments and some months they were not able to pay at all.

A common theme that arose during the interviews is that residents in Khayelitsha have an understanding that during negotiations following the period of water disconnections, it had been agreed that the arrears would be written off and there is some confusion as to why they still are expected to pay off these amounts.

Attitudes towards monthly service bills

One of the explanations for the shift towards cost recovery has been described as a way of dealing with non payment for services. There are two possible explanations for this non payment. Firstly, a widely accepted view is that non payment is the result of a "culture of non payment", where people have become accustomed to not paying for services during the years of anti-apartheid rates boycotts and now feel that they should still receive their services for free (McDonald & Pape, 2002).

The second explanation relates to the issue of affordability (McDonald & Pape, 2002). Although in no way generalisable, the data from these case studies seems to favour the second explanation over the first. Although only 1 household in Khayelitsha is contributing to the payment of the monthly service bill, at least 3 have made attempts to negotiate with the council in an attempt to

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pay an amount that is affordable for them. One household speaks of making an agreement to pay R50 per month but this amount has proved to be too much for her.

> I went through to make arrangements because I'm not able to cover everything. I arranged that I pay at least R50 per month towards my arrears and I can't afford that arrangement either.

Others attempt to make payments when they are finances available

> I don't know because all I do is go through to the centre and pay about R30 something towards my bill. I don't do that on a monthly basis though.

In general the case studies point to a situation not where residents are not paying for their services as a result of a "culture of non payment" but as households are struggling financially to meet the daily needs of the home and therefore other issues take priority such as food and school fees, compete for their limited resources.

> I'm a terrible payer because I struggle; the thing is my daughter goes to school, so I don't pay regularly.

In many cases there is only one household member who is employed at a low wage (N=4), or the household relies solely on a social grant (N=4).

> He doesn't work, I'm the only one who works, the older child goes to technikon, so often I have to work in order to pay for his travelling ticket, and I don't make that much money from the people I work for. My big daughter is now doing her 3rd year at the technikon, so it's very difficult to pay for these services.

Therefore in the cases of the households in Khayelitsha, non payment seems to be the result of an inability to pay as opposed to unwillingness to pay. In Klipheuwel, non payment of arrears appears to be the results of ignorance as to what is expected of them.

Another theme that comes through in many cases is a sense of hopelessness and a feeling of being overwhelmed by huge bills and arrears. Households seem to feel swamped by the debt that

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no matter how much they pay, the bill just keeps on increasing and they see no way they will ever be able to pay it off.

> We once attempted to pay, but the amount that was too much was……It was a lot of money, there's no ways we could have afforded to settle that amount, it was about R9000. So that doesn't make us relax at all, because at the back of our minds we are aware of the possibility that it might get switched off, but we cannot afford to pay it , not at all.

In one case the household would not even open their bills anymore.

> I throw them away nowadays because the more I pay, the more the bill escalates.

Impact of arrears and monthly service bills

Household

The impact of the arrears on households seems to include a constant sense of worry and fear of what will happen as a result of their accumulating arrears.

> It bothers me a lot, more especially regarding the uncertainty and possibility of losing my house. I wouldn't know where to begin or what to have as surety if I were to ever get summons to go to court. Let me just say, things are really not easy for me.

Caregivers appear to feel a conflicting burden and responsibility as it is their job to provide food and yet they feel that by sacrificing paying their service bills to provide this food they could end up loosing their homes or having their water cut off. "If I don't pay they cut my water off".

Member with mental disorder

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In two cases where the member with the mental disorder was a son in the family, they commented that they experience stress as a result of the inability of their household to pay service bills. One was worried that there would not be enough food for the family as a result of the service bills.

> [I feel] terrible because all the money goes there and leaves us with little to eat here at home. Having to pay for rent and services takes out a lot of money and leaves us with a shortage here at home.

Another reported that "I feel hurt" as a result of seeing his mother worry about service bills and arrears.

Water

Strategies to minimise water usage

In Klipheuwel, households prepay for their water and therefore had many more strategies in place to minimise their water usage in an attempt to ensure that their free water would last as long as possible. Although 6 out of the 7 households in the Khayelitsha area are not paying for their water, many have strategies in place to try to decrease their water usage in order to avoid accumulation of arrears. Despite these strategies, none of the households was able to keep their water usage to the free kilolitres provided (this was confirmed by looking at household bills).

Households described how they would use their dirty washing water to flush the toilet with.

> No, we used the same water we wash with and then add some if it's too little.

> Like with the toilet, I flush it with the water from the washing.

Others were very conscious of the usage and tried not to use more than was necessary.

> For instance with the laundry, I use one tub for washing and one tub for rinsing and make sure that I don't spill any water in the process .

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> But then you can only rinse everything once. You have to be careful with how you use the water. Ja, you can't do the washing everyday.
>
> I mean, we don't have small children that need to be bathed and all that kind of thing. It's only the three of us here. She does the washing only every two weeks; we don't do the washing every day. She does the washing on a Friday, and once she's done, that dirty water goes on the flowers again. We don't just water everything. We use the water sparingly because it's a lot of money.

Two of the households in Klipheuwel had very strict bathing arrangements. They would not bath but put water in a bucket and then share that water to wash themselves.

> We seldom have a bath. We've got a bucket that we wash in….The two who are working with the coal, they are very black, so they both wash with the same water. And when Davie[2] and I wash ourselves, we share the same water. Tanya and Anthony use their own water.

Another household in Klipheuwel reported that they put a bowl of water out at the beginning of the week for people to wash their hands in.

> Ja, we always have a bowl of water for washing hands. We put it there on a Monday morning maybe. It's just for washing your face and your hands.

Another common theme was that households were not able to have their own gardens and grow their own vegetables for fear of large water bills.

> These children recently spoke about growing vegetables that side, but the problem is, garden maintenance will use up a lot of water. With more free water I'd be able to plant crops; I still plant with the little that we have.

[2] All names are pseudonyms

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In Klipheuwel one household was attempting to grow vegetables by using their old washing water to water the garden. "You can't waste that water. Ja, once you've done the washing up, you can use it again to water the flowers."

However, this strategy did not provide enough water for the vegetables to be able to grow and therefore the household decided to abandon the garden.

> He could plant all the vegetables like potatoes and cabbages, because he'd be able to give them enough water. We can't do that now. They have to use the water sparingly. He can't make a vegetable garden now because he doesn't have enough water for that.

The third household in Klipheuwel, although they reported that they were conscious of their water usage and didn't waste their water, was not as strict with their water usage. They reported that "Ja, when we bath we can use a lot of water. It's not like we're scared that the water is going to run out."

Although this household also reported having great financial stress, they were slightly better off than the other 2 households and therefore their financial stress appeared to be more related to saving for tertiary education and school related expenses.

One of the women from a household in Khayelitsha was involved in a garden project where she was able to grow vegetables that she could bring home to the family or sell. She reported that there were problems with the water now and that the members may be expected to pay for the water that they used. In this case, she reported that she would not be able to continue with the project as she would not be able to afford to pay for the water she would need to grow her vegetables.

Impact of limitation of water usage

Household

One household spoke of stress and conflict caused by their neighbour's using their outside tap. The household tried to keep their water usage down in order to prevent the accumulation of arrears but as no one was home during the day they were unable to prevent people from using their outside tap. This caused them a great deal of concern. "We are unable to [save water]

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because we have this tap outside. One saves their own water and make use of our tap outside….It does [cause conflict] and forces one into arguments."

A household in Klipheuwel spoke of the impact of having to prepay for water on their lives.

> When there is no water, what can we do? We can't go to the other people and ask them for water. We have to go to the white people and ask them for a little water. There are little kids here and they need to have water.

Member with mental disorder

In one of the Klipheuwel households, where the member with the mental disorder was the father, the impact on the father appeared to be very severe as he would worry a great deal about paying for water and electricity as he felt it was his responsibility to provide for the family.

> Ja, I do sometimes get stressed about the water; the kids waste a lot of water. I get angry. I don't hold anything back. I let everything out. But then I calm down and I'm fine again. They keep on using the water…. they drink and wash….all those little things.

