

Women surviving chronic poverty and psychiatric disability

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ABSTRACT

Background: Chronic poverty affects many South Africans and compounded with psychiatric disability, has a significant effect on human occupation. This dynamic interaction was investigated amongst a group of isiXhosa women with enduring mental illness living in adverse socioeconomic conditions in a peri-urban informal human settlement.

Methods: A descriptive qualitative approach using focus group discussions, conducted in Xhosa by an external facilitator, yielded narrative data which was deductively analysed to describe interactions between poverty, disability and occupation.

Findings: Two themes within a central plot emerged: one highlighting the daily grind of meeting basic survival needs and one pointing to the personal and social costs of managing a mental illness in the context of socioeconomic hardship. The plot suggests that while survival is promoted through a range of practical and relational strategies, quality of existence is compromised by the monotony and strain of performing occupations in an under-resourced environment.

Conclusion: Implications of these findings are discussed in relation to what the women were able to accomplish everyday in spite of being affected by a serious mental illness. Providing information for practitioners addressing mental health and community development in the context of poverty, it argues for greater attention amongst occupational therapists to the impact of context on people's occupational performance.

Key words: Chronic poverty, Psychiatric disability, Livelihood strategies

Introduction

Background

As a developing country and young democracy, South Africa continues to experience the aftermath of the political and social upheavals of Apartheid. The eradication of poverty as a legacy of apartheid remains high on the national development agenda¹. In this context, South African occupational therapy has had the opportunity to evaluate its purpose, place, methods and scope of practice². Occupational therapists focussing their efforts in hospitals and rehabilitation settings on the functional consequences of health conditions, may have limited appreciation of the impact of poverty on people as occupational beings in their lived environments³. Chronic poverty, a reality for many South Africans, compounded with psychiatric disability presents unique circumstances affecting human occupation. Occupational therapists need to know more about these circumstances in order to promote contextually relevant practice². The researchers of this undergraduate study investigated a group of women with chronic mental illness living in the context of chronic poverty and looked specifically at their perspectives on the occupations they used to secure a livelihood. A livelihood comprises the assets and activities and the access to these that enable the individual or household to earn a living⁴. The study formed part of a larger study⁵ in which the lead researcher gathered occupation focused data to inform occupational therapy services for disabled people and their households.

Literature Review

Literature on chronic poverty, disability and occupation as the focal areas of investigation are briefly reviewed.

Chronic poverty

The chronically poor are people who experience poverty for the duration of their lives or for considerable periods of time and whose children will most probably continue living in poverty⁶. It includes those who have benefited the least from economic growth and development programmes such as people living in slums, remote rural areas, and contexts characterised by ongoing civil unrest, war, and violence. The chronically poor are also victims of structural poverty – their position in society remains static due to the limited access to resources available to them within existing social power relations⁷.

Disability

Disability is a health and social issue that has been inextricably linked with chronic poverty and can be viewed as both a cause and consequence of poverty^{8,9}. A disproportionate number of disabled people live in chronic poverty making it difficult for them to meet their basic needs and develop their human potential^{8,9}. Turmusani⁸ shows that disabled people are particularly disadvantaged by adverse socioeconomic circumstances that may compromise the quality of their existence. Yeo⁹ suggests that because disabled people are marginalised they are “the least likely to be represented by any research”. In particular, the relationship that exists between mental health and poverty is under researched¹⁰. In a paper discussing chronic poverty in the urban areas of developing countries, Mitlin¹⁰ points out that the subject of *mental health* is greatly overlooked. Although it is not responsible for as many deaths as infectious diseases, mental illness causes greater disability as it starts early in life and lasts longer¹¹. Persons with



psychiatric disability are likely to face multiple challenges such as "poverty, social stigma, a lack of affordable housing and limited employment opportunities"^{12,26}.

Occupation

How people living in poverty who have a mental illness go about managing their various occupations, is under researched in occupational therapy. Occupation, including work, provides people with mental illness with a means through which to pursue personal development, an antidote to health problems and a source for social gain and financial independence¹³. However, individuals with a mental illness may be less productive or find work less enjoyable than people who are psychologically well¹⁴. They may feel unable to participate in valued occupations including employment due to the functional implications of their mental health condition¹⁵ or due to restricted choice of occupations and work opportunities^{16,17}. Unemployment, a contributing factor to poverty, affects quality of life because it leads to the loss of a valued role that adds structure, purpose and economic benefits to daily tasks and activities¹⁸. Some resistance to employment may also arise from the fear of losing government welfare assistance or not making enough money to survive¹⁶.

