

# The burden of psychiatric disability on chronically poor households: Part I (costs)

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## ABSTRACT

*Studies in occupational therapy on the costs associated with the intersections between chronic poverty and psychiatric disability are rare. This study, published in two parts, identified costs related directly to the illness behaviour of the mentally ill household member which eroded precarious assets including property, disposable income and savings. Psychiatric disability, a feature of social exclusion, added to the indirect cost burden that households with a mentally ill member had to absorb due, in part, to the stigma and cultural sanctions associated with illness behaviours. The multiple layers of action, reaction and interaction by everyone in the household in managing the daily struggle for survival in the presence of mental illness, suggests that disability is multiplied in the context of chronic poverty. Socially engaged occupational therapy, cognisant of the direct and indirect costs of psychiatric disability, could work towards enhancing individual and household resilience through occupation focussed interventions that are aligned with the basic tenets of community based rehabilitation and disability inclusive development.*

**Key words:** poverty, mental illness, psychiatric disability, cost burden, resilience

## Introduction

This article, presented in two parts, describes the costs people incur due to psychiatric disability (Part I) and the strategies they use to cope with the health compromising circumstances associated with chronic poverty (Part 2). It reports on a sub-study done as part of a longitudinal, mixed method research project which commenced in 2004 that is investigating the relationship between chronic poverty, disability and occupation (PDO) in households living in peri-urban informal settlements in the Cape Metropole and in remote rural villages in the Eastern Cape, South Africa. The PDO project is based on the assumption that occupation is a function and outcome of the opportunities and choices available to people who are marginalised by deprived socioeconomic cir-

cumstances. Occupation refers to "engagement or participation in a recognisable life endeavor"<sup>1,2,78</sup>. The aim of the PDO study is to describe how chronically poor households and in particular their disabled member(s), meet their needs and achieve their aspirations through recognisable life endeavours ie. the ordinary things they do every day. Two research questions frame the PDO study: what does the occupational asset base of the index (disabled) person and his/her household comprise and in what ways are occupations orchestrated and why? The purpose of the PDO project is to inform occupation based occupational therapy practice in primary health care and community based rehabilitation. This article contributes to this purpose by reporting on one of the PDO study objectives which was to describe how the occupational performance of the index disabled person impacted on the household's poverty status.

## Rationale

The reform and subsequent rationalisation of tertiary and secondary level public mental health services in South Africa over the recent past has focussed on the deinstitutionalisation of people with mental illness<sup>2,3</sup>. Discharged into marginalised communities, chronically poor and mentally ill people rely on their social networks and under-resourced primary level public mental health services for care<sup>4</sup>. Families, non-governmental organisations, community service organisations and prisons are absorbing the cost burden associated with the needs of people requiring public mental health care<sup>5,6</sup>. The cost burden of illness refers to “expenditure in seeking treatment (direct costs), production and income losses (indirect costs), related coping strategies, and their consequences for the household livelihood in terms of indicators such as the number of workers and working days, asset portfolios, income and food consumption levels”<sup>7,277</sup>. The cost burden of illness for poor households may be cumulative across a number of health conditions besides mental illness present amongst household members such as the triple burden of chronic diseases of lifestyle, tuberculosis and HIV/AIDS<sup>8,9</sup>.

Mental illness is under-represented in health economic research and in recent disability literature<sup>10</sup>. Deeper understanding of the mechanisms of asset depletion in chronically poor households associated with psychiatric disability is indicated in the fight against poverty<sup>11</sup>. Very little has been written in occupational therapy literature about the contexts within which chronically poor, disabled people live and even less about the dynamics of the occupations used by poor households to ensure survival while coping with the cost burden of mental illness. Information about the costs resulting both directly and indirectly from mental health impairment(s) and the consequences for poor households will contribute to the evidence base for effective care packages and poverty reduction strategies<sup>11</sup>.

## Costs and social exclusion

The costs of mental illness arise from and contribute to complex social processes such as marginalisation and deprivation. Findings from the Grand Challenges in Global Mental Health initiative suggest that “the suffering caused by mental, neurological and substance-use disorders extends beyond the patient to family members and communities. Thus health-system-wide changes are crucial, together with attention to social exclusion and discrimination”<sup>11,28</sup>. Although mental illness is not responsible for as many deaths as infectious diseases, its global toll perpetuates poverty and disability because it often starts early in life leading to lost social participation and human potential and may last a lifetime leading to reduced quality of life<sup>12</sup>. While most people living in poverty do not develop mental illness they are at greater risk given their social marginalisation and the multiple deprivations that characterise their lives<sup>12</sup>. Marginalised people refer to those populations who are bypassed by most economic, political and social activity and are likely to have precarious livelihoods which make it difficult for them to absorb the costs associated with poor health<sup>13</sup>. Deprivation is associated with “a lack of welfare, often understood in terms of material goods and resources, but equally applicable to psychological factors, relative to the local community or the wider society to which an individual, family or group belongs”<sup>14,69</sup>. Marginalisation and deprivation combine to create particular socioeconomic circumstances in low and middle income countries which precipitate and perpetuate the vicious cycle of poverty and disability<sup>11-15</sup>.

