"I call it survival skills "

Living everyday life in recovery.
The experience of five men living with severe
mental illness in Zambia

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Acknowledgement

Writing this thesis has been a challenge, but most of all it has been an opportunity to reflect on my professional experience and to learn more about a subject that engage me deeply. The work with this thesis has brought me back to my first work experience in the late 70's. I was only 18 years old and it was my first real employment. I worked as an occupational therapy assistant in a male ward in a mental hospital with so-called 'chronic patients'. They were older men who had been there for most of their adult lives. They had little hope of ever returning back to the places that once had been their homes. The experience from the work there made an impression on me as a person, but has also influenced my professional career. I chose to become an Occupational Therapist, and my training was greatly influenced of the 'new' paradigm in mental health; de-institutionalization and normalization, where Kristjana Kristiansen was a major inspiration. After graduating I continued to work with people with mental health problems, and now as a teacher in occupational therapy I still feel inspired by these early experiences. Some years ago I had the opportunity to work as an Occupational Therapist in Zambia and I found that my previous experiences were still relevant and useful contributions to the team I worked with in our joint efforts to improve the services for people living with mental health problems. I experienced my work as very meaningful and rewarding. Writing this thesis has in a way rounded up my personal engagement in mental health issues and my history of working with people with metal health problems.

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As for recovery, writing a thesis is both an individual and a social process.

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Abstract

This master thesis is about how people living with severe mental illness experience recovery in the context of everyday life in Zambia. The study is a qualitative research where 5 men between 25 and 40 years were interviewed. The study is guided by a hermeneutical approach and data were interpreted using content analysis.

The background for this thesis is experience from my work in Zambia and recent research on recovery in the context of everyday life. In this perspective the person's subjective experience is central and how the person can live with and master severe mental illness within his or hers community. An everyday life perspective also emphasizes the role of the social context and the material living conditions. International studies has shown that people with severe mental illness from developing settings is more favourable than for people from developed settings. This study does not intend to say anything about differences in different cultural settings. It is only aiming at being a contribution to the growing knowledge about recovery and how it may be experienced by people living with severe mental illness in Zambia. The study shows that the participants to a large degree participate in social settings and have access to valued roles in their community. They present themselves as able, competent, and contributing members of society. They present their ordinary way of being as being well, but this is disrupted by periods of illness and distress. When they are well they seem to be able to maintain their roles as family members and contributing members of their community, but in times of illness and distress their ability to maintain these roles are challenges. The families represents considerable support in periods of illness and distress, but the study also shows how persisting mental illness impact on the whole family and put their welfare at stake. The participants in this study make a distinction between mental illness and madness. Madness seems to be a social category appearing when the support from family and community is exhausted. This study is in accordance with other studies on recovery that shows that recovery takes place in the context of everyday life, where the arenas of everyday life and significant others plays is of great importance and the access to work and other socially valued activities are of significant importance.

Sammendrag

Denne masteroppgaven handler om hvordan personer med alvorlige psykiske lidelser i Zambia erfarer bedringsprosesser i en hverdagslivssammenheng. Det er en kvalitativ studie hvor 5 menn mellom 25- 40 år er intervjuet. Studien har en hermeneutisk tilnærming, og data er tolket ved å bruke innholdsanalyse. Bakgrunnen for denne studien er erfaringer fra eget arbeid i Zambia og nyere forskning om bedringsprosesser i et hverdaglivsperspektiv. I et slikt perspektiv er personens subjektive erfaring sentral og det er fokus på personers egen innsats for å mestre og å leve med psykiske lidelser i sitt nærmiljø. Et hverdagslivsperspektiv vektlegger også den sosiale konteksten, og de materielle levevilkårene. Internasjonale studier viser at bedringsprosesser for personer med alvorlige psykiske lidelser fra utviklingsland synes å være gunstigere enn for personer fra utviklede land. Mulige forklaringer knyttes til større grad av sosial deltagelse. Denne studien kan ikke si noe om forskjeller mellom ulike land eller settinger. Den har kun som hensikt å bidra til mer kunnskap om hvordan recovery kan erfares av personer med alvorlig psykisk lidelse i Zambia. Studien viser at deltagerne i stor utstrekning deltar i sosiale sammenhenger og har tilgang på verdsatte roller i sitt nærmiljø. Deltagerne presenterer seg som dyktige, kompetente og bidragsytende medlemmer av samfunnet. Mens de er friske ser de ut til å greie å opprettholde sine roller som familiemedlemmer og medlemmer av lokalsamfunnet de lever i, men i perioder hvor de er plaget med psykiske lidelser greier de ikke å opprettholde sine roller og forpliktelser. Familien representerer en betydelig støtte i sykdomsperioder, men studien viser også hvordan det å leve med psykisk sykdom over tid setter hele familiens velferd i fare. Deltagerne i skiller mellom psykisk sykdom og galskap. Galskap synes å være en sosial kategori som oppstår når støtten fra familie og omgivelser er oppbrukt. Denne studien er i samsvar med annen forskning om at bedringsprosesser skjer som en del av hverdagslivet hvor hverdagslivets arenaer og nære andre er av stor betydning og tilgang til arbeid og andre verdsatte aktiviteter er erfart som spesielt viktige.

Acknowledgement

Abstract

Sammendrag

1. Introduction

This thesis is about how people living with severe mental illness experience recovery in the context of their everyday life in Zambia. The study describes and interprets how they experience their ordinary everyday life, their participation in the family and community and how periods of mental illness and distress affect their participation in everyday life.

There is no consensus about the term 'severe mental illness' but it is commonly used about enduring mental health problems referred to as schizophrenia, bipolar affective disorders, severe depressions or anxiety(Jordal and Repål 2009). It is used when problems are of such intensity that the persons are prevented from performing in everyday life the way it is expected from the person's social and cultural background (Creek 2008).

Severe mental illnesses have up to recently been seen as chronic conditions with little hope of recovery. But researches from the last years have changed this. Research on onset, course and outcome of schizophrenia and other psychosis-related conditions has proven that severe mental illness can not be regarded as a chronic condition (Sullivan 1994a; Borg 2007; Hopper, Harrison et al. 2007). The WHO International Studies of Schizophrenia (ISOS) from 1978 were the first ones to suggest that a chronic course was not inevitable for severe mental illness and in the years to come there have been a large number of studies supporting this (Hopper, Harrison et al. 2007). A increasing number of studies from people with firsthand experience and users/ex-patients/survivors movements has contributed largely to the knowledge on recovery in mental health (Borg 2007).

The ISOS studies from WHO also showed that recovery from severe mental illness was more favourable in developing than in developed settings, and this has been confirmed by several follow-up studies (Borg 2007; Hopper, Harrison et al. 2007). Though the explanations are still hypothetic Sullivan (1994b) and Rosen (2006) propose that there is a more favourable social environments for people living with severe mental illness in developing settings.

There has been little qualitative research based on experience (Rebeiro Gruhl 2005; Borg 2007) compared to the number of epidemiological studies about recovery in severe mental illness. Most studies are from western settings and it has proved difficult to find studies on recovery from an African setting, especially studies from the service user perspective.

The concept ''recovery' has become very 'popular' and it is widely used and widely debated. There is no unambiguous definition or consensus of the concept. It is being referred to as a an idea, a new vision, a new paradigm, a philosophy, a strategy, a process, a phenomenon, a set of values to mention some (Kristiansen 2005; Borg 2007; Bonney and Stickley 2008) Recovery is also referred to as a field of research and an international alliance or a social movement of sorts. Jacobsen in Borg (Borg 2007) says that: "*The meaning of recovery will vary, depending on who is asking and interpreting, in what context, to what audience, and for what purpose.*"

In this study recovery is seen as a dynamic process where individual as well as environmental perspectives have to be addressed. The relationship between material, social and individual factors are considered as essential to understand recovery. Recovery is about taking back control and finding one's own ways of overcoming barriers and getting on with life, moving towards a state of being empowered, where hope and self-determination regarding ones prognosis and illness is central (Deegan 2001; Kristiansen 2005; Borg 2007). Recovery is not about being cured or elimination of symptoms, but to have the opportunity to utilise the potential within oneself and in one's environment to live a worthy, dignified and meaningful life (Borg 2007; Creek 2008).

A meaningful life is lived in community with others where one share the experiences of the everyday life through participating in valued everyday life activities and performing valued social roles. Everyday life consists of ordinary, 'small' activities like self maintenance, caring for others, play work or socializing. (Hasselkus 2006). Gullestad (1993) says that everyday life is the infrastructure or the cement that binds together the different arenas where we perform our everyday life activities.

People living with severe mental illness may in periods of their lives be hindered from carrying out expected activities and roles in their everyday life because of illness or distress. This may endanger the person to be excluded from the community; the person may be at risk of being devalued and excluded from being a participant in society (Kristiansen 1993; Borg 2007). The issue of stigma is one of the major hindrances for participation and being valued in the community for people with severe mental illness (Deegan 2005; Borg 2007; Kristiansen 2007; Creek 2008).

A recovery perspective on mental health problems implies a change of focus for health providers. Instead of being oriented towards illness focusing on diagnoses and symptoms,

there is need to focus on the individual person in his or her environment, and the resources he or she holds – in him-/herself and in the environment. Health professionals must look for the resources available to support him/her in the process of having a better life (Kristiansen 2005; Borg 2007).

1.1 Background and research question

Some years back I had the opportunity to work as an occupational therapist in a mental health unit in a hospital in Zambia. I was part of a multidisciplinary team and we worked with both in- and outpatients. My role in the team was to contribute with occupational therapy in the development of rehabilitation services at the hospital. The existing mental health services at the hospital were mainly medical treatment. The hospital had limited facilities for admissions and the supply of medication was unstable.

I experienced that people with mental health problems were reluctant to come to the hospital for treatment. The team were approached by the community health workers from time to time and asked to consult people living in the community with severe illness. Some of them were in a severe state when we saw them. Others had been abandoned by the family and chased from the community. These people were usually found roaming the streets in town, much to the disguise for the general public. But I also experienced that some of the persons living with severe mental illness recovered fast and managed to maintain their roles and responsibilities and remained as included members in the local community. These observations triggered my curiosity and led me to my research question:

> **What can we learn about recovery from the experience of people living with severe mental illness in Zambia?**

My intention with this study is to contribute to the knowledge on recovery in an everyday life perspective. As there is little research from the perspective of service users in an African setting, I hope this can serve as a contribution and enhance the understanding of what can be experienced as significant in recovery with a special focus on possible promoting factors. I hope this study can be an acknowledgement of the efforts to cope with everyday life for those living with severs mental illness and their families. I also hope that the study may be useful for health care providers and policy makers in their efforts to improve the social conditions and health services for people with mental health problems in Zambia.

1.2 Structure and content

The next chapter in this thesis is an overview of different perspectives and recent research in the field of recovery in mental health and a conceptualization of recovery in the context of everyday life. Then follows another chapter with theory I have found relevant to use in the analysis and the discussion of the findings from the interviews. In chapter four I present my choice of method, how I conducted the interviews, analysed the material and finally an evaluation of trustworthiness, verification, transferability and ethical considerations. Chapter five is a presentation of the findings where the focus is on the participant's ordinary everyday life and their lives when they are challenged with illness and distress and how they experience recovery. In the following chapter I am discussing how the findings in light of literature presented in previous chapters, focusing on what seems to be of significance and promote recovery. In the final chapter, I am trying to highlight the most important findings and reflect on possible implication for health care providers and policy makers. At the very end I am sharing some ideas of possible future studies based on my experiences during this study.

2. Perspectives on recovery in mental health

The understanding of mental health problems has for a long time been dominated by the positivistic tradition and the medical perspective where mental health problems are seen as psychiatric disorders and explained in an individualistic view of illness and a body-soul dualism. In this perspective bodily processes are regarded as the most central illness entity, and a persons life circumstances are rarely considered. Mental health problems have been explained as individual, inherent and internal. A number of classification systems (e.g ICD 10, DSM III) has been developed to diagnose, predict prognosis and indicate treatment (Borg 2007).

Recovery research is primarily concerned with people with serious and long-term mental health problems. Psychiatry has continued to follow the Kraepelinian definitions of these disorders where chronicity is named as a defining characteristic. This denies hope of improvement and contributes to hopelessness (Kristiansen 2005). However, a substantial amount of research on the phenomena of recovery has confirmed that people with severe mental illness can have satisfactory, hopeful and contributing lives in the community with others (Sullivan 1994b; Borg 2007).

