The burden of psychiatric disability on chronically poor households: Part 2 (coping)

Madeleine Duncan MSc OT (UCT), D.Phil (Psych) (Stell)
Associate Professor, Division of Occupational Therapy, University of Cape Town

Leslie Swartz PhD
Professor, Department of Psychology, University of Stellenbosch

Harsha Kathard D.Ed
Associate Professor and Director, Department of Health and Rehabilitation Sciences, University of Cape Town

ABSTRACT

Studies in occupational therapy on the strategies which people with psychiatric disability and their households use to navigate the daily struggle for survival in the context of chronic poverty are rare. This qualitative study, published in two parts, identified multiple layers of action, reaction and interaction used by everyone in the household to cope with the demands of daily subsistence including the costs of poor mental health. Major organising ideas centred on the discursive social forces that shaped people's daily activities, tasks and roles. While poverty aggravates the precarious situation of mentally ill individuals and their households, they mobilise coping strategies by drawing on locally relevant ways of knowing and 'being-in-the-world'. Socially engaged occupational therapy, cognisant of the cost burden of psychiatric disability, could work towards enhancing individual and household resilience through occupation focussed interventions that strengthen self-action and inter-action within indigenous explanatory frameworks.

Key words: poverty, psychiatric disability, coping strategies, relational economy

Introduction

This article reports on a sub-study done as part of an ongoing, longitudinal mixed method research project that is investigating the relationship between chronic poverty, disability and occupation (PDO). Part 1 described the background to the PDO study and the direct (financial) and indirect (socioeconomic) costs associated with psychiatric disability which five chronically poor households living in peri-urban informal settlements in Cape Town, South Africa experienced over a three year research period[1]. The consequences of the identified costs included compromised productivity amongst household members and the sporadic erosion of financial and relational assets linked to the fluctuating mental health of a household member[1]. Part 2 builds on Part 1 by describing the coping strategies used by the members of the study households during the same research period.

Rationale

Coping strategies are defined as a set of actions that aim to manage the costs of an event or process that threatens the welfare of some or all of the household members[2]. Poor households and individuals adjust the mix of coping strategies required to offset the costs of ill health, their actions being determined by emerging circumstances and the changing context in which they live[3]. The set of actions people use to cope with their circumstances influences their occupations, defined as engagement or participation in a recognisable life endeavour[4] ie. the ordinary and extraordinary things that people do every day, occupation is a function and outcome of the opportunities and choices available to people in their lived environments. Deeper understanding of the strategies which chronically poor households use to cope with their circumstances including caring for a mentally ill member will guide occupational therapists concerned with mental health promotion, psychosocial rehabilitation and occupation-based development practice.

Literature review

Poverty, coping and mental illness

Although there are many different forms of poverty[5], absolute poverty highlights the extent of material deprivation which the poor have to face and why the additional cost burden of illness and disability may exacerbate or even entrench their poverty[6]. Absolute poverty refers to subsistence below minimum socially acceptable living conditions and requirements for physical well being (amount of calories needed to stay alive) based on international criteria of $2 a day at local purchasing power parity per adult and adult equivalent (two children under age 15 years)[6]. When the PDO study commenced in 2004, the poverty line in South Africa fell between R322 (lower-bound poverty line) and R593 (upper-bound poverty line) per month per person in 2000 prices[7]. Approximately 18 million South Africans (45% of the population) were living on less than $2 a day (about R16) with households using a range of microfinance strategies to manage their limited resources[8]. While having paid work is a buffer against poverty, earning a low wage doesn't guarantee a way out of destitution. Almost one-fifth (some 1.4 million) of unskilled formal sector workers in South Africa earned less than R1000 ($126) in the mid-2000's. By 2008 about half of the workforce was in badly paid casual and temporary jobs[9]. The average unemployment rate for middle income countries is in the 5-10 percent range; in South Africa it is about 25 percent. Add workers who have given up looking for jobs, and the actual rate rises to 35 percent[9]. Seekings[10] argues that South Africa has an emerging unemployed underclass which are so deprived and disadvantaged that they are unlikely ever to break out of the poverty trap. While the "rewards of South Africa's modest economic growth are being cornered in small sections of society, punishing costs are being imposed on the poor"[9:2] which entrench their vulnerability to absolute poverty.

Although the "dollar-a-day" view on absolute poverty focuses attention on how little money people survive on, it only highlights one facet of what it means to be poor [8,11]. Living in poverty requires unrelenting vigilance in cashflow management to cope with highly irregular and unpredictable income patterns[8]. Poor households also have to cope with the risks of living in less healthy neighborhoods with weaker security, face income volatility tied to the swings of local supply and demand and deal with emergencies such as health crises that can derail families with little reserve[8,11]. Research into poverty and common mental disorders in developing countries confirms an association between poor housing, overcrowding, job or income insecurity and the incidence of common mental disorders such as anxiety and depression[12]. Poverty increases the vulnerability of households to mental distress while mental ill health increases the risk of households remaining trapped in poverty[12,13]. Social grants, designed to assist people who cannot fend for themselves due to age or disability, separate millions of South Africans from

destitution by providing some financial relief for coping with their circumstances[14].

Coping and social security

Although a grant is intended to provide social security for the recipient, in reality it is often the only steady income and means of survival for a household. According to Statistics SA grant beneficiaries soared from 2.6 million in 2000 to about 14 million in 2010. Although the sums are small and the activities modest, the grant income is absorbed within recipient households' practices of livelihood making[8,15]. Grants are used to fund productive investments, such as petty vending, education of children and even savings. Research into social security and psychiatric disability suggests the grant influences the disabled person's self image because s/he is seen to be a contributing and therefore important member of the household[16,17]. "Given the difficulties associated with generating an income, the disability grant represent(s) a very powerful tool to improve the well-being of persons with [mental] disturbance"[18:84]. The advantages of the disability grant for the recipient is however dependent on a range of extraneous circumstances including complex social dynamics and coping strategies operating within households and across social networks.

