

THE ELEPHANT IN THE SHACK: ONE WOMAN'S OCCUPATIONAL STORY OF SURVIVING PSYCHIATRIC DISABILITY AND CHRONIC POVERTY IN AN INFORMAL SETTLEMENT

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Abstract

The message of this presentation, written in valedictory honour of Jock Murray for his singular contribution to occupational therapy in South Africa, is a call for increased commitment to socially engaged occupational therapy practice. Priorities for reflexive engagement with the social demands of our context are highlighted using a single case as point of reference. In keeping with the theme of the colloquium, the dominating influences of poverty and disability in the life of one woman living in a peri-urban informal settlement on the outskirts of Cape Town are metaphorically described as an elephant in her shack. Conversely, the resilience she displays in the face of enduring hardship is likened to the strength of an elephant. The agency of a mentally ill person is foregrounded, firstly through a description of four factors that influenced her productivity and secondly, through a macro occupational analysis of her primary role as provider and entrepreneur for a four person, chronically poor household. It will highlight her ability, despite an unstable mental state and considerable social stigmatisation, to secure a meagre livelihood through the calculated use of her disability grant as seed money for running a small informal business of selling second hand clothes. The presentation concludes with some recommendations for addressing the critical disjunctions facing the profession as it seeks to promote socially engaged practice.

Acknowledgement

In celebrating Jock Murray's exemplary contribution to occupational therapy in South Africa, I want to honour, in particular, the agency he has displayed in promoting the profession through his leadership in education and regional services. Agency refers to the "capacity of intention.... that is individuals, through rational thought, free will, motivation or emotion, are able to direct their behaviour or make particular choices (Hayes, 2004, p.179). Jock displayed singular capacity of intention in the pursuit of knowledge; the development of new ideas and service areas and in directing his professional choices towards benchmarking excellence in occupational therapy education. To uncover agency is to look for the things that motivate people and direct the focus of their life's work. Jock was motivated by a desire to make a difference. Understanding agency however also requires an appreciation of the discursive factors that influence what people are able to do; factors such as organisational politics, the hegemony of medicine and, of course, economics. Thank you, Jock, for fighting the good fight in claiming a piece of the pie for occupational therapy in many 'behind the scenes' negotiations with the discursive elements that invariably go with the territory of being a 'baanbreker'.

Introduction

I was privileged to work with Jock for a number of years when the occupational therapy programme at UOFS first started in the late seventies. Thinking back over the past twenty odd years since then other discursive factors shaping South African occupational therapy come to mind such as the continued dominance of Eurocentric and Western worldviews in our theory and practice; the press for contextually relevant interpretations of comprehensive primary health care; the promises of occupational science and, most pressingly, the imperatives of historical redress and nation building. I will use a single case study to highlight these factors and in so doing, argue for an increased commitment to socially engaged occupational therapy practice, that is, practice that actively promotes equity, social justice and development (London, 2008).

Poverty, disability and what people are able to do as occupational beings (PDO) are critical social issues in South Africa with political, racial, gender, spatial and cultural dimensions that are linked to our colonial past and segregationist history. Current trends in occupational therapy literature suggest a growing swell of practitioners committed to a deeper understanding of the relationship between PDO (Kronenberg, Simo-Algado & Pollard, 2005; Watson & Swartz, 2004). I will use a brief review of PDO as a backdrop for one woman's occupational story of surviving psychiatric disability and chronic poverty in an informal settlement. Like a metaphorical elephant in a shack, the enduring hardship associated with deprivation, discrimination and exclusion dominates every facet of her life on the margins of society. The reverse also applies. The agency that she displayed may, metaphorically, be compared to the endurance and strength of an elephant. Like many other disabled people living in poverty, she was intent on finding practical solutions to the challenges of daily survival, displaying resilience and productivity in the face of adversity. Tapping into this human potential is where I believe socially engaged practice will find its most significant expression with due consideration of the discursive forces that operate in developing contexts. I return to this again later but first briefly review some critical dimensions of poverty, disability and occupation.

Poverty

Many different definitions of poverty exist. In the 1960s poverty was defined as a low income problem and in the 1970s as a lack of basic needs which refers to the minimum that an individual requires to survive and fulfil his/her humanness such as income, food, clothing and shelter (De Haan, 1999). In the 1980s the concept of livelihoods was introduced and refers to the way in which a household meets its present and future needs and pursues its aspirations

(Hulme, Moore & Shepherd, 2001). Livelihood comprises the capabilities, assets, and activities required for a means of living (Department for International Development, DFID, 2002). It considers the choices people are able to make by virtue of their available resources, the risks they face, the insecurity and vulnerability of their circumstances and the strategies they use to cope with life changes (Chambers & Conway, 1992). Assets consist of various forms of capital that can be accumulated, exchanged, expended, depleted and lost, thereby affecting a household's level of livelihood security, quality of life, and its coping strategies (Frankenberger, Luther, Becht *et al.*, 2002). Capital refers to any source of benefit, assistance or wealth, in whatever form, that can be used to produce more wealth. It may be physical (for example house, livestock), financial (for example wages, rents, savings); human (for example education and health), natural (for example land, water, trees), social (for example kinships and social networks) and political (for example franchise) (Ellis, 2000 a,b).