Recovery research is trying to confront and stand in contradiction to established medical traditions. Central in recovery research is the belief that relevant knowledge come from people with lived experience and a central aim is to discover and interpret meaning rather than causality. Recovery research put the subjective experiences of individuals and their everyday life in focus. Traditionally medical psychiatry see atypical behaviour and expressed feelings as symptoms, delusions, fantasies and defence mechanisms, and explain this as belonging to the illness and only to be expected. This creates a situation of self-determined prophecies; a kind of locked circles which is difficult to break out of. These circles are even found on a structural and societal level; poverty, social isolation and unemployment are seen as something to be expected if one has a mental health diagnosis (Kristiansen 2005).

There is a growing amount of studies done by people who have first hand experience from living with severe mental illness (Deegan 2001; Ridgway 2001; Deegan 2005; Lauveng 2008) which have contributed hugely to the knowledge. The research shows that recovery in mental health about how they can contribute to their own recovery and the strategies used to live with severe mental illness and to cope with the challenges of everyday life. They have also contributed to the knowledge about what people experience as useful help from the

environment, like family, community and the professional mental health services (Borg and Krisitansen 2004). Recovery research offers an arena of hope, where service users and survivors of the psychiatric system and their families meet academics in a power-sharing effort aiming to understand what kind of help is actually helpful. The breakdown of myths of hopelessness and chronicity is central to recovery research and often essential for the person in recovery (Kristiansen 2005). Recovery in mental health is about getting on with one's life; managing most of the things most of the times. Learning to live with and manage what is distressful. It is about how one lives with the experience of mental distress and its consequences in the context of the everyday life. It is about needing help and support from family, friends and health care services (Kristiansen 2005; Kristiansen 2007).

Development in health care services goes towards a more recovery-oriented practice where user participation and person-centeredness is central. Users are struggling to take back the control over their lives and decisions about what kind of help is needed. Kristiansen (2007) says people with serious mental ill health should be actors in their own futures. The hope of international recovery lies in the partnership between people with lived experience and researchers interested to learn more about what is helpful in ways that challenges traditional ideas of progress and evidence, and who learn together with people with lived experience (Kristiansen 2005).

2.1 The WHO international studies on recovery

The contribution to recovery studies from the professionals has roots back to the 1960's when WHO initiated the International Pilot Study of Schizophrenia (IPSS) (Borg and Davidson 2007; Hopper, Harrison et al. 2007; Bonney and Stickley 2008). The main purpose of the study was to develop methods to carry out epidemiological research in mental disorders in cross-cultural settings. Additionally they wanted to explore the nature and distribution of schizophrenia in different parts of the world. The main findings were that the methods were feasible for such studies and that schizophrenia existed as a disorder in all centres that were involved in the study. A two- and five-year follow-up study found that people in developing settings had better social and symptomatic outcome than people from developed settings (Hopper, Harrison et al. 2007).

WHO introduced several other studies to explore the findings from IPSS. A two-year follow-up study of out-come in again favoured persons in developing settings. Other studies were exploring frequency on life events, emotional interaction in families with schizophrenic

patients and perception of schizophrenic patients by their families. All these studies have contributed to the understanding of recovery in severe mental illness (Hopper, Harrison et al. 2007).

25 years after the IPSS, another major international study of schizophrenia (ISoS) was introduced by WHO (Hopper, Harrison et al. 2007). Some of the major findings from the ISoS study are that the long term out-come for over half of the persons involved were good. The results rank among the most favourable long-term out-come to date. Consistent with earlier findings, course and out-come for people in developing settings were more favourable than for persons from developed countries. Work and employment was one of the items more often reported for people from developing settings (Sartorius 2007).

Despite the consistent findings that people with severe mental illness have more favourable course and outcome in developing settings, there are still no clear answers to the questions regarding the difference (Luhrmann 2007). Kim Hopper re-examined the previous results from the three WHO multinational studies. He looked for possible bias by questioning the attrition, the groupings, diagnostic ambiguities, use of outcome measures, gender and age. Re-examining after eliminating possible biases, the findings remained the same; people diagnosed with schizophrenia are far more likely to meet criteria for recovery in the developing world than in the developed world (Sartorius 2007). Several other studies examining the outcome of severe mental illness have been consistent in demonstrating a broad heterogeneity and that people diagnosed and treated for severe mental illness can recover. It has also been consistent in demonstrating that people from developing settings has a more favourable outcome than people from developed settings (Borg 2007).

2.2 Conceptualization of recovery in the context of everyday life

Historically there seems to have been two main sources influencing the development of recovery in mental health; the user/consumer/survivor movement with first-hand experience from mental problems and the professionals in health services and in research projects. The term recovery was used already in the 1930's by the user controlled movements. As the user-controlled movement was strengthened through the legislative foundations of disability rights, the anti-discrimination and the civil right movements during the 1960's and the 1970's, they became strong agents in the development of recovery as a concept and a practice (Borg 2007).

The term 'recovery' is usually used about getting back to a previous position or rescuing something. In the health context recovery is usually understood as getting cured or making

considerable improvement. But the biomedical perspective does not provide a sufficient perspective to understand the process of recovery in mental health. Borg says that " …*such individualistic models of understanding and defining a person's experiences, circumstances, feelings and perceptions are essentially deficit models, based on assumptions of inadequacy and pathology of the person involved*" (Borg 2007:15)

However, the recent research and contributions from people with first hand experience from recovery in mental health has influenced the concept to also comprise living with symptoms and/or endure relapses as well as emphasizing the social aspect as well as a the individual aspect and a dialectic process rather than a causal one (Borg 2007).

Social and relational models of disability may contribute in the understanding of recovery. These models address social, physical and material barriers like inappropriate dwellings, unemployment, poverty and stigma (Kristiansen 1993; Borg 2005; Kristiansen 2005). There is need to draw more attention to knowledge from the field of sociology and social psychology in order to broaden the understanding of mental health problems. Knowledge about institutionalisation, labelling and stigma based on the works of among others Goffman and Scheff is relevant to understand the social processes people with mental health problems may experience (Borg 2007). McGruder (2001) says that medical models are sometimes used in a way that takes away the meaning of the illness experience. She says psychiatry is a social practice embedded in a social world, and that the experiences called symptoms have meanings and may have positive and pleasurable aspects for the person (McGruder 2001). A phenomenological approach to mental health will investigate the persons subjective experience and draw on non-medical explanations to make sense of the mental health problems (McGruder 2001; Borg 2007).

Deegan (2001) is taking recovery into the everyday life. She says that "*recovery is about changing lives, not the biochemistry*". Mental distress is experienced in people's everyday day life in social contexts, and recovery is about how people live with severe mental illness and handle their activities, social relations and the material world. It is within the social context and everyday life that people and their situations need to be understood and supported. An everyday life perspective on recovery can inform health professional about how they can be of support for people recovering in mental health (Borg 2007; Kristiansen 2007). Deegan (2005) says this perspective is a shift from pathogenesis to salutogenesis where the focus is on the whole person in context – not on the pathological or disease processes.

<u>Recovery is an individual as well as a social process</u>. As already stated, in this perspective recovery is seen as a process, not an outcome. Recovery is by many researchers still viewed as mainly an individual, personal and unique process of overcoming distress and environmental barriers. Rediscovering an active self and valuing one's own expertise and knowledge is emphasised (Borg 2007). Anthony (1993) describe recovery as " *a deeply personal, unique process of changing one's attitudes, values, feelings and goals, skills and/or roles.* He said that recovery was a way of living a satisfying, hopeful and contributing life even with the limitations caused by the illness. Recovery involve developing new meaning of purpose in life and recovery from stigma (Anthony 1993).

Every process of recovery is personally unique and what is experienced as helpful or as turning points may have no meaning for other people (Kristiansen 2007). But even if recovery is of unique and personal nature, recovery is also a social process, recognizing the reciprocity between the individual and the social supports (Topor, Borg et al. 2006; Topor, Borg et al. 2009). Recovery is in interaction with other people within the whole of the society. Krisitiansen (2007) is also emphasizing the societal process and says there is need to change the psychiatric mind-sets and altering societal attitudes (Kristiansen 2007). Borg (2007) and Kristiansen (2005) says that personal distress of mental problems can be severe, but the social consequences are often more disabling.

Recovery in an everyday life perspective is about regaining a present, not previous state of life and to regain control over one's life or distress (Deegan 2001; Kristiansen 2007). Borg says that recovery includes issues such as health and illness, power and citizenship rights. She says that people with mental health problems first and foremost are human beings and need to be met that way. This view emphasises that recovery is personal and takes place in the context of everyday life (Borg 2007). The understanding of mental illness and recovery is often discussed with a polarization between a social model and the medical model; the social model partly claiming that mental illness is a social construction and the medical model focusing on the individual bio-medical conditions or psycho-emotional states. Both models are likely to simplify the experiences of personal distress and social consequences for the affected individual. Understanding recovery requires a more multi-dimensional perspective and more complex frames of understanding (Kristiansen 2007).

3. Recovery experienced in the context of everyday life

The previous chapter gave an introduction to recovery as a concept and to different perspectives on recovery. My position to recovery in mental health is to a large degree influenced by the work of Borg and Kristiansen as well as by the work of their colleagues within the same research network. Another source of inspiration is research from people with firsthand experience from mental health problems like Deegan (2001; 2005), Ridgway (2001) and Lauveng (2008). Central in this understanding of recovery in mental health, is that recovery takes place in the context of everyday life, it is an individual as well as a social process, and finally the way we can learn more about recovery is to listen to the subjective experience of people living in recovery.

This chapter will present some of the existing knowledge about recovery in mental health which I found to be relevant to interpret the interview material and to discuss the findings from the interviews; to a large degree contributed from people living in recovery, either first hand or through professionals or researchers.

As already mentioned mental health problems and recovery can not be understood per se, but must be understood in a context (Borg 2007; Kristiansen 2007). In order to provide a background for understanding the experience of the participants in the study, the first part of this chapter is about everyday life as an arena for the individual experiences and social interaction. Social class, lifestyle, income, gender, age, religion are factors influencing the way everyday life is lived. People's lives have to be understood on the background of the social and cultural context where the everyday life takes place (Gullestad 1993) It is in this context challenges and distress are experienced, it is where people work on their recovery and it is also where people can find meaning to their experiences and where they can find solutions and mobilise resources (Borg 2007; Kristiansen 2007).

The next section of this chapter is a presentation of different ways that mental health, illness and recovery can be understood in an African setting and some views on the differences between developing and developed settings. Then follow a section about salutogenesis and some of the central aspects of recovery which people living with severe mental illness have found to be import in their recovery.

3.1 Everyday life as a context for recovery.

The everyday life perspective in recovery is important because everyday life is life itself (Borg 2007). Every day life is what we know as the real world; what we perceive as normal

and what we hold in common with others (Gullestad 1993; Dahlberg, Drew et al. 2001). Every day we engage in trivial activities like waking up, going for work, eating supper with our family or chatting with friends. These activities can be seen as trivial and insignificant in our ordinary everyday lives, but they may not be as trivial as they may seem to be (Borg 2007; Kristiansen 2007). Hasselkus (2006) talks about these ordinary, everyday activities as "the small experiences". These small experiences may only be noticed when our way of being in everyday life is challenged or altered. That is when we become aware of the apparently trivial and insignificant activities of everyday life and realise the importance they play in our lives. Gullestad (1993) says everyday life have two perspectives; one is the practical, concrete way we organise and live our lives. The other one is the lived experience of the everyday life; how people are present in the world, how they experience situations and encounters with the social and material world, and how they make meaning in these experiences (Gullestad 1993; Dahlberg, Drew et al. 2001).

Exploring peoples' everyday lives provides a context to look for meaning. Everyday life also provides the larger societal arenas for supporting the recovery process. An everyday life perspective in recovery shifts the focus from pathology to everyday life activities and societal conditions. This provides a more holistic picture with a larger context for analysis, interpretation and solution-findings. An everyday life perspective also connects recovery to civil rights and an acknowledgement of people's personhood and citizenship (Kristiansen 2007).

3.2 Perception of mental illness and recovery in African cultural settings

There is a rich diversity of beliefs about mental illness in African cultural settings. But within this diversity there are a number of shared concepts and the understanding is intimately related to traditional religious beliefs and to some extent shared by many African peoples (Patel 1995). The experience of mental health problems must be understood in the cultural context where it is experienced (Borg 2007; Teuton, Bentall et al. 2007). The way mental health problems are understood may influence on the nature of the illness and the experience itself. Non-medical explanations may provide meaning for the individual and their families and have positive impact on the nature and course of the illness (Teuton, Bentall et al. 2007). Individual patients and their families often have their own concepts and categories of illness, which may differ from those held by health professionals. The way ill health is perceived and how experiences are interpreted will influence on help seeking, choice of treatment, ability to

cope, use of social support and the quality of life. The sociocultural meaning of illness may all form part of the total picture and needs to be taken into account (Aidoo and Harpham 2001).