Forms of coping amongst the poor

Offsetting their vulnerability, poor households cope with their circumstances by using a range of strategies, including putting more family members to work, petty trading, avoiding basic goods which represent luxuries to them, increasing their household size, withdrawing children from education, constructing their own shelter, establishing patron-client relationships with local leaders (and sometimes loan sharks), borrowing across the social network and reducing spending on food, clothing and health care[19]. Coping strategies also include making use of different forms of help shared across the social network such as material help (for example borrowing money, materials and tools, clothes, food) and non-material help (for example care giving, information giving, domestic help, emotional support, protection, manual labour, communication, transport)[20]. These forms of help are offered vertically (from richer to poorer as a form of development assistance and charity) or horizontally (between the poor themselves) in response to imperatives such as lack of assets / commodities / funds, emergencies such as natural disasters, lifecycle events such as funerals and weddings and during times of development change such as money for school fees or starting a new business[20]. A set of rules or conditions exist such as who and why help is given or received including fees paid, interest charged and the amount that is loaned. These and other tacit rules of engagement impact on the social dynamics within which forms of help operate and influence changes in the size and function of social networks over time. Kinship networks for example "transcend the urban-rural divide as people move from household to household in response to structural and economic changes and changing livelihood opportunities"[21:130]. The informal relational economy within which households operate is unpredictable and does not always work for the benefit of all, especially vulnerable members such as women, the elderly, children and those who are disabled[21,22].

Coping and relational economy

The complex range of social relations, affiliations and alliances within which each household operates may bolster or undermine their ability to cope with the cost burden of illness and disability. Poor people may opt for the slippery slide of dependency in exchange for security, choosing to manage risk in the short term over investment in the future[23]. In their desperation to survive, they incur debt to secure food and resources to meet basic needs even when this may result, in the long term, in dependency on exploitative individuals (for example loan sharks) or the erosion of goodwill when they are unable to meet debts repayments[23]. Poor households tend to rely more on *exclusive* social capital, that is, the assets and resources of close family and other kin[24]. Exclusive capital is inward looking and binds people from similar sociological niches (for example clan lineage), reinforces homogeneity and is useful for "getting by"[24]. *Inclusive* social capital serves as a bridge to wider social networks[24]. It links people to more distant acquaintances who move in different circles, generates broader social identities and wider reciprocity and is useful for "getting ahead"; climbing the social ladder as it were[24].

Social capital in Cape Town urban areas include church organisations (54%), funeral associations (58%), stokvel (credit scheme) (1%), groceries groups (7%) and community credit associations (3%)[25]. Despite this network of social support, 6% of people in urban Cape Town reported having no-one to turn to in times of need and 10% had received no gifts of food or money in the preceding month[26]. What this suggests is that the relational economy may not be as robust for some households as is presumed to be the case. The burden of care placed on households by psychiatric and other forms of disability is likely to exacerbate the volatility of the relational economy. Mosoetsa points out that "while the household does provide refuge for those who want to hide their poverty and disease, not everyone has the advantage of belonging to a household that 'works' for all its members"[21:130].

Part 1 of this article revealed the socioeconomic costs of psychiatric disability to households participating in the PDO study[1]. It argued that while the relational economy amongst some African poor is presumed to be guided by cultural meaning systems and values such as 'ubuntu', solidarity, reciprocity and altruism, in reality intra and inter-household relations are strained and conflictual due, in part, to unequal gender and inter-generational power relations. 'Ubuntu' conveys the idea that 'a person is a person because of other people' and is believed to be the cohesive element within African communities where people share resources, time and energy to cope with their circumstances[20,27]. Despite the normative value of ubuntu, people do not always co-operate for the benefit of all including the disabled member and may seek spiritual assistance to address interpersonal conflicts. Amagqira (traditional diviners) are considered the spiritual custodians of ubuntu[28]. They are consulted to provide answers to troubling questions such as the causes of and cures for adversity including mental illness and their powers are invoked to resolve perceived injustice, jealousy or other precipitants of disharmony [28,29]. In short, poor households use a range of strategies to manage the pursuit of precarious and survivalist livelihoods and in so doing, become relational sites of both stability and conflict. The next section reports on the findings of a sub-study within the PDO study that investigated the strategies used by chronically poor households to cope with the cost burden of psychiatric disability.

Research design

The research design of the PDO study as described in Part 1 applies here[1]. In summary, entry into the research context was facilitated through community based organisations offering services to people with disabilities. Case study methodology was used to achieve the research aim which was to describe how chronically poor households and in particular their disabled member(s), expend their time, energy, interests and skills in meeting their needs and aspirations through the ordinary things they do every day. Five instrumental case study households were purposively sampled using a vulnerability scale. Data were gathered through semi-structured questionnaires, focus groups, participant observation and a series of in-depth interviews. Cross case data analysis was used to describe the operations (costs and coping strategies) associated with the burden of psychiatric disability in the context of chronic poverty. Based on one of the PDO study objectives, the following research question is addressed in Part 2: how do poor households living in peri-urban informal settlements cope with the costs of psychiatric disability?