His wife's view was similar to his. She described how he would get very angry with the children for using any water and electricity; this would also impact on her stress levels and burden. She felt that he got more stressed and angry than was expected as a result of his mental disorder.

> I get very angry when he gets stressed like that, because he was in the hospital for that schizophrenia of his. Now, he stresses a lot, and then I just keep quiet because I know it's due to his illness. He gets angry very quickly.

In another household in Klipheuwel, the member with the mental disorder described how his pills make him feel thirsty all the time and how he would become frustrated when the water would run out and he would have to go and borrow water from the neighbours in order to alleviate his thirst.

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Free basic water

All households were aware that they received a monthly free supply of water however only one knew the exact amount. They also were not aware of the block tariff system and were shocked to hear of the rapid increase in rates. The common view was that the free basic amount provided was by no means sufficient for them to lead dignified lives as even with their strategies to save water, the free amount was not enough. One household in Klipheuwel felt that they would be able to grow vegetables if they were provided with more free water.

Discontinuation of water services

Reasons for discontinuation

One of the households in the Klipheuwel area had experienced a water disconnection due to non payment. This occurred before the prepaid water meters were installed. Reports of the length of the cut off differ between family members; the father reports that it was disconnected for 2 weeks and the wife reports that it was two days. During this time they would go to the squatter camp which is situated approximately 1km from their home and fetch water in a can from the communal prepaid taps.

> Interviewer: And where were you getting your water from? Participant: We fetched it from the other side….we filled the can every time.

The household describes the reason for this disconnection. One of their water pipes had been broken and they had not been aware of it and therefore a lot of water had leaked out. This resulted in a large amount of debt being accumulated which they struggled to pay.

> It was because one of the kids smashed the water pipe. We weren't aware of it and so it accumulated. So then we had to pay extra. We first had to pay a deposit and then they turned it on again.

The household had accumulated arrears of over R850 during that period. They had to pay a deposit of R300 to have the water turned back on and then pay off the rest over the next few months.

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In Khayelitsha, 3 households indicated that they had experienced a period of time where their water supply was disconnected due to non payment of service bills. There were inconsistencies in the recollection of this event within households in terms of whether the household had been cut-off or not and for how long the disconnection had lasted. For example, in one household we were told by the husband of how the water had been cut off for a week and the strategies employed by the household in order to access water during this time. However when we spoke to his wife, she didn't recall ever having their water cut off. It is difficult to know the reasons for this. However, possible reasons for these inconsistencies may include, husband could have possibly been fabricating the cut-off, giving us information he thought we wanted to hear. On the other hand, the wife could have been denying the cut-off out of shame as she was very concerned about what we thought of her and kept apologising about the state of her house and that she was not able to give us any tea or food.

Of the other 2 households, one reported that their water had been disconnected for 'about a week' and the other household reported that it was disconnected for a day.

Strategies to access water during cut-off

During this time households had different strategies in place in order to access water. One household spoke of trying to get water from the taps of her neighbours that were still dripping once the water had been disconnected or borrowing from those whose water had not been disconnected.

> Actually not everybody's water supply got disconnected, so we asked the ones who still had water within the neighbourhood to supply us with some. Others used drops of water coming out of others' taps.

Others spoke of filling containers with water and storing it as they had been warned that the water would be disconnected.

> But because our brother worked for the committee, he advised us to save big portions of water in big containers, because he was aware that they were going to cut it off. The

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> disconnection hardly lasted a week and fortunately I have a big blue drum which I filled up with water, as well as all the big pots, that's how we managed to save up for water .
>
> They would inform us when the water will get cut off and we made preparations and store them in big containers.

Other strategies included fetching water from the neighbourhood school where the water had not been disconnected. "We used to fetch water from the school."

Impact of cut-off

In general households describe this time as a stressful one, filled with uncertainty and worry.

> It was stressful, but it didn't last long.
>
> It was hard when it got disconnected.
>
> It causes a lot of stress because my concern was that it doesn't last up to a week or two, because really, what would one do without water.
>
> We struggled.

Households also described problems with the water they had stored in containers. "You know how water gets like when it stands there for a long time, it's no longer fresh after sometime, even the taste is different, but what could we do."

The group that describes feeling the biggest impact of the water cut-off was the members with a mental disorder.

> It was indeed [a hard time], because one couldn't even do laundry from those drops, one could only use them for cooking purposes. I begged them to reconnect stating that I couldn't even take my medication (Pills for nerves), the next day it was reconnected.

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> It was so bad I even cried when they came, stating that I couldn't even take my pills, then one man took note of my sickness and the effect this could have towards my health and asked them to open the water for me.

This impact seemed to be even more pronounced in the case where the member was the father in the household or the caregiver.

> He suffered the most in terms of stress and think what made matters worse is that he is already in the state he is in and is a male on top of that, so it was more stressful for him.

Resolution

Stories of the events following the cut-offs are very similar. Households described how they went to the office to protest and negotiate with the council as they were unable to afford the bills in order to have their water reconnected. "Everyone in the community protested (Toyi toyi)".

Households also expressed confusion around the arrangements made following the negotiations. Many felt that it had been agreed that the arrears would be written off which did not happen.

> We went to Stocks & Stocks, there at the office and they suggested that we make payment arrangements. The arrangement was that we paid bit by bit, at the same time there had been a meeting arranged by the community , where it was concluded that we shouldn't pay because of an enormous account, we then had to start afresh in terms of payment and ignore the previous debt. From there onwards the people were not paying, then water was reconnected again. The council thereafter agreed on the idea of not paying the previous balances and starting a fresh account. We waited for the council to come back to us and verify the agreement and they never came back since.

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Electricity

Strategies to minimise electricity usage

Households employed a number of strategies in order to keep their electricity usage down to a minimum. None of the households used electric heaters for warmth as these were seen to use far too much electricity. Many used paraffin heaters for warmth but as paraffin is also expensive, many either used an open flame for warmth, despite their knowledge of the danger of this form of energy. “We use a paraffin heater for instance because the electric one uses up a lot of electricity”. Others had no form of heating in the house. Our interviews took place during winter and we experienced how cold some of the households were. One of the households had placed pieces of newspaper in the gaps between the roof and the walls in an attempt to keep the wind out. The roof was an open tin structure with no insulation. In two households the front doors wouldn’t close properly and kept blowing open allowing great gusts of wind and rain to blow in. In another household, during the interview with the member with the mental disorder, his teeth were chattering so much he was hardly able to speak. The family would walk around the house covered with blankets.

Households also reported that they would use a two plate burner stove for cooking but towards the end of the month when there was not money available for electricity they would switch to cooking on the fire. “Look, when she’s using that little stove and we see the electricity is getting low, we just stop using the stove because that’s where all the electricity goes. She then makes food outside for us.” Others used a gas stove instead of the two plate. When they were using the stove and oven, households described an awareness of their electricity usage and attempts to minimize use.

> ….moreover we don’t cook that much, and I would make enough at night so that it lasts throughout the day. The same applies to bread.

> We also didn’t use the two burner stove often. Foods that take longer to cook like samp[3] and beans are cooked on the paraffin heater to save on electricity.

[3] Traditional dish consisting of an assortment of dried beans

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In many cases (N= 7) households in both Khayelitsha and Klipheuwel described having to borrow money for water or electricity from their neighbours or family. “She does that a lot, often she’ll go visit her friends in order to borrow money for electricity or paraffin.”

Many described the feelings of same and embarrassment at having to borrow money but also expressed that they did not have a choice.

> Yes [I feel embarrassed and ashamed] because some people get quite rude at times.

> Hey, I do feel bad but I really can’t help it, there’s nothing I can do.

Households in Khayelitsha also informed us that the electricity boxes had been replaced in order to prevent tampering. They felt that the new boxes the electricity ‘went a lot faster’.

> They said that people tampered with the old boxes, yet now they are the ones that rob people because, people no longer tamper with electricity boxes, they are still consuming the same amount of electricity, yet it moves faster.