The 1990s introduced issues of 'voice', 'well-being' and 'participation' into definitions of poverty. Currently a rights-based, developmental approach dominates poverty debates. According to Sen (1999) it is not possible to live a full and free human life without access to 'doing' and 'being' capabilities; that is, the extent to which a person has the right and the freedom to choose what s/he desires in all matters concerning their own lives. He believes poverty to be the lack of capabilities, both intrinsic (for example personal, individual attributes) and instrumental (for example health, income, education and political rights) that prevent or constrain people from attaining certain functionings (things they want to do) and beings (states of existence they want to experience). Irrespective of which definition is adopted, poverty is a very complex, multifaceted socio-political phenomenon underpinned by inequity, vulnerability, exclusion and underdevelopment (Scott, 2002).

According to the World Bank (2000) an estimated 900 million people globally will be living in poverty by 2015 - even if international development targets are fully met. The majority of these will be chronically poor and living in sub Saharan Africa and South Asia. Chronic poverty is concerned with those people who have little likelihood of emerging from poverty in their lifetime and who are likely to transfer poverty across generations (Chronic Poverty Research Centre, CPRC, 2004). South Africa has amongst the most extreme disparities in wealth in the world. South Africa's Gini-coefficient is estimated to be between 0.59 and 0.64 (Padayachee, 2006, p. 4). The Chronic Poverty Report (CPRC, 2004, p. 37) notes that "economic growth in countries with high initial levels of inequality will be relatively ineffective at assisting the chronic poor". Where social exclusion is high, chronically poor people and disabled people in particular, have little chance of benefiting from economic growth and are unlikely to increase their assets. Sunter (2002, p. 35), writing about the economics of surplus and scarcity in the

new millennium, suggests that "... poor people aren't poor because of a scarcity of products and resources. They are poor because they are denied the opportunity to make money for themselves". The problem is that it is extremely difficult to create large scale opportunities for poor (and disabled) people to lift themselves out of poverty because they are up against structural inequities situated at a systemic level. Socially engaged occupational therapy practice will be cognisant of the sociopolitical realities of people's lives working at grassroots level in solidarity with people in creating and /or optimizing the opportunities at their disposal.

The Taylor Committee (2002) reported that 18 million people (45% of the population) in South Africa live on less than \$2 a day (about R16). Poverty is linked with unemployment which increased from an estimated 2.2 million in 1996 to 4.2 million in 2001. In 2003, the unemployment rate in South Africa stood at over 45% according to the broad definition which includes people who have given up trying to find work (Aliber, 2003). For those in the poorest 20% of households, the unemployment rate is 53 %. The unemployment rates for females is 15% higher than that for males (Serumaga-Zake, Kotze & Madsen, 2005). While poverty alleviation remains unrealised, social inequality is increasing. The poorest 40% of households, comprising 50.5% of the population, receive only 11% of the overall national income, while the richest 10% of households, comprising 7% of the population, receive 40% of the national income (May, Woolard & Klasen, 2000). Some 60% of South African children live in the poorest 40% of households (measured by income); three quarters of these live in rural areas. Ravaged by high rates of HIV/AIDS and disadvantaged by a lack of skills, education, location, capital to start a small business, duration of unemployment and eroded social capital, the number of unemployed people in South Africa is growing exponentially. Seekings (2003) describes an emerging unemployed underclass, a group so deprived and disadvantaged that, excluded from access and opportunities, they will never break out of the poverty trap. This trap is exacerbated by the onset or presence of disability.

Disability

Disability, according to Mitra (2005, p.8) occurs when "an individual with an 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.)". Poverty and disability are inextricably related. The World Bank (2000) reports that disabled people account for one in five of the world's poorest. 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 from 10.5 % of the total burden to 15% by 2020 (WHO, 2003a,b; Jenkins, 1997).

Miller (2006, p. 461), discussing the global incidence of mental illness reports that “ the majority of the world’s 450 million people who suffer from neuropsychiatric disorders live in developing countries and that fewer than 10% of these people have access to treatment ”. Cross national surveys have shown that common mental disorders are about twice as frequent among the poor as among the rich in Brazil, Chile, India and Zimbabwe (Patel et al 1999 cited in WHO, 2001c). Miller (2006) reports that the World Health Organisation estimates that there are approximately 450 million people in the world with neuropsychiatric disabilities with the majority of them living in developing countries with high levels of poverty. Patel and Kleinman (2003) point out that while most people living in poverty do not necessarily develop mental illness they are at greater risk given their marginalisation in society. 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 lost quality of life which in turn leads to lost productivity (Patel and Kleinman, 2003).

Based on the 1996 census, StatsSA (2000) estimated that 2.7 million people in South Africa were disabled. Of these 1.6 million were adults between the ages of 20-65. The 2001 census estimated that more than 5.5% of the total South African population has moderate to severe disabilities. This is an estimated 2 255 982 out of a population of approximately 44 819 778. Using data from the 1996 census, Aliber (2003) reports that the unemployment rate for black South Africans with disabilities was marginally above the general unemployment rate at that time (45.3% compared with 42.5%). Addressing development policy in South Africa, Aliber (2001b, p.34.) found that unemployment rates are not very much higher amongst disabled than amongst black South Africans but “ 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 ...”. Disability, in other words, tends to be just one of a numerous barriers or extreme circumstances that poor people in South Africa have to deal with in an underdeveloped environment. This leads then to the question: what do people do under these circumstances? A brief review of the various dimensions of the construct which we call ‘occupation’ is indicated.