A persons relation to illness is produced in interaction with others where values and conceptions are learnt, formed and changed through a long life, and which again is passed on to others. Ingstad (2007) calls this the cultural formation of illness. She says that illness is formed by culture in different ways: by interpretation of symptoms, by the way symptoms are presented, by legitimating the illness and by (possibly) creating illness. The way health and illness is understood in a certain culture will change over time as the society changes. The conceptualisation of health is under influence of the increased availability of alternative world-views by the introduction of communication technology like internet, which a growing number of people worldwide have access to. The biomedical model was introduced to African countries by the European canonicalization powers, and health programmes and health education are often based on these western models (Teuton, Bentall et al. 2007).

In African societies many aspects of life are believed to be influenced by spirits. The spiritual world is presented as real and exerting an influence on the living world. Fortune and misfortune, like metal health problems, is in this perspective believed to emanate from the spiritual world. For some people rituals to ensure good fortune and prevent misfortune is part of everyday life (Teuton, Bentall et al. 2007).

3.2.1 Different explanatory models of severe mental illness in African settings

In most African countries the biomedical model of 'psychosis' is the sanctioned form of health care. Still many people or their families continue to approach traditional and religious healers for treatment when they find that the problem could be caused by spirits, or when the conventional medicine doesn't seem to cure the illness (Teuton, Bentall et al. 2007). About 70-80 % of people living with mental health problems in Zambia are consulting traditional healers before they consult the public health service (Mayeya, Chazulwa et al. 2004).

Several religious healers believe that God is responsible for everything, including disease, and is central in the development and healing of madness. Some look at western medicine as a 'short-cut' to healing, while others believe that spiritual healing is the only way to cure mental illness, especially where biomedical treatment is either inadequate or not available (Teuton, Bentall et al. 2007).

Traditional healers build on the relation between the individual, the social world and the natural world and less on psychological impact of personal experiences. Social and natural

trauma or misfortunes are often attributed to the spiritual forces. Even if people relate to this in a practical way, spiritual practices have to be attended to in order to turn into good fortune (Teuton, Bentall et al. 2007). Traditional healers are local practitioners and include herbalists and diviners (spiritual healers). Traditional healers make a differentiation between the ancestral spirits and sent spirits. Religious healers attribute madness to evil spirits while the good spirits (God/Allah) are seen as the healing force. Traditional healers seem to be able to hold several models simultaneously. (Teuton, Bentall et al. 2007).

Spiritual explanations. The spiritual world contains both good and evil spirits, and both can inflict mental illness and cause problems for individuals and their families. Evil forces are constantly in conflict with the good spiritual forces and illness and misfortune may be the outcome of the conflict. The cause of the problem is usually seen as a collective problem, involving the whole family. Any family member could have brought about the anger of the spirits, but the whole family needs to gather and seek advice from the spirits on how to solve the problem usually by performing certain cultural rituals to the ancestral spirits. To refuse can be costly for the whole family with further suffering and misfortune. In cases where mental illness is believed to be linked to the individual's behaviour, the treatment will be directed to the individual, not to the whole family. It is usual to place charms in the path of the person, or make tattoos[1] on his body. Interventions are specific to the individual and the traditional healer negotiates with the spirits about a settlement. The person has to comply with this settlement to get cured (Teuton, Bentall et al. 2007).

Strange or abnormal behaviour can be seen as a manifestation of spirit possessions or that the individual is relating to the spiritual world, not to the social world. According to traditional healers, these problems can only be solved by communication with the spirits. The solution of the problem is always determined for each individual by the ancestral spirits (Teuton, Bentall et al. 2007).

Muzungu's madness – the 'white man's madness'. The understanding of this madness is distinctly different from 'spiritual' madness. It is believed that different physical conditions as fever, HIV/AIDS and to some extend syphilis can cause this kind of madness. Malaria and different infectious diseases are often termed 'fever'. These conditions affect the physical body and may result in unusual behaviours. Some believe that madness can be inherited through blood and sexual intercourse. This form of madness are understood similar to the western medical model, and can not be treated by traditional or religious healing. The person

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[1] Small cuts in the skin where medicine is applied

is usually referred to medical doctors and hospitals. This madness is often associated to the brain (mind or head). It is believed that fever of the brain or problems with the blood vessels and nerves in the brain can cause this madness. It is likely that individuals will expect medication to be short-term and curative, rather than long-term and prophylactic. These expectations, combined with an experience of troublesome side effects of psychopharmaca, may result in non-compliance with treatment (Teuton, Bentall et al. 2007).

Religious explanations. Religion plays an important role in the lives of most Zambians and 50-75 % of the population belong to Christian communities (CIA 2008). It is quite usual that some of the independent churches combine indigenous spirituality and Christianity (Haynes in Teuton, Bentall et al. 2007). Mental illness is seen as manifestations of evil or as a punishment from God. If a person engages in taboo or unaccepted behaviour the evil spirits get an opportunity to enter the person and make him 'a bad person'. Evil forces can also get access to a person who does not engage as expected in cultural practices and traditional rituals. The person can be cured by denying Satan and seek alliance with God and attend church activities. Religious healers may also believe that mental illness is caused by suppressed feelings which builds up and then erupt. Madness is the eruption. The approach to this understanding is to encourage the person to confront his experiences, thoughts or emotions that are being suppressed. Then the person is offered more practical support such as money or employment. Cognitive and emotional reactions to worries, sleeplessness or 'thinking too much' may cause somatic or physiological reaction which in turn can result in madness. Except from expressing the worries, some religious healers use herbal medicine to rectify physiological functions (Teuton, Bentall et al. 2007).

Witch-craft. Mental illness may also be caused by beliefs which are instilled in the person by others in the community. Emotional and behavioural consequences of these beliefs may cause madness. Witchdoctors are believed to knowingly perpetuate beliefs about witchcraft in order to create anxiety. The treatment may be to leave the beliefs and practices associated with them; destroy charms[2] and amulets, or to change religious practice (Teuton, Bentall et al. 2007).

Mental illness can also be caused by disharmony in the social world. Somebody could be jealous of someone who has been successful, and consult a witchdoctor to inflict madness on the successful person. Madness caused by witchcraft can only be healed by a traditional healer by using herbs or a vessel sucked on to the body of the person in order to remove the physical

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[2] Items believed to have magic powers

charm from the person. These processes are understood as the traditional healer's use of the good spiritual forces against the evil forces used by the witchdoctors (Teuton, Bentall et al. 2007).

<u>Individual and family explanations.</u> Mental illness is understood as a result of experiences in the social world. Responsibility for the illness is to some extent located in the sufferer and/or their family. It can be reactions on different personal and social problems in life, like poverty, HIV/AIDS in the family, loss of dear ones, conflicts within the family. Counselling is often suggested as a useful approach where the individual is enabled to express the problem. Counselling could be to explore the underlying problems or to recognise that the situation is not as bad as it seems. Counselling also provide practical advice and guidance on how to deal with the problem, promoting reconciliation or forgiveness, changing the person's expectations and encouraging the individual to submit to their social situation. Conveying hope and optimism, willingness and ability to help is a central aspect in the counselling approach (Teuton, Bentall et al. 2007).

3.2.2 Impact of mental illness on everyday life

Mental illness may impair the individual in his ability to function in everyday life and the social consequences of this distress and daily struggle are often devastating (Borg 2007). One in four families has at least one family member with a mental disorder and the family members are often the primary caregivers. The extent of the burden of mental disorders on family members are difficult to assess and quantify, and is consequently often ignored. Mental illness has a significant impact on the family's quality of life (WHO 2003).

People with severe mental illness in Zambia are often stigmatized. People fear them, and they are often humiliated. Even family members are affected with stigmatization and are affected mentally and socially by having a sick family member. The support from the community to people with mental illness is low because they are looked upon as invalids who has little to contribute to others. A mentally ill person is perceived as a danger to himself and society, at least in the sense that he/she disturbs the peace of the family and community environment (Mayeya, Chazulwa et al. 2004).

Mental health problems are closely related with poverty. Poverty increases the risk of mental health problems, and mental health problems increase the likelihood of descending into poverty. Common mental health problems are twice as frequent among people living in poverty as among people considered to be rich (Patel and Kleinman 2003; WHO 2003).

Mental health problems generate costs in terms of treatment and loss in terms of reduced productivity. At the same time, factors like insecurity and hopelessness, rapid social changes and the risk of violence or physical ill-health are recognised to contribute to mental health problems. The most consistent association seems to be between low education and mental ill-health. Other factors are inadequate housing and malnutrition People that are homeless or unemployed are among the people that have a higher risk of developing mental health problems. People living with mental health problems are likely to experience violations of their human rights, stigma and discrimination (Patel and Kleinman 2003; WHO 2003; WHO 2007).

3.2.3 Recovery in mental health. Differences between developed and developing settings

The WHO studies about a more favourable course and outcome in severe mental illness have been followed by a other studies that may contribute to understanding the differences. Factors mentioned are that people in developing countries often live in extended families (Luhrmann 2007) and experience grater inclusion and social integration. People with severe mental illness are included in traditional healing rituals which reaffirm communal inclusion and solidarity. There is availability of an adapted, but valued work role and availability of an extended kinship or communal network (Rosen 2006). Luhrman (2007) says that there is access to less stressful and less demanding work and the affected person can be a contributing family member without being the main breadwinner or caretaker. The membership and role in the family seem to be of importance, but also the emotional atmosphere in the family seems to have an impact in the recovery process. Juli McGruder's study from Zanzibar (2004) showed that fewer families exhibited expressed emotions than in developed countries.

Luhrmann (2007) is critical to the way severe mental illness have been treated I western countries and says that is may even make things significantly worse by turning psychotic reactivity into chronic clienthood and by that create a condition for social defeat. The increasing in studies in recovery from developed and developing countries is adding to the knowledge of important factors for a successful recovery process, but need to be further investigated. There is still little research on recovery from the developing world (Luhrmann 2007; Teuton, Bentall et al. 2007; Borg 2009)

3.3 A salutogenic approach to recovery

Salutogenesis is a concept that explores the origin of health, not disease. In this concept of health chaos, stress and disease occur everywhere and all the time, and must be seen as

natural conditions and part of life. In this view, health is a relative concept on a continuum, and the focus is what causes health, not reasons for illness. When Antonovsky (2000) explored how people were able to survive stress and disease over time, he found that some people had biological, material and psychosocial factors that made it easier for them to perceive their life as consistent, structured and understandable. He called this generalized resistance resources (Antonovsky 2000). Typical generalized resistance resources are money, knowledge, experience, social support, culture, intelligence, traditions and ideologies. If these resources are available, there is a better chance to deal with challenges in life. Generalized resistance resources lead to life experiences that promote a strong sense of coherence. Sense of coherence determinates the subjective experience of health and is developed and maintained in a social context. It is a personal dispositional orientation towards oneself and the surrounding world, which enables the individual to find the best coping strategies for managing the ever-present internal or external stresses of life (Bengtsson-Tops, Brunt et al. 2005). When people experience loss or change, the continuity of life is disrupted. We interpret events that happen to us in terms of their meaning for our life stories and this gives life a sense of coherence (Christiansen 1999). Antonovsky (2000) describes sense of coherence as a global attitude to events in life and says that people with a sense of coherence view their lives as comprehensible, manageable and meaningful. Comprehensibility is the ability to perceive everyday life as ordered, consistent, clear and structured. Life is experiences as explicable; having a continuous, but dynamic confidence in inner and outer environment. The life is also experienced as predictable; the world is ordered, not chaotic. Manageability is the ability to perceive that inner and/or outer resources are available, under control and adequate to meet the environmental demands. A confidence that things will be as good as they can be under the current circumstances. Meaningfulness is the extent to which the individual finds the demands as important, challenging, committing and worthy investment and engagement. Meaning is also derived from believing that we have done the right thing and that we can justify our actions. We also derive meaning from our feeling of self-worth. We meet this need through the approval of others and by viewing our own asserts and abilities favourably (Antonovsky 2000; Bengtsson-Tops, Brunt et al. 2005).