Two households in Khayelitsha spoke of having problems with their electricity boxes. They described how when the boxes were installed they were not secured to the wall properly and had therefore fallen down shortly after instalment. When they contacted the council to complain of the problem they were informed that they would have to pay R500 for it to be fixed.

> Mine isn’t properly mounted either, this person came alone here and couldn’t drill a hole in the wall because the bricks are tough , I asked why its skew and he said no its stable, there’s nothing wrong with it.

In the case of one of the households, the caregiver was the member with the mental disorder and the fact that the box was not properly secured was a source of great stress and worry for her.

> One other thing that will make me sick is that box over there, can you see it. That box was not tightened properly on the other end, I reported it, I called at first, they promised to come, I even sent my youngest grandchild to report it and they said I should pay R500. He said no it’s still in a working condition. The person who put it there didn’t tighten it

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> up properly hence we have to use other measures to balance it. They said I should pay R500 and I said 'not for something I haven't messed up'.

On the first occasion we visited her she was very distressed and worried about the box. She had been to the council a number of times to complain about the box as she was terrified that the children could get electrocuted while she was out of the house.

> Can you see that this box is in a hazardous position and can cause danger? If I had a baby that crawls someone would have been badly hurt, a box should be mounted further up and get tightened.

She was evidently very distressed about the situation. That the households would have to pay R500 to have the boxes fixed was confirmed by the author who phoned the electricity hotline a number of times. There was no way she could afford the R500; she was already struggling to make ends meet with her disability grant. On our last visit, she had hired a private contractor to come in and secure the box. For this she had to pay R250.

Impact of limitation of electricity usage

Household

One household in Khayelitsha spoke of the impact on the children.

> Children would be happier in being able to switch on the TV whenever they like as opposed to visiting other homes at night to watch TV. Their mother has promised to buy them a cassette radio. They would be able to stay at home. It's hurtful for children. It hurts to me as well.

One household spoke of being worried about the amount of times the member with the mental disorder made himself coffee "With him, He cooks water in the kettle every minute for tea….I did get a flasks twice and they both got broken."

Another theme that came through from 2 of the households in Khayelitsha was the view although they were struggling, that was the way it was and they had to make the most of it. "We tolerate it, because we can't do much about it."

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Member with mental disorder

In the household in Klipheuwel where the member with the mental disorder was the father, he described a great impact on his stress levels regarding paying for electricity. He would get very anxious whenever the children used the electricity and get angry and this would result in family fights. “The same thing happens with the electricity as well – I stress very quickly….They’ve got the TV and everything else turned on. They don’t want to listen when I speak to them.”

Another member in a household in Khayelitsha spoke of the impact of being cold all the time. “Like now for instance, it’s cold outside and the house is cold but we can’t warm it up to save electricity.” This was also observed by the interviewers as the interviews were conducted during the winter and this member was observed to be shivering and struggling to keep warm.

In an instance in Khayelitsha where the member with the mental disorder was the son, he spoke of being worried and upset to see how his mother struggled to pay her bills. His mother became very tearful during the interview when speaking about her struggle to make ends meet financially. He spoke of feeling hurt and worried by this.

> Participant: Yes, It does, it worries me. Interviewer: What worries you the most? Participant: It’s the account debts. Interviewer: How does that impact on you. What worries you about it? Participant: It’s the fact that she can’t afford to pay for her accounts

He described how he would take steps to try and keep the electricity usage of the household down. I switch the refrigerator off…. I usually do in order to save up on electricity.”

Free basic electricity

In general households were aware that they received a set amount of free electricity per month but many were not aware of the specific amount they received for free. Households all felt that this amount was far from sufficient as even with the strategies they put in place to minimise their electricity usage, they still have to pay a substantial amount every month towards electricity.

> It’s not sufficient, I bought some yesterday and it’s already finished now.”

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It’s not sufficient but I add on some more”.

One household in particular was a good example of how insufficient the free electricity was. The amount of 50kw of free electricity per month was calculated based on a household size of 8 members (McDonald & Ruiters, 2005). This particular household consisted of 5 members with 2 members living in the shack next door. Until very recently the household only used electricity for one light bulb in the lounge and the kettle in order to heat up their bathing water. “I don’t even have a stove, all I use is the kettle, we use the flame stove for cooking”. They used a fire to cook with and heat the house. Despite this, the household still had to supplement their electricity from the disability grant.

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MENTAL HEALTH SERVICES

Experiences of clinic services

The clinics that were attended by the household members with mental disorders included Durbanville day clinic (N=3), Site B day hospital in Khayelitsha (N=2) and Michael Mapongwana clinic in Harare, Khayelitsha (N=5). Members visit the clinic once a month to collect their medication. Should they relapse they may be admitted to the state psychiatric hospital which serves the area. Lentegeur psychiatric hospital serves Khayelitsha and Stikland psychiatric hospital serves Klipheuwel.

No problems were reported at Durbanville and Site B clinics. Staff were said to be friendly and the members did not have to wait long for their medication as the staff were efficient and the folders were organised and ordered. However, households reported that they experienced problems at Michael Mapongwana. The most common problem experienced that was reported by all households attending the clinic was the long queues and waiting time when collecting medication. Members spoke of having to queue from early hours in the morning often in the rain and being in danger while they queued as they were only able to enter the premises from 8 o' clock.

> The problem is not opening the gates around 5am or 6 am. It would be better if people could be inside the premises because there's a shelter there and people would feel safe when it rains for instance, there is no safety outside.

> It gets extremely cold in winter, others buy blankets. You see that's why I bought mine in town so as cover myself and get warm, because we stand outside in the rain. Where have you seen sick people standing in the rain?

> They pick pocket us even during the day….It's really tough in Cape Town. People get wet in the rain while waiting in the queues at the clinics; they get asthma attacks, epileptic fits. When I went to fetch your medication the other day, criminals were collecting jewellery from people because they were queuing outside the premises. Even cell phones, it's really tough.

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> Perhaps they should have their own section at the clinic, because sometimes they probably get tired of standing in the queue in the dark. At that time they leave home without having had a meal. Having to leave home to get to Harare or Matthew Goniwe by 5 o'clock is too early. So they stand there the whole day and come home around 3 o'clock. They should at least have someone to specifically look after them because they already know what tablets to give to them, it's their appointments. By twelve or one they would be finished and come back home to eat and take their tablets. It's very difficult. At times when I come home from work, he would have just arrived, starved and drinking tea. They really are supposed to look after them and not make them stand out in the rain, in the dark. There's skollies too.

One of the households had experienced so many problems at the clinic that she had resorted to taking her son to Lentegeur hospital every month to collect his medication.

> What's hard for us at the clinics that even my mother struggles with having to stand in a long queue from early hours of the morning regardless of the weather, but now I attend Lentegeur since I came back.

She did however report that there were problems here as there was no one to translate for her when she goes to Lentegeur. "The problem there is that there's no Xhosa speaking member amongst the staff".

The households also told stories of how patients would become impatient and leave before collecting their pills, thus defaulting on their treatment and being at risk for relapse. "They freeze completely, and the psychiatric patients get nervous and leave."

We were also told informally after one of the interviews that some patients would not take the correct dosage of their medication, e.g. would take one pill instead of two so that they would only have to go to the clinic every two months instead of every month.

Two households also described how on a few occasions, the nurses would not dispense medication unless the patients brought old packets with them. They were sent back home without their medication which was very hard as they would have to pay taxi fare in both directions and then return and have to queue all over again.

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HOUSEHOLD'S EXPERIENCE OF MENTAL DISORDER

Attitudes towards member with mental disorder

In all of the households the person with the mental disorder appeared to be a valued family member with family members actively involved in their care and supporting their treatment. The fact that the sample in Khayelitsha was drawn from members attending support groups would have had an effect on this and is not necessarily a reflection of a general attitude towards mental disorder in the area.

Family members were supportive in reminding patients of their clinic dates and accompanying them to the clinic, reminding them to take their medication and monitoring their behaviour in order to pick up early warning signs of relapse.

> At times my mother gives me [my pills] then at times I remember how many to take.