Occupation

Christiansen & Townsend (2004) describe occupation as the ordinary things that people do everyday and the way they expend their time, energy, interests and skills in meeting their needs. Much controversy surrounds the distinctions and similarities between the concepts of ‘occupation’, ‘activity’ and ‘task’ in occupational therapy (Gollidge,1998; Kielhofner, 2002;

Kramer, Hinojosa & Royeen, 2003). General agreement is that activity is a sub-component of occupation that involves “brief units of human doing” (Nelson & Jepson-Thomas, 2003, p. 149) and that a task is “an objective set of behaviours necessary to accomplish a goal” (Dunn, Brown & Youngstrom, 2003, p. 226). Christiansen and Baum (1998) concur, seeing occupation as the composite of activities (for example writing notes), tasks (for example studying for a test) and roles (for example being a student).

Occupation is directed at a goal with actions organised into predictable patterns of behaviour called occupational performance. According to Nelson (1999, p.77), occupational performance is the voluntary doing by the person within the context of the occupational form which he defines as “ the objective pre-existing structure or environmental context that elicits or guides subsequent human action ”. The interaction or process that occurs between the “doer” (a person with a unique developmental structure, subjective meanings and purposes) and the occupational form is imbued with perceptual, symbolic and affective meaning (Nelson & Jepson-Thomas, 2003). People perform occupations with a purpose in mind. That purpose, defined as the “ experience of desiring an outcome and having a motive for doing something”, may or may not be personally meaningful for the individual (Nelson & Jepson-Thomas, 2003, p. 106). The meaning of occupation is experienced affectively. It involves perceptual and symbolic interpretation of occupational form and is elicited by the unique developmental structure of the individual. Different people will attribute different meanings to the same occupational form.

Occupation as form is objective; that is, the various steps or tasks involved in its doing, the components of body function and structure involved, the materials and tools used and other aspects can be identified and systematically recorded (Nelson & Jepson-Thomas, 2003). The product(s) of occupation may be tangible (can be seen, touched, smelt etc) or intangible (cannot be seen as in sleeping or daydreaming but nevertheless involves the body functions and structures in active use of time and engagement in doing something). Occupation as form guides, structures and dictates what is to be done by the person and includes materials, characteristics of the physical setting, as well as sociocultural dimensions that affect perceptions and interpretations of actions taken in a particular context. The temporal features of occupations suggest that they extend over time, may be habitual, and help people adapt to and gain control over their physical environment. How the form of the occupation begins, how it is controlled and what is involved in the doing, points to occupation as active participation; in other words, people are aware that they are doing something, are able to exert control over their performance (this depends on presence of an impairment), recognise that it requires energy, interest, attention and motivation and that it involves body functions and structures (Hocking, 2000). The important point here is that occupation as form, in relation to poverty and disability,

can be used as an indicator of changes in income poverty and health status; for example an individual may have to downgrade the demands of occupational form following the onset of impairment and subsequent disability and in so doing, be forced to engage in occupations yielding less income.

Occupation as process is concerned with the dynamics of how occupations happen when actor, occupation as form and environment interact. According to Wilcock (2006, p. 202) occupation entails the phenomenology of 'doing' (meeting basic prerequisites of health and survival), 'being' (finding meaning, purpose and belonging through doing) and 'becoming' (doing according to capacities and potential). People constantly move from one state of occupational engagement to another, occupying as if it were a state of liminality in which their essential being may be focussed on one or more human endeavours (forms of occupation) simultaneously. Occupation as process engages performance components such as the thinking, feeling, motor and physiological dimensions of the person including a sense of self, cultural identity, spirituality and interpretive understanding associated with what is being done. Other meta-determinants of human behaviour such as gender, race, ethnicity, ability, history, ecology and politics also influence occupation as process at an individual level (Hocking, 2000). It is tacit and symbolic; embedded in discursive social practices, values and norms. This means that particular indigenous ways of 'being' and 'knowing' influence the dynamics of 'doing'. For example, when the Nguni people of Southern Africa say a person *uyaphila /o ea phela* (he or she has life), they are referring to more than biological life; the person has a relationship with his/her milieu (seen and unseen realm) that influences what is done and what happens in the doing space (Mkhize, 2004). The concept of 'person' in isiXhosa culture is that of 'person-in-relation' (Mkhize, 2004, p 40). Personhood is earned; it is a 'processual' nature of being; an unfolding of becoming and belonging through shared doing. It is through participation in community that a person finds meaning in life. Ways of knowing are passed between the parts (individuals) and the whole (collective). Occupation as process means that one does not only know by watching but also by participating. The occupational form, for example slaughtering a beast, cannot be separated from the processes underlying the act which are imbued with cultural and spiritual meaning and gendered injunctions for example the tasks and activities of slaughtering are seen to be masculine while those associated with cleaning the meat, cooking and selling are considered feminine. This applies to many other occupations for example those associated with the circumcision rites of passage for young men; the celebration of significant events such as weddings or the feeding of clan members who gather to appease ancestors after some adverse event in the household such as a death or a natural disaster.

Occupation as means refers to the use of occupation as the vehicle or mechanism for achieving a particular set of outcomes. Occupation as form (for example scraping and washing intestines for sale) and occupation as process (for example imbedded cultural values and knowledge about this food source) are integrated with occupation as means (for example its use as the vehicle for securing a particular outcome, in this instance money). Occupational therapists use occupation as the means (mechanism) of addressing the functional implications of health conditions that is, the ordinary things that people do and need to do everyday becomes the focus of and conduit through which intervention and change occurs. Looking beyond individual therapeutic actions, Wilcock (2006) has argued for an occupational perspective of public health in which occupation offers a means for health promotion, quality of life improvements and prevention of health risks. From a development and socially engaged perspective, it could be argued that occupation, in the context of poverty, is the means for securing livelihood, promoting various forms of capital and for enhancing potential and agency. I now briefly explain the research background to the case story.