Much of the current recovery research has a salutogenetic approach; looking for factors that promote recovery and health in general. Prominent themes mentioned by people living in recover are: identity/self, personal agency, power and control, hope and optimism, risk and responsibility, the social domain, service provision agenda (Deegan 2001; Deegan 2005;

Bonney and Stickley 2008). According to Kristiansen (2005) mental illness must be recognised as a sort of condition, as real and as part of human diversity. In this perspective recovery may promote an up-ward process with access to more valued roles, expectations and responsibilities, increased autonomy and feeling of self-worth. Deegan (2001:29) says that "…*recovery is a unique process for each person, but there are common themes, challenges and strategies that can be used by most people*".

3.3.1 Identity and sense of self

Sense of self and the person's role in recovery is argued to be most important in recovery in severe mental illness (Estroff 1989; Davidson and Strauss 1992; Estroff 2004; Deegan 2005; Geanellos 2005; Kristiansen 2005; Marin, Mezzina et al. 2005; Borg 2007). Self can be seen as *"the basic private biography, the developing, but continuous logic of self, the private and lifelong embodiment of one's uniqueness"* (Estroff 1989:191) Identity is seen to be largely influenced by social phenomena and inextricably tied to our relationship to others (Christiansen 1999). Christiansen's (1999) understanding of identity and self are based on Mead's work from 1934 with a focus on development of identity and self as a reciprocal process between the individual and the society (Christiansen 1999). Christiansen (1999) says that the identity and self concept are shaped by a person's competencies and capabilities in comparison with others and in relation to social standards or expectations in society. The society represents rules and conventions of social interaction and this preserve our identity. Christiansen (1999) says that through our interaction with the social environment we piece together experiences from everyday life to create an understandable self; an identity that is comprehendible to ourselves and to others (Christiansen 1999).

There are two layers of self; self as known to ourselves and self known to others must overlap to some degree, otherwise the individual is likely to experience radical estrangement or hyperalienation and the identity and self may be incomprehensible and lead to psychosis (Estroff 1989). Christiansen (1999) says that the individual and society are interdependent and that identity is "the great integrator of life experience".

Identity, self and everyday life. People shape their identities through their daily occupations which are performed in a social context that gives them symbolic meaning. One of the basic needs for every human being is to be able to communicate our identity in a manner that gives meaning to life and as a competent person. Identity is instrumental to social life and identity provides a context for deriving meaning from the everyday life experiences and it interprets

life over time (Christiansen 1999). Participation in everyday life activities serves to be able to experience or realize our personal identities. In everyday life one has different kinships and other roles. These different roles exist in the social world and we fill them with our own particular versions; e.g me being a father or me being a husband. Our memberships in different groups and our different roles contribute to what we experience and to the meaning or the significance of events or emotions. It is through interaction with others we validate or share experiences, and we come to know ourselves and become known to others. Kinship, gender, ethnicity and age are categories that transcend the individual, but our portrayal of them are unique (Christiansen 1999). Estroff (1989:192) says that "… *there may be others like us, but no one else is us*". Each person has a unique profile of experiencing everyday life. We have belief and symbol systems, influenced by culture that we derive from the experiences we have alone and with others. Estroff (1989:192) says that this is "*the meaning-making, world-knowing and experience-having self that forms part of the core of each of us*".

Another important aspect of identity and self is the 'possible selves'; the views we have of our identity in the future. These imagined selves are powerful as motivators of goal –directed actions and can be both positive and negative pictures. Possible selves give personal meaning and structure to a person's thoughts about the future. We are living for a purpose and deriving a sense of meaning in our lives, trying to fulfil four basic needs: purpose, efficacy, value and self-worth (Christiansen 1999). Recovery can be seen as a daily struggle to gain control and improve living conditions in life and in a possible future (Marin, Mezzina et al. 2005).

Identity, self and illness. Estroff (1989) says that living with severe mental illness may result in transformation of self as it is known inwardly, but also as known outwardly; by others. But she says that the self is an enduring entity that precedes, transcends, outlasts, and is **more** than the illness diagnosis. She says "*Illness can make us different persons, but we are still the same*" (Estroff 1989:191).

A personal history is situated in a lifetime, and is not an illness history according to Estroff (1989). Life experiences like illness may bring about change, losses and gains of functions and relations, but the core of self will still remain. She says that in western culture sickness is implicitly altering the self and when we are sick, we may say 'I was not myself'. We are not ourselves in some profoundly cultural and symbolic way when we are sick or injured. But yet – we are! We seem to reject the dysfunctional self as 'not me' and different from the other familiar or claimed self. When illness persists; being 'not myself' becomes myself, it may bring about a struggle for inner self and social identity. The individual might experience the

inner self as persisting, but with some new features or incapacities. There may also be some differences between the inner self and others perception of self; the social self (Estroff 1989). Deegan (2001:17) says: *"I am a person – not an illness"*. She claims to be seen as a whole person with lived experience and unique qualities. She says that being given a psychiatric diagnose is labelling the person. Being labelled with mental illness can often lead to pathologised interpretations from others and a loss or a broken self; an internalised stigma (Deegan 2001). Because schizophrenia affects profoundly how we present and experience ourselves, the person and the disease is often linked together. She says becoming a schizophrenic is essentially a social and interpersonal process. It is not an inevitable consequence of primary symptoms and neurochemical abnormality (Estroff 1989). Deegan (2005) says it is important to reject this stigma and learn not to be ashamed of oneself.

<u>Concept of self in egocentric and sociocentric cultures.</u> The notion of 'self' as autonomous and independent is relatively modern. It emerged during the 'Enlightenment' in Europe where science and reason dominated over religion and the spirituality. The societies which have adopted this egocentric-contractual model of self focus more on intra-psychic and advocate self-reflection on desire and cognition. Key features of modern concept of self are the individual self as distinguished from the natural and social worlds, the ability for individuals to initiate change, and to act for themselves in a purposeful way. E.g. psychoanalysis and cognitivism suggest that meanings are individualistic, and generated in the mind, and these meanings need to be attended to through introspection so that the person's concept of reality is realigned. The model of this modern self as autonomous and independent is not shared by all cultures and societies. In African settings, self is seen as integrated with the social, natural and supernatural worlds. Both traditional and religious healers see 'self' as inextricably linked with spiritual forces. This sociocentric model of self place grater emphasis on managing experiences within the social context and promote grater social relatedness. This may reduce the negative social consequences associated with madness and facilitate re-integration following a psychotic episode, resulting in better prognosis (Teuton, Bentall et al. 2007).

The egocentric concept of self can interfere with recovery. By imposing a psychiatric explanatory model and system of intervention there is a danger of disrupting the sociocentric model of healing currently engaged in the community (Teuton, Bentall et al. 2007).

3.3.2. Active agency and self-help strategies

The active agency of the affected person is central in recovery (Deegan 1988; Strauss 1989; Davidson 1994; Sullivan 1994b; Deegan 2001; Borg 2005; Deegan 2005; Kristiansen 2005; Borg 2007; Kristiansen 2007; Davidson 2008). Being in recovery involve having more control over one's life and being an active agent in change. This include that the subjective lived experience and expertise of the person affected are considered as valid (Kristiansen 2005; Kristiansen 2007). One issue frequently mentioned by those who have first-hand experience of severe mental illness is to be making one's own decision to get well and to develop new and different identities beyond the label of mental illness (Deegan 2001; Borg 2007). New identities may enable people to feel strong and to derive meaning from difficult experiences of their illness. Other important issues mentioned are managing symptoms, knowing ones physical and mental limits, as well as having a strategy for preventing getting ill again; learning from their experiences, and trusting them. Further the importance of recognizing the illness as part of themselves, and to understand and value the suffering and struggles they have experienced (Deegan 2001; Marin, Mezzina et al. 2005). Resilience is sometimes mentioned in relation to recovery as a potential or a capacity to cope with challenges in life. Borg (2007:31) says that people living with severe mental illness *"need to be met as ordinary people with extra-ordinary problems"*. According to Deegan (2001) recovery is a self-directed process of healing and transformation where it is important to learn to build a sense of self efficacy and confidence in ones own abilities to tolerate and persevere discomfort. Studies have shown that self-help strategies are considered to be more important than the help from the professional mental health services (Borg and Krisitansen 2004; Deegan 2005; Kristiansen 2007).

The feeling of control is closely related to feeling competent. Competence is to be effective in dealing with the challenges of everyday life that comes in our way. If we experience success, we enhance our view of ourselves as competent beings. This encourages us to explore and engage in the world. Feeling competent in performing everyday life activities contributes to identity shaping and the realisation of an acceptable identity which again contributes to coherence and well-being. It is important to portray ourselves as competent and to perform competently in order to gain recognition from others. Self-appraisal is highly dependant on feeling accepted by others. This connection between behaviour and social approval influences our sense of self (Christiansen 1999).

3.3.3. Future perspective and hope.

Recovery has a future perspective. Deegan (2001) says that it is not about going back to what or where one once was, but to move on in life. Recovery is a process of becoming new; to discover limits and how limits can open for new possibilities; recovery is about using life experience to be an altered 'self'. She says: "*I am not the same person I was before I went crazy. My madness has been a kind of fire through which I have walked and through which I have been changed*" (Deegan 2001:17).

The future perspective on recovery also holds the notion of hope. Deegan (2001) says that hope is critically necessary in recovery. Hope for a better tomorrow arise from the confidence of finding one's own ways to cope with distress and improve well-being. Hope is described as the discovery of meanings in life, including possibilities beyond the adversities, a multidimensional life force; an expectation of a better tomorrow with possibilities in the context of interpersonal relationship which gives purpose and meaning in life. Hope enables the individual to transcend current difficulties and distress and promotes positive changes in life (Noh, Choe et al. 2008).

Kristiansen (2005) says there four different aspects of hope: The first one is believing <u>me</u>; to trust one's own experiences. The other one is believing <u>in</u> me*;* to believe that one has the potential to change. The third aspect is believing <u>that</u> my future can be different; believing that life in general can improve. The fourth one is believing that <u>I</u> can make a difference in my future: that <u>I</u> can bring about change in my life. Instilling and offering hope should be a major concern and is experienced as one of the most important contributions from professionals in a recovery (Deegan 2001; Borg and Krisitansen 2004; Kristiansen 2005).

Spirituality is another issue often related to recovery and hope. Spirituality may for some offer a way of finding meaning in the suffering, and that in turn helps the person through difficult periods with anguish and fear (Deegan 2001). Spirituality may also provide encouragement and comfort during illness, and reduce the burden of illness and be a source of social support (Sullivan 1994b).

3.3.4 Personhood and Citizenship.

A recovery perspective on mental health is promoting citizenship instead of clienthood. Role perception and how people are treated by society is central in promoting recovery. When people are labelled with mental illness or madness or diagnosed, they are placed in a world of 'other-ness' where citizenship is not an available identity or social role. Recovery means

being included in local community life and having fellow humanity and one's civil rights recognized. This means having access to decent standard of education, housing, employment, income, societal participation and access to a variety of roles other than clienthood (Kristiansen 2005; Kristiansen 2007).

Citizenship is about participation in a broad sense; participation in clubs, in school, voting and having intimate relationships. Research shows, however, that the same environments that can be supportive also have a potential to emphasise exclusion and isolation. Stigma, being different and not participating in ordinary social life is found to be the major barriers to recovery (Mezzina, Davidson et al. 2006b; Borg 2007; Kristiansen 2007).

A tolerant environment promotes well-being and recovery. An environment that tolerates diversity versus dividing the world into normal /abnormal provides opportunities for a person to be open and get to know the illness and to overcome the fear and master ways to navigate through it (Deegan 2001).

<u>Work/other activities.</u> Participating in activities gives meaning and purpose in life and gives routines and structure in the everyday life (Gullestad 1993; Deegan 2001; Borg 2007).Being occupied or busy with everyday life activities alleviate various types of distress, such as anxiety, confusion, lack of concentration, depression, sleeplessness, distressing voices. Self initiated self-care activities is experienced to decrease symptoms and improve moods, thoughts, behaviour and overall sense of well-being (Deegan 2005). Studies show that participating in activities perceived as "normalizing" and productive are important factors contributing to quality of life. Other factors are personal time use, social interaction, a feeling of belonging, illness management and personal choice (Haertl and Minato 2006). Being involved in intimate and reciprocal relationships is another important issue. Friendship and having a partner has impact on the self esteem. It is important to experience being worth loving and to have something to give to others. Helping others in formal or informal ways, and having reciprocity in relationship is also experienced to enhance quality of life and promote recovery (Sullivan 1994b; Deegan 2005). Participation in vocational activities and work has been found to be of significant importance and a powerful strategy in recovery (Sullivan 1994b; Deegan 2005; Mezzina, Borg et al. 2006a; Borg 2007; Borg and Kristiansen 2008). Work provides a source for meeting the basic needs in life, structure, self esteem and reciprocal relationships and a way of making a contribution to others (Sullivan 1994b).