Data analysis and interpretation

Deductive data analysis identified codes that pertained to objective and subjective actions taken by informants to cope with the costs of psychiatric disability[1]. 'Doing' codes were defined as instances where participants described objective, embodied actions unfolding through time that were directly aimed at addressing the costs of an event or process that threatened the welfare of some or all of the

household members. Codes were then sub-categorised within the category of extrinsic coping strategies. 'Being' codes were defined as instances where participants described subjective, attitudinal stances or ways of experiencing their existence that helped them secure the best possible strategic outcome in managing costs. 'Being' codes were sub-categorised within the category of intrinsic coping stances. No thematic analysis was done on this data sub-set because deductive coding was used. The interaction between 'doing' and 'being' reflected the coping strategies that offset the impact of poverty and particular forms of exclusion and marginalisation associated with psychiatric disability.

Findings

Figure 1 depicts the extrinsic strategies and intrinsic stances used to cope with the economic burden of poverty and psychiatric disability for participating informants. Substantive quotes are included and attributed to relevant participants who were introduced in Part 1[1].

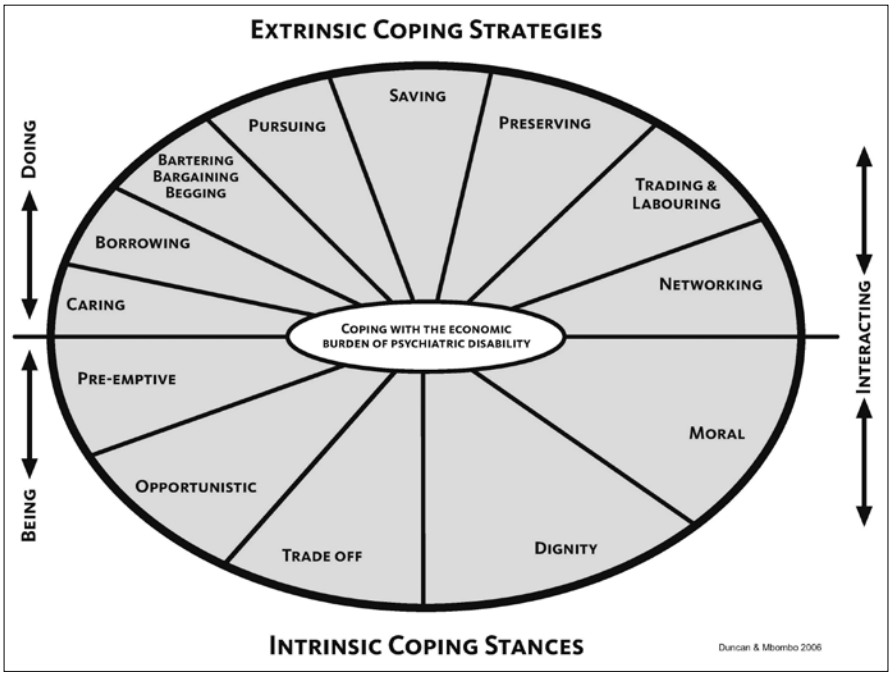

Figure 1: Coping with the economic burden of poverty and psychiatric disability

Extrinsic coping strategies

Caring involved instances where "investment in social relations with an expected return" was reported[20:102]. Caring served two purposes: a form of income and a means of maintaining social capital. Four of the five households secured an additional income from the child support grant. Children were taken in for care due to overcrowding in their natal dwelling, death of the parent or no-one at home during the day to look after the child. In one household, two profoundly intellectually and physically disabled children were taken in for permanent care. The psychiatrically disabled member was charged with the responsibility of looking after these children when other members of the household were elsewhere engaged. Gendered and highly fluid decisions were made in households about who took on care giving roles and who managed the grant. There were double edged spin offs to caring strategies. For example, a girl child (aged 9) was taken out of school to do menial household tasks and to care for a new born baby so that the adult member (the psychiatrically disabled person) could secure some income from informal trading.

"… there are two children that I care for and gain income through caring ... for my grandchild I get R200 and for my tenant's child I get R150 as he attends preschool" [P1]; "… I was given this child by my family because I cannot wash my clothes anymore so she is doing that for me… she does the shopping too and I am educating her, I am responsible for her …"[P5] ; "… she is getting grant for the children. With the money she just buy small groceries and takes the remaining one to her boyfriend who is always abusive … if she is beaten up by her boyfriend she comes here and takes all that anger to the children and beats them up … we (sisters) have to look after them but do not get the money for them …" [P3] "… my role is like that of the mother … like last month my little sister was raped by my other sister's boyfriend … I have to run around to take care of everything" (finding money for transport to get sister to the clinic, reporting incident to police, paying someone to drive around the community to find the perpetrator) [P3].

Borrowing and lending involved asking for or extending loans in cash or kind from and to people who belonged to the relational economy of the particular household. As a coping strategy to deal with the costs of psychiatric disability, borrowing occurred in a tenuous interpersonal space of trust and mistrust.

"… if he get sick I have to run around and borrow money …"[P4] ; "… if we do not have maize my mother would send us to borrow from other homes. She usually say that 'a person is a person by others' so that you can borrow something from other homes as well like they borrow from you …if maybe we don't do this we will see suffering…."[P3] ; "… always look up for someone else ... don't fold your hand for that person ... if someone wants something from you and you have it, you must give it to him so that you too can live life …"[P2] ; "… I go to my brothers … they give me whatever I'm short of …" [P1].

Bargaining emerged as a strategy for acquiring marketable goods with which to keep small informal businesses afloat or to acquire material goods for subsistence. One participant said begging for old clothes to sell did not work; it was better to barter by offering people something in exchange, such as Tupperware or ornaments. One household made use of begging in times of dire need; bargaining with potential donors for discarded food or clothing.