Background to the case story

The single case study, on which this presentation is based, forms part of an ongoing, longitudinal qualitative research project in the Division of Occupational Therapy at the University of Cape Town (UCT) that is funded by the 'Poverty and Inequality Node' of the South African Labour and Development Research Unit (SALDRU) at UCT and the South African Netherlands Partnership for Development (SANPAD). With the aim of investigating the relationship between poverty, disability and occupation (PDO), the study objectives focus on a description of how households and in particular their disabled member(s), view, orchestrate, draw meaning from or attribute purpose to, and cope with their circumstances through the everyday things they do. Theorised within occupational science (Yerxa, Frank, Clark et al., 1990), the purpose of the study is to guide the development of contextually relevant occupational therapy practice. Ten disabled participants and their households were purposively sampled in one peri-urban (Cape Town) and one rural (Eastern Cape) district using the following inclusion criteria: a household size of at least three people, one of whom was a disabled person and the other a key informant sufficiently familiar with the disabled person and the household to give substantive and augmentative information; income of not more than R740 per month (amount of disability grant at that time) for every adult or adult equivalent (i.e. two children under 15 years); more than three years duration of poverty and degree of vulnerability based on a scale developed by the researchers. Maximum variation sampling was indicated in terms of age, gender, history of disability, residential locality, and socio-economic and family history. Finding households that met the inclusion criteria occurred through snowballing

technique and the assistance of community health workers associated with two Disabled Peoples' Organisations (DPOs). Approximately half of the disabled participants in the sample had to have a severe physical health condition or impairment, while the other half had to have a history of enduring mental illness. Using collective case study methodology (Stake, 1995), all participants signed informed consent (Duncan and Watson, 2009, in press) indicating their willingness for prolonged engagement over a number of years in a range of research methods including semi-structured questionnaires; focus groups; observation and a series of in-depth interviews. Qualitative data was captured, translated and transcribed with the assistance of isiXhosa interpreters after which the content was thematically analysed, critically interpreted and triangulated through member checking. The findings are being disseminated through feedback sessions at multiple levels including local community structures; DPO's; government departments and professional publications (K & Duncan, 2006; Watson & Duncan, 2008, in press). The following selected aspects of a case story highlight four factors that pre-empted, mediated and supported the agency of a particular participant whose story is representative of other people in similar circumstances. It also illustrates the capability of a psychiatrically disabled person to maintain a sufficient level of productivity to secure a meagre livelihood for her four member household through the strategic use of her occupational skills and limited resources.

Case story

Dorcas, now aged 55, was born and raised near Mount Freire in the rural Eastern Cape. Like so many other households at that time, her father worked on the mines in Johannesburg and sent remittances home whenever he could. Her mother contributed to the family income by selling indigenous medicinal plants foraged in the Transkei mountains. The youngest of five children, Dorcas learnt from an early age how to tend the soil, plant and harvest maize and vegetables, mind livestock, raise poultry, crochet scarves, knit jerseys and run a homestead. Each family member was allotted chores and everyone contributed to the livelihood of the household irrespective of age.

- **A first factor supporting agency and productivity an ability to access her occupational genesis which instilled a work ethic and equipped her with informal trading skills during early childhood. She would recapitulate these activities, tasks and roles throughout her life as a livelihood strategy.**

"... we were planting seeds and each and every child had his own plot. We used to wake up in the morning and irrigate our plants, after that clean the house then prepare the meal. After we have done all that we used to do our parent's washing and go to the bush to look for wood.

Then we irrigate the plants again in the evening ...". Girl children crocheted wool products (scarves, hats, jerseys, bedspreads) which they sold at a local trading store. Boy children herded livestock and tended the land. Dorcas's eldest brother bought a knitting machine and everyone in the household took turns in working the machine to produce knitted garments for sale and personal use. *"... we were crocheting wool bedspreads, mats, socks and children's hats and wool overalls to sell ... so that's what me and my sister did to help the family in poorness ..."*. One brother bought newly hatched chickens in bulk and each member of the family raised an allotted number of chickens for sale, in the process learning to budget, plan, solve business problems and save enough profit to buy the next batch. *"... my brother had poultry... he put them in a box with a lamp for three days so they grow perfectly without cold and we used to divide the chickens so each person had a few themselves. Then after three months we would sell them so that we can have money ..."*. Dorcas's older brother, at this stage working at a dairy in Cape Town, sent home second hand clothes for his sisters to sell. Dorcas learnt how to trade clothes, a skill that would prove to be very useful later in her life when she moved to the city. *"...people who came from Cape Town used to bring along the second hand clothes and we barter with them. We use to take woods to those people and get second hand clothes in return which we then sold ..."*.

- **A second factor supporting her agency was having first hand experience of occupations linked to a network of distributed human capital. She learnt how to barter with occupation within a social network that operated to ensure the livelihood of the collective.**

After her father's death, when Dorcas was 12 years old, her mother distributed the five siblings amongst her extended family to raise. Dorcas, raised by an aunt, completed Grade 7 at a Catholic school. *"... my mother divided us and put us on other homes for work. I was put on the location called ... I went there to study and baby-sit my cousin's baby. Those people educated me ..."*. In return for accommodation, each child was expected to contribute something towards the livelihood of the household where s/he was placed such as shepherding, livestock husbandry, ploughing fields and caring for younger children and housework. *"... we used to plough maize and cultivate that ... we had bags of maize and beans to sell to get money so our brothers could get circumcised ..."*. Later in her life Dorcas would also look after a niece in a trade off of human capital for financial capital when she took in a ten-year-old niece to look after her grandchild when she (Dorcas) was out selling second hand clothes. *"... I was given this child by my family since I cannot wash my clothes so she is doing my washing, looking after the baby and I am educating her (referring to cultural role training and not schooling) ..."*. Dorcas was able to remain productive by resolving functional,

financial and other life challenges through bartering and negotiating support within an extended clan system.