## Chronic poverty and psychiatric disability

The majority of the world’s estimated 450 million people who suffer from neuropsychiatric disorders live in developing countries and fewer than 10% of these people have access to treatment<sup>16</sup>. In 1990 five of the ten leading causes of disability worldwide were psychiatric conditions (unipolar depression, alcohol abuse, bipolar affective disorder, schizophrenia, obsessive compulsive disorder) with projections indicating that psychiatric and neurological disorders could increase their share of the total global burden of disease to 15% by 2020<sup>17</sup>. A report by the World Health Organisation on macroeconomics and health states that “talking about mental illness means talking about poverty: the two are linked in a vicious circle”<sup>18,25</sup>. While there is extensive research on poverty and mental

illness in African countries including South Africa<sup>3,19</sup> studies on the intersections between chronic poverty and psychiatric disability are rare. Disability occurs when “an individual with impairment is deprived of practical opportunities and results from the interaction between resources available to the person, personal characteristics (type of impairment, age, gender etc) and the environment (physical, social, cultural, political, economic etc.)”<sup>4,8</sup>. The defining characteristics of chronic poverty are duration, multidimensionality and severity<sup>20</sup>. People are considered chronically poor if they have been unable to emerge from poverty in their lifetime; experience several enduring forms of disadvantage and deprivation and there is likelihood that their poverty is being transferred across generations<sup>20</sup>. The adverse interactions between disability and chronic poverty are compounded in contexts characterised by high levels of social inequality. According to the Chronic Poverty Research Centre “economic growth in countries with high initial levels of inequality will be relatively ineffective at assisting the chronic poor”<sup>20,37</sup>. Inequality in South Africa, in particular the extent of chronic poverty amongst Black citizens and their spatial segregation in informal human settlements on the outskirts of towns and cities, can be traced to the legacies of structural violence associated with colonisation and apartheid<sup>21,22</sup>. Addressing unemployment rates and development policy in South Africa, Aliber states that “the incidence of joblessness and poverty are so extremely high, being disabled is in a sense superfluous, though it may make one’s poverty worse”<sup>23,34</sup>. Deeper understanding of the costs associated with mental illness and psychiatric disability will shed light on the ways in which poverty may be impacted in affected households living in marginalised communities.

## Study Context

A résumé of the PDO study, conducted in three phases, will frame the research context. Phase I involved the application of selected criteria of marginalisation and deprivation to census data<sup>24</sup> in order to identify geographical locations where the designated research population of chronically poor households were most prevalent. Two peri-urban suburbs in the Cape Town Metropole were identified: Site B in Khayelitsha and Brown’s Farm in Phillipi. Spread out over approximately 30 square kilometres, Khayelitsha and neighbouring Phillipi was home to just under 400,000 people when the PDO study commenced in 2004. The average size of a household in Khayelitsha in 2002 was 5.6 persons, 47% of the households had an income below R19,200 per annum and the majority lived in informal dwellings (shacks constructed from corrugated iron, wood and plastic bags) serviced by communal taps and toilets. A quarter of the population had no income. Unemployment rose as high as 43% with no apparent differences between formal and informal housing areas<sup>25, 26</sup>. The people living in Khayelitsha are predominantly isiXhosa-speaking. Xhosa-speakers are divided into the Mfengu, Thembu, Mpondo, Mpondonise, Bhaca and Bomvana clans which are identified by territory, history, dialect, cultural practices and patrilineage<sup>27</sup>. A hierarchical system of kin networks and chiefdoms hold authority while ancestors guide cultural practices and customs<sup>27</sup>. Households are stretched across different geographical locations as members migrate between their rural clan homes in the Eastern Cape and their urban dwellings in search of work, healthcare and socioeconomic opportunities<sup>28</sup>.

## Study methods

### Sampling

Based on snowball sampling with the assistance of community health workers from two Disabled Peoples’ Organisations in the identified research areas and using semi-structured interviews and focus groups, demographic data was gathered from 32 households who met the following inclusion criteria: a household size of at least three people, one of whom was an adult disabled person and the other a key informant sufficiently familiar with the disabled person and the household to give supplementary information; income of not more than R740 per month (amount of the disability grant at the time of the PDO study) for every adult or adult equivalent



(two children under 15 years)<sup>29</sup>. A household was defined as a social group which resides in the same place, shares the same meals and makes joint or coordinated decisions over resource allocation and income pooling<sup>30</sup>. The aggregations of individuals in a household were assumed to be relationally linked (although not necessarily) through “consanguine and affineal ties and to share a common interest in ensuring their mutual future security around a set of resources”<sup>31:8</sup>. Households that attained a score of 12 or more on a self-developed vulnerability scale were included in the sample (see Table 1). Vulnerability was defined as the susceptibility of the disabled individual and their household to sudden shocks or longer term stresses imposed by changing health, economic, environmental, social or political circumstances<sup>32</sup>.

Table 1: Vulnerability Scale<sup>29</sup>

VULNERABILITY	1 (low)	2 (moderate)	3 (high)	4 (severe)
Household size				
Income/Assets				
Duration of poverty				
Capability				

**Key:**

**Household size:** number of interdependent people living under same roof relative to size and type of dwelling.

**Income/assets:** amount of disability grant per month per adult (or adult equivalent) or less; reported assets (eg. livestock, equipment, land, remittances).

**Duration of poverty:** at least five years (constant or erratic based on reported risks, hazards and windfalls).

**Capability:** access to opportunities and choices to do, be and become (eg. access to/uptake of work opportunities, health and social services; extent of reported social inclusion and participation).