"… even for me to get something to wear or eat I go around asking for second hands clothes or food … we do not buy clothes from shops …"[P3] ; "… she taught me how to barter.. how to use my disability grant to buy the Tupperwares and to exchange that for second hand clothes…"[P5] ; "…she (disabled person) *does not borrow money, she just goes around looking for scraps* (left over food, discarded fruit or vegetables) *from neighbours and in the market place to feed her family …"[P4].*

Pursuing describes the relentless effort put into following up leads for potential sources of income and ways of bypassing regulatory structures to avoid paying fees for public services such as train fares.

"… even tomorrow I will wake up for hunting … I hunt and hunt with my foot unless there is someone who will feel for me and give me R5 for a bus … Sometimes I get a job, sometimes I don't and then I come back home with nothing ..."[P3] ; "… I came across this guy … I explained my situation to him that the doctor refused my grant … he then understood after much explaining and then he considered employing me …"[P1] ; "… I wake up very early and go to the farms in Paarl and stay there to save transport money …we targeted times when we thought there would be no securities and ticket officers at the train stations so we do not have to pay …" [P4].

Saving consisted of strategies to stretch the Rand such as bulk buying schemes; being on the look out for shop specials (people would spend substantial amounts of time walking from retailer to retailer hunting for bargains and comparing prices in order to save a few Rand); joining an informal saving association (called a stokvel) and being judicious in the use of goods.

"… I save in the stokvel banking … maybe when my grant stops we have something…" [P1]; "… so I want her to do business like me so

she can make a living … she must learn to buy in bulk … 10 kilograms not 2 kilos, 20 litres paraffin , not buy small things …"[P3] ; "… we walk the twenty kilometres to Mitchells Plein to hunt for clothes, that way we save money…"[P5].

Preserving was a strategy to turn discarded objects into functional ones or finding ways to make produce last for longer periods of time. Aimed at decoration, this strategy was linked to a number of household occupations where members adapted the functions of objects to increase utility or made other innovative cost saving environmental adaptations. For example, one research participant, in an effort to save money to pay off a debt incurred by breaking things during a psychotic episode, plastered his room with newspaper and flour glue instead of buying paint. He was also adept at preserving social relations that would pave the way for getting casual jobs through friends.

"… the household has no furniture but we use crates for chairs and a makeshift trolley as a cart to fetch wood …"[P3] ; "… the patch of tilled ground has a small garden producing spinach and pumpkin. She sometimes bottles produce that can be preserved…"[P1] ; "… not just anyone gets a job there … it depends on who you are, who you know, who you live with … I got the piece job because those people know me very well … I have a history with them … when I get there I do not just start working … you must first greet … first check it out…"[P.1]" … as a person you must be able to do anything by yourself … like this trouser I am wearing, if I see it needs to be sewed I do that myself so I can still wear it to save money …"[P2].

Labouring involved sustained physical effort in securing an income through informal, home based trade such as selling soap, sugar, sweets, cakes, cooked meat and clothes. In a context where almost everyone is unemployed, the disabled person's efforts to labour and trade were indispensable to the livelihood of the household. Disabled participants in this study did not perceive themselves more or less fragile than other people when it came to their ability to labour.

"… we are doing this hard labour together. We take ownership of the task … we take these collections to the scrapyard to sell them there and that is how we make money to get something to eat …"[P3] ; "*… I get injections* (anti-psychotic medication) *but if I forget my date, I will get terrible headaches, sometimes I even forget my clinic card but they still give me my injection and then I am ready to go and trade my second hand clothes …"[P5] ; "… I spend my day visiting friends, but they are not ill … we enjoy ourselves listening to music and chat. They have a stand so I keep myself busy there by packing potatoes ... I want to keep my day going because I do not want to sit around and do nothing …" [P1]; "… I do piecework on the farms … I sometimes labour during specific seasons; maybe I get work 5 months of the year …"[P4].*

Networking involved building and maintaining an informal relational economy that supported the exchange of cash and kind. The network extended outwards from the immediate household members to distant relatives, neighbours to street level bureaucrats and to shop owners and social groups such as burial societies and saving schemes.

"… I teach my children to take a collective decision about everything that happens around here … one has to look for this and the other for that … each and everyone of us finds something to do as a contribution to whatever needs to happen …"[P3] ; "… we are friends because we sell clothes together … she sells for me and I sell for her … if one is busy or has a problem, the other one will sell for another one …"[P5]; "…. we buy the cutlery and Tupperwares at low prices at discount at a shop where we are regular customers. In December we get presents from that shop for being good customers. I store my stock with the Rasta, he is my homey…" [P5].

Intrinsic coping stances

Pre-emptive stances were adopted in anticipation of events so that productivity was preserved. Pre-emptive stance ensured proactive management of anticipated or imminent set backs related to health, social events and household dynamics. Participants were 'forward thinking' and made contingency plans in terms of their fluctuating health and finances. They were able to anticipate potential consequences of a health relapse and set mechanisms in place to pre-empt possible adverse outcomes.