3.3.5 Partnership and power-sharing

Recovery requires a different relation between the person experiencing mental illness and professionals is part of the recovery process than the usual expert-client relation. Recovery requires a give-and-take balance where the affected person is the more active and initiating and the professional is supporting opportunities and inviting and engaging. The experiences of persons living with mental health distress need to be humbly and seriously listened to and also address their societal situation (Davidson and Strauss 1992; Deegan 2001; Kristiansen 2005; Borg 2007).

Power and powersharing is central in a recovery orientation. Empowerment places the power by the professionals who is going to 'empower' the affected person, while recovery is about partnership; learning from each other and co-producing knowledge (Kristiansen 2007). Deegan (2005) says that the professionals should help people discover their own strategies that are helpful to reduce symptoms and increase well-being (Deegan 2005). Such helpful relationships contain trust and to be seen; that ones humanity and uniqueness is recognised and appreciated. It contains being listened to, feeling understood, honesty and powersharing (Kristiansen 2005) .

Helping relations are described as professionals who are able to be supportive and welcoming, to stand by the user in times of distress and being able to offer tangible aid and offer activities and structure (Sullivan 1994b).

Kristiansen (2007) says that the professionals also have a role to play in society. There may be need for professionals and to advocate for societal changes and to address distressful and potentially devastating conditions for people with mental health distress. Being in recovery includes being perceived and treated as a citizen with social roles and civil rights and being able to use their citizenship rights for change (Kristiansen 2007).

4. Method

The aim of this study is to understand more about recovery and describe how people with severe mental illness experience recovery in the context of everyday life. Developing descriptions and analysis of social phenomena and interpretation of human experiences implies a qualitative approach (Dahlberg, Drew et al. 2001; Kvale 2001; Malterud 2003; Thagaard 2003). Malterud (2003) says that as human beings we are part of a sociocultural context, and qualitative research can open up for scientific insight in such kind of processes. Qualitative methods can be useful for developing new descriptions and concepts and can also be useful to describe diversity and nuances.

In qualitative studies the researcher is an active participant in the development of knowledge. The knowledge is developed in interaction between the researcher and the participant. It is only in the light of what we already know that new knowledge can emerge. Gadamer (2004) explain this process as a hermeneutic circle. As human beings we are already present in the world with our experience, history and culture which is also what shapes our pre-understanding. This is how we meet new experiences and develop new understanding about ourselves and the world we are part of. The challenge in this kind of research is for me as a researcher to be aware of my pre-understanding and to make my pre-understanding as explicit as possible throughout the research process (Malterud 2003).

Malterud (2003) says that the process of developing knowledge will never be completed as a universal truth, but is more a process of developing new questions. All kinds of data material are more or less successful re-productions of real life. The data material is filtered and reduced by the choices I do through all stages in the research process. The data used in qualitative research is subjective and specific, but the objective is that this data gives us knowledge to make new descriptions, concepts or theoretical models which can be used in other contexts than where they were taken from (Malterud 2003). My intention is that the findings from this study can contribute to the understanding of recovery, not only in Zambia or other African settings, but in western settings as well.

4.1 Methodical approach

There are different ways to get knowledge about other people's experiences, opinion, attitudes or life stories. Relevant approaches might be interviews, observations or focus groups. I have chosen to use individual semi-structured interview. I have developed an interview guide (Appendix 1) which allows me to be more open to what happens during the interview and to

make follow-up questions and comments. A qualitative interview can encourage the participants to narrate about their experiences, how they look at themselves and they can clarify and elaborate on their relation to the social world (Kvale 2001). The questions in the interview guide are derived from the research question. An open interview without a very strict structure offers good opportunities to utilize the researcher's skills, knowledge and intuition (Kvale 2001).

In a broader study it could be relevant to combine two or more methods like focal groups, participatory observation or narratives in addition to the qualitative interview. A limitation in using only interviews is that the main access to the persons experience is what the person can articulate. Embodied and tacit knowledge is silent (Kvale 2001). Observation gives access to different data, like observing the participant in his ordinary everyday life.

The study has been guided by a hermeneutic approach. My understanding expands in the encounter with other opinions or experiences and the process of analysing the material starts already during the interview. By responding to a statement, this statement has already been interpreted. This interpretation influences on the next response or next question which again impact the response from the participant (Kaarhus 1999). The development of knowledge continues in the encounter with the text. Geanellos (2005) says that understanding is situated in language and co-created in the dialogue between me and the text.

4.2 Data collection

I have used strategic sampling to find relevant participants to the study. I chose to invite adult men only. The participants were chosen because of their knowledge and experience in mental health and recovery in the context of everyday life. While working in Zambia, adult men where the majority users of mental health services and women and elderly men rarely came to the hospital for treatment. I expect men and women to have diverse experienced about mental illness and recovery since their roles and participation in everyday life are very different. If the participants have too diverse experiences, the variety may be too wide to give deepened knowledge about the topic. In this study I wanted to pursue observations and experiences from my work in Zambia and to deepen my understanding about the experience of severe mental illness and recovery in adult men.

To ensure that the participants had experienced living with severe mental illness, I used "being diagnosed with schizophrenia" as an inclusion criterion. Schizophrenia is a diagnosis based on a the presence of a number of symptoms and is considered to be a severe mental

health condition (Creek 2008; Jordal and Repål 2009). It is not of my concern whether this diagnosis was 'correct' according to formal diagnostic systems. My concern was that the participants and their families had experienced their mental health problems severe enough to be in contact with mental health services and where the medical doctor also experienced the mental health problems as a severe mental health condition. The second inclusion criterion is age. People diagnosed with schizophrenia usually experience the first episode of mental illness at young age[3] and I wanted to talk to persons who had lived with their illness for some time. I chose to ask for participants between 25 and 35 years old who had been given the diagnosis more than three years ago or more. It turned out to be more difficult than expected to find enough participants between the age of 25 and 35, so one of the participants was 39 years old at the time for the interviews. I chose to include him in the study, since I expected him to have lived longer with mental illness, and had broad experience to share. Being able to understand and to speak English was the third inclusion criterion. It was important for me to be able to have direct communication with the participants. To support the communication I also brought in a Zambian colleague as a linguistic and cultural interpreter. In qualitative research the interaction between the interviewer and the participant is very influential on the content and the quality of the data material (Malterud 2003).

I did not want to interview persons who were in an acute psychotic state, and this was an explicit exclusion criterion. I made sure that the mental health worker who contacted the potential participants made that judgement. This was first and foremost an ethical consideration; to make sure that the integrity and interests of the participants were secured.

A mental health worker from the Hospital was appointed to assist in finding participants for the study. He identified a number of twelve to fifteen persons based on the inclusion and exclusion criteria. I was never informed about these names. I went through the project plan and briefed the health worker on the inclusion and exclusion criteria. I made sure he understood the purpose of the study, and that he understood the meaning of informed consent. After this briefing, he was the one who contacted potential participants. He briefed them on the purpose and content of the research and made sure their consent was informed when they signed the forms for participation (Appendix 2).

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[3] According to Kringlen and Mjellem et al. the age is between 18 and 25 years. Kringlen, E., N. Mjellem, et al. (2008). Psykiatri. Oslo, Gyldendal akademisk.

4.2.1 Presentation of participants

All participants in the study are given fictive names.

Andrew is 35 years old, single, but engaged to be married. His family stays in the same town and he visits them regularly. He lives in a house which he shares with other families. He is the caretaker for the house, and his responsibility is to see to the cleaning and security and that the rents are being paid. He also has a small workshop and a katemba[4] where he is selling some groceries. He attends church services and participates in church activities whenever he can.

Benjamin is 34 years old. He is married with four children. He stays in a house together with his family and five other family members he is supporting. He is employed in a private company. He is working shift and he says the work is very hard physically. He is an active member of his church.

Charles is 39 years old. He is divorced, but has a daughter who visits him regularly. He stays near by his sisters and his nieces. He is working within building and rehabilitation of buildings.

David is 26 years old and single. He stays with his sisters and makes his living from piece-work and favours to his friends.

Eden is 35 years old. He is married with three children. He doesn't have his own place to stay, and lives temporarily with his brother. His wife and children stays with the parents of the wife in a different town. He is self-employed by making crafts.

4.2.2 Issues to consider when doing research in a different cultural setting

There are several challenges related to understanding and interpretation when doing research where the participants and the researcher both have different cultural and social experiences and speak different languages. English is the second language for both parties. Most Zambians have vernacular language as their mother tongue, while English is the second language. Zambian English are spoken with a certain accent, and words and terms may be used differently from the British English. To meet some of these challenges I asked a former colleague, a Zambian mental health nurse to join me in the interview situations. We used to work together in Zambia and she has some knowledge about me as a person, a professional and about Norwegian culture. This may give her some ideas of my shortcomings and

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[4] A stand or a small tuck-shop

limitations in the interview situation. Moreover she is included in the participant's culture, which made it possible for her to "translate" both cultural and linguistic issues. Her role during the interview was to assist in communication; to clarify if there are obvious misunderstandings and otherwise explain to both the interview person and me if there were questions, statements or expressions that were not understood. She could use both English and vernacular depending on the situation. Though most participants spoke English well, it might be difficult to express personal and emotional issues using a second language. The participants were encouraged to use words or sentences in local language if they didn't find a good way to express themselves in English. Using a second language may also restrict both participants and myself as a researcher to come forward with the immediate and spontaneous feedback in the situation, but all together the skills in English were good enough to have rich conversations. Zambian languages are characterized by being narrative and rich with metaphors, so this quality of the information might have been limited.

In addition to the verbal language a lot of information are being communicated through the tone of voice, choice of words and body posture and gestures (Kvale 2001). Kaarhus (1999) writes about "contextual cues"; the signs and keywords which indicates how verbal statements should be interpreted within the current conversation. I do not have enough cultural knowledge to identify these cues, but my colleague was asked to be aware of non-verbal communication and contextual cues and to take notes during the interview.

Another issue I found important to consider was the lack of symmetry between the participant and me. As the researcher I had already set the agenda when I met the participants, and I had information about the topic and was prepared with an interview guide for the conversation (Kaarhus 1999; Kvale 2001). The cultural setting was potentially reinforcing the imbalance. The Zambian society has a hierarchic structure, and people have different status depending on gender, age, formal position and so on. Being a guest and probably because I am a muzungu[5] I am usually given a relatively high status. In addition to being a guest and a muzungu I was older than the interview persons, and as a researcher I also had a high social status. Women may rank lower in the social hierarchy, but I believe that the other capacities I was ascribed made up for that. Both my colleague and I might appear as authorities from the health care services. Due to this imbalance the interview persons were offered to bring a companion to the interviews. This might also contribute to transparency and avoid suspicion from others. It is important that I am aware of this possible asymmetry, but it is equally important that I

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[5] White person, usually of caucasian origin

relate to the participants as subject to subject. I can only get access to the other person's perception on his life through dialogue. The dialogue depend on trust and confidence, so that the interview person feel comfortable enough to talk about sensitive topics and meaning (Kvale 2001).

I also found it important to address the issue of proximity and distance. As already mentioned there are several challenges regarding being a Norwegian researcher in health care meeting Zambian service users. But I think this difference in experience may also have some advantages. It is in the encounter with the unknown and unfamiliar that we become aware of dimensions with life that are usually hidden, or taken for granted (Paulgaard 1997). The meeting may enable both me as a researcher, but also the participants to discover new things about our views and experiences that we otherwise would have taken for granted.

4.3 Conducting the interviews

Four interviews took place after working hours in an office in town which I had rented. Neither I nor the participants had any relation to the office. The fifth interview took place in an office at the hospital, upon the request from the participant. There were no other people present during the interviews except from the participant, myself and my colleague. None of the participant chose to bring a companion with them. The interviews were recorded on tape in English. The interviews lasted from 1 hour up to 1 hour 50 minutes. In addition I had a shorter second interview with three of the participants.

I started the interviews by presenting myself and my colleague, and clarified my colleague's role during the interview. I explained the purpose and content of the research and made sure that they had understood the meaning of the informed concent. All participants seemed to have understood the information. Before closing the interviews, I asked the participants if I could come back again if there were need for clarifications or additional information. All participants agreed to that.