> We go together to get the pills. I used to give him myself before but now he takes them on his own, I'll show him so that he makes sure on how many he should take.

Even the children were aware of the disorder and what to do in cases of relapse "They don't get scared, they know what to do when he gets sick , we make them aware of his sickness and what to do when he starts getting sick".

As discussed earlier, in one household the children would go and collect their grandmother's medication from the clinic if she was too tired. They would also help with household chores in an attempt for her not to become stressed and relapse.

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Family reasons for disorder and causes of relapse

Cultural explanations

There were different explanations that households provided to explain why the patient had become ill. Some described the disorder as the result of amafufunyana, which is a form of spirit possession experienced amongst Xhosa and Zulu speakers (Swartz, 1998).

> We thought perhaps he started seeing things and assumed it was the bad spirits (evil spirits).

> Its (amafufufunyana) (bad Spirits), someone inflicted him with (amafufunyana) because he would see them calling him.

Substance abuse

Others explained it in terms of a reaction of the brain in response to substance abuse, either alcohol or cannabis[4]. "The doctors said he smoked dagga and his system could not handle it."

Non adherence to medication

In terms of factors that would lead to relapse the most common factor that households identified was adherence to treatment.

> Not getting treatment would cause a relapse, I noticed that when I went over to him in Transkei , as well as poverty , not knowing what to eat.

> I don't know why he got sick again because he really likes his treatment.

[4] The high prevalence of substance use in schizophrenia is widely recognised (Hamera, Schneider & Deviney, 1995). This raises the question of the direction between psychosis and substance use, as cannabis is hypothesised to induce psychosis (Verdoux, Tournier & Cougard, 2005).

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> I personally cannot put my finger on it, because at times he wakes up not being himself even if nothing had disturbed him, so it's hard to say… But since he now takes his medication regularly, he's fine, but as soon as the treatment gets finished he relapses.

Patient reasons for disorder and cause of relapse

Patients also had different explanation as to the reasons that they became ill.

Substance abuse

One member attributed it to substance abuse.

> Taking drugs, because such substances undermine one's mind and make them believe they can do this and that. It's such substances like dagga that cause one not to have common sense, because the mind goes backwards.

Previous head injury

Another explained it in terms of an earlier head injury "In was in 1977 when I got had the head injury, I got sick thereafter."

Stress

Another common theme was that the disorder had occurred as a result of stressors in the patients' lives.

> Yes, when I'm stressed then I get sick. That is why I have to stay on the tablets.

> I was playing football when this illness begun, I broke this leg, and went to Tygerberg Hospital in 1977, thereafter I came back with a plaster (cast) then I began getting sick, because I was stressed out about my leg, I thought of not being able to perform the same way as I did before, thereafter I became sick, It was in 1977, I was at the Oscar Mpetha High School at that time.

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> What gets me admitted in Hospital is usually when things don't go right at home, that has a very stressful effect on me, I don't even disclose that to my sister sometimes, I hold it in so as to maintain peace amongst my siblings and not sound as if I'm badmouthing anyone and cause a fight. I remain quiet and that's wrong because I strive to forget then it stays in me as a result I get sick sometimes.

Impact of mental disorder on family

Households spoke of the pain and heartbreak they experienced when the member first became ill.

> When he started getting sick we were heartbroken because we knew how nice this guy is.

> [I feel] very sore. I don't know how somebody else feels – but my heart is very sore.

> He affect the family, it's painful for us, we are aware of his sickness when he behaves in certain ways. When he's not sick he's a very nice guy who talks about love and peace all the time. The family knows him the way he is. We have to be sensitive and easygoing towards him as a family.

Others spoke of their shock and disappointment.

> I was completely shocked because he was very clever at school; I was in a complete shock… I'm the one who was supposed to be in hospital from being shocked.

> I thought he would study and be successful at school. I worked so hard for his success. But when he was at school he began to see things, would often get scared and see people following him and had (amafufunyana). I've consoled myself now because I have a heart disease. I don't have a lot of children but my grandchildren at least give me hope. I now believe in them. I'm educating Shaun now, my grandchild with the hope that someone will at least get educated within the family. I don't know whether I'll see that through.

> That broke my heart; I was convinced I was going to get sick as well because I had nerves all the time. I dreamt that he was going to be somebody; it broke my heart so badly that I ultimately gave up on it.

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The households also spoke of the difficulties of living with the person when they were ill; some would be aggressive and physically attack family members.

> I was hurt, extremely hurt, badly hurt, it was so painful because he used to physically attack me to a point of getting swollen, whenever I took him to hospital. When coming back from hospital he would kick me and continue doing so until he goes back again.
>
> And when he refuses to go to the clinic especially when he was still very ill. Because he would run away from taking his injection and stress me out to a point of getting asthma attacks. I ended up that way and am on treatment.
>
> In the beginning, I was under a lot more pressure because he was very sick – a lot more than he is now. I had my hands full then – and it gave me a lot of stress.
>
> At first, when he started getting ill, he would get up during the night and then I'd have to go and look for him. When I find him, he's kind of bent double, or he would just fall down. So then I'm awake and all the children are awake too. They got such a big fright when that happened. So then I would try and revive him, but sometimes he'd almost be like someone who is in a coma. If I sponge him down with vinegar then he'd be all right again.

The children from 1 household in Klipheuwel spoke of the impact of their mother's mental disorder and hospitalisation on them.

> It was very difficult when my mother was in the hospital. My dad had to look after us. I was still very small and can't remember exactly what it was like. It was very difficult. We never went to visit my mum. My dad went; [we] didn't like hospitals. I went once when we fetched my dad, and it was very difficult for me to see the people in a place like that! It was not very nice and I was just so glad that my mum could come home again.
> It was one of the most difficult times in my life. I thought I was never going to see my mother again. And I don't know how I survived it. It was terrible. … What really hurt me a lot was when I went to the hospital to see her and she didn't recognise me. It was painful. But I'm just glad she came out … I think if it wasn't for His help, our family would not have survived. I don't know how I survived it. If I think about it now, I can

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> just say, thank you Lord for giving us the strength to get through this. Thank you for helping us to get through every day. I wouldn't wish it on anybody – to go through what we had to go through. … I thought she was never going to get better. But there was also that period after she came out of the hospital. She was just so aggressive. [She] got better again. I'm so glad about that. But we survived it!

One household reported the impact on them when trying to get their nephew to eat when he relapsed.

> Later on for supper he didn't eat, then again for breakfast he still didn't eat. He didn't want food, fruit, and drinking water. That's when we knew he was starting. That was now the second day. It was not easy for us as we could not make him eat even though we know about his sickness. And one cannot force him when he is in that state. The following day he still refuses to eat.

On the whole, all of the households reported the situation to be vastly improved, with members being able to live improved lives with their support and treatment from the clinic.

One of the women told us informally after the interview that her husband's family had warned her not to marry him due to his mental disorder. She reported that it had been very stressful living with him and that is why she has high blood pressure.

Medication side effects

Medication side effects were explored as compliance has been hypothesised to be influenced by side effects experienced (Bergen, Hunt, Armitage, & Bashir, 1998).

Patients described a variety a side effects of their medication, including:

- the tablets made them drowsy. "I get tired'. Some reported that this was a side effect that they welcomed as they would otherwise struggle to sleep. "They're doing very well. If I don't take them, I don't fall asleep". "No it's alright because as soon as I get the injection I fall asleep".
- Dryness of mouth "It's only the dryness in the mouth. I just have to take a drink of water and it's fine again. But I have to drink a lot of water."

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- Shakes. “It’s this one leg of mine. I can’t put all my weight on it because it’s a bit wobbly”. This impacted on his ability to work in the garden as he couldn’t put weight on it for any extended period of time.
- “I find that it makes me dribble a bit”.

Employment and education

Of the 10 households, 8 members with mental disorder were of employable age, however all were unemployed. One had been in matric when he became ill and had returned to school at the beginning of the year to complete matric.

Other household members also reported having problems securing employment.