- **A third factor influencing agency was the use of cosmology, values and beliefs to provide a rationale for and meaning to role performance and illness behaviour.**

In 1966 Dorcas married a shepherd with very few assets. According to culture, she was expected to move to his clan location where she had to serve the older women while continuing to secure an income by cultivating and selling vegetables and crocheting goods. *"... I got married to a very poor shepherd who was staying with his parents ... I was under that family and I was very unhappy ..."* . Dorcas reports that the marriage was very unhappy mostly due to a clash of values and beliefs. *"... I was bewitched. My man wanted to get rich and got himself a big snake from a witchdoctor that he believed would bring him wealth. I was not supposed to see that snake and when I saw it I became ill. I was shocked by the snake he received from the witchdoctor. The spirit of the snake shocked me purely because I did not agree with what my husband was doing and we fought about it daily ..."* . The snake, a river spirit, is considered very potent. It is capable of multiple metamorphoses, including masquerading as a woman who seduces married men. Illness caused by seeing the snake is always considered more severe and may even lead to death if seen without the necessary ancestral protection]. Dorcas had her first psychotic breakdown in 1979 as a result, she says, of bewitchment. *"People go to witchdoctors that bring them wealth but then these snakes are dangerous, not everyone should see them. As the wife of that man I had to accept the snake idea if I wanted to be okay with it and not get ill when it comes to my sight. I became ill because I disagreed with the whole idea basically. I told my husband he did not have to go far because we are not living alone here on earth, there are other people who can help us but he said he did not want to be a beggar all his life so he went to the witchdoctor ..."* . Floridly psychotic, Dorcas set fire to two huts causing her husband's family significant asset loss. She was bound up and locked away for two days until her family sent an ambulance to take her to a psychiatric hospital where she stayed for an indefinite period of time (she is unable to recall). *"... my maiden family is evangelist Christian and my family-in-law is very much into ancestors and rituals and witchdoctors and in my family that is not accepted. The blood of Jesus is what we believe in. My maiden family took me from my family-in-law by force and they took me to hospital and to church for healing...."* . Dorcas continued to operate within a syncretic cosmology, believing that her productivity and endurance was motivated by external forces.

- **A fourth factor shaping agency was the active use of a support system to help her manage her illness behaviour, the demands of her business and the consequences of social stigmatisation and marginalisation**

Dorcas had a number of admissions to psychiatric hospitals in Cape Town for psychotic behaviour, such as running around naked in public and becoming generally unruly and irrational. “ ... (friend speaking) *Dorcas must not be shocked ... when she is shocked she becomes ill ... you know 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 ...*”. She received monthly anti-psychotic medication which causes extra-pyramidal symptoms such as hand tremors, a drooling mouth and fatigue. As a cost saving initiative, public mental health clinics are supplied with a very limited, and often outdated, range of medication. This means that the side effects of the medication are often as debilitating as the mental disorder itself. Her older brother took responsibility for her and she had one close friend, Modloko, who looked after her on a daily basis. “... *she (Dorcas) does not have anybody to help her not even with her household chores ... I (Modloko) check up on her and find she is ill then I clean her house and sometimes even bathe her ‘til she is better ...*”. Dorcas acknowledges the significance of this friendship with Modloko who is also her business partner. “... *when the illness starts I pray that Modloko will come and lock me up here at home and give me my medication and I lie down so that I do not make a nuisance of myself ... When I am ill I am not a good sight ... I take off my clothes and try to run away ...*”. She has to adapt her occupational performance according to her fluctuating mental and physical health, run her home and manage her business all the while tolerating public abuse. “... *even when I go to the tap to get water the children make fun of me calling me ‘rakie’ (mad person)... ; ‘... sometimes people take their waste shit and put their toilet in a plastic bag and put it by my front door ...*”. Faeces may be used to convey a curse or it may be used to ward off a curse believed to originate from Dorcas because she is mentally ill. “... *some can be very cruel to mentally ill people like me ... they try to fit some clothes on and tell you it’s too small, but they continue until the clothes tear and then leave them so I cannot sell them ...*” “... *some boys came and threatened me with weapons ... they tore the clothes and left them there ... I think they did that to me because they know that I am a mentally ill person and I am too old to do anything to protect myself ...*”. “... *people tease Dorcas in many terrible ways ... when she is sitting there they do not take her seriously ... they still think that her selling clothes is part of her illness and not just a business like everyone else’s ...*”. Dorcas’s disabled son, Christo, shares a similar story of prejudice. He carries his best friend, a cat, in a bag on his back wherever he goes because two previous cats have been stoned to death or severely injured by people in his community who believe that his disability is a sign of witchcraft.