*"… when I return from hard work collecting cardboards, I can have an attack and I try to stay calm so that I do not become ill when I have to work again… I just sleep the whole time because I know I am about to get ill … that way is an indication I am about to get ill and they leave me to heal …"[P3] ; "… when winter rains come I request leave … I become jealous of uMulungu (*white person*) because we all stand in the rain as his workers and he sits inside his car and never gets wet like his workers and that angers me … so to avoid that anger so I do not get ill again I'd rather be off work … anyway I do have the grant so it's not like there is much loss when I take time off during winter …"[P1] ; "… when I am slowly becoming ill at work my indication is when I frequently quarrel with my colleagues … I sometimes want to hit them and when they see that they remind me to take my medication because they know that calms me down …"[P1] ; "… my so called seasonal work is affected because I have to leave suddenly to care for him so I choose to work sessions to be more flexible …"[P4].*

An **opportunistic stance** demonstrated cunning in reading and interpreting situations or events as potentially income generating. It involved scanning the environment for objects, opportunities and materials that could be exploited for financial or relational gain and recognising when a bargain was to be had (even if obtained illegally).

"… sometimes I go hunting and I come across someone cutting his garden trees. I would go in but first ask for coffee and at that time she went in to make coffee I would continue cutting that tree and if she is satisfied with my job she gives me R20 … so that is brilliancy … to me that is the technique I use to get something on hand …"[P3] ; "… even as I walk around and come across materials that we are collecting, maybe iron, wood or cardboard I pick it up and pack them here until there is enough to sell and make money …"[P4] ; "... I look for bargains and sales …" [P2]"… I buy that microwave for the business cheap from the thieves …"[P1].

A **trade-off stance** was adopted when 'playing to the audience for gain' was indicated; doing a favour or helping someone to bank goodwill in anticipation of trading in on it at a later stage or when bartering was required in order to secure material goods. 'Trade off' attitudes were sometimes viewed as manipulative, exploitative or immoral means of coping.

"*… she uses her disability … she agrees with her sickness … that is the only thing that she is good at… to 'vat en sit' (*to exploit*) so she can get what she wants … when the days are dark she knows we are the first people she comes to …"[P3] ; "… when you owe something to someone you have to pay them back thinking about the future that maybe they will have to help me on something else later.." [P5]; "… there is a lot of nepotism and corruption in community upliftment projects … the people get their friends jobs … that's how they get ahead …"[P2] ; "… I asked uMlungu (white person) for a piece job. He said he had nothing for me but I could do something for him for R50 … I felt it was very little but because I had nothing I thought I might as well accept whatever offer because I needed soap, toothpaste and we needed food at home …"[P1] ; "… she is surviving by asking money from men and by sleeping with these men … I do not like that because she will teach her children what I am not doing …"[P5].*

A **dignity stance** refers to the innate sense of pride and self worth that enabled participants to keep the indignity and dehumanising effects of poverty at bay. Poverty, shared by so many others around them, was nevertheless a private matter, something to be borne with fortitude and handled with determination.

"…I don't exactly want to take the poverty outside of the home so I just keep working … if you didn't get yourself employment you are a nothing, you are just a person … if you can't go out and get a job then there is always something that you are doing with your hands to make you a somebody" [P2] ; "… the child who is poor must not look poor … when she goes to school she must have lunch packs so she does not

sit without food and find herself impoverished even at school …"[P5] ; "… this (recycling) *is the one thing that we just have to do … there is no other way out of it … I am collecting because of the embarrassment of begging … I don't ever want to have to beg …"[P3] ; "… the church has given us new life and dignity … we have peace in this house now and even my reputation and personality is different with people … I don't have friends that mislead me now … I just look up to God now … I even leave the house in good order now …"[P4].*

A **moral stance** provided the cultural and spiritual value base from which participants operated, such as commitment to the family and clan ties, honouring parents, spirituality and self discipline. All five households maintained a compound belief system integrating isiXhosa tribal customs with Christianity.

"… God puts me in this way of poverty … When I get those negative thoughts I look up to God for help because in the end I have to keep living and I ask him to set me free … God … when will you please take me out of this? …"[P3] ; "… God stood me up and got me out of all kinds of problems and suffering. So if a person can put faith on Him, He will free you on every problem that you come across with same as He did for me …"[P5]. "… I always set myself as an example to her and even ask her to look at my path, I tell her that if she can quit her addictions she can do many things, like me, she can see my efforts that I make and she can also make the same but she does not want to…."[P3] ; "… I take all my money and give it to my parents and stay there penniless and I don't mind as I know I didn't waste or throw it on the beer, I gave it to support the family …"[P2]

Discussion

The blurring between general livelihood strategies and those specifically deployed to deal with the economic implications of psychiatric disability could not be isolated because it becomes superfluous in the context of pervasive suffering associated with chronic poverty, high unemployment and structural underdevelopment. Often indistinguishable from other shocks and misfortunes amidst the grinding hardship of life at the margins, disability becomes assimilated into the economic burden of everyday life[30]. Coping with poverty and coping with psychiatric disability were, in effect, conflated experiences of dealing with deprivation, adversity and enduring financial constraints. Households had to deal with numerous health and social problems besides having a mentally ill member for example HIV/AIDS, alcoholism, intellectual disability, incest, rape and domestic violence. Against this backdrop and the aim of the study, three main issues emerging from the findings warrant discussion: occupation located in three life worlds; the influence of the relational economy on occupation and the dubious assumptions about human resourcefulness in the face of enduring hardship.