Survival however becomes the driving force behind occupations in the presence of chronic poverty. Fourie, Galvaan & Beeton³ cite Fourie's single subject case study that explored the relationship between poverty and occupation in the life of a woman with numerous health concerns including major depression. The subject spent much of her time and energy on occupations that would generate some form of income either in cash or kind. Poverty imposed constraints on her physical environment, limited the development of skills and interests and had negative occupational and health effects³.

Occupation and health

Occupational therapists believe that occupation has the power to influence health and well-being and can be used therapeutically to restore function¹⁹. While research shows a positive relationship between activity engagement and quality of life^{20,21,22}, it has also been found that health professionals do not know much about the daily occupations of people with a mental illness²³ making it difficult for them to discern appropriate points of action. Most occupational therapy research occurs in developed countries and its relevance to the adverse socioeconomic contexts in which many South Africans continue to live cannot be presumed. Little is known about the impact of grinding poverty on activity engagement and life satisfaction when daily occupations are survival orientated.

Methods

Study design

The aim of the study was to describe the perspectives of women about what they do to survive chronic poverty and psychiatric disability.

To narrow the study down it focussed on women because research has shown that women (and children) are particularly vulnerable to loss of welfare due to their gender and social positioning⁶. The geographical location was a peri-urban informal human settlement inhabited by primarily Xhosa-speaking people who moved to the area during the apartheid era. It is characterised by shack dwellings and underdeveloped public services. Both the study location and population (chronically poor)⁷ were predetermined by the lead study as were the inclusion criteria for the research sample⁵.

Study participants

The selection of the study population was based on income (not exceeding the disability grant which at the time of the study was R740 per month); duration of poverty (set at three or more years surviving on the grant amount or less per household); capability (self reported extent of economic and social participation) and vulnerability (determined by health and social records). People

are considered vulnerable when their well being is insecure due to a changing environment, which in the case of chronic poverty, involves the constant risk and stress of welfare loss associated with a precarious livelihood⁴.

Six women were purposefully selected through snowballing within a community based organisation offering services such as support groups, psycho-education and social activities for mental health consumers. Aged between 29 and 53, three of the women had the diagnosis of schizophrenia, another two of schizophreniform disorder and one of schizoaffective disorder. Each of the women had a longstanding history of mental illness (more than five years); a record of admissions to psychiatric hospitals and none had been able to secure employment since becoming ill.

Study approach

A descriptive qualitative approach using semi-structured focus group discussions was used²⁴. This allowed the researchers to explore the participants' perspectives on and experience of everyday life focussing on the details of their livelihood strategies from an occupational perspective. A Xhosa speaking male occupational therapy student facilitated the groups using a set of focus group questions authored by the researchers: How do you meet your needs? Why do you choose to do this? If you don't meet your needs what do you do to get around this?

Procedure

The study was granted ethics approval in January 2006 (REC REF: 033/2006). Adherence to the principles of informed consent, confidentiality, autonomy, non-maleficence and veracity ensured an ethical stance²⁵. Community entry was obtained through a district occupational therapist of the Provincial Government of the Western Cape. The names of the participants have been changed to ensure confidentiality.

Methods

Two focus groups²⁵ meeting for approximately two and half hours each yielded approximately five hours of qualitative data. The groups were held at an accessible community centre. Three student researchers and a Xhosa speaking facilitator-interviewer with basic competence in in-depth interviewing²⁶ were present. The discussions were recorded on audiotape with the participants' consent. Data obtained from the first focus group was deductively analysed and emerging themes were then used in the second focus group to confirm and gather more information. The iterative engagement between analysis and feedback from respondents served as member checking thereby promoting the trustworthiness of the findings.