Phase 2 of the PDO study, the basis of this article, commenced in 2006 and involved prolonged engagement over a three year period with five households who were purposively selected from amongst the larger PDO study sample identified during Phase 1<sup>33</sup>. Variation sampling was indicated in terms of age, gender, history of the index person's health condition, socio-economic status and household composition. Phase 3, which commenced in 2007, replicated the peri-urban PDO study in seventeen villages in the rural Eastern Cape (Alfred Nzo district) with the aim of contrasting and comparing the impact of structural and temporal environments on PDO dynamics<sup>34</sup>. Table 2 summarises the profile of the research participants and their households in the Phase 2 peri-urban sample on which this article is based. Pseudonyms are used to protect the confidentiality and anonymity of the persons concerned.

## Methodology

Instrumental and collective case study methodology enabled learning about specific events (occupation) and persons (disabled informant and/or key household member) within a bounded system (household) to occur<sup>35</sup>. A case is an integrated system, a ‘functioning specific’ that is purposive, has working parts, identifiable features and patterned behaviour that can easily be recognised as belonging to a bounded whole<sup>35</sup>. Russell suggests that “just as clinical sciences can use cases to understand disease causation, so social science can use cases to understand and build theory about poverty causation... it is one thing to identify vulnerable groups and their characteristics and another to understand the mechanisms that have made them vulnerable and how these operate within households....”<sup>36:277</sup>. Viewed as an instrumental case study of the PDO dynamics, data from each of the five households were first analysed separately and then jointly. An instrumental case study is a “particular case that is examined to provide insight into an issue or refinement of theory”<sup>35:237</sup>. A collective case study is not the study of the collective but rather the instrumental study

Table 2: Profile of research participants<sup>33</sup>

Pseudonym of disabled person [coding number]	Vuzi [P1]	Siyanda [P2]	Sesetu [P3]	Fuzile [P4]	Dorcas [P5]
<b>Household name</b>	Bekwa	Kamana	Nombewu	Sojolo	Somngesi
<b>Age</b>	38	30	25	50	55
<b>Gender</b>	Male	Male	Female	Male	Female
<b>Marital status</b>	Single, no children	Single, no children	Married, 3 children	Married, 4 children	Divorced, 2 children
<b>Medical diagnosis</b> (verified through clinic)	Bipolar mood disorder & episodes of substance abuse induced psychosis	Schizophrenia	Neuropsychiatric disorder Epilepsy (not a mental illness)	Organic brain disorder with alcohol abuse Mild hemiplegia (head injury)	Bipolar mood disorder
<b>Cultural explanations for health condition</b> (see Table 3)	Ndine iinerves Phambana Ukugula ngengqondo Ukuphazamiseka ngengqondo	Uyacinga kakhulu Inkenkqe Phambana Ukugula ngengqondo Ukuphazamiseka ngengqondo	Idliso Amafunyane Ukuthakatha	Ukugula ngengqondo Ukuphazamiseko ngengqondo Andikho zingqondweni	Phambana Ukugula ngengqondo Ukuphazamiseko ngengqondo Andikho zingqondweni Ukuthakatha
<b>No of hospital admissions</b>	Once for 2 years Psychotic episodes are managed at outpatient clinic	Once for 6 months Psychotic episodes are managed at outpatient clinic	None Epilepsy managed at outpatient clinic	Once for six months	Multiple psychotic episodes are managed at outpatient clinic
<b>Level of education</b>	Std 2 / Grade 4	Tertiary B Tech (teacher)	Std 4 / Grade 6	Std 7 / Grade 9	Std 5/ Grade 7
<b>Locality</b>	Browns Farm	Site B	Browns Farm	Browns Farm	Site B
<b>Social security</b>	2 x disability grant 1 x child care grant	1 x disability grant	1 x disability grant 2 x child care grants	1 x disability grant	1 x child care grant 1 x disability grant
<b>Household size</b>	6	8	14	8	4
<b>Primary sources of income</b>	grants, fruit vending	grant, entering competitions	grants; recycling	grant, seasonal fruit picking	grants, selling second hand clothes

extended to several cases in order to better understand a process<sup>35</sup>. Prolonged engagement with each case household involved 1-3 visits every 2-3 months on different days and times during the week over a period of three years. Each visit lasted between 2-3 hrs and on occasion, an overnight stay for observation of household activities.

## Methods

Phase 2 data was gathered using a range of qualitative research methods including fieldnotes, semi-structured questionnaires, focus groups, participant observation and a series of in-depth interviews. While the primary source of data was the mentally ill index participant, the data set also needed to reflect the perspectives of the household. This approach was culturally indicated because personhood in African thought is defined relationally<sup>37</sup>. Mkhize<sup>37,47</sup> points out that "because of the interdependence between the individuals and the community, personhood cannot be defined solely in terms of physical and psychological attributes. It is through participation in a community that a person finds meaning in life". The research questions changed over the life-cycle of the study according to emerging understanding of the data and, during each interview, according to the responses of index participants who exhibited signs of psychiatric impairment (for example thought disorder) from time to time. Each of the five participants had one or two periods of mild to moderate relapses during the study period which were addressed at a primary health clinic. None were readmitted to hospital. Interview data were verified and amplified with collateral information from other members of the household. isiXhosa speaking research assistants familiar with the context and the Xhosa culture were employed to promote the plausibility of the findings.