Occupying three life worlds

Participants in the study inhabited three occupational worlds: the *'here and now'* of daily doing; the *'there and then'* of the informal relational economy (rural-urban linkages) and the '*beyond'* in which activities and tasks were regulated by deferring to the living-dead. Occupying disparate yet dynamically related existential planes or realities, three lifeworlds as it were, meant that coping was facilitated not only by what was done, produced or achieved in the 'here and now' but also by what would maintain or strengthen relationships in the 'there and then' and the 'beyond'. Time, especially how, with whom and why it is spent, takes on particularly nuanced meanings in African cosmology[27]. Productivity, agency, time use, orientation to nature, human activity and interdependent relationships are organised according to metaphysical imperatives. A hierarchy of 'beings' are involved with 'doing' and therefore with coping[27, 28]. The nature, direction and influence of action and the motivation to be productive is determined by the amount of *isithunzi* or *sereti* (life force, energy, power) allotted to each object or organism within the circle of life[27]. It is believed that things never happen by accident because created beings and objects are ontologically connected to one another, organised hierarchically and mutually influential[28,31].

Poverty and disability press for productivity that is aimed at meeting immediate subsistence needs. People cope by attending to the 'here and now' needs of survival, doing the tasks and activities that enable subsistence while providing care to the disabled member. Coping with the cost burden of adversity including illness and disability is supported by attending to 'being' concerns such as saving for a decent funeral; one that will appease the *iziyanya* (ancestors); by providing for *ukubona* (for example, paying for relatives and friends to visit the family) or by covering the costs of visiting a diviner to obtain direction for the future. In between today and tomorrow life is lived teleologically; that is, coping unfolds for particular reasons at particular localities and points in time[27]. To 'do', or to be 'occupied', is to participate in the dynamic process of interaction between the parts (the individual occupational human) and the whole (the cosmic unity of the seen and unseen community). The individual's *inkambo* (becoming), irrespective of whether they are a disabled or non-disabled member of the household, is determined by a 'life force' both internal and external to themselves that dictates what needs to be done and how the doing needs to unfold[27].

The relational economy influences occupation

The findings suggest that cosmology was closely linked to social control in the sub-text of participants' coping strategies. The sublime goodwill of the ancestors and neighbours could not always be assumed[32]. Financial and personal progress and by inference what people actually did very day or felt they were able to do was constrained, on occasion, by fear of bewitchment and jealousy. Power and politics, operating as forms of jealousy, were couched in meta physical discourses that attributed suffering and social inequalities to occult force[33]. People coped by making sense of their deprivation and suffering as forms of benign or malevolent metaphysical influence. This perspective adds another dimension to the notions of 'doing', 'being' and 'becoming' described as subjective, individual self-realisation processes in the occupational science and occupational therapy literature[34, 35]. Distinctions between self care, work (productivity) and leisure that are used to describe occupational performance, while recognisable in form, only partially align with the way of life experienced by people subscribing to collectivist worldviews. Africans conforming to traditional belief systems tend to pay more attention to the sociocultural aspects of occupational form, that is, to relationships with ancestors (the living-dead) and others (the living) than they pay to themselves as actors engaged with occupations that can be categorised into hours spent at work, at leisure, caring for self or sleeping. Their 'doing', 'being' and 'becoming' is intricately shaped by the relational and subsistence economy of their lives and less so by the neoliberal drive for self actualisation.

Coping is a dubious assumption

A combined reading of Parts 1 and 2 of the article paints a sombre picture of the cost burden of psychiatric disability for chronically poor households. Despite tapping into vital social connections and using multiple occupation based survival strategies, the study households lacked a thrust powerful enough to propel them out of poverty. There was little evidence in their stories of longer term accumulation that would ensure economic advance. At best, they were managing to keep head above water in a parlous and chronically insecure state of existence[36]. Marais[9] argues that implicit in the discourse of coping in the context of poverty and inequality is an acceptance, an endorsement even, of the way things are. A focus on coping diverts attention away from the wretched social inequality and exploitation to which the poor and other marginalised groups are subject. Coping strategies then are not about success but about failure; they enable poor households to survive but not to transcend their circumstances.

Marais[9:221] suggests that "a hallmark of the neoliberal era is the emphasis placed on the presumed pluck, grit and altruism of the poor". Development literature routinely 'talks up' the resilience, perseverance and agency of marginalised people, as are "interventions that can 'empower' people, strengthen kinship and community safety nets and support coping strategies" [ibid:221]. Home and community based care systems are based on the assumption that

chronically poor households are able to overcome the amputated options and foreclosed alternatives associated with their positioning on the margins of society. Underpinning this discourse is the increasing subordination of social life to market forces. "As more dimensions of life and work are ceded to the market, the responsibility for providence and calamity, for life and death, is being lodged with ever-smaller units of society (and is ultimately, in the neoliberal ideal, assigned to the individual)"[9:223]. What this means is that the poor including people with disabilities are expected to pull themselves up by their own boot straps using their assumed unfathomed vigour, invention and coping abilities. While a vibrant civil society including disability inclusive development is a pathway out of poverty it has to proceed from rights based demands on state resources. Despite the evolution of post apartheid economic and social development policies since 1994, none of the households in the PDO study have been able to access the basic citizen rights of a decent house, running water on site, proper sanitation and electrification. Their plight has however been mediated by access to social security. The proposed re-engineering of primary health care will also create avenues for bringing mental health services closer to the coalface of intra-household relational and material economy.

Recommendations

The dynamic interaction between poverty, disability and occupation warrants intensive investigation. Considering occupation focussed practice as the core business of mental health occupational therapists, a three life world perspective introduces new challenges for identifying contextually relevant approaches. The evolving discipline of occupational science is opening up vistas of occupation as self-action and inter-action; as the relational glue between the individual and the social[37]. Occupation is the means through which "humans and context exist in an ongoing process of reproduction and occasional transformation, dependent on one another for their current states of existence" [37:162]. Part 1 and Part 2 of this study confirm the applicability of this description of occupation in the context of poverty and disability. It is therefore recommended that occupational therapists concerned with alleviating the cost burden of mental ill health and psychiatric disability to poor households focus on strengthening self-action and inter-action within an occupational justice framework suited to social realities in the majority world[38].