Data management and analysis

The focus group facilitator transcribed and translated the focus group discussions into English. Using back translation, an external Xhosa speaking person reviewed the English transcriptions and found that the participants' meaning was conveyed accurately. The four phases of data analysis described by Marshall and Rossman²⁵ were used to understand the content of transcripts. First, the data were coded, sub-categorised and categorised after which themes were generated. Secondly, emergent themes were confirmed by ensuring that categories were saturated. Negative instances of the patterns observed were checked with respondents. Thirdly, a comprehensive audit trail was kept, and lastly alternative explanations for the linkages among the data were explored and described in relation to the whole data set²⁵.

Findings

Table 1 on page 6 shows the central plot of this study as **JUST Existing... Just EXISTING**. In essence, the women's perspectives were that they were barely managing to eke out an existence, hardly making basic subsistence possible through the things they did to survive everyday. Preoccupied with strategies aimed at meeting basic needs, the women perceived themselves as just existing; the drudgery of everyday life a monotonous cycle of hardship and hard work. Being mentally ill was seen as part of life; just another bur-



Table 1: Table of Results

Plot	Themes	Categories	Sub-categories
JUST Existing... Just EXISTING	If we don't eat we can't survive	Illness as means	Meeting basic needs with the grant
			The grant is insufficient
		Weighing down the household	Dependency
			Burden
	Work does not work	Desire to work	Internal barriers
			External barriers
	Giving and taking	Borrowing	Lending and Saving
	Finding myself in this disability	Being the illness	Support
			Stigma
Ill woman must still do		External expectations	
		Internal expectations	
Keeping the illness at bay		Understanding the cause	
		Choosing to do	

den to manage in the process of making ends meet. The plot was supported by two main themes pertaining to survival and coping with a mental illness in the context of pervasive economic hardship.

Theme 1: If we can't eat, we can't survive

In the first theme, the women's sense of urgency to provide for their families and meet basic subsistence needs were portrayed. The sub-category **Illness as means** explained how the four participants gained regular access to money in the form of a disability grant (DG). Being chronically mentally ill and disabled were considered assets as the condition secured the means for survival. The DG was the main or only source of income and was used for **meeting basic needs with the grant**. Through the DG, the women fulfilled their main roles as mothers and providers, bringing a certain amount of satisfaction to daily existence. "I use my grant money to get my children things for school and I buy them clothes, so I don't mind that much if it finishes because I have done those things that I need to do with it." [Maria]. Although grateful for the financial relief provided by the DG for consumption needs, it was felt that **the grant is insufficient**. The experience of those women not receiving a DG, was that they were **weighing down the family**. In this situation they used the strategy of **dependency** because they had to rely on the income of other household members. "My need is that I stay with my sister, I don't have a house and I am unemployed, I am just dependent on my sister." [Lerato]. **Being a burden** in the home reportedly affected the women's sense of self-worth as they were concerned about not contributing financially to the household. Their wishes were to ease the burden of care on their family (be less dependent) as opposed to a desire to do better for themselves. "There is nothing else that I do besides the daughter that I said is working. I am just a 'parcel' in the home." [Thelma]. The feeling of being a burden on the family also extended to those receiving a DG as they felt that their contributions were insufficient.

The category **Work does not work** captured the sense of emptiness associated with seeking and desiring paid work that never materialised. The women had a **desire for work** but faced numerous **barriers** to making this a reality. Work was considered desirable because their income strategies (dependency or receiving a DG) did not involve active doing and yielded insufficient resources to meet consumption needs. The women desired income generating jobs that involved familiar home maintenance occupations: cooking, cleaning or care work. None of the women had taken any practical steps to find work for many years; having given up trying to find work matched to their skills and interests or being unable to retain work due to illness related functional limitations. Work did not work for them because of various **internal barriers** (disrupted schooling and low literacy) **and external barriers** (general lack of

employment opportunities). "I started being ill at an early age and couldn't learn most things properly ... and ended up not getting a chance to learn. I wanted to become a nurse," [Maria].

Although the community in which the study took place is generally poor⁵, a sense of responsibility for the welfare of others motivated a range of survival strategies embedded in existing social networks. **Borrowing, lending and saving** money, goods or kind were strategies used to disperse and stretch the DG. Existence was immersed in **Giving and taking** within a relational matrix that took strain from time to time accentuating the feeling of being a burden. "I have to bother my mother for money and I am certain she is getting tired of it." [Eunice]

Theme 2: Finding myself in this disability

Ironically for the participants, illness was their biggest asset to ensure survival as it enabled access to a regular monthly income (DG). Often the main or only person in the household with a steady income, the women held some status as provider.