Both my colleague and I were prepared to take notes during the interviews to record non-verbal language and other expressions. But few notes were taken. This might be because we didn't observe many things we found relevant to record or because we were so focused on the verbal interaction that we failed to pay attention to non-verbal communication. After completing each interview, we sat down together to reflect on the interview situation and the content. I used the log to take notes from these reflections to have these in mind for the next interview.

The first interview lasted for almost an hour. I was deeply impressed by the openness and willingness from the participant to contribute. I was emotionally moved by the way he shared his experience with us. I felt very humble to be given this confidence. I don't think I was prepared to meet this kind of openness and very direct and personal contribution. I felt I was very sensitive to what was said, and how it was said during the interview. I went through most topics in the interview guide, but I was reluctant to ask follow up questions to explore more of how he understood and related to some of the experiences he presented. I was careful because I was afraid that I could make him feel embarrassed or to bring up sensitive or painful emotions in him. Since this was my first interview - ever - I also needed to find my way of interacting with others in this particular situation. So after finishing the first interview I decided to do a second interview.

Before the third interview I made a checklist as a complement to the interview guide based on the experience from the previous interviews. After completion of the third and fourth interview, I found that these two interviews were extensive enough after one meeting. I met three of the participants for a second interview.

I conducted all first interviews together with my colleague. She also participated in the second interview with the first participant. For the other two second interviews I was on my own. This was mainly because my colleague was committed to other assignments, but I felt comfortable to do these two second interviews without her.

<u>Reflections on the interview situations.</u> The focus in the study changed during the course of the interviews as a hermeneutic circle. I believe this happened as an interactive process between me and the participants. I believe I was influenced by their stories and that I again influenced them by my response to their stories (Malterud 2003). I decided to trust this development as I believed that these were the issues that were important for the participants to bring forward, and I found the information equally interesting and relevant for the topic of the study. The interview guide was open enough to be used throughout the interviews but other questions were added and explored.

I experienced the interview situation as an interaction between two partners with different roles and different experiences from life in general and from mental health in particular. I think these differences represented a potential for learning. I got the impression that the participants appreciated this opportunity to share their experience and put forward their views.

4.4 Processing and analysing the material

The data material consists of the transcribed interviews and my log. The log contains observations made during the interviews as well as comments and discussions with my colleague. I also recorded my own reflections on own reactions and emotions in the meetings with the participants. All interviews were recorded on a digital recorder and the transcriptions were done immediately after each interview. I have tried to transcribe as accurately as possible. According to Kvale (2001) transcription of an interview is not merely a technical exercise, but an interpretive process on its own. Listening to the recorder transform the interview into a de-contextualized form (Kvale 2001; Malterud 2003). And I really experienced this. It was quite another experience to try to grasp what was said, when I didn't have the social atmosphere and physical environment and not expressions and gestures from the participant present. In the interview situation, I felt my English and my understanding of the Zambian English was sufficient to have a fluent communication with the participants. But when I started transcribing the interviews I found it really hard. There were quite a number of words and sentences I simply couldn't get. I marked those words and sentences with question-marks in the text. Fortunately I had the opportunity to ask my colleague to listen through the interviews and correct my transcriptions. She managed to extract more words and sentences than I did, but a few were left which neither of us understood. Kvale (2001) says that it is not possible to make a true, objective translation from oral to written form. Transcription can never be a copy or reproduction of an actual reality. He says that we have to look at the purpose and let the purpose guide the extracts, and ask: "*what is a useful transcription for my study?*" (Kvale 2001:105)

Another challenge during the transcription of the interviews was to decide where to end a sentence and put a full stop. Kvale (2001:102) says is pointing out: "*Transcription is not a set of exact data; they are artificial constructs of communication from oral to written form*". And there are still other choices to make which is part of the interpretive process during transcription. I decided to record all the small words as ehh, ahh, aha, hmm and so on as accurately as possible in the transcribed text. I also had to decide when to define silence as an end of a sentence or a brake in the communication. I was just using my sense of the situation to get this as correct as possible. I included laughter and what kind of laughter in the transcribed text; for example ex. 'shy laughter', 'a bit of laughter' or just 'laughter'.

Two of the interviews were more challenging to transcribe than the others. One of the participants spoke with a low and a bit monotonous voice. If I had noticed during the

interviews I would have asked them to raise the voice. One of the interviews was also a bit fragmented with sudden change of topics and difficult to follow. I didn't want to force my own conceptions onto the transcribed text, and decided leave those parts of the interview out from the analysis.

I gave the interview persons fictive names when transcribing. I also left out named of relatives and other people that could be identified. I left out a few names of places, but kept most original names. In publishing there will be no names of places.

I chose not to convert the transcribed interviews into grammatical correct English. The participants had very different ways of expressing themselves, and I think some important aspects of meaning will be lost if their expressions are re-formulated. I feel the oral and genuine expressions enrich and give life and meaning to the text.

Some of the quotations used in the text have been edited. Some of the participants repeated words or sentences, or left out small words as "and" and "to". I have been very careful to edit in order not to loose out any meaning that could be inherent in a repetition or a word. I have only edited expressions when I think it has removed "noise" and clarified the message. I have tried to be as loyal as possible to the participants' expressions.

For the process of analysing the data material I have used content analysis as it is described in Graneheim and Lundman (2004). They say that reality can be interpreted in various ways and is depending on the subjective understanding of the interpreter. Analysing qualitative data is to ask questions to the material and to read the material in light of this to organise the material and re-tell it in a systematic and relevant way (Malterud 2003). I started the analysis process by reading through each interview as a whole unit to facilitate my understanding of the different parts in the interview. Then I went through each interview and identified parts after the structure in Graneheim and Lundman's (2004) content analysis. But I went back to the whole several times during this process to check out for alternative interpretations.

In the analysis process I had to keep parts of the material that could provide new descriptions and knowledge to the research question, and put aside material that was of less relevance (Graneheim and Lundman 2004). Throughout the analysing process I opted to be as open as possible to what was there in the text, and tried to be aware how my pre-understanding influences on my interpretation of the material. Firstly I had to identify my pre-understanding of severe mental illness, recovery and everyday life in a Zambian context. I had to be aware of

how these pre-understandings influenced my interpretations and tried to challenge my interpretations where my pre-understandings were present (Geanellos 2005).

I read through the material to identify meaning units; words, sentences or paragraphs relating to each other through their content and context. Then I went systematically through the text to identify the meaning units from the text relevant to the research question. I found it challenging to set aside parts of interesting, but for this purpose, not so relevant material. From there I condensated the chosen meaning units; I removed what I interpreted as access information, and remained with the core of the meaning unit (Graneheim and Lundman 2004).

Then I made abstractions with codes, categories or themes. Each meaning unit was given a code. A code should be understood in relation to the context. After labelling the meaning units with codes, I developed categories and sub-categories. Ideally the categories should be exhaustive, but also mutually exclusive (Graneheim and Lundman 2004). I found this exercise quite challenging, since many of the meaning units could fit under different categories. But as I worked in dialogue with the text, and related the meaning units to the context, it became more apparent to which category the meaning unit fitted in to. As a final step in the process, I identified several underlying themes through meaning units, codes or categories. These themes serve as chapters and sub-chapters in the thesis.

The process of analysing the data has not been a linear process from the first to the last step. It has truly been a hermeneutical process where I have been back and forth to the different steps many times. As I worked with the data I got new insight, and I understood things differently than in the previous reading. I also re-read or read new literature which also gave me new insight. The openness in the interview situation allowed the dialogue between myself and the participants gradually to change focus from how people with severe mental illness experience participation in everyday life activities to the recovery process in severe mental illness. The final analysis as it is presented in the thesis has evolved in an ongoing dialectic process between the text and my ever-changing pre-understanding. It has been like a travel with new discoveries along the way; very interesting but also quite exhausting at times. Geanellos (2005:9) says:

> "*The hallmark of this dialectic is a speculative, undogmatic openness on the part of the interpreter – a willingness to consider other interpretations and to understand the text in new or different ways*"

I do not assume to have reached a point of saturation in the data collection. For that I think my research question is too broad and the thesis too small to encompass a saturated presentation of this kind of experiences. But despite this, I have found the material very interesting and it has given me enhanced knowledge on the topics in question.

4.5 Presentation of results

I have chosen to present the results of the study in English to make it accessible for those who are the main stakeholders in this study; participants and their families, health workers and policymakers in Zambia. I also believe the study has a potential to contribute to the knowledge about recovery in a wider African setting and be of interest for a broader group of service users, health workers and policy makers both in African and in western countries. The everyday life perspective and the significance of community participation and work activities should also make the thesis interesting for occupational therapists and occupational therapy students.

Writing this thesis in English has been quite challenging. My vocabulary has not been sufficient to express details and nuances, especially during the analysis process when I was struggling to grasp meanings inherent in the material.

4.6 Trustworthiness, verification and transferability

The use of the terms generalization, reliability and validity to assess qualitative research is debated. They origin from the positivistic tradition and were transferred to qualitative research. Some scientists see the terms as suppressive and positivistic , others say the terms can only be applied to quantitative research and that they have a different meaning and are not relevant in qualitative research since qualitative research is contextual (Conneeley 2002; Thagaard 2003). Kvale (2001) do not reject the use of these terms and says they can be relevant for qualitative research depending on how 'truth' is defined. Dahlberg (2001) says that data analysis in qualitative research can be expressed in a general structure; in hermeneutics this will be an interpretation which means that the general structure lifts the result above the concrete level, but it is still within a certain context. Even if a phenomenon is understood within a certain context, it doesn't mean that it can't be of use within a different context. This study is about recovery in everyday life for people living with severe mental illness in Zambia, but mayt also have a potential to contribute to the understanding of living with severe mental illness in other African settings, and perhaps also in western settings. It is the quality of the data material and the processing that decides whether new knowledge has

been achieved and can be generalized and developed into theory. Another important factor is to what extent the researcher has been open to the phenomena and given account for the pre-understanding.

"*You can not enter the same river twice*" (Heraklit 500 BC in Dahlberg, Drew et al. 2001). I think this citation illustrates the challenge in qualitative research. Studies of other person's experiences and their social world will always be contextual; a conversation or an interview can never give the same result if repeated. In order acknowledge the results as being of scientific value openness and exposure of the pre-understanding have to be present throughout the research process (Dahlberg, Drew et al. 2001). What remains as prominent in the data material are influenced by my particular history and experiences; from Zambia, from working in mental health services both in Norway and in Zambia and my personal life story, including my beliefs and values in life.

Thagaard (2003) suggests using the terms trustworthiness, verification and transferability which has become increasingly more common (Malterud 2003). To assess trustworthiness it is important that the research process is transparent, especially with regards to the pre-understanding and context. Engaging in a reflexive process may capture and analyse the subjective elements, and in that way enhance the trustworthiness (Conneeley 2002); the researcher has to account for the development of data throughout the process and enable the reader to assess the value of the results. Verification refers to the quality of interpretations and if the results are being supported by other studies. A study has good transferability if the interpretations based on one particular study can also be relevant in other contexts (Thagaard 2003).

As a qualitative researcher I am always involved in the research situation (Thagaard 2003). The choices I make will impact on the study from the early planning to the presentation of the study. It has been challenging to maintain awareness of own pre-understanding and how my pre-understanding impact on the interpretation of the situation. I have tried to make my pre-understanding and my position explicit during the whole research process and to make clear distinctions between the contribution from the participants and my interpretations. I have tried to be sensitive and true to the information given from the participants. Measures I have taken are to actively use the hermeneutic circle where I alternate between the parts and the whole to ensure that the parts remain contextualized and to check out my understanding against my colleague's understanding of the interview content.

Trustworthiness also involves a reflection on the relation between the researcher and the participant and how this influences the information from the participants (Thagaard 2003). My relation to the participants changed from the first interview situation to the last. In the first interview situation I was unsecure and reluctant to ask follow up questions. The information I got was limited. During the following interviews I became more relaxed and had a more pro-active approach to follow up descriptions and statements from the participants. This increased the interaction between me and the participant and gave richer information. I have earlier raised the issues about symmetry in the relation between the participant and the researcher. I believe that I as the researcher had more power and control in the situation, and I have little information about expectations and motivation for the participants to take part in the study. I also know little about if and how they benefitted from the situation. What I know is that they shared eagerly and generously of their experience, and those who were asked were positive to do a second interview and it was my impression that they appreciated this chance to talk about their experiences and to be listened to. This might be an expression of politeness or an obligation to meet expectations from people they may see as authorities or it was a genuine wish to contribute.