## Data management

The task of translation and transcription was fraught with ambiguities of language, communication and interpretation for example, the word 'poverty' may be translated as *intlupheko*, but, depending on the context of the narrative and where it is placed in a sentence, it may mean any one of the following: trouble, affliction, worry, grief, annoyance, want, inconvenience or frustration. In addition, some of the informants were members of the Bhaca clan who use a distinctive form of isiXhosa which was unfamiliar to the translators. Two experienced isiXhosa speaking data managers ensured that approximate meaning was attributed where precise translations were too complex. An orthography of isiXhosa words with a range of situated meanings that cropped up regularly during the transcription process was developed to assist translation. Sections of the data were back translated by an independent translator to verify the approximate accuracy of the transcripts. Table 3 provides examples of the explanations given for the illness experiences of the index household member.

Table 3: Cultural explanations for health condition<sup>33</sup>

isiXhosa	Approximate English translation
Ndine iinerves; Ixhala; Ukuba nenhala	feelings of distress, anxiety, tension
Phambana; Ucabamane	mad/psychotic
Ukuphazamiseka ngengqondo Ukugula ngengqondo	disturbance of the mind (disruption of its order)
Inkenqqe	emotional upheaval; could indicate a call to become a healer
Uyacinga kakhulu	thinking too much
Idliso	bewitchment by poisoning
Amafufunyane	idiom for distress, phenomenon or experience of being bewitched, spirits speaking from the abdomen
Ukuthakatha	malevolent witchcraft
Ingqondo ziyanishiya	the 'mind has gone away' (to interact with spirits)
Indiki	possession by alien spirits, who as a result of not receiving a proper burial, occupy the bodies of living people

## Data analysis and interpretation

An interpretive theoretical orientation was used with the acknowledgement that authentic interpretation requires cultural familiarity and that "interpretivists do not seek universal laws or predictive generalisations, only to develop understanding of individual cases"<sup>38,20</sup>. The first layer of data analysis involved coding in consultation with three experienced isiXhosa speaking health professionals. Kvale's<sup>39,191</sup> iterative processes for developing meaning from qualitative data namely "condensation, categorisation, narrative structuring and meaning interpretation" enabled speculative understanding about the costs and coping strategy operations within and across the case study households to emerge. These processes involved a) identifying 'meaning units' as codes; b) compressing essence of textual data and field observations into meaning units and c) clarifying core emerging ideas from reading transcripts in their entirety.

Part 1 of this article is based on the first layer of deductive data analysis investigating the research question: considering the occupational performance of the mentally ill member, what are the costs of psychiatric disability to chronically poor households living in peri-urban informal settlements? Using the World Health Organisation's<sup>40</sup> description of disability as a conceptual frame, costs were identified as follows: expenses or asset depletion incurred as a result of florid mental illness (performance component impairments), activity limitations (occupational performance dysfunction) and participation restrictions within the lived environment (compromised occupational engagement). Data codes were identified that addressed (a) the financial and social antecedents of illness behaviors, (b) the illness behavior itself and (c) the personal, financial or social consequences of the mentally ill person's actions. These codes were sub-categorised into meaningful units that addressed either (a), (b) or (c). The sub-categories were in turn categorised into direct economic and indirect socioeconomic costs to the household. Direct economic costs were defined as instances where financial payment was required as a result of the index person's illness behaviour. Indirect socio-economic costs were instances where reported social exclusion or participation restrictions occurred either for the mentally ill person themselves or for their immediate household as a consequence of illness behaviour. Direct economic costs to the household were associated with impairments and activity (functional) limitations and indirect socioeconomic costs were linked to the participation restrictions that the index person (and other members of the household) experienced as a result of the illness behaviour. Since deductive coding was used, no thematic analysis was done on this data sub-set.

## Rigour

Each co-data analyst, having received a hard copy of selected transcripts, the research questions and the data analysis procedures, was asked to apply their cultural insights, theoretical perspectives and practical-professional knowledge of the field as a critical lens. Trustworthiness was promoted by subjecting the research process to regular checks for plausibility (discussions with cultural insiders), weighing evidence of how events were reported (noting patterned regularities across research events and observations by debriefing and reflective discussions after every field trip with research assistants), following up on queries (returning to informants with questions), triangulating with theory (literature review), and obtaining feedback from informants (focus groups to clarify findings and experiences). Findings were disseminated to participants through local disability service organisations.

## Ethics

Phase 2 of the PDO study was granted ethics approval by the Department of Psychology, University of Stellenbosch in April 2004. The complexities of socially responsive research ethics and informed consent emerging from the PDO study have been documented elsewhere<sup>41</sup>. In summary, ethics involved a series of moral choices that had to be made in situ with due consideration of cultural imperatives, household dynamics and individual rights. Every encounter was subject to the simple edicts proposed by Silverman<sup>42</sup>: do no harm, do not cheat, respect difference and withhold judgment. The

ethical obligation was to make referrals when particular health or social needs were discerned.

## FINDINGS

Figure 1 depicts the direct and indirect costs associated with psychiatric disability in poor households living in impoverished socioeconomic environments. Other household expenses such as paying to use communal toilets, schooling and fuel were identified but are not reflected here as they did not relate directly to the mental health condition.