Mental illness was paradoxically accompanied by social stigma and compassion; both combining to intensify and alleviate the struggle to survive. The women did not see themselves as different. **Being the illness** meant that they were who they were. "I didn't understand why my sisters would go to work but they told [me] I am getting a grant because I am ill but I couldn't understand why because I am the same as other people." [Maria]. Despite being perceived by others as different, the women acknowledged the role of the community in their survival offering **support** in times of trouble. "They help a lot in the community, if I get ill they will arrange for me to be taken to hospital." [Lucy]. **Stigma** affected the women in their relationships and inclusion in family life. What they considered to be 'normal' behaviour was often misinterpreted to be a result of the illness. Although they felt able to contribute to the household, their efforts were often undermined. This was a cause for frustration and despair.

Ill woman must still do embodied the **external expectations** from others that the women *needed* to perform their duties around the home – regardless of their mental state. On the other hand, the women internalised this sense of duty (**Internal expectations**) as was seen through their need to maintain the home. Neither the families, nor the participants viewed the women's illness as disabling their capacity to contribute to the running of the home. "We are supposed to do these things in the home, and with me I am not supposed to sit and do nothing." [Lucy]

Keeping the illness at bay described how the women's unique understanding of their illness informed their activity choices. Many of the activities that the women were **choosing to do** were connected with spirituality. Attending a psychosocial group at the clinic provided emotional support and a feeling of universality amongst people facing similar hardships. Taking medication also helped to manage the illness. Conversely, the women were **choosing not to do** activities in which they felt they would be unable to perform as a result of the side effects of medication or the illness symptoms. There was a tendency to avoid activities requiring social interactions for fear of stigmatisation. "I also listen to the radio, but I don't like being amongst people due to my history." [Maria]

In summary, the consequence of using all of their available resources and assets to meet basic needs affirmed the plot: daily existence in the context of poverty and disability was hard impacting on what the women chose and were able to do.

Discussion

Ellis⁴ definition of livelihood includes the assets, activities and access to these that "together determine the living gained by the individual or household". All the livelihood strategies used by the women such as the disability grant (DG), depending on others, borrowing,



lending and saving were mediated by social relations within institutions such as church groups, savings clubs or public sector services. The performance domain of their occupations was primarily social. Moreover, their mental illness was used as a form of income; a means to access financial and social assets. Fundamentally, these strategies involved or required engagement in tasks, activities and roles that were socially rather than personally mediated.

One might be inclined to propose that these livelihood strategies are devoid of occupation if one understands occupation as active doing of a purposeful (and ideally meaningful) cluster of activities and tasks towards a particular outcome in the stream of time. In the context of poverty, it may be assumed that people DO something to make money or to ensure that daily subsistence needs are met. The role of 'provider' or 'worker' is traditionally linked with roles, activities and tasks which make up occupation²⁷. However, if one understands occupation as encompassing more than doing but, as Wilcock proposes, "a synthesis of doing, being and becoming"²⁸ then the women's livelihood strategies were not devoid of occupation. Their livelihood strategies also relied on internal social capacities such as agency, reading social cues, understanding cultural parameters and the desire to stay connected in order to survive. In essence, the survival of these women was closely linked to the quality of their 'being': their personal human assets were a pre-cursor for the kind of social capital they could rely on.

The women's **role** of provider centered largely on their financial contribution to the household through the DG, a livelihood strategy devoid of active doing by the recipient. The DG was in essence the means for poverty alleviation rather than the means through which the recipient's personal needs emanating from the health condition could be addressed. It could be argued that in situations of chronic poverty there is a greater environmental press on the person with a mental illness to identify with being 'mentally ill' because this may give the person the hope of accessing financial assets not otherwise available. However the DG recipient is deprived of the opportunity to 'become' who they hope to be through active choice in exercising their interests, skills and agency. These conditions for well being through occupation are sorely lacking in the context of poverty³.

