

DUNCAN RESEARCH PROJECT

Project Title:

AN ANALYSIS OF THE LIVELIHOOD OCCUPATIONS OF ONE WOMAN WHO IS SURVIVING CHRONIC POVERTY AND PSYCHIATRIC DISABILITY IN AN INFORMAL SETTLEMENT IN CAPE TOWN

Project Purpose:

To generate knowledge about the occupational needs and capacities of persons living with enduring mental health concerns in environments characterised by structural violence and chronic poverty. This understanding will inform the implementation of community based mental health and social occupational therapy including psychosocial rehabilitation.

Literature Review:

Scholars, advocating for the development of a new occupational science and for attention to the majority, developing world, have started sharing multi disciplinary perspectives about human occupation as a central feature of individual experience and social organization (Christiansen & Townsend, 2004; Hasselkus, 2002; Wilcock, 1998). An unprecedented occupation focused study about poverty conducted by an occupational therapist in South Africa, revealed how one woman survived a life of poverty through diverse, innovative self-initiated occupational strategies (Fourie, 2002). The constant and all consuming struggle to make ends meet however left her exhausted and unable to pursue the few choices or escape routes that did come her way. Fourie (ibid 2002) demonstrates how the epistemology of human occupation may be advanced through qualitative research guided by feminist ideology. The occupational strategies used by Xhosa speaking research participants are likely to be influenced by an 'unwritten corpus of long-standing customs, beliefs, rituals and practices that have been handed down from previous generations (Guma, 2004)'. Guided by Afrocentric epistemology and critical theory (Creswell, 1998), this proposed minor research project will focus on literature that promotes an understanding of the occupational human living with chronic mental illness and livelihood occupations in contexts of poverty, deprivation and vulnerability.

Poverty Dynamics

Existing development research is prolific and increasingly focused on nano-level descriptions of

poverty. Hulme (2003) for example, offers a compelling rationale for the steady decline into destitution of a two-person family living in Bangladesh. They survive on informal loans, borrowing, charitable gifts, bartering; state social security and begging. Their decline may be traced to social exclusion based on gender and disability; major health 'shocks' and poorly regulated private and civic action. The relevance of a critical-emancipatory research paradigm in seeking explanations for poverty dynamics is evident. Of interest here is that Hulme (ibid, 2003) states...' it points to the personal agency of Mofizul and Maymana(they) are not poor because of any lack of action on their part. Their agency may be severely constrained by a host of structural factors but they are constantly seeking out ways of improving their position -they may be down but they refuse to be out (p.17)'. Guided by critical theory and, where indicated, by feminist approaches, this project will review literature that sheds light on agency and resilience as it manifests through the occupational strategies of one person coping with psychiatric disability.

Psychiatric Disability

Adherence to the social model of disability in accordance with the South African National Integrated Disability Strategy (Mbeki 1997) and corresponding critical theory, will guide both the process and outcome of this minor research project. Disability, in the social model, is viewed as a political issue and a social construct situated in prejudice and subsequent marginalisation of persons living with physical and/or mental impairments. It argues for the full integration, equalisation of opportunities and social inclusion of disabled persons (Duncan 2004). This has implications for understanding the dynamics of poverty in poor families because many survive on the disability (or other social service) grants of disabled household members. Despite the impact of their psychiatric impairment on productivity and participation, disabled individuals are able to demonstrate resilience and innovation in sustaining a livelihood. This resilience needs to be better understood and optimised by professionals seeking to promote the psychosocial rehabilitation and social inclusion of disabled people. The influence of indigenous ways of knowing; unemployment and an under-developed public service makes it difficult to operationalise the emancipation and Eurocentric ideals associated with the social model of disability (Alwan, 1999). Indigenous explanations for living with and managing disability in the context of poverty are therefore indicated (Cohen, Kleinman & Saraceno 2000).

Protocol:

Aim of study

This study aims to provide a detailed macro and micro activity analysis of the livelihood occupations of one woman living in Site B, Khyalitsha, an informal settlement in the Cape Metropole

Objectives of study

The objectives are to:

- describe the macro livelihood occupations visible in Site B, Khyalitsha
- profile the index disabled participant detailing her demographic features and disability status with reference to mental state, activity limitations and participation restrictions
- describe the meaning and purpose of livelihood occupational forms & roles as perceived by the research participant
- macroanalyse the most significant livelihood occupation with reference to its sociocultural attributes, principles, positions, possessions, patterns, products and processes

Specific research questions:

- what meanings are ascribed to the survival occupations (or lack of occupation) that the index person participates in by herself?

What meanings do significant others attach to the occupations (or lack of occupation) of the index person?