Another evaluation to be made is the verification of the interpretations made. This implies a critical review on my own interpretations and the process of analysing data (Thagaard 2003). In the process of identifying themes and topics it was easy to focus on the similarities and to leave out data that represented a difference between the experience in the participants or to my own experience or other studies. The difference in experience may not be of relevance to the study, but differences are often a potential for new understanding and new knowledge about something. To make these judgements I have used my experience from my previous stay in Zambia and from my work with people with mental health problems. Findings from this study seem to correspond with other studies about recovery on the importance of inclusion in social practices and everyday life activities. There are very little qualitative studies on recovery in the context of everyday life in an African setting, so I have used theories and research from western settings. Based on my experience from both western and African settings I believe that recovery as a phenomenon is about universal human needs like the need to be part of a family, to be included in the community, to be able to meet the expectations from the society, to valued, to have hope for a better future to mention some.

This study is based on the experience of five men in Zambia, which is a small and narrow sample. But referring to the 'universality' of recovery I believe this study has a potential to contribute to increased knowledge about recovery in both western and African settings.

4.7 Ethical considerations

The research was approved by The Regional Committee for Medical Research Ethics, Norway, Norwegian Social Science Data Services, Minstry of Health by the Provincial Health Office, Zambia and ERES Converge, Zambia. After the research proposal was approved by Ministry of health, an application was sent to ERES Converge. ERES Converge had some objections which I made note of and the study was adjusted according to the comments.

- Letter of confirmation from the Norwegian supervisor should be signed.
- A local supervisor should be appointed.
- I was not allowed to interview participants in their home, due to lack of confidentiality.
- I had to justify how I decided to interview only 5 participants in the project proposal.
- To include contact details for ERES Converge in the information sheet and consent form for the participants.
- The interview guide should be included in the application for approval.
- To correct some grammatical and typographical errors and some incomplete references in the project proposal.

After final approval from ERES Converge and Ministry of Health I contacted the Hospital. A health worker was appointed to assist in finding participants for the study. When meeting the participants for the interview, I checked out that they had given an informed consent and that they understood their right to withdraw at any point until the study was published. One of the informants asked for a small contribution for his participation, and I realized I had to make it explicit that there was no payment or other favours in exchange for their participation. I explained the implications of paying or giving any kind of contribution to participants in a study and all of them accepted this condition.

One challenging ethical issue was the lack of symmetry between me and the participants which I have addressed by offering the participants to bring a companion to the interviews. The uneven positions were there, and I have tried to account for this throughout the research process.

I have tried to present information from the material in a way that does not compromise the participant's identity. I have also tried to present the information in a respectful and ethical manner. I hope I have managed to be honest and truthful to their contributions. I also feel that I have an obligation to publish the results from this study for others to take part in the knowledge they have contributed to.

5. Findings. Or how can living with severe mental illness in everyday life in Zambia be experienced?

This chapter will present the main findings that emerged from the analysis of the interviews, and are presented as five sub-topics. One of the major findings is that the participants presented their everyday life as an ordinary everyday life as being well and an extraordinary everyday life when they experienced illness and distress. The first part of this chapter is therefore about the participants' ordinary everyday life, as it is experienced with family life, work and social activities. The second part is about how they experience the challenges they encounter in their everyday life during times of distress and illness. The next part is about how they experience the illness relating to their own person and to the social environment followed by a part about their experience from treatment. The fifth and final part presents some reflections and recommendations on what people with mental health problems need and how mental health services can be improved from the service user's point of view.

5.1 The ordinary everyday life: being contributing and competent members of the community

The ordinary everyday life consists of different activities taking place on different arenas and with different others. The most important activity seems to be work. All participants have access to income-generating activities, to a smaller or larger extent. They also participate actively in ordinary social activities such as family life, socializing with friends and going to church. Some are members of organisations and participates in voluntary work.

5.1.1 Contributing to the welfare of the family.

The analysis shows that contributing to the welfare of the family is a major concern and for some of the participants a major responsibility. Benjamin and Eden, who are married and have children, are expected to provide food, health care and education to their family members. Being the head of the family they have to work to generate income for the sustainability of the family.

Benjamin has a household of 11 persons who all depend on his income:

> *"I make sure my family is living in a good health. I provide everything which is required that I can afford, to the right time. Each time one is sick, I'm the one taking him to the hospital. (…) I have to budget and budget. I have to work hard, really hard. (…) There are many people to sustain".*

Benjamin seems to be able to provide for the basic needs for the family, thou he says some people may ask themselves how he is managing: *"Maybe somebody can think I'm using charms. It is only that I'm addicted to that climate. They are able to eat breakfast and supper. With the little money which I get"*. Both Eden and Benjamin seem to be confident with their performance as heads of their family and main bread winners.

Andrew, Charles and David are not married, but they also need to generate income to provide for their own needs, but also to contribute to other family members. Charles says he doesn't receive much help from others, but seems confident to be able to sustain himself: *"It is always myself. No one has ever taken any cash from his pocket to help me. Otherwise, God help me that I find piece-works. I do a lot of things. So I sustain myself in fact"*. David lives with his sisters and he is also expected to contribute to the householdHe manages to contribute with small amounts of money which he gets from piecework he finds from time to time.

Andrew is a caretaker in the house where he is staying. In return he gets accommodation there for free. He describes his duties as a caretaker with confidence and pride:

> *"The places must be clean. And I don't want quarrels and violence. (…)I'm looking people who has come there, if they are just come to visit their friends or they just come to steal - or what. Even at night, I must make sure there is no thieves. In fact there is no thieves there.(…) Because they have liked that place. So they are coming to asking, they want a room for rent…"*.

He has put up a small workshop outside the house where he is doing some mechanical repairs. He is also selling some groceries: *"It's the way I found money. (…) And you see that eggs there, when you come there, it is me who are selling. I just buy it at the marked.(…) Ya, I'm business-minded"*. He seems to be proud of his achievements; knowing how to repair things and having his own business: *"- so I started working there, under the tree of the mangos. I was worked with somebody - so even me I was joining him. That's the way I learn. Sure. I didn't know the way how to repair these things"*.

Eden has also established his own business to generate income. He says he has developed his creative skills to a profession. He produces items of art which he is selling at the market or to individuals on request: *"I'm an artist by profession and I'm affiliated with the Art Association. I'm a member there"*. He is also obviously proud of his achievements and says:

> *"So it's like something that was pushing me, to say; you have hands. These hands can do something. And according to the scriptures it says; even I can do all things and Christ Jesus will strengthen us. So that was like a conviction- it was a weight on my life - to say; with these hands I can do something.(…) So from there – that is how I*

began. It was just from the conviction that I had. It was just the creativity part – that led me to it. I'm just a self employed person. And that is how I'm earning my life".

Eden seems to be content with his performance and his work, and he says he has a further potential to pursue; "*I will not say I have developed everything. In fact I'm looking forward where I can expand this what I've learned, or share thoughts with others*".

These findings indicate that even if the participants are living with severe mental illness they are able to maintain their main roles and responsibilities as contributors and breadwinners in the family most of the time. They seem to see themselves as active and contributing members of the community who are competent and confident in their performance and in these roles. They also seem to be proud of the way they are utilising their own potentials and the opportunities the environment offers to find ways to generate income and provide welfare to themselves and their families.

5.1.2 Being active participants in social life

The interpretation of the material shows that besides their efforts to provide welfare for their families, they do also take active part in and contribute to their local community. They perform their roles as fathers, they socialize with their family and friends and they participate in church and other social activities.

Being a father is a role that emerges as an important and valued role by the participants. Benjamin and Eden say they are involved in raising the children and shows concerns about their welfare. Eden says:*" So the purpose is to secure the children, so that we have a sound family. They'll say, 'at least our parents struggled to reach this far'"*.

Charles has a son who visits him occasionally and he says he is happy to be able to assist him in his homework: "*I have been going to school, let me show you a-b-c-d*".

Another important part of social life for the participants is maintaining friendships. They socialize with friends and neighbours, and they present themselves as persons who have something to contribute and who is able to make an impact on other people's lives: Benjamin has stopped taking alcohol and hopes to influence his friends for a better lifestyle:

> "*It is very bad for me to avoid my friends just because I'm not in that category[6] today. Because if I run away from them, I can't culture them up to church services. I share knowledge with them. One day or the other, the Holy Spirit will come into them, and they will know, - the salvation. Till they'll follow me*".

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[6] of drinking alcohol

Eden has found that the contact with elderly people benefits him and he seeks more the friendship with older men: *"In my recovery process, I have befriended people that are older than me. These are all family men. So at times I emulate them"*.

The church seems to be of significant importance for the participants, both socially and spiritually. Benjamin attends church services and bible studies several times a week: *"You find that when you gather at church, the knowledge you share there, will comfort you. And they'll give you the way. Yes. And you have sound mind. Even if you are stuck, it looks like you are not stuck"*. He says church is also an important support in raising the children: *"They grow in a polite way, in a disciplined manner. They will know what is discipline, what is respect. (…)I am looking into a bright future. Leading a good life. Knowing The Almighty"*.

Andrew is a leader in his church and he brought the certificate with him to the interview. He seems proud of having this position: *"I'm learning the church when there is no priest. Or even the priest is there, I'm learning the church. (…) I can lead the church and finish the whole service. I have to teach people, I have to serve"*: He says he is familiar with the different church activities, and as a leader he is involved in different projects. He is also involved in charity work through the church: *"Then sometimes you go to visit those people who have funerals, sometimes in the hospital"*. He seems to have been well recognised in his congregation and he says the people there are supportive: He smiles when he says: *When I was just OK, people used to love me, sometimes people used to assist me"*. He says he is not performing as a leader when he is sick, only when he is well.

Andrew is also involved in a campaign in environmental health. They are teaching people how to deal with the waste and to keep the environment clean: *"It is very dangerous, cause we have a lot of dirts. Like when you are going at marked areas, compounds, we got to talk of environments. So the problems that we look for – to solve those problems"*.

Some of the participants are also members of an user organisation for people with mental health problems where they work to improve the conditions for people with mental health problems: *"Cause we must have a shelter for them. And food for them, and clothes and treatment"*.

These findings indicate that the participants perceive themselves as active members of the community and as persons that have the capacity and an obligation to contribute to others in the community. Through their commitments and contributions they make efforts to improve

the lives of their families, their friends and to the community at large. They talk about these commitments with pride and with confidence to their own performance.

5.1.3 Planning for a better future

When the participants talk about their ordinary everyday life, they also talk about potentials and opportunities for improving the everyday life for themselves and their families. They seem confident in their own capacity to initiate change and to realise opportunities in their lives. Eden has bought a piece of land as part of his long term planning. He sees different opportunities for how he can develop the piece of land to make a better life for himself and his family:

> *"I have this land which needs to be developed and put it into a slow perspective. (…) At least I need to put some fruit trees and maybe a simple hut there…(…) I looked at it, in diverse ways, even a better house to be built there. (…)Because there maybe I'm able to keep traditional chickens, I'm able to keep the goats. Because the land, I can utilise the land. I wanted, had also a plan, where to dig a well. As one has a well, it is easy, it becomes easy. (…)Because from now we need to plan. It is not the immediate needs. The immediate needs are where maybe you say 'what am I going to eat for breakfast..(…) But we need now to live beyond that. At times even to sacrifice not even to have breakfast, for you to have profit".*

Andrew also wants to improve his living conditions. He is planning to find a partner and expand his workshop: *"We buy spare parts, then we fix the things, and to start re-selling. We are supposed to start this year. (…)Now because of this short of money. I have made a project proposal for that"*. He also sees a potential in developing his tuck-shop: *"I've seen the business of shopping complex of groceries, they are moving. So I had a plan to have my own shop, in the main market and other places"*.

Benjamin also wants to develop his potentials. He has a dream of going to college to learn a profession, but says his current financial situation does not allow him: *"Meantime I don't have enough capital. I can't do minus money. If you have money you can go to some courses, I'm still young, and I can start. Now you find I don't have the resources"*.