Being a disabled entrepreneur

I now turn the story towards Dorcas's agency and productivity as an entrepreneur in the informal sector. In so doing, I foreground two potentially significant contributions of socially engaged occupational therapy: strengthening the entrepreneurial capacity of disabled people living in poverty and demonstrating that, with appropriate infrastructure, disabled people are able to be productive, contributing members of society. According to Narayan (2005, p. 3), poor people are trapped in poverty because they are barred from opportunity and therefore live their lives with little expectation that "tomorrow will bring anything good except their arduous work". Although their freedom of choice to take action and shape their own lives is hampered by limited access to the resources and opportunities needed to maximise their assets and capabilities, their occupational performance nevertheless enables adaptation to the demands of the context. When this health status becomes irreversible they are eligible for a disability grant, which in households surviving chronic poverty, may become the main or only stable source of income. Disadvantaged on multiple levels, the individual and his or her household must then find ways to stretch the meagre grant amount and whatever other monies do become available, not only to make ends meet but also, if possible, to finance other income generating enterprises. Poor households and disabled entrepreneurs, in so doing, contribute in substantive ways to the informal economy. It is here that socially engaged occupational therapy can make a significant contribution to equity, social justice and development.

Conventional development wisdom is that disabled people are incapable of earning an independent living, are economically dependent and a quantifiable burden on society in terms of treatment and social security costs (Devereux, 2002, cited in Mitra, 2005). He states that disabled people "survive by being cared for within their families or communities by institutional redistribution from the state (funded by taxes bid by the economically active) or by charity and begging which is a form of work ... disabled people are not expected to participate in livelihood programs yet benefit from cash transfers" (*ibid*, p.6). Such narrow medicalised conceptualisations of disability demonstrate little appreciation of the personal and economic costs associated with marginalisation nor do they recognise or affirm the rights of disabled people to be included as equal, productive citizens (Oliver, 1996; Seirlis & Swartz, 2006). Baingagan (cited in Miller, 2006, p. 461), a Ugandan psychiatrist advising the WHO on mental health issues, warns that policy makers do not have enough evidence to recommend investments in mental health services in poorer countries. He suggests that "...convincing sceptics will require demonstrating the economic costs of untreated illness more clearly and countering the persistent view that a person with a mental disorder will never function at a normal level ... [W]hen we show that people with neuropsychiatric disorders can be productive, then we will have greater interest". Socially engaged occupational therapy can work alongside

disabled people in challenging the views of policy makers and sceptics. I now use a stepwise macro occupational analysis (Hagedorn, 2000) to highlight Dorcas's productivity and agency in selling second hand clothes as a livelihood occupation.

Macro occupational analysis of being an informal trader and entrepreneur

1. Principles of the occupation

Dorcas recognised the **principles of business in relation to the general state of the economy, including how the rise in unemployment impacted on the profitability of her enterprise, the occupation of selling second hand clothes.** She supported two adults and two children on a disability grant of R870 and two childcare grants ranging from R90-R120 per month (grant amounts at the time of the research). For a while after her first discharge from hospital in Cape Town, Dorcas ran a spaza shop from her home selling sweets and cigarettes. But the competition from neighbours doing similar income generating projects reduced her profits over time. She then decided to start a second hand clothes business recapitulating occupations and small business skills acquired as a child. *"... I was very poor, not receiving a grant, living with my brother. He was working at night and came back in the mornings. I was very hungry, struggling to get something to eat. I decided to sell clothes during the day while he was sleeping. I would use that money for food ..."*. When she first started the business she had the finance and the energy to travel long distances by public transport to acquire stock from bulk sellers of second clothing in an industrial area of Cape Town. *"... I used to sell chips and sweets from my house and people used to buy a lot of those from me. The business was really running smoothly. As time went by there were too many other people who sold the same things and I saw my business was becoming worse and worse. I chose then to sell clothes instead, clothes do not spoil like food and they do not get rotten. It's the best way to go about making a business now ..."*.

This viability of the business changed as transport became too costly, her physical stamina deteriorated and she discovered the benefits of bartering cutlery and Tupperware for old clothes. *"... when I started I would go to Kraaifontein waking up at 4 am. When I get there I sit and wait for the trucks that are selling clothes, when we were still buying clothes. We do not buy clothes now. We simply ask around for clothes by exchanging with cutlery, ornaments and Tupperware (plastic containers) here in Mitchell's Plain (a closer suburb) ... 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 ..."*. *"... in previous years people used to buy a lot from me and my business was running smoothly but this year (2006) has been just another bad year ... people do not have money out there like in the past, they do*

not have jobs, so if few of them are working I will not see success in my business because I depend on them ... from my side our business is running beautifully ... if people are generally working then we get money as well but if they are poor and unemployed then it is difficult for us to get money from them ...”.

2. Purpose of the occupation

Dorcas linked **the purpose of selling second hand clothes to her household livelihood** stating that the ostensibly meagre income, “... *the little ten Rands ...*”, often made the difference between eating and not eating. She saw this purpose as overriding the demoralising personal costs of keeping the business going.

“... if I don’t sell clothes and just depend on the grant, I am unable to make enough groceries ...” “... we (Dorcas and Modloko) get tired but we are motivated by the fact that we have got nothing to lose but all to gain by walking so far ... we get clothes and even food for our children that way ...”. “... but the business is not going anywhere ... sometimes there are too few customers and you return with only R10 for the day’s work ... there is nothing better than if you do not have enough money because what if you do not have electricity or paraffin? ... You buy one of these two and the money is gone ... At the same time we are motivated to stay there because we know that nobody else will give us the little R10’s we get there ...” .