- how does the index participant's demographics (ie. age, gender, race, religion, ethnicity, ability, socio economic status, mental health, education etc) affect his/her occupational engagement in this geographical location with this occupation?
- why was this particular occupation chosen by this person and not others?
- what is the livelihood potential of this occupation ?

Methods, methodology and approach

The study will make use of occupational science (Zemke and Clarke 1996) and activity analysis (Hagedorn, 2001) methodology. The approach will be participatory and based on client centred practice principles (Christiansen and Baum, 2001).

Research Environment

The geographical location for this study will be in the participant's informal house in Site B, Khyalitsha as well as on the sidewalks where she sells her goods.

Sampling:

The participant is currently a research subject in an existing lead study by the grant applicant. The sample in the lead study consists of fifteen households with a member who has a psychiatric disability. The participant is purposefully and conveniently sampled because she is information rich.

Gaining Access and Ensuring an Ethical Stance:

Access to her household has already been gained through gatekeepers from a service organisation (Cape Mental Health) who has existing relationships, trust and good reputation with disabled clients and their households in Site B

In keeping with the social model of disability , participants in the lead study are considered equal partners in the research process by:

- negotiating access through recognised advocacy channels. A presentation of the lead study was made to consumers (C M H Advocacy Group and representatives of the PGWC Wellness Group) requesting their assistance in identifying households who meet the inclusion criteria (see below) and who may be interested in participating in the research.
- securing introductions to the identified household through appropriate channels. Once permission was granted by consumer representatives, gatekeepers (social workers) in the key geographical areas were approached to identify fifteen households with one known member who is:
 - currently being treated for a mental illness or
 - has an intellectual impairment that precludes him or her from gainful productivity in the formal labour market or
 - has a history of admission to one of the three psychiatric hospitals in the Cape metropole or
 - is a member of a CMH psychosocial rehabilitation support group
- ensuring that the gatekeeper negotiates participation in the lead study with selected households and index persons prior to introducing the researchers to them.
- clarifying expectations, conditions and terms of participatory research (De Poy & Gitlin,1994) namely: informed verbal consent, confidentiality, anonymity, freedom to withdraw at any time, negotiated feedback and discussion about research results
- explaining limitations (the research will not lead to direct action besides referral to appropriate resources if indicated) and benefits (a small monetary token of appreciation to the value of R30 per interview).

Approach

- the researcher will conduct all visits in collaboration with a graduate (social or health sciences) Xhosa-speaking research assistant who will be an occupational therapist.
- the research assistant will be familiar with activity and macro occupational analysis and will follow the interviewing process through in-situ translation for and with the primary researcher as needed
- the researcher and research assistant will visit the research participant a minimum of two and a maximum of four times to gather data (depending on capacity of the disabled person to give a rational account of herself on the day of the visit). The number of visits will be determined by data saturation and will occur over a period of two months.
- a client-centred approach will ensure that the needs of the participant rather than the research agenda drives the data gathering process.
- each session will be tape recorded and backed up with written field notes. The translation and transcribing of the tapes will happen simultaneously and will be reviewed prior to the following visit to inform the focus the interview based on the specific research questions .
- interview sessions will last approximately one and half hours.

Data analysis and interpretation will:

- commence with NUD-IST computer program as an adjunctive conceptual network builder.
- be guided by the five forms of analysis and interpretation of case study research suggested by Stake (1995) and Cresswell (1998) namely categorical aggregation (a collection of instances from the data that hold issue-relevant meanings); direct interpretation (drawing meaning from single instances by pulling data apart and then putting them back together in more meaningful ways); patterns (looking for correspondence between two or more categories); naturalistic generalisations (lessons learnt) and description (comparisons and contrasts with published literature).
- be integrated into appropriate case study reporting structures recommended by Stake (1995) and Yin (1989) for building ideas about the form, function and meaning of the livelihood occupation.

Quality Control and Verification

The trustworthiness of qualitative, descriptive methodology depends on the process of triangulation of information (searching for convergence of information) from multiple data sources (namely surveys, interviews, checklists, observations, field notes), theory, methodology and investigator reflections (Stake,1995). Additional attention will be paid to standards of quality and verification by:

- bracketing researcher bias emanating from cultural difference by personal journalling and fieldnotes

- member checks in which the credibility of the findings are scrutinised by participants. The participant is illiterate and findings will therefore be checked by key informants such as gatekeepers (social worker with CMH) or alternatively presented verbally to her.
- external auditing of findings and interpretations by an occupational therapist not involved with the project

Deliverables -What are the expected outputs of this project? [publications, new techniques]

One publication in SAJOT

Inform doctoral dissertation ; possibly one chapter

One conference presentation at OTARG Conference 2005, Tanzania