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. Poverty exists across all race groups in South Africa. The findings must therefore be tempered with due recognition of bias and particularity. They pertain to individual circumstances in a particular context at a particular point in time. The research participants had a chronic psychiatric disorder linked to periodic episodes of florid psychosis. The findings are likely to be different for common mental illnesses such as anxiety and depression. The theoretical limitations of the study lay in the complexities of defining the three primary constructs under investigation. With little consensus in the literature, it is difficult to arrive at clear-cut conclusions about the dynamics between occupation, chronic poverty and psychiatric disability. These constructs are elusive in terms of definitive parameters and unfathomable in terms of scope and impact. At best their combined influence can be subjectively experienced and qualitatively described.

Conclusion

The burden of psychiatric disability on chronically poor households highlights the paradoxical interface between individual and social dynamics. Personal beliefs and cultural practices located in the relational economy simultaneously compound and alleviate the cost burden of mental illness and psychiatric disability. While poverty aggravates the precarious situation of mentally ill individuals and their households, they nevertheless mobilise financial, human and material resources for livelihood and participation in life through their daily occupations. Driven by the urgency of survival, the daily activities, tasks and roles of household members are highly fluid, gendered and subject to co-operative conflict. Structural barriers imposed by underdeveloped public mental health services combine with discursive social forces to shape the different forms of coping available to poor households, locking them into a marginalised state of existence. Occupation focussed practice that strengthens self-action and inter-action in the pursuit of citizen rights including disability inclusive development will go a long way towards alleviating the alienation and marginalisation experienced by chronically poor people.

References

1. Duncan M, Swartz L, Kathard H. The burden of psychiatric disability on chronically poor households: Part 1 (Costs). SAJOT, 2011; 41:3. In this edition.
2. Sauerbom R, Adams A & Hien, M. Household strategies to cope with the economic costs of illness. Social Science and Medicine, 1996; 43(3): 291-301.
3. Ellis F. Household strategies and rural livelihood diversification. Journal of Development Studies, 1998; 35(1): 1-38.
4. Christiansen CH, Townsend EA. Introduction to occupation: the art and science of living. New Jersey: Pearson Education Inc., 2004.
5. Banerjee AV, Bénabou R, Mookherjee D. Understanding poverty. Oxford: Oxford University Press, 2006.
6. Hulme D, Moore K. Shepherd A. Chronic poverty: meanings and analytic frameworks. Chronic Poverty Research Centre, Institute for Development Policy and Management. Manchester: University of Manchester, 2001: Working Paper No. 2.
7. Hoogeveen JG, Özler B. Poverty and inequality in post-apartheid South Africa: 1995-2000. In Bhorat H, Kanbur R (eds). Poverty and policy in South Africa. Cape Town: Human Sciences Research Council (HSRC) Press, 2006: 1-17.
8. Collins D, Morduch J, Rutherford S, Ruthven O. Portfolios of the poor: how the world's poor live on $2 a day. Cape Town: UCT Press, 2009.
9. Marais H. South Africa pushed to the limit: the political economy of change. Claremont: UCT Press.
10. Seekings J. Do South African unemployed constitute an underclass? Centre for Social Science Research (CSSR), Social Surveys Unit. Rondebosch: University of Cape Town, 2003: Working Paper No. 32.
11. Narayan D, Chambers R, Shah MK, Petesch, P. Voices of the poor: crying out for change. New York: Oxford University Press, 2000.
12. Patel V, Kleinman A. Poverty and common mental health disorders in developing countries. Bulletin of the World Health Organisation, 2003; 81 (8): 609-615.
13. Lund C, Breen A, Flisher A, Swartz, L, Joska, J, Corrigall J, et al. Mental health and poverty: a systematic review of the research in low and middle income countries. The Journal of Mental Health Policy and Economics, 2007; 10 (Supplement 1): S26-S27.
14. Patel L. Social welfare and social development in South Africa. Oxford: Oxford University Press; 2005.
15. Lund F. Gender and social security in South Africa. In Padayachee V (ed). The development decade? Economic and social change in South Africa: 1994-2004. Cape Town: Human Sciences Research Council (HSRC) Press, 2006: 160-179.
16. MacGregor H. 'The grant is what I eat': the politics of social security and disability in the post-apartheid South African state. The Journal of Biosocial Science, 2006 (*38*): 43 -55.
17. Eidelman T, Gouws V, Howe C, Kulber T, Kumm J, Schoenfeld L, Duncan M. Women surviving chronic poverty and psychiatric disability. South African Journal of Occupational Therapy, 2009; 40 (3): 4-8.
18. Macgregor H. Maintaining a fine balance: negotiating mental distress in Khayelitsha, South Africa. Philosophy doctoral dissertation, Darwin College: University of Cambridge, 2002.
19. Haddad L, Hoddnott J, Alderman H. (eds). Intrahousehold resource