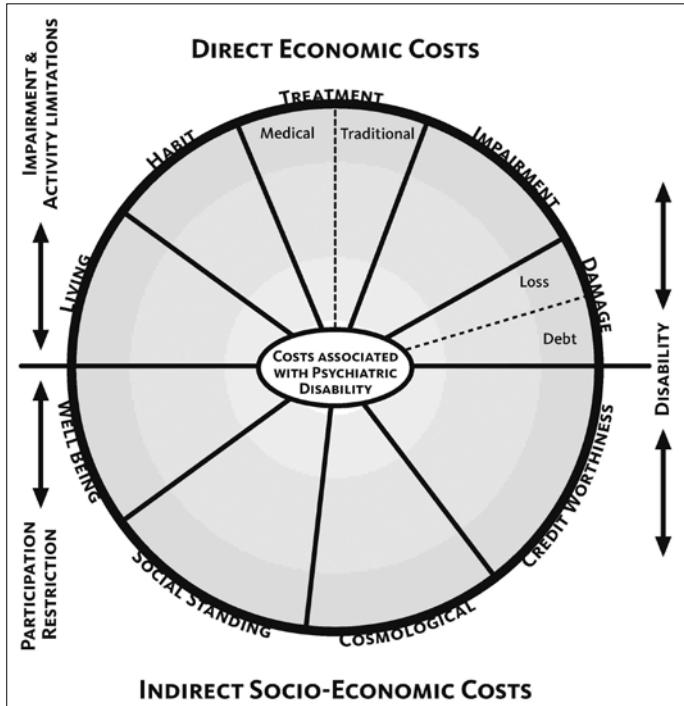


Figure 1: Costs associated with psychiatric disability

### Direct economic costs

**Living costs** refer to expenses associated with subsistence needs of the mentally ill household member such as food, shelter, clothing, transport and fuel.

“... people with mental illness have lots of needs ... they must eat before taking their medication...and then they eat a lot more than usual ...”[P2]; “... when his illness comes and he has an episode he will open the things in the fridge with a knife and will want to eat everything at once. If you buy something and he wants it he will just take it ... he eats too much ... we buy more food now ...”[P4]; “... he always complains now that he's got nothing like underwears, clothes, shoes ... compared to when he had an income but I look after him and buy everything that he wants ...”[P1].

Living costs were also incurred in maintaining culturally prescribed practices. Households were diligent in keeping burial society fees up to date because it is believed that a proper burial ensures smooth transition into the afterlife for the deceased and acceptance by the ancestors for those who remain behind<sup>37</sup>. The inability to meet burial society fees or the costs of initiation due to poverty or illness was a source of concern.

“... he struggles to give the finances for the burials but he must pay ...”[P1]; “... all my people were buried using the disability grant ... I would speak to the burial society's organiser and explain to them that I will pay them in instalments using the disability grant till my debt is paid up ...”[P5]. “... during my illness and circumcision there were many things I did not do as the result I didn't go well on other things, if you still owe some customs your things won't be smooth. So your ancestors will be cross for you because you were not introduced to them so they will make your life complicated ...”[P2];

**Habit costs** refer to expenses incurred as a result of habitual routines and predictable daily behaviours such as the regular pur-

chase of alcohol, over-the-counter medication, nicotine or other substances. The mentally ill household member was not the only person in the household (ab)using substances. The tranquilising or stimulating properties of these substances reportedly helped people cope better with their circumstances.

“I buy additives of treatment which could help keep me fit, healthy and have stamina like multivitamins and anti-stress tablets...”[P2]; “... when he relapses he smokes a packet in a day ... money would be wasted on alcohol and sometimes there is no money for the entire month for groceries ... now I have to take from the business money to keep him calm ...”[P1]; “... then if I have maybe R4 left I will go buy some beer ... my favourite is African beer ... if I ordered a bucket of beer please do not disturb me let me finish the whole 5 litres ...”[P3]. “... it (alcohol and dagga) makes my troubles go away ...”[P4]. “...he smokes excessively and spends lots of money as I buy the cigarette carton (R120) monthly but it only lasts 3 weeks...”[P1]

Treatment costs refer to expenses associated with attending public mental health services and seeking healthcare from traditional healers. Households reported that transport generated the biggest cost. When the illness behaviour became particularly bizarre or violent during the night or over a weekend, easy access to health clinics within walking distance of the household was of little use to caregivers. They had to either call the police (with social implications) or incur taxi fare costs (at increased after hours rates) to travel to medical emergency units at provincial hospitals because local clinics only offer maintenance treatment, operate during limited weekday hours and do not deal with after-hours psychiatric emergencies.

“... when I was sick, the taxi was hired ... it drove around from doctor to doctor all night until I was taken to V (mental institution) ... it cost a lot ...”[P5].

The fee exemptions that exist in the public health service are not available to persons seeking treatment from traditional healers

“... the poverty would not have been so bad if she was not ill ... we have to divide the income to take her to African healers ...”[P5].

Although traditional healers were reportedly flexible in terms of re-payment plans, they tended to be very expensive.

“...She must wait until I have money to take her to the traditional healer to take that poison out ... African healers charge sometimes R200, others R300 ...”[P3].

Households incurred travel costs to access the services of particular traditional healers who lived in places of tribal or clan origins (for example rural Eastern Cape) because they were considered more powerful. The further the person travelled to receive traditional healing was also seen as evidence of a wide social network and therefore social influence. It sent a tacit message of retaliation and protection back to those who were believed to have caused the problem. The costs were however not always seen to be worth the outcomes.