> Yes I want a job now because my house is empty. I do have a daughter but she stays on her own .I would like to get a part time job so as to settle my accounts.

Factors impacting on their ability to work included:

- Inability to travel long distances due to cold. “I use to sell vegetables before and did chars in Rylands, It was better then, but now I’ve stopped…. because it would get extremely cold at times.”
- Lack of funds to set up own business. Some households reported wishing to be able to supplement their income by selling sweets but didn’t have the capital necessary to start such a venture
- Limited employment opportunities. “Jobs are scarce.”

Stigma

Household reports of their experiences of stigmatisation as a result of their mental disorder varied amongst households[5]. Two households reported that members did not experience stigma. “No it doesn’t happen, they accept him and feel sad when he gets ill because he gets on very well with people.”

[5] Stigma may influence preferred treatment modality and help-seeking behaviour (Hugo, Boshoff, Traut, Zungu-Dirwayi & Stein, 2003).

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Others reported that they were either teased at school or in the streets and in one case even by a family member. “They call me ‘patient ‘.”

> Participant: Yes, there’s a term they use for a mentally disturbed person, they say ‘I buy from Yona (Supermarket) even if it’s closed. Interviewer: How does that affect you? Participant: I get hurt but I choose to keep quiet because I don’t want to beat anyone up.”

> It was terrible. Some of the kids at school made jokes about it. I can still remember, one girl said, your mother looked in the mirror and got scared of a ghost. Ja, that was really painful.

> The feeling stays and remains stressful inside. It remains in my heart even after a while, the fact that so and so makes fun of me in front of others because of my illness.

> It’s various people, even my own brother, the elder one in Nyanga called me a mad hatter (mental case) when we were discussing rent issues ‘My own brother’ because he didn’t want to give assistance in paying the rent, yet he also gets paid, and that stressed me out because he is my blood yet he made fun of me.

Two members spoke of making an effort to walk away when they were being teased as they were worried about the consequences of possible actions.

> I get heartbroken and choose to disappear in front of such a person because that will give me stress and I’ll find myself doing hurtful things that may upset my community members which thing I’ll regret when the police arrive, when I injure someone or I myself gets injured. I can avoid the situation and run away and ignore the person or tell a person that they don’t know what they’re talking about.

In one case the fear of being stigmatised was so great that the member did not wish to apply for a disability grant.

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Disability grant

Out of the 7 households receiving disability grants, 4 reported having experienced problems, in particular a delay in payment when the grant is up for review. Patients reported that their grants were suspended for up to six months. Although in most cases this money was paid out once the grant was renewed, it left the patients without any income for the period. In 2 households this grant was the only income on which the whole family lived, times of suspension caused a great deal of anxiety and stress for the member with the mental disorder and the family. In the other 2 households, the grant formed 50% of the total household income and thus suspension also had a great impact. Households reported that during times of suspension, members were more likely to relapse. “He gets sick when his grant gets stopped.”

> We had no money. We had to go and ask other people for food. It’s not nice when the food cupboard is bare. We had to wait for his money to come so that we could go out and buy our own food again.

> We struggled because the money that I earn on its own is very little. We struggled but we tried to make do with what was available.

> What I’m aware of is worrying due to his payment not going through and therefore disable him from assisting me with groceries because it does get stopped sometimes for a period of three months at times. That’s usually what bothers him the most because he really is a caring person.

In one household, the suspension of his grant caused the member with the mental disorder a great deal of stress as he felt responsible as his grant was supporting the whole family. He would try to borrow money for the family to make up for the lack of the grant. “[It is very stressful] to have to ask other people for money. You have to ask for money until you get paid again.”

We spoke to the community spokesperson in Klipheuwel who was involved in helping families with issues such as grants. She told us that while his grant was suspended he would come to their house every day to ask if they had heard anything about the grant. In her view he was very agitated and distressed. She reported that during this time he relapsed and was admitted to

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psychiatric hospital. During this time the family subsisted on packages from the church and leftovers from her shop. They had to borrow money from her for water.

GENERAL STRESSORS

In addition to the stressors relating to municipal and mental health services and mental disorder discussed in detail in the sections above, households spoke of additional stressors that will be discussed below.

Household

The most common theme of the stress experienced by households was one of financial stress. Households spoke of frustration of not being able to find employment, in most cases casual work, in order to relieve this stress. As mentioned above, this stress was exacerbated when social grants were reviewed and suspended.

> When you don't have money and everything in the house is nearly finished. You are stressed because you don't know where it's going to come from.

> Yes, I do feel stressed when I can't get some casual work. I mean, where will I get a little work to do – because we've got nothing in the house at the moment.

> He is also not working so we struggle to make ends meet.

> The biggest worry was always finances. How am I going to pay this account at the end of the month? The kids want this or that. But you don't have the money – and that's very stressful.

> The other worrying thing is my husband who does not work, because we have children whose school fees we cannot afford. When the month ends I always have to buy groceries because children are wasteful, by the time the month ends everything is finished and I have to start from scratch.

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> It's the phone because it's prepaid; I don't have airtime as we speak. I also have to rent it on a monthly basis otherwise it gets cut off. And it is a necessity, for emergencies and attacks.

After one of the interviews one of the women apologised to us and expressed her shame and embarrassment at not being able to offer us any tea or coffee.

One woman told us how she had had to borrow money from her work in order to have her house built. She now had to repay the amount that she had borrowed at a high interest rate.

Another reported how her son's school tracksuit had broken but she was unable to afford to buy him another one and thus he was often cold.

When there was no money, some households reported feeling stress at having to ask neighbours for money or food.

> I used to get stressed when we like didn't have sugar for the child's tea bottle. Then my mum would say, go and ask this or that auntie. Now, a person feels really bad…you feel very unhappy if you have to go and ask other people all the time. Then I'll say, no, I'm not going to ask. But then my mum says, just go and ask for a little so you can give it to the child. Don't worry about us. We are grownups. Just get something for the child's bottle. So perhaps that little bit won't last for the whole of the next day, and then I must go and ask again! That is when I get stressed.

One household also reported that it was stressful for them not to be able to visit their relatives in the Eastern Cape as they could not afford it.

> Yes to such an extent that, when we have to go home to the Eastern Cape and are unable to because of the little money that we have, when someone passes away and we can't afford to go.

In one household in Khayelitsha the caregiver spoke of her worry about who would take care of her brother, the member with the mental disorder, if something was to happen to her; how others would cope with and possibly misinterpret the change in behaviour in the event of relapse.

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> What concerns me is that, he's very comfortable here with me , but it could so happen that I die , and there's no guarantee that my children will accept him the way I do, they might not. That's my worry ….. The other problem is, when these people start getting sick, they get violent and no one really wants to take action, the police don't take action... These are the kinds of problems we have. For instance there would be a family member they despise when they get sick,

This caregiver also spoke of her worry as to how the community would respond to his behaviour when he relapses as it had not happened yet.

> It gets difficult for one to have control over him until someone he is able to listen to comes around; someone to tell him that he has to go to hospital. It's really hard when the police and community members distance themselves in such situations. So that's what I fear the most because one could get severely injured. The people around this community have never seen him sick before, he's just arrived here, on the same note I can't hide the fact that he's mentally ill within the community because I might not be around when he relapses. Lately he has a tendency of taking his clothes off; he would for example leave his pants in the loo and stand at the gate or inside the house naked. Some people view him in a different manner and misinterpret his behaviour.

Member with mental disorder

In addition to the issues discussed earlier, patients identified other aspects and issues that they found to be stressful.

One reported that he felt a great deal of stress in his previous household where he was living with his brother as he had to take all the responsibility for making sure the rent and bills were paid. The brother was also selling alcohol from the house which he found bothered him. This resulted in him making the decision to come and stay with his sister. "That caused too much stress for me and I wasn't well, hence I then decided to stay over here."

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Another stressful factor that was identified was the impact of conflict[6].

> When someone makes me angry, or talks badly to me or shouts at me, I feel that thing and it stays on my mind and makes me feel angry, I try to calm myself but it stays in my heart , I would like to forget about it but it stays. That makes me stressed, not taking my medication regularly gives me stress, but now I do take it regularly.