allocation in developing countries: models, methods and policy. Baltimore: John Hopkins University Press, 1997.
20. Wilkinson-Maposa S, Fowler A, Oliver-Evans C, Mulenga CFN. The poor philanthropist: how and why the poor help each other. The Southern Africa-United States Centre for Leadership and Public Values. Graduate School of Business: University of Cape Town, 2005.
21. Mosoetsa S. Eating from one pot: the dynamics of survival in poor South African households. Johannesburg: Wits University Press, 2011.
22. De Swardt C. Cape Town's African poor. Programme for Land and Agrarian Studies (PLAAS), School of Government: University of the Western Cape. 2004; Chronic Poverty and Development Policy Series No. 3.
23. Wood G. Staying secure, staying poor: the Faustian bargain. 2003. World Development, 31 (3): 455-471.
24. Field J. Social capital. 2003. London. Routledge.
25. Chronic Poverty Research Centre (CPRC). The chronic poverty report 2004-05. 2005. Manchester. Chronic Poverty Research Centre. www. chronicpoverty.org/resources/cprc_report_2004-2005_contents.html. [April 3, 2005].
26. Seekings J, Alexander K, Joost T, Matzner M. The 2003 Cape area survey: a user's guide. Centre for Social Science Research (CSSR). Social Surveys Unit. Rondebosch: University of Cape Town. 2003; CSSR Working Paper No. 32.
27. Mkhize N. Psychology: an African perspective. In Hook D (ed). Critical psychology. Cape Town: University of Cape Town (UCT) Press, 2004: 24-51.
28. Yen J, Wilbraham L. Discourses of culture and illness in South African health care and indigenous healing, Part 1: Western psychiatric power. Transcultural Psychiatry, 2003; 40(4): 542-561.
29. Lund F. Gender and social security in South Africa. In Padayachee V. (ed). The development decade? Economic and social change in South Africa. *1994-2004.* Cape Town: Human Sciences Research Council (HSRC) Press, 2006: 160-179.
30. Aliber M. Study of the incidence and nature of chronic poverty and development policy in South Africa: an overview. Institute of Development, Policy and Management (IDPM). Manchester: University of Manchester, 2001; Chronic Poverty Research Centre Working Paper No.3.
31. Teffo, L. J. The concept of ubuntu as a cohesive moral value. Pretoria: Ubuntu School of Philosophy, 1994.
32. Yen J, Wilbraham L. Discourses of culture and illness in South African mental health care and indigenous healing, Part 11: African mentality. Transcultural Psychiatry, 2003; 40(4), 562-584.
33. Niehaus I. Witchcraft, power and politics. London: Pluto Press, 2001.
34. Wilcock AA. A theory of the human need for occupation. Journal of Occupational Science, 2002; 9 (special issue): 3-9.
35. Wilcock A A. Reflections on doing, being and becoming. Canadian Journal of Occupational Therapy, 1998; *65*(5): 248 – 256.
36. Eidelman T, Gouws V, Howe C, Kulber T, Kumm J, Schoenfeld L, Duncan M. Women surviving chronic poverty and psychiatric disability. South African Journal of Occupational Therapy. 2009; Volume 40 (3): 4-8.
37. Cutchin MP, Aldrich RM, Baillard A L, Coppola S. Action theories for occupational science: the contributions of Dewey and Bourdieu. Journal of Occupational Science, 2008; Vol15 (3): 157-164.
38. Galheigo SM. Occupational therapy in the social field: concepts and critical considerations. In Kronenberg F, Pollard N, Sakellariou D. Occupational Therapies without Borders: Towards an Ecology of Occupation-Based Practices, Edinburgh: Churchill Livingstone Elsevier; 2011: 47-56.

Acknowledgements:

With many thanks to:

Funders: Andrew W. Mellon Foundation and the South African Netherlands Partnership for Alternatives in Development (SANPAD)

Research assistants: Akona Mbombo, Debbie Bub, Johanna Keikelama, Siphokazi Gcaza, Thembakazi Nkunkwana, Zameka Ndzotyana

Conceptual review: Associate Professor Ruth Watson, Marion Fourie

❑

Corresponding Author
E. M. Duncan
E-mail: eve.duncan@uct.ac.za

Return-to-Work (RTW) of Patients after Lumbar Surgery

Herculene van Staden, B OT, M OT (Vocational Rehabilitation)
Occupational Therapist in Vocational Rehabilitation and Medico-Legal Private Practice

René Kemp, B OT, M OT
Lecturer – Division of Occupational Therapy, Department of Inter-disciplinary Sciences, Faculty of Health Sciences, University of Stellenbosch

Susan Beukes, B OT, M OT
Head, Senior Lecturer – Division of Occupational Therapy, Department of Inter-disciplinary Sciences, Faculty of Health Sciences, University of Stellenbosch

ABSTRACT

Background: Return to work (RTW) after lumbar surgery due to a work-related injury poses a challenge internationally. Work hardening is used as an intervention for acute and chronic lower back pain (CLBP), but it is not necessarily used in post-operative treatments. Method: The RTW rate of an experimental group (Group A) of unskilled labourers was compared with that of a control group (Group B) of unskilled labourers. Group A received multidisciplinary intervention, including a work hardening programme with ergonomic adaptations, while Group B received only physiotherapy after surgery as a multidisciplinary team was not available. A RTW questionnaire was used as an outcome measure for both groups. During the multidisciplinary intervention, the improvement of pain and functionality of patients from Group A were also evaluated from the pre-operative state to 24 weeks post-operatively with the Visual Analogue Scale (VAS) and the Oswestry Disability Index (ODI) as additional outcome measures. Results: There was a positive tendency to successful RTW after work hardening for Group A, but no statistical significance between Groups A and B. The improvement of pain and functionality in Group A was highly significant from time of surgery to six months post-operatively. Conclusion: Work hardening was found to have a positive tendency towards ensuring RTW for work-injured patients after lumbar surgery, with a highly significant effect on pain and functionality.

Key words: Work hardening; work-injured patients; lumbar surgery; return to work (RTW); multidisciplinary approach