“... before I go to bed I usually use my traditional medicines (obtained from a healer in the Eastern Cape) to drive away evil spirits ...”[P2]. “... the evil spirits are those things like animals that affect your mind ... she ate this thing, it is inside her ... she can go to traditional healer to take that off because it is not her illness, it's just something that is put by someone else ...”[P3]. “... I took him to the traditional healers (in the Eastern Cape) and I wasted my money as I don't even have a cent left ...he is still not better...”[P2]

Impairment costs were incurred due to mental instability. Income was lost or foregone as a result of impaired functioning. Most of the index participants had held jobs at some stage in their life, for example domestic worker, dairy worker, bricklayer, gardener and factory worker. They lost their jobs or were unable to secure permanent jobs either due to illness, general retrenchments, unemployment or unregulated labour practices in the informal sector (some were retrenched at the whim of employers when they became ill). All the index participants were however active in the informal economy adjusting and adapting their participation

in income generating activities in accordance with their fluctuating mental health, and residual occupational performance abilities<sup>43</sup>. Performance component impairments such as low endurance; poor judgement and memory, fluctuating mood and reduced volition influenced how individuals participated in the household activities required for daily survival.

*... when she is ill it is not a good sight, she takes off her clothes and she runs outside. We must actually lock the doors when her things start ... "[P5]; "... I even lose all my grant payment because my memory goes ... "[P5]; "... I don't have power anymore ... I can't work anymore and even if I found a job they usually dismiss me as they say I am weak ... "[P4]; "...she also has low energy levels so I do not like it when she goes with me to collect cardboards because she gets sick in the middle of the job when she works too hard so we lose money that way ... "[P3]; "... when he got his grant money he bought a watch for R800 (lack of judgement during manic episode) and we had no food that month ... "[P1].*

Damage costs were incurred as a result of violent illness behaviour that led to loss of material household assets or to debts incurred by damaging neighbours' property. These debts took a long time to settle, placing a strain on limited material resources. In some households, the illness behaviour was attributed to lack of compliance with medical treatment regimes.

*... he is really destructive when he is ill ... he burnt my house and the bed ... he almost burnt the house down twice ... the other time when I bought groceries he burnt it all ... "[P1]; "... he broke my tea-set that was R1200 ... he broke them only after three months that I bought them ... even the damages from December when he burnt my belongings can reach up to R5000... "[P4]; "...he would throw stones to the windows and put fire by cars...if he damages other people's property I need to cover those costs ... I pay the debt bit by bit ... I spent R500 already on his debts from his illness ... "[P1]. "... her illness affects us very much because she refuses treatment ... she seldom takes her medication ... then she is violent and that makes the family suffer losses ... "[P3].*

### Indirect socioeconomic costs

Indirect socioeconomic costs were incurred in relation to the impact of the mentally ill person's behaviour on the social networks and livelihood systems within which the household subsisted. Social sanctions operated both internally and externally to the dynamics of the household thereby indirectly undermining the social capital they relied on for survival. Social capital was defined as the social networks and associations in which people participate, and from which they can derive support that contributes to their livelihoods<sup>30</sup>.

Well-being costs were incurred as a result of the socio-emotional environment which existed in the presence of demanding, erratic, strange and sometimes violent behaviour (during psychotic episodes) of the index household member. Intra-household dynamics were also fraught with tensions and contradictions that were not directly attributed to the mentally ill member.

*... we are not on the same track or sleeping with the same blanket (cultural idiom for unity) ... if we were we wouldn't be struggling under poverty ... "[P4].*

Key informants reported that living with and caring for a mentally ill person impacted on their energy levels, mental well-being and subsequent productivity.

*... the only thing as a household we can do is stand together and assist each other but she (disabled person) is unable to assist and work with us except getting babies all the time and we shout and tell her to get contraception because you keep getting these babies and they expose us to more hardship. Now she is pregnant again (fourth child) and she is affecting our ments, we worry because we know that the baby will become our problem ... "[P3]; "... I promise you there would be no poverty (material) at all and I wouldn't be on poverty (emotional) if he did not have this illness... "[P4]. "... its very painful. These people affect you because of their illness. You have to worry and care for them. You don't find much enjoyment and sometimes you find yourself feeling*

*the same as them because of the things they take you through... "[P2].*

Household members rationalised their feelings towards the mentally ill person by suggesting that, as the source of a regular income in the form of the disability grant, they were willing to tolerate his /her illness behaviour.

*"... I am suffering very much but I've managed to cope under the situation with the help of the grant even though at times I almost lost my mind ... "[P1]; "... we cannot enjoy life because he is ill ... we only look to the grant for support now ... "[P4].*

Social standing costs resulted from the responses of people in the community, either towards the mentally ill person directly or towards the household in general impacting, in subtle ways, on their access to income generating opportunities.

*"... here your involvement depends on who you know as community members prioritise their friends ... like the street cleaning project where we could get employment, only my neighbours who have assets were taken and I (disabled person) ended not being employed...this gives me dynamics (social tension) ... "[P3]; "... I feel valueless ... when people are looking at me they see I have got nothing and they can read me because I am not well and I don't like it ... "[P1]; "... when she (disabled person) has money she is able to buy the insides (intestines) to sell them but people do not want to pay her because she has had misunderstandings with them. People have jealousy, some people can be amazed or frightened by her behaviour and when she comes to collect her money they always tell her stories, so I advised her to first solve her problem with them then she can be able to do money ... "[P3]; "... they know here in the community that I am not well so its hard for me to engage myself in social activities ... "[P2] ; "... people used to help each other but now people are cruel and usually when people help you they expect gains and you are aware that there are no gains that you can offer and then it is better not to seek assistance... "[P4]*

**Cosmology costs** refer to the tacit socio-economic repercussions of breaching cultural observances that are based on a metaphysical worldview which is defined as people's ideas about reality, their position and purpose in the universe and their relation to others and the environment including their understanding of illness and well-being<sup>37</sup>. African cosmology (not a singular phenomenon across indigenous groups) generally informs people's sense of time, space, causality and existence in relation to a hierarchy of beings<sup>37</sup>. Cosmology concerns weighed heavily on participants who, for financial reasons, were unable to meet their traditional obligations.