In two cases, members spoke of their disappointment and shame they felt when comparing themselves with the people they had been at school with.

> Certain worries include noticing the progress that my peers have made in life, when I have none, It stresses me out but then again I admit my situation knowing that God knows what he is doing ….Because people I went to school with are now educated, Some are teachers, some electricians, some with careers such as nursing and that gives me an inferiority complex, and makes me fear even greeting them unless of course they greet first, then we chat, then I feel better.

Another spoke about being lonely and stressed that he couldn't find a girlfriend. He felt that the women were only interested in him at the time when he received his grant as they were only interested in him for his money.

> I don't have a girlfriend, I get bored, and I sleep and wake up get bored. My current girlfriends are only after my money, they call me often when I get paid, ask my mother. They only love me when I have money and go away thereafter.

Finally, in one of the households in Klipheuwel, described how she was restricted in the work she could do as she found some work too stressful.

> I can't work inside the factory because it's too stressing, so that's why I do the cleaning now. I keep the eating areas clean because I can't work inside the factory.

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[6] High expressed emotion has been proposed as a factor indicated in relapse in patients with schizophrenia (Leff, 1994). There are three components of expressed emotion; namely critical comments, hostility and over involvement.

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SUPPORT AND COPING STRATEGIES

In Klipheuwel, 2 of the 3 households had family who lived in the area who were able to provide them with financial and emotional support. These 2 households also spoke of the support they received from the members of their church. The children spoke of how they belonged to the church choir, which they found helped them when they were feeling overwhelmed. The third household was given administrative and financial support from the community spokesperson, which helped them with their grants and gave them food and lent them money.

In Khayelitsha, households reported getting support from family members, church members and two reported receiving support from people with whom they worked. Neighbours were also a source of support, both in lending money and food and in some cases assisting the family when the member with the mental disorder relapsed.

> You see I have two brothers, one has a wife and the other doesn't. The one working at Shoprite is usually there for me, and helps me solve my problems. He usually helps with funds for my children in school matters like money for trips and so on. So that eases out the stress levels.
>
> There is a woman I work with, that I usually go to. She's usually able to notice when I'm suffering emotionally and she'll usually ask what's wrong then I open up to her.
>
> Yes, I think so. Sometimes, I'll go and talk to my grandmother. My mother's mother, we are very close, and I talk to her and my grandfather. I feel better when I talk to her. She is just great.
>
> Ja, they help us. My mother doesn't really have a job. She does housework one day a week. But when I need something, she will give it to me. His mother gets an old-age pension. So she gives us a little money when we are short – and then we do the same for her again when she needs something.

One reported that her neighbours also supported her by keeping an eye on her son to make sure he wasn't being negatively influenced by peers.

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> They would assist to an extent of giving us their phone numbers so as to call when there's a crisis. Some would help me watch if he has any friends that are of bad influence.

In one case the caregiver reported having no support financial or emotional and became tearful when speaking of her burden in taking care of her brother, son and two grandchildren and having to earn a living as well. She was given the number of Cape Mental Health.

One household reported how her old employers had heard of her struggle to put her daughter through university and had settled her fees.

> Miraculously, the white people I worked for in Berkley paid off her outstanding fees, they reduced her debt, and then she was told she could graduate.

I have presented the themes that emerged during the case study interviews. In the next chapter I will discuss the possible implications of these themes for the experience of mental health.

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CHAPTER 5: DISCUSSION

The aim of the present study was to gather in-depth data in order to generate themes to inform further study. This chapter will discuss the implications of the data, and, in addition, the themes elicited will be explored. I shall consider how social factors may act as barriers for activities such as caring for family members with mental disorder and for people with mental disorder to reach their full potential.

FACTORS IMPACTING ON DATA GATHERED

A number of factors may have impacted on the content and quality of the data gathered.
Firstly, it is important to consider the role the demographics of the interviewers may have played in the data collection. One of the interviewers was a young white woman and this would have had implications for the interview process. This may have impacted in many ways, both positively and negatively. Participants may have felt more comfortable to share with someone from a different background; however they may also have provided information they thought we wanted to hear. The other interviewer was a Xhosa-speaking woman who had worked as an auxiliary social worker running support groups for people with schizophrenia and had worked to some extent with most of the participants with mental disorder. This may have had implications: participants may have been able to share more openly as a relationship of trust had already been established. However, they may also have tailored the information they presented in line with what they expected she wanted to hear. In analysing the data I was very aware of these issues and carefully examined the data for evidence of response biases. I was not able to find evidence of such biases. I also discussed the data with my co-interviewer and she, too, did not detect bias. This does not mean however that biases were not present, and this should be borne in mind.

The interviews were translated directly into English from Afrikaans and Xhosa which may have resulted in meaning being lost in translation. Measures were taken to minimise this. One of the interviewers for whom Xhosa was her first language, listened to selected recordings of the interviews which were conducted in Xhosa and compared these to the transcripts. The other interviewer, for whom Afrikaans was her second language, listened to the interviews that had been conducted in Afrikaans and compared these to the transcripts.

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Interviews conducted in Klipheuwel were conducted in Afrikaans which was neither of the interviewers' first language. This may have implications for the data collected as interviewers may has misinterpreted answers, not picked up on areas to pursue or not phrased questions in a way that would facilitate information to be obtained. We decided to use only the two interviewers (as opposed to working with a third interviewer who was a native speaker of Afrikaans) in order to provide some consistency across all the interviews and because both interviewers were experienced in the field of interviewing and in working with families with members with mental disability. They were also knowledgeable of the objectives of the research.

Limited data were collected and therefore all hypotheses and statements are tentative and by no means generalisable.

It is through the lens of these limitations and potential limitations, that the following discussion should be read.

Various themes were identified regarding the areas of municipal and mental health service delivery which I will now discuss in more detail with reference to the literature.

MUNICIPAL SERVICES

As the study formed part of the Municipal Services Project, a major focus was on municipal service delivery. As mentioned in the review of the literature there is a scarce literature on the impact of issues associated with service delivery and the consequences for mental health. However, factors that could be relevant were drawn from the poverty and urbanisation literature to inform investigation.

The first theme which emerges from this study is the economic stress experienced by many households related to municipal services. As a policy of cost recovery has been adopted by government, households have to pay full price for services once they use more than their free basic amount. Preliminary evidence suggests that the free basic services was insufficient for basic needs of the household, though further investigation would be required to substantiate this claim.

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There is evidence that economic stress plays a role in common mental disorders (Patel et al., 1997). There is also evidence that economic stress has implications for caretaking patterns within the family (Richter, 1994). This is therefore an important area to examine further. In two cases the household head was a single mother caring for a member with a mental disorder and working for a low wage. Issues related to services were not the only source of the burden experienced by these women. Nevertheless, the stress and anxiety related to payment and worrying about consequences of non payment, together with the burden of having to make arrangements for alterative sources of electricity and water when unable to afford these services, appeared to be placing them under a great deal of strain. Having to walk long distances in search of alternate sources could also place them at risk for being attacked. This strain and burden on women is a theme that is common in the literature - women in poor conditions fulfil multiple, burdensome, roles (WHO, 2001). In all 10 case studies, the caregivers were women, again, a not unexpected finding in the light of the literature on care work (Higson-Smith, Richter & Altman, 2004), and the burden they carried could have implications for their own mental health.

It would be interesting to know more about competing demands on caregiver time and energy. For example, the time taken to seek alternate means of energy and water or having to borrow money from neighbours or walk long distances to borrow money from family may act as a barrier to providing direct care and support to the family member with mental disorder. As will be seen below, activities related to health service provision are also important to consider in terms of caregivers' use of time.