3. Processes of the occupation

Although Dorcas **discerned and adapted to the social processes involved with trading second hand clothes**, she was also subject to harrassment and financial losses when people could not repay debts owed for clothes taken on credit:

“... at first they (people in a more established neighbourhood) used to give us (clothes) for free but then they realised we were making money out of their clothes so the stocking system changed. Now it is an exchange type of stock where we buy Tupperware and exchange it with them for clothes. I take those clothes, bring them home to sell and make money to buy food ...”
“... people do get fed up with us ... they say ‘we do not have money’ before you even tell them you are selling not begging ...”. “... sometimes ladies and youth come in to my dwelling to buy because they were embarrassed to buy from the street corner while everyone is watching, they ask for my address and directions because they do not want people to know they are poor ...” .

While Dorcas understood the bartering and buying behaviour of her clientele and adjusted her selling techniques accordingly, she remained vulnerable to exploitation, even by her business

partner. Her friendship and business partnership with Modloko appeared to be based on a mutual trade-off rather than trust, suggesting that social capital was not necessarily beneficent.

“... she (Modloko) is a thief, her children are thieves. She accepts stolen goods and we see police going to her house ... she is getting lazy and going deeper into stealing and selling stolen goods ... she helps me when I am sick and I give her paraffin, rice and other items when I get my grant ...” . *“...sometimes people take clothes on credit and then they wear it and wear it and wear it and when I go collect my money they just give me my clothes back with no explanation ...”* . *“... people ask for credit and in the end they cannot repay and get angry when we want our money ... in 2001 I got beaten up by this other lady who took clothes on credit from us ... I was hospitalised ... we tell them we do not have money to buy food, we depend on the money they are withholding from us and then they simply tell us ‘we also don’t have’ ...”* .

4. Patterns and positions of the occupation

The action patterns and geographical positions of the second clothes business influenced the volume of trade it was able to generate. Dorcas modified the physical positioning of her business to accommodate trade patterns, the weather and her fluctuating health: *“... we use the weekdays to collect stock from Mitchell’s Plain ... we sell on Fridays and Saturdays ... sometimes we put clothes out on a Sunday depending on the mood of the weekend ... we leave home at anytime whether it be 12 pm or 8 am it really depends when we are ready to leave our homes to go sit there on the corner all day ...”* . *“... we used to sell in Site C at the taxi rank but more and more taxis are joining the rank and it became too full around the spot where we were stationed ... there was too much competition ... now we are just selling here on this street corner ...”* . *“... we were looking for a place where lot of people pass ...”* . *“... we go door to door selling when it’s raining and the wind distracts our set up. So I take the bags and go house by house selling clothes. Sometimes you get something, sometimes you get nothing ...”* . *“... sometimes I do not go to the street corner because my feet are swollen but the business does not stop there ... people even come to my shack to find things they saw on the street corner and I get it out for them and boom!! ... R50 comes in with little effort ...”* .

5. Products of the occupation

Second hand clothes have to be in good condition, clean and reasonably priced. Dorcas and Modloko developed **a system of preparing, storing and displaying products** including contracting out certain of the tasks associated with getting clothes into good enough condition

to sell when Dorcas is unwell. However, contracting out has cost implications that have to be subtracted from the profits or subsidised from the disability grant.

"... I look at the faults of the clothes for example I look if the zip is functioning and all the buttons are there, then its when I value it but if there is something wrong with it, I will lower down the price ...". "... we don't fix very torn clothes ... we just throw them away ... the clothes must look unused even though they are second hand ... we wash dirty clothes all the time, iron (using wrought iron heated on open fire) them before they are laid out at the street corner ...". "... you get home, you sift the clothes, take your wash tub and start washing right away ... sometimes she cannot handle that so she asks someone to do it for her ... Dorcas hires someone to do it for her at the charging rates of R10 to R20 which she usually pays when she gets her grant ...".

6. Practical requirements and performance demands of the occupation

The **practical requirements and performance demands of selling second hand clothes** included storage space in small, cramped shacks, having to walk long distances to collect and carry stock, setting up and taking down the clothes display on a dusty pavement with no protection from the weather as well as budgeting. The overheads of the business, for example buying large black plastic bags to carry and store clothes in, paying 'sub-contractors' to wash and iron the clothes and purchasing enough bartering stock (cutlery, ornaments and Tupperware), were all intricately monitored to ensure maximal profit or gain which is not always monetary. Clothes could, for example, be used to secure credit and storage at the nearby Rastafarian spaza shop Dorcas estimated that she put aside approximately half of her daily earnings (trading two days a week) towards bartering stock. Her net profit in a good month, often shared in kind with Modloko, ranged from R300-R400, depending on a number of factors such as quality of clothes collected, number of days worked, weather and debts owed.

"... we keep some of the profit so we still have some money to buy Tupperware for the Coloured in Mitchell's Plain because that is how we barter for clothes ... we put aside about half of our profit for bartering, the rest we use for fuel and food ... like if we get R30, we will put away about R12 for more Toppers ...". "... we do get tired because these places are far for us to walk the distance (28 km) but we cannot help that because this is our only way of trying to help ourselves ... "... the biggest challenge is the actual selling of these clothes at the street corner ... we get attacked by dogs and we must clean their shit away before laying out our clothes ...". "... I store my stock with the Rasta, he is my homey because I have no space and it is too far to carry heavy bags ...".