*"... we did not do traditional customs or celebration of umgidi (circumcision) because of scarcity of money. The difficulties of life are customs because you have to follow them and maybe you dreamt (messages from ancestors) about something and then you must do it, you have to follow those things if it was shown to you. You are responsible, you cannot refer it to someone else. You can call all your relatives but you must be the one who addresses it... "[P2].*

Cosmology also directed social roles including gender relationships. Particular costs were incurred as a consequence of patriarchy. Abusive male behaviour, including habits that depleted scarce resources, was not confronted by women for fear of further abuse.

*"... alcohol is viewed like a social engagement for men and if that was taken away from me I will feel like women have defeated me ... (It will be) like losing identity as a cultural being in my social circle ... "[P1].*

Receiving a disability grant (a regular income which neighbors did not have) was a point of envy, contention, bargaining and social status. Cosmology was used to explain conflict arising from access to social security.

*"... my father hated too much for us to visit other homes because he said when that family dishes they will dish a separate plate for you and maybe it's the time they put poison ... because they can see you are so good for your family (brings in a grant) and you are the person your family can lean on ... "[P3].*

Creditworthiness costs were linked to the perceived privilege and social worth of the individual in receipt of a disability grant for



bartering, extending credit, incurring debt or making debt repayments.

*“... if I can labola (bridal dowry) everything will be fine. I will have credit if I can get grant and a wife because I will have status in the community even if I am ill...”[P2]; “... I picked up manipulation as most community members knew that I was poor and would only give me things like small basins of sugar ... and on the side I had these starving children ... I had no credit with them ...”[P3]; “...they tease me and tell me I am government property because I receive a grant. They say I do not depend on the casual job like they do because I have something on the side that assists me while they do not have this luxury...”[P1]; “... my wife enriches herself with my grant. It’s like she is the one who gets paid when I receive the grant. She chose me and agreed to be in marriage with me. Now I am ill she has the full obligation of a wife to take care of me. The thing that makes me angry is she is taking advantage of this; it’s like she has won the lotto.”[P4].*

Having a grant led to the accrual of credit which, unchecked, could outstrip the monthly grant amount setting in motion a cycle of debt which households had difficulty reconciling.

*“...the thing is we eat our credit from the disability grant. We end up having to eat the very same meat we are supposed to sell. My business is not growing because I use the same money I get from selling to buy other things like what he (mentally ill member) needs...”[P2];*

## Discussion

### Clusters of disadvantage

Chronically poor households operate internally and externally within “clusters of disadvantage”<sup>44:3</sup>, one such cluster being the multiplication of disability. A poor household’s ability to cope with disadvantage, in terms of illness costs, their access to strategies and the affordability and sustainability of these strategies, is linked to the type of illness with which they have to cope<sup>9</sup>. Mental illness generates a set of costs that leads to the multiplication of disability in two ways. Firstly, in an environment where basic survival is dependent on the pooled labour of household members, the presence of performance component impairments and occupational performance dysfunction associated with mental illness (in one or more members) places strain on the productivity of the household as a collective income generating unit. Untreated or poorly managed mental health problems increases household vulnerability because it erodes the efficiency of collective functioning which in turn influences the spiral into or out of poverty<sup>15</sup>. Secondly, the irrational and sometimes violent behaviour of the (untreated) mentally ill household member renders the individual and his/her immediate household susceptible to stigmatisation and cultural sanctions both of which have economic implications because the social networks to which the household belongs also operate as livelihood systems<sup>43</sup>. In short, the resilience of the household is compromised when the mentally ill individual is medically untreated; socially unsupported or unable to respond to or make use of psychotherapeutic (including cultural) and rehabilitative interventions (assuming they are available, relevant, accessible and affordable).

### Compromised resilience

Resilience has three defining characteristics: the amount of change a system (in this case the household) can undergo and still retain the same controls on function and structure; the degree to which the system is capable of self organisation and the extent to which the system is able to learn and adapt<sup>45</sup>. Mental illness shifts the function and structure of a household by requiring forms of self organisation and adaptation which members may not be equipped to handle for example when assets are destroyed during a psychotic episode or the person’s illness behaviour affects the interpersonal climate in the home. Having to stop work due to ill health, an indirect cost, has more serious long term impoverishment implications than the direct cost burdens associated with seeking treatment<sup>7</sup>. In households where no-one is working, livelihoods are generated through informal income generating activities<sup>22</sup>. Everyone, including the disabled person, makes a contribution by bringing in a few Rand

from recycling, getting an odd job, bartering, caring for someone’s child or running an informal trading enterprise; their pooled productivity and philanthropy promoting survival<sup>43</sup>. Often the sole provider of a regular income through the disability grant, the (albeit limited or sporadic) productivity of the psychiatrically disabled person augments household income. A mental health relapse or withdrawal of a disability grant therefore has serious implications for the resilience of poor households and for their collective efforts to spiral out of poverty<sup>46</sup>.