Related to this theme of economic stress was the role stress associated with service delivery may play in a patient's relapse when the patient is the household head. In both cases where the person with mental disorder was the household head, issues related to services appeared to be causing them a great deal of stress. This has implications for their mental health, as stress has been indicated to play a role in relapse in schizophrenia (Bergen, Hunt, Armitage, & Bashir, 1998). Stress on whole households may decrease possibility for support and care for the family member with mental disorder. This also may have implications for spouse's burden. In both cases in our study where the person with mental disorder was household head, the wife would attempt to shield the husband from this stress and deal with the bills and make the necessary arrangements herself. This also has implications for the children - in one case the husband was so worried about paying for services that he reported becoming very angry when they would use water or electricity.

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On a practical level, attempting to keep water and electricity usage down to free basic levels had implications in a number of areas. All of these areas may have consequences for quality of life for the member with the mental disorder as well as the household as a whole. Many of these consequences of cost recovery mechanisms of service delivery have been described in the literature.

Challenges included:

- Inability to afford sufficient water, served as a barrier for household's ability to grow their own vegetables. This has important implications when in many cases they were struggling to buy food.
- In some cases this inability to afford water lead to a decrease in hygiene behaviour with regards to washing and bathing. This has implications as well for dignity and quality of life of household members. This may also impact on ability to secure employment. Decreased hygiene behaviour also creates the ideal environment for the spread of infectious disease.
- This water limitation also had implications for comfort. Family members with mental disorders in some cases were not able to quench their thirst (a side effect from their medication). Water was also necessary in order to take their pills.
- Households' struggles to pay for water also appeared to have consequences for neighbourhood relationships as households would not want to share water with neighbours which in some cases lead to conflict. Thus this could be seen as a barrier for social support as most of the households had migrated from the Ciskei and many had no form of support structure. This has implications, as a mediating factor between poverty and mental ill health may be social cohesion and support (Patel et al., in press). Inadequate social support has been implicated as a factor associated with relapse in schizophrenic patients (Bergen et al., 2001).
- Inability to afford sufficient electricity also acted as a barrier to comfort and quality of life in that households were unable to warm their houses during winter. In many cases this would have been vital as in many cases houses were observed to be poorly insulated and constructed and therefore very cold in winter. This could also lead to illness which would further serve as a barrier to activities. Illness in caregiver or other family members would also have implications for the family's ability to care for the person with mental disorder.

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- Inability to afford sufficient electricity also leads to households' seeking alternate sources of energy. This has safety implications as the dangers of open wood fires in the house are well known and paraffin usage has also been implicated in fires. Wood fires also have implications for health as may cause air pollution and respiratory infections (von Schirnding & Yach, 1991).
- Attempting to keep electricity down to a minimum also has implications for entertainment. Most of the households were observed to own a television and radio but would be cautious to use them as they use a lot of electricity. One family member reported being bored at home and therefore spending time with peers who encouraged him to smoke dagga. This also has important implications as comorbid substance abuse has been indicated to play an important role in relapse of schizophrenia (Bergen et al., 1998). This may also render household members open to be victims of violence as many poor households live in areas were violence is an everyday occurrence.
- Households reported that having to pay for water and electricity in some cases left them unable to afford extras such as money for taxis. They would therefore have to walk long distances to shops and the clinic etc.

Although the households in the case studies had access to services in their homes, their access was dependent on their ability to afford services. The impact of factors related to services appeared to have a greater impact on poorer households as opposed to better of ones.

The stressors associated with municipal services appear to impact on the household and influence the experience of mental disorder on two levels.

Impact on caregiving environment

The factors associated with service delivery discussed above may increase levels of stress and burden for the caregiver. This indirectly impacts on the family member with mental disorder, as the caregiver's ability to care for the member (and the family) may be compromised. This stress and burden may also have implications for caregivers in terms of their own mental health which also has implications for their ability to care for the member with mental disorder.

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Direct impact on the person with mental disorder

There are also direct effects on the member with mental disorder, resulting from the restriction of services, e.g. inability to quench thirst and feeling cold during winter. When the member with the mental disorder is the household head, factors associated with services also lead to increase the stress on this person which has been associated with rates of relapse.

These preliminary data provide some evidence for the view that factors associated with conditions of poverty may play a role not only in the causation of common mental disorders but also in relapse in severe mental disorders.

MENTAL HEALTH SERVICES

One hypothesis described in the literature as a possible role of poverty in the experience of mental disorder was inadequate access to health care (Saraceno & Barbui, 1997), which has implications for recovery and course of disorder.

As described in the review of the literature, the new mental health policy in South Africa emphasises a shift towards community-based care for chronic mental disorder. Problems associated with implementation of policies mentioned in the literature review include: shortages of mental health personnel (Freeman, 2000; Lund & Flisher, 2002), limited resources and budget cuts, ineffective management of these resources, lack of a broader mental health care approach due to a scarcity of human resources (partly as a result of a lack of time to provide more than basic medical and nursing care), stigmatization of mental disorders, and competing priorities on an already overburdened health care system (Lazarus, 2005). I shall now consider how these issues affect participants in the current study.

When households were satisfied with clinic services, they described the system as positive in that the member could live at home as part of the family. In these cases clinic staff were described as friendly, efficient and in many cases households were satisfied with the service.

One of themes that emerged was around the organisation and management of one of the clinics. Patients attending this clinic had to travel long distances and wait in long queues in order to collect their medication. This appeared to have the result that some people would leave before

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collecting their medication, or modify their dosage in order to visit the clinic less often. This has serious implications for rates of relapse. Households verified that an important factor in relapse was adherence to medication (Agarwal et al., 1998). One of the motivations for the integration of mental health services into the primary health care system was to afford people with mental disorder more dignity and protection from abuse of their rights. Paradoxically perhaps, integration of services seemed to be linked to having to wake up early, travel long distances and then stand for hours in a queue – all of which are burdensome rather than enhancing of dignity and protection from abuse. The burden was felt by caregivers as well, as they would have to accompany their ill relatives to the clinic. Activities involving instrumental care for the family member with the mental disorder, such as accompanying them to the clinic and waiting in long queues, may also affect both the time available for activities directed towards emotional recovery and the emotional energy caregivers may have to play an optimally supportive role. It would be useful to compare actual activities undertaken by carers in poorer and more wealthy households, in order to address the question of whether time-consuming practicalities such as fetching water, standing in queues, and providing ongoing supervision interfere with the emotional availability which the literature has shown to be necessary for the best outcomes for the person with mental disorder.

Another theme that emerged in relation to having to stand in long queues in order to collect medication was that related to exposure to violence. Households reported having to leave early in the morning and stand in queues in the dark. Some reported being mugged while waiting. As exposure to violence has important implications for mental health (Kilpatrick & Acierno, 2003), this situation is in need of urgent attention. Although violence is directed not only at people with mental disorder, people with disabilities of any form are generally more vulnerable. This has implications as these progressive policies to integrate mental health services into the primary health care system may not be feasible in the context of violence.

In a number of cases, family members appeared ill-informed about mental disorder and strategies to support people with these conditions. They also seemed poorly informed about legal issues such as those surrounding the certification of people who are mentally ill. It is unclear what the source of this misinformation may be. For example, could it be that the health system is not conveying this information? Or is the information being conveyed in such a way that it is not understood or is being misinterpreted? Is the information accurately conveyed but subject to a decay effect over time, so that family members forget what they once knew? Are recent

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legislative and health system delivery changes confusing families? Clearly, further research addressing these and other possibilities in the local context could be helpful. Without conducting a study on what health messages are conveyed by the services to families it is not possible to be sure that such information has not been disseminated.

OTHER FACTORS OF IMPORTANCE

Other factors arising from the interviews and observations that may have implications for fulfilment of potential included the following:

- The role of the disability grant in the household economy had implications for the livelihood of the household by impacting on what they were able to do. In some cases this grant was the only source of income on which the whole household was dependent. Therefore periods of grant suspension during reviews impacted not only on recipients of the grant but also on the whole household. In one case, the grant had been reported to be suspended for a period of six months. During this period the household had no stable income. This impacted of the recipient in terms of stress and members of the community reported that during this period he relapsed. The disability grant may also provide an incentive to stay ill in order to provide an income for the household.
- There are also limited employment opportunities and this has obviously implications for people's ability to secure work.
- There are also large time costs for those who have been able to secure employment as they mostly have to travel long distances on unreliable public transport.
- High levels of violence and crime also have implications for the range of activities people may pursue
- Stigmatisation of the family member with the mental disorder as well as the household may also impact on the range of activities they may be involved in.
- The structure of the house and ability to afford furniture and household goods and appliances also has implications for activities. For example, one household had one light bulb in the lounge and no table which would have implications for the children's ability to complete their homework. Another reported not being able to have visitors as she was unable to afford cups to offer them tea and there wasn't sufficient living space or furniture for them to sit.
- Two households reported wishing to supplement their income by selling sweets but didn't have the income to start this activity.