The significance of having income generation strategies, which rely heavily on the person's 'being' and very little on active doing, should be of great concern to occupational therapists. According to Yerxa cited in Duncan "engagement in occupation is an essential mediator of health adaptation...an essential ingredient of mental health and well-being"²⁹. 'Doing' allows one to "exercise, maintain and develop physical and mental capacities on which health is dependent"²⁸. Not doing actively, not having the opportunity to do or having to rely on socially mediated tasks and activities (borrowing, lending, DG) may therefore impact negatively on a person's health, well-being and inclusion in society³⁰. The findings of the study suggest that the dynamic between occupation and chronic poverty is focused primarily on the use of social capital when the additional shock of psychiatric disability occurs. What this means is that the disabling factors in people's environments warrant as much attention in occupational therapy actions as do the functional needs of the person.

Max-Neef³¹ considers each instance when a human need is not met as a human poverty. The findings of this study showed how mental illness impacted greatly on the women's abilities to meet needs beyond subsistence needs (e.g. need for understanding and social participation). Thus, mental illness may be understood as adding another dimension to their poverty - a kind of human poverty that is not shared nor understood by other family/community members. Van Niekerk³² draws attention to the fact that people with psychiatric disabilities have to deal with the barriers resulting from the illness symptoms as well as those imposed by society. Social stigma is one such barrier¹¹. The women experienced their character as being judged only by their illness symptoms (e.g. being known as "mad") and so they became their illness in the eyes of others. The findings of this study suggest, however, that the self-perception of the women is one of having the capacity to

make a meaningful contribution despite their symptoms. This is supported by Lorenzo³³ who found that disabled women in South Africa were resistant to accepting the stigma and stereotypes linked with their disability, choosing instead to embrace their right to carve a meaningful life through activism against prevailing social circumstances

Patterns of engagement, such as choosing to do and not to do may be related to the women's own understanding of the cause of their illness. They have an inherent understanding that by choosing certain occupations and avoiding others they can manage stress and influence their health. This is consistent with Minato and Zemke's¹⁸ finding that people with schizophrenia deal with stress in everyday life by using self management strategies including occupational choice. This study showed that occupations chosen by the women allowed adaptation to the stress associated with chronic poverty and psychiatric disability, which increased productivity in the home - ultimately aiding survival.

Summary

The women perceived their existence as dominated by their socioeconomic position rather than their psychiatric disability. They actively strategised to ensure survival. However, in all their strategising it was mainly basic needs that were being met. In some cases the strategies used were devoid of active doing, which potentially has serious consequences for health and well-being. Because the women's livelihood strategies only just met their basic needs, they perceived themselves as **JUST existing** i.e. barely managing to survive. While some of the women experienced support from the family and prided themselves on being providers of a regular income through the disability grant, others experienced stigmatisation and isolation creating a feeling of **just EXISTING** i.e. a monotonous, marginal life.

Limitations of the study

Differences between the researchers and the research participants placed a limitation on the researchers' ability to analyse the data with an understanding of the Xhosa language and culture. Also, having a male facilitating a group of women created a dynamic within the group that could have affected the type and quality of information shared. Lastly, due to the limited time in which to complete the undergraduate study the member checking was based on incomplete analysis of the data and insufficient exposure to context to adequately appreciate the barriers and opportunities presented by poverty and disability.

Recommendations for future practice

The fact that the strategies that are used by the women are devoid of active doing is important for occupational therapists. Occupation (both doing and being) is essential to health and well-being that promotes optimal becoming²⁸. By advocating and being involved in the design and implementation of strategies aligned with a developmental social welfare framework, occupational therapists may promote the occupational engagement of the people they serve. From a macro perspective, occupational therapists could use their skills in the management of community development projects, as opposed to individual therapy.

Persons with psychiatric illness are generally not recognised as capable of contributing to the economy and may be seen as unproductive. There needs to be more emphasis on what people with psychiatric illness can do and what they are capable of contributing to the economy. Occupational therapists need to continue to view people in terms of their capabilities and not their disabilities, advocating for the inclusion of people with psychiatric illness in the workforce through supported employment and other inclusive income generating interventions. A broader focus of occupational therapy would include attending to occupational imbalance, deprivation and alienation¹³ as features of adverse socio economic circumstances that create particular forms of vulnerability. By shifting from a biomedical view to a more holistic one, occupational therapists acknowledge the importance of contextual factors that impact on health and well-being.



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