### Multi-layered costs

Collective productivity does not presuppose unitary models of households characterised by sharing, altruism and co-operation. Instead of household unity, there exist many voices, gendered interests and an unequal distribution of resources through which learning and adaptation have to be negotiated<sup>47</sup>. Not everyone in the household has an equal chance at development because economic vulnerability feeds into the power-laden nature of the social networks on which individuals and groups rely for identity, survival and dignity<sup>22,28</sup>. Disability stigmatisation adds another layer of vulnerability. Built on trust, reciprocity and alliances, social capital consists of “the norms and social relations embedded in the social structures of society that enable people to co-ordinate action and achieve desired goals”<sup>48:1</sup>. Often described in ‘plump and benevolent’ terms, the contribution of social capital to the full inclusion of people with psychiatric disabilities is in reality quite limited and ambiguous. The ‘good things’ that are assumed to exist are shaped by complex social norms, meaning-making practices and ideologies that determine how resources are distributed and who gets to be included and excluded<sup>49</sup>. Debt changes relationships with creditors and can result in undesirable consequences, including harassment and paralegal action as well as provoke feelings of fear, shame and bravado<sup>50</sup>. The route out of debt can become an “all consuming problem that casts a shadow over sense of self, identity, and mental health as repayments swallow up what little money does come in”<sup>50:235</sup>. Dependency in poor communities is high, employment opportunities low and income from grants and other informal income activities restricted so that the socio-economic resources that are shared through networks become depleted very quickly, especially when relationships are challenged by the irrational behaviour of a mentally ill member.

### Hidden consequences

The hidden consequences of the costs of psychiatric disability and their implications for poverty operate within and through elaborate cultural practices. According to Wilkinson-Maposa et al.<sup>51:49</sup> “money that is borrowed from friends is normally paid back without interest. Usury amongst friends is strongly discouraged. What is accumulated is a sense of trust. Friends who pay back at agreed times accumulate greater creditworthiness”. They point out that “a high level of clarity exists on who one does not lend to or borrow from: people who are untrustworthy, who you are not on good terms with, who are healthy but lazy, people of dubious character and people who waste money on alcohol and drugs”<sup>51:40</sup>. The tolerance of the network is compromised when the mentally ill person acts out during (untreated) psychotic episodes. Illness behaviour may be explained through pathogenic constructions of envy, jealousy and offence and is usually resolved through complex social mechanisms of inclusion and exclusion, all of which have implications for the efficiency of livelihood systems. Holland<sup>52:13</sup> points out that “if someone in the community wrongs another- for example, be stealing valuables, refusing to pay a debt or committing adultery - and the victim is unable to obtain redress through legal (customary) channels, he can seek a medium with the power to punish the guilty party by inflicting madness, illness or death on successive members. The vengeful attacks persist until their cause is recognised and blame accepted by the offending family”. These and other hidden consequences of poor mental health are multiplied when there is a limited supply of material and psychological goodwill doing the rounds. Against this background, the costs of psychiatric disability warrant consideration as a factor in the revolving door



phenomenon faced by mentally ill people who are discharged to resume survival in poorly resourced environments.

## Recommendations

The direct and indirect costs of psychiatric disability to chronically poor households may be tempered by improved access to effective treatment, rights based public education policies, social grants and household support<sup>3,46</sup>. Community environments that promote physical and mental well being throughout life will benefit from culturally sensitive interventions at household and individual level<sup>11</sup>. The hidden consequences of psychiatric disability may be ameliorated by enhancing the productivity of the mentally ill person through appropriate livelihood strategising as a member of a survival orientated support system ie. the care-giving household. To achieve these recommendations, occupational therapy is increasingly being aligned with the tenets of occupation based practice and community based rehabilitation<sup>53, 54, 55</sup>. Occupational therapists are positioned to build opportunities for human development through addressing the occupations embedded in the daily life of chronically poor households. Occupational therapists could promote the capacities of households including people with psychiatric disabilities to dent the impact of poverty firstly by refocusing life skills training towards culturally relevant ways of dealing with the direct and indirect costs of illness behaviour and secondly by reorientating work readiness programmes towards income generating competencies suited to the informal economy.

## Limitations

The logistical challenges involved with gaining access to the community and people's lives, while indicative of the realities of their circumstances, nevertheless detracted from the efficiency with which data were gathered. Cross cultural and class differences as well as language barriers between the researcher and the research participants posed methodological limitations on the type, depth and breadth of data that was gathered; the rigour of translations and transcriptions that occurred and the quality of meaning interpretations that were made. Although conceptual assertions are made about the insights gained, the findings cannot be generalised. The small sample consisted of poor people from a particular ethnic group in a particular geographical setting. Poverty exists across all race groups in South Africa. The findings must therefore be tempered with due recognition of bias and particularity. The research participants had a chronic psychiatric disorder linked to periodic episodes of psychosis. The findings are therefore not applicable to less severe, common mental illnesses such as anxiety and depression.

## Conclusion

The impact of deinstitutionalisation and under developed primary public mental health services on poor households and on the fight against poverty cannot be underestimated. Mental illness, in particular psychotic disorders that are untreated or poorly managed, introduces a range of costs that may fall under the radar of health economists and mental health service providers. The impoverishment and asset depletion associated with mental illness in the context of chronic poverty, suggests that psychiatric disability is not an individual experience. Untreated and inadequately supported mental illness incurs costs which multiplies the impact of disability across the household. Intent on supporting the development efforts of individuals and their households, mental healthcare interventions including occupational therapy, should ideally be located within community based livelihood and sociocultural systems. Households caring for a mentally ill member need to be supported in regaining or attaining resilience. Such a focus will involve the revitalisation of primary health care principles and endorsement of community based rehabilitation approaches.

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