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- Another important factor mentioned during the interviews was the implications of not being able to afford a telephone for the ability to secure employment. One household reported trying to find a job but prospective employers would not be able to contact her. Her sister, who had a university degree and was therefore able to find a job, bought her a phone and she was able to secure employment almost immediately.

The discussion above indicates that there are a number of factors associated with poverty that may have implications for the experience of mental disorder as well as impact on the ability to engage in activities required for fulfilment of potential.

IMPACT OF CONTEXTUAL FACTORS ON THE EXPERIENCE OF MENTAL DISORDER

The themes identified above raise some serious concerns. Although limited data were collected and the findings are not generalisable, this study has bought to attention some areas that are in need of further investigation. These may have considerable implications for the course and experience of mental disorder in the South African context.

From the data, a range of factors that are part of the daily lived experience for many people living in conditions of urban poverty have been identified, that appear to have implications for the experience of mental disorder.

Factors associated with basic service delivery (municipal and health) may have implications not only for the quality of life of the people with the mental disorders but also for their households – the primary environment from which they receive care. We now have a preliminary indication that these factors, which have not been previously considered, may impact on the course and experience of mental disorder a number of ways that have been described in the data analysis and discussion.

We can present a tentative narrative of experience and a description of a cycle through which factors discussed above may impact on this experience. Factors associated with municipal services may lead to increased stress and burden on households as they either have to make sacrifices in order to afford basic amounts of water and electricity or seek alterative sources if they are not able to afford them. The sacrifices and the costs in terms of time and energy this

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requires have implications for the environment of care. Having to make choices between paying for food or for electricity and water also has important implications. The consequences of non payment also places stress on households and leads to insecurity about the future as they worry that their homes will be repossessed. Thus although the households have physical access to services by means of location, their access is restricted based on their ability to afford it. In many cases households have access to less than the desired amount of basic services and this has implications and consequences for their quality of life. As examined in the discussion above, this also has implications for activities they may wish to pursue.

In terms of mental health services, integration into the primary health care system may present major management and logistical challenges for service delivery (Van Wyk, 2005). These challenges to optimal management and organisation of clinics, and under-resourced and underdeveloped services, may lead to increased burden on households in the form of time costs, waiting in long queues and having to get up early in the morning. Frustration and impatience with waiting in these queues, as well as fears for safety and health may result in people leaving before they have collected their medication or modifying the dosage in order to frequent the clinic less often. This situation may necessitate supervision, and as employment of the caregiver in many cases is casual labour, that would mean losing a day's wage.

This situation described above may have serious implications for adherence to treatment. These considerations are important for clinicians as many of these challenges that have been identified are beyond the realm of the imagination of people who do not live in these conditions. These factors have implications for adherence and are beyond individual control. Even if this experience is rare (and further research will need to establish how common it is), this knowledge may prove very helpful for those involved in treatment and management plans.

Much of the data from the present study suggests the value of an holistic approach to understanding mental disorder contextually. It also appears helpful to locate the issues raised here in a broader public health perspective. Relapse has implications for the burden on the family as well as for an overburdened health care system. During periods of relapse people with mental disorder, as evident from the data, may not have the ability to take sufficient care of themselves, and may become violent and aggressive.

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Apart from the public health context, the other broad context for this work is, of course, the experience of living in poverty. The psychological reactions to poverty that have been described in the literature such as sadness, hopelessness, helplessness and fear of the future have all been highlighted as observed during the interviews, which have important implications for mental health.

The themes raised in this study have implications for the process of policy development. Globalisation appears to have an impact in that policies are developed in a way as to fall in line with international trends.

This study seems to provide some evidence for the dangers of this strategy as policies that are feasible and applicable in one context may not necessarily be to another. To what extent, when global policies are made about service delivery, for example, is there due consideration given to the fact that a proportion of those who will be affected by these policies are at the same time dealing with the burden of mental disorder or other disability (Lorenzo, 2004). In order to answer this question and related questions, we need to develop a documentary evidence base which takes the context into account, informing policy decisions and advising implementation strategies. This study is a small step in the direction of developing the evidence base. Even if the data from the study are seen as unconvincing on the basis of the number of respondents being small, the questions raised by the data clearly point to the importance of taking the time to develop a more nuanced sense of how poor families coping with disorder and disability live.

It is easy on the basis of research such as this to identify problems and to make recommendations. This study did not however explore the complexities of providing adequately for the needs of families living with mental disorder in the context of a wide range of complementary and competing demands in terms of public policy and provisioning. This study cannot comment on the feasibility of changes in provisioning; the data however may well be of use to those who have to take a broader view in terms of service provision and delivery.

Participants in this study clearly showed how narrow concerns about mental health care are embedded in the context of other challenges. A poor public transport system, high levels of violence and crime, high chronic unemployment, and greater risk of physical illness, are challenges to all poor families – including those with particular mental health challenges. The context of HIV/AIDS and the burden it places on families – though not discussed by respondents

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to this study – also needs careful consideration. The question of how, given the embeddedness of the challenges faced by participants in this study in a wide range of broader demands and threats, one envisions support commensurate with the level of need, is not one that can be answered here. But it is clear that this difficult question must be asked.

Similar considerations must be applied to the role of social grants. Does the provision of the grant serve as an incentive for people with mental disorders not to get well? And what are the implications for people with mental disorder and their families when the grant is suspended or reviewed? Data from the interviews revealed the grant may play an important role in the household economy.

As I have mentioned before I am not in a position to generalise from the data we have gathered. However, I do believe that the findings from the study raise serious concerns and indicate an urgent need for further study and action in this field. Research is needed to investigate the feasibility of deinstitutionalisation in the South African context and identify possible barriers to optimal implementation. Research into households' perceived needs and burden is also vital in informing this process. We also cannot make assumptions about the relative weight the factors and themes identified have in the general population. It would therefore be important to conduct a larger scale study to investigate these further. Quantitative research using pathway analysis may be able to assist in developing a model of directionality.

From this study we now have a taste of how, in the Western Cape in South Africa, political, social and economic forces may shape the context in which mental disorder is experienced together with the context in which care is provided. We also have a taste of how these forces may impact on the course and experience of mental disorder. The study therefore highlights the importance of examining contextual factors as well as individual psychological characteristics in the experience of mental disorder.

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CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS

It is known that mental disorders such as poverty play a role in the aetiology of mental disorders (Desjarlais et al., 1995). However there is a paucity of research examining this relationship, particularly in developing countries. The role of services and the impact of policies have also been hypothesised to impact on this experience, as these factors may shape the context for risk for mental disorders as well as the context in which care is provided (Farmer, 2003).

This study aimed to address this gap in the literature by collecting exploratory and in-depth data and generating themes that would inform further study in the field.

The themes generated from the data analysis indicate that factors associated with service delivery, both municipal and mental health, may have implications for the experience of mental disorder in poor urban environments. These implications are both in terms of a direct impact on the member with mental disorder and the household that forms the primary caregiving environment. This has implications for the course and experience of mental disorder. These claims are tentative and further research is needed to substantiate them.

Quantitative research using pathway analysis could be beneficial in developing a model of directionality, as well as in developing a more complete understanding of factors that impact on mental disorder in these contexts. It would also be important for future research to examine the role of the disability grant in the household economy and factors associated with administration. Research focussing on the development of an adequate indigent policy, which I believe is in process, would also be important. And finally, more research is needed on mental health services and households' perceived needs and burden on households in order to develop adequate methods of support.

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