Dorcas had bipolar mood disorder. Demands on biopsychosocial performance components such as critical thinking, problem solving, memory, volition and mood are numerous in an occupation such as selling second hand clothes. The capacity of intention, that is, the ability to apply rational thought, energy and motivation towards goal directed behaviour was affected making it difficult for Dorcas to achieve and maintain optimal productivity, especially when she relapsed. Volitional and drive dysfunction, coupled with enduring affective and cognitive impairments such as thought disorder and unstable mood, made it difficult for her to engage effectively with the functional demands of everyday life especially as her medication began to wear off. "... I (Modloko) make her loads easy to carry and monitor her so that she does not get tired quickly ... that's how I help Dorcas ... she has problems walking long distances but we stop along the way and try hitchhiking because Dorcas is a bit old. She shakes very much when she is tired. Sometimes people give us lifts there and back to help us ..." . "... we use less energy selling here on the street corner closer to her home and within reach of her strength and endurance ..." . "... I (Dorcas) get so tired and frustrated by the business that I sometimes feel like going to bed for the whole day and sleeping because I cannot handle it but then no-one works and brings in money when I am ill ..." . The impairments associated with mental illness erode the agency and resilience of people making it all the more important to have an efficient public health service that provides the necessary medical and social support for example easy access to medication and/or community based rehabilitation that will underpin the capacity of poor people to sustain a livelihood.

Discussion of the case

Appadurai (2004) notes that successful development involves more than redressing material deprivation. It means having a sense of agency, feeling that you can influence what affects your life, that you have a voice because you belong and that you have the means to choose your identity and that you have access to opportunities to realise your potential through goal directed action. Poverty and disability only have meaning in the contexts where they exist. What one person considers the bare essentials for life may differ radically from someone else's depending on culture, climate, politics and a range of other personal and social factors. The disrespect of others and Dorcas's own feelings of exclusion, powerlessness and discrimination are however common to poor people wherever it is that they struggle to survive (Godinot, 2003). Listening to what Dorcas had to say about her experiences revealed the meanings and crushing burden of her deprivations (Narayan, Chambers, Shah *et.al*, 2000). Employment alone will not lift people out of poverty. A more intensive skills growth path is indicated. Poor people suggest that poverty is not merely about being unemployed, suffering materially or being discriminated against. Poverty also erodes their capacity to aspire.

Unemployed, unskilled and disabled workers require exposure to a variety of experiences and opportunities to reverse the stagnation of their abilities. The ability to do a job well, participate meaningfully and develop as a person depends on a range of occupational performance building blocks, including knowledge, skills, attitudes and values. Watson (2005) asks us to consider what human resources are available within the multiple capabilities of each household that are either keeping people going or are not yet utilised, and therefore available and waiting to be developed? What lessons can we learn from Dorcas's story and what does it say about socially engaged occupational therapy?

Lessons from the case study

- A sense of self-efficacy may be developed during childhood through the guided performance of necessary, livelihood and committed occupations.
- Lifelong learning opens up horizons of choice. Self-efficacy and agency in adulthood may be regenerated by recapitulating childhood occupations.
- Psychiatrically disabled individuals can be economically productive provided they are supported in actively managing their mental illness, for example by adapting their productivity to match residual functional abilities with adequate support and a facilitatory infrastructure
- Strategic use of the disability grant sustains informal businesses.
- Structural barriers consistently place a ceiling on the agency of individuals.

Tentative recommendations for practice and further research

- Socially engaged practice will interface with public health and primary health care philosophies and approaches. The most pressing recommendation is therefore the most obvious one: faster roll out in meeting the basic human right to live in a decent house with access to basic amenities that enable people to realise their occupational potential.
- Investment in poor people's assets and capabilities on a large scale requires changes in the opportunity structure within which they pursue their interests (Narayan, 2005). This means that increased access to, ownership and control of physical and non-physical spaces to 'do' are indicated. For example, Dorcas obtained gardening and sewing certificates, but it is of little use as she has no land to cultivate nor does she have a sewing machine or enough space in her shack to sew. Communal activity

centres linked to regulated credit organisations that support informal entrepreneurs will create the kind of opportunity spaces in which people may multiply their agency. Given Dorcas's innate business acumen and self-efficacy it is likely that she could have prospered towards a marginally better life if she had free access to basic business guidance, ongoing entrepreneurial support (for example a co-operative of other second hand clothes dealers), regulated credit facilities and even a small plot of land for home-based or communal gardening.

- Although Dorcas attended the local mental health clinic monthly for many years she reports that no-one ever told her about the availability of community-based psychosocial rehabilitation. Having access to collective support systems would strengthen social networks, provide information, foster a sense of inclusion and participation, promote accountability and mobilise local organising capacity - all precursors for the fight against social attitudes which marginalise disabled and poor people.
- As the profession grows towards socially engaged practice, we will need to pay greater attention to the relationship between poverty, disability and occupation. Embedded in such an understanding will a commitment to the politics of diversity in our education, service and research including the deconstruction of Eurocentrism, affirmation of indigenous knowledge, development of cultural competence and the promotion of equity and social justice.

Conclusion

This presentation has demonstrated that being able to shape one's own life in accordance with one's own development objectives is subject to prevailing circumstances and the context in which one finds oneself. For poor people like Dorcas, that context is always the site of powerful social forces that impose barriers to economic and personal freedom. It has argued that the counter forcefulness of discursive factors deserve particular service, research and education attention as well as practical support on the ground, where real people live real lives against real odds. The linkages between unemployment and poverty suggest that low skilled and unskilled people stand very little chance of ever having a full time job, much more so those living with a chronic health condition. They may not have skills that are needed by the formal economy but they do have agency and occupational potential that deserve, as a basic human right, opportunities for creative expression and economic application. Socially engaged occupational therapy will seek to make this a reality.

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