Getting their own homes and a family seem to be pertinent for the two participants who are not yet married. Charles is currently staying with his two sisters, but he wants to have a place on his own: *"Just applying to someone to find a plot, buy it and be independent. (…) Then concentrate on looking for a decent wife"*. The issue of getting married and having a family seems to be very important for social position and respect in society. David says:*"I want to get married and have a son. When you just get married and have a son, that is the respect that are given from society: 'he is now matured, he is an elder person"*. For Charles the issue of

getting married also seems to be pressing: *"I'm thirty-nine now. And forty next year. God willing, I'm planning now to marry. (…)If I don't marry at forty, then I am finished. I have to do something, otherwise -. It is very important. I am very serious about it"*. Andrew is engaged and saves money to be able to marry in the coming year.

In their ordinary everyday lives, they seem to be active participants in the community with access to valued social roles and activities. They seem to have an optimistic view about their future, seeing potentials and opportunities which can be utilised to improve the welfare of their families and their future everyday lives.

5.2 Extraordinary challenges in the everyday life

Though the participants are involved in different activities in the ordinary everyday life activities, their participation and performance seem to be challenged when they experience periods of distress because of mental health problems. The interpretation of the material suggests that when they are not able to maintain their roles and responsibilities towards their families, this may compromise the respect from others and their position in the society. Benjamin says:*"That's why the whole family was very much disappointed when I got sick. Cause they were affected completely. (…) Knowing that I am the breadwinner, so they were always trying by all means, to say once we loose this man, we are also doomed"*.

5.2.1 When the capacity to work is challenged

The material shows that in periods of mental illness and distress, the capacity to work is challenged, and the participants are not able to generate enough income for upkeep and the sustain of their families. The welfare of the whole family is endangered and available resources may be exhausted.

Andrew describes how his health and living conditions are deprived because of the illness: *"My body has finished – and now I failed because of sick. Because on those jobs you need to work hard and be fit physical. So if you are not fit, you can't work."* He says that the illness has disturbed his progress in life, and he compares his achievements in life to his friends:

> *"When you have little money, at least you can not expect life to be as a worker man. My friends are working. Some they have bought vehicles. They just stay well. (…) I was supposed to be rich at this time – if I'm not sick. Because I have lot of plans to do. To save myself, to save my family. Now, because of jealousy, I became poor. I became poor because of sickness"*.

Andrew says he used to keep a bank account with some savings, but that he spent his money on treatment, and seem to feel he is on bare ground: *"Cause I run out of lot of money.(…)I just*

tried to look for medicine, but I was just spending my money for nothing. (…) 'Cause it had disturbed my life. I suffered for a long time. (…) All my plans are gone. I have to start anew again".

Benjamin also describes how his resources have been exhausted and how the illness has affected the progress in life for himself and his family: *"But they are not satisfied. They know that there was time wasted. And I was disturbed here and there. So I couldn't make progress. (…) You find that everything is exploited. You touch here, you have to start at square one. You touch there, you have to start at square one".*

Also Eden's work performance was affected during the illness, and he was still out of work at the time for the interviews. He describes how the whole family's resources were exhausted: *"We had some goats when these problems befell us. We began to sell them for us to find some money".* But was obviously not enough, and he needed help from his brother: *"So even having meals, it was just my brother taking care of us as a family; my wife, and my three children and myself. He took the full responsibility".* After some time the financial burden became too much for Eden's brother as well, and Eden's wife and the children had to move to her parents' home. Eden is aware that he is expected to provide for his family and says: *"….because as old as I am, I need to be the bread earner, to take care of the family".* Not being able to meet the expectations of providing for his own family might have compromised Eden's role as a husband and head of the family. But in Eden's case the family took up the responsibility, without devaluing him: *"They are quite understanding. They don't look at me as an outcast or useless person and so forth. They handle everything with integrity. Despite the sickness".*

These findings show that the capacity to work is crucial and one of the most important responsibilities for a man in a Zambian community. A man's role and position may be compromised if these expectations are not met. Thou the extended family are contributing and give support, periods of mental illness and distress seem to lead to deprived living conditions and marginalization and exhausted material resources for the person affected and for the whole extended family.

5.2.2 Experiencing social exclusion and devaluation

Despite experiencing themselves as valued members of the community, all participants tell about situations where they have experienced being socially devalued or discriminated against because of their mental illness. They say that some people are looking at them as non-persons

and that they are not shown respect the way they are supposed to be. The participants look troubled when they talk about these kinds of experiences. Charles says that people with mental health problems are *"…deprived from certain social values…"* and Andrew says that they are not seen as people who can reason: *"Because they don't count you to understand for something. But we do understanding something"*.

David tells about younger boys shouting at him and calling him names: *"' Ahh, you are mad. Hallo, hallo. You are mad'*. David says he gets very angry and tries to hit back by sometimes yelling at them: *"They say yes, yes, this person is mad! Some they say 'ofunta[7]"*. David says: *"we think we are the condemned ones, - maybe we are the better. More than those people who are there condemning ourselves"*. Andrew says that these kinds of attitudes just add on to their problems: *"Now because of some people's discrimination; 'you go away, you are just a mental person', just like that. Because, when you try to come to the people, people are just mistreating you. It increases the problem"*. Thou the participants express feelings of humiliation and devaluation in these kinds of situations, they seem to be able to stand up for their dignity and claim their human rights, and can even be understanding:

> *"So some they say 'what do you want here'? So they meaning I has got anything to do-. Maybe I'm just a mentally? I can just stay - just like that, to not attend the wedding. I'm just like a sort of an animal, or what? They are not thinking like a Christian, or at the law of Zambia. Because everyone, as long as a mental is a person-. It's not an animal you know. The animal is an animal, the person is a person"*.

Andrew seems to find it hard to understand that even some people that are regarded as 'mature' shows this kind of disrespect to people with mental health problems: *"The matured people - have you seen? At least they were -they are also supposed to respect the human spirit.* (…) *"Maybe they just lack of some teaching and some other things"*.

Another issue emerging from the analysis is that the participants experience that mental health care is devalued and that this reflects devaluation and discrimination of people with mental health problems. Eden says: *"…we are cut off from certain things, certain services. So it is like us, we're being pushed - to the end of society. Thinking maybe this people can not recover, or can not do anything that they feel like"*. Andrew also says that that he thinks there is discrimination between care for people with mental health problems and others. He says that the nature of mental illness is different from other illnesses and need to be taken even more seriously than other illnesses. Meanwhile people with physical conditions as TB are receiving more attention than people with mental health problems:

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[7] Mad person in local language

> *"Some of them is for a lifetime. How are you going to sustain your life? Now, at the end of the day, you are just in the streets. Walking naked, picking food from the bins, because you are not monitored. It's just once and for all, and you are forgotten. Because this is a different disease. It's not like TB. You see, TB patients are being monitored-. But TB is not as serious as this mental health one. It can be more complicated".*

The analysis shows that all of the participants experience discrimination and devaluation to some degree because of their mental illness. But all of them refuse being perceived as non-persons and claim the respect and rights they are entitled to have as human beings and citizens of Zambia. They claim to be socially included as valued members of their community.

5.2.3 Support and assistance from the family and the social environment/network

As described earlier, when one family member is affected with mental illness, the whole extended family seem to be affected. The analysis also shows how the community also provide support to the affected person or the family by help from friends, neighbours, colleagues and church congregations. But it is the immediate family that seem to be the most important. The participants describe how the family takes up the responsibility for them when they are ill. They take them for treatment and they care for them during admission in hospital. In most cases it is the male family members who take them for treatment, while it is the female members of the family that stays with them at the bedside during hospital admissions. Benjamin describes the concerns from his family and how even the children were involved in looking after him:

> *"So they all take responsibility of me. You find, even during the night, when I didn't sleep, the whole family won't sleep(…) You find that you are going, they are all following(…)Even that children couldn't rest, because they are afraid, to say, when I go, I go for good.(…)So you'll find that they follow you- everywhere you are going they follow. You start off, they also follow. You sit down, they also sit somewhere there waiting for you".*

Even if a father being monitored by his children may not be very common and socially recognised, Benjamin seem to acknowledge their worries, and accepted the situation in light of what his family has been through during his illness: *"To me it's normal. Yes. According to what I have experienced – it's normal. I don't have to make some homeless moves".*

Especially the wives seem to be of significant support during illness periods. Both Benjamin and Eden describe the encouragement and firm support from the wives. Benjamin expresses his gratitude to his wife:

> *"Especially my wife. I give respect to my wife. I was married to a good choice. I appreciate. Really. I appreciate.(…) If she was like this girls growing up now (…) She*

could just wrecked me like that, running out from me. Now you find that my wife did not have that desire. She was always with me. When I don't eat, she doesn't eat also. When I don't sleep, she doesn't sleep. Yes. Yes. It is really great to have such a wife. So I owe a lot to our Almighty. For given me such a good choice. She's a very supportical wife".

Eden also appreciates the way his wife have supported him during his illness, and says that the relationship to his wife is even closer than before:

"Now after seeing my stability, it's like she has come back and say that it is one of the things – 'let us just look to God'. She is even able to encourage me: 'Eden don't look to man – look to God. Don't have programmes to do with negative things - just be positive'. So I - that's how I felt that she is with me. The relationship has been strengthened".

The unmarried participants are also supported and taken care of by their families during periods of illness. David seems to appreciate the support from his family when he was admitted in hospital: *"They were with me. The whole day. They were there, outside seated whenever I was on the bed"*.

In the beginning of Andrew's illness it was usually his father who took him for treatment and cared for him, but even other family members were contributing. But it seems like the support is on the decrease: *"… my father tried here and there. Then he said toalema[8]; 'me I'm tired now'.(…)'May God to help us'. I'm fighting on my own – myself. And my family, they sometimes assist me"*.

When the whole family is suffering the consequences of the illness, it seem to be in the interest of everyone in the family to support the affected member and try to help him back to his ordinary position as a worker and breadwinner for the family. But there is also a danger that the family may be exhausted if the illness persists and the person are not 'cured'.

Friends and neighbours are also sources of support for the person affected with mental illness and to their families. When Benjamin fell sick, the neighbour and friend to the wife came to help. The neighbour's father was a traditional healer and she organised an appointment for him:

"So she advised my wife to say; it's been a long time your husband is suffering. Maybe you try to go and see my father there. Even if this time I'm broke, I'll accompany you to negotiate with my father to say at, do something to this man-. When he gets well, he will pay you".

The neighbour escorted them to the place where her father stayed, and Benjamin and the wife remained at his place for treatment.

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[8] I am tired

In addition to the support from family and friends, church seems to be experienced as an important source of support. The church seems to offer relief and guidance in times of illness and distress.

5.3 Experiences of severe mental illness in the context of everyday life

The participants were at different age when they first time experienced mental illness. The frequency and the duration of the illness are also very different between the participants. Andrew and Charles have experienced recurring episodes of mental illness for the last 15 to 20 years, Eden for the last 10 years, while Brian and David have experienced only few episodes during the last 5 years. Charles says he was 'ok' for a period of four years before he fell ill again after the first episode, while Eden says his illness seems to occur annually.

5.3.1 Being well as the ordinary state of being

Though the material shows that their experiences in mental illness are diverse, there are still some common features deriving from the analysis. One of the main findings relating to being ill is that they all talk about the ordinary state of being as 'being well' or 'being OK'. There are two things to this. The first issue is that the participants all seem to consider their experiences of mental illness as episodes of illness and distress, not a permanent or chronic state. The participants experience the illness occurring in different frequencies and it interrupts their ordinary everyday life and disturbs their ordinary state of 'being well'. Benjamin says: "*Because that other year, it was just maybe for two weeks I didn't feel Ok. Now last year- it was for almost a month*". The second issue emerging from the analysis is that they all express that they recover or 'get well' after an episode of illness. Charles says: "*I felt fully recovered. By 1992 I was Ok. And I was ok up to 1996*". Another issue mentioned by the participants is that they seem to experience the onset of the illness to be quite sudden. Charles says: "*So all of a sudden, I heard as if my heart is (beating his chest)… and to come out of here* (pointing at his top of the head). *Just like that. Now I felt weak and dizzy*". But the recovery takes time: Eden says: "*It is not very difficult to get sick, but to get well, it takes time*".

5.3.2 Mental illness - a complicated and serious condition affecting the body, the thinking and the self

All of the participants describe their illness experiences in a very detailed way. They seem to have a high degree of awareness of how they have experienced the illness and from the way they talk about it, the illness episodes seems to have been very dramatic incidents in their

lives. Andrew says that the illness is "*… very dangerous and has lot of conditions*" and Benjamin felt the illness was life threatening: *"Because it was terrible (...)…that time I could have died".*

Benjamin gives a very detailed description of the severity of the illness and how the illness affected him in various ways:

> *"I was not myself. Walking around,aimlessly. No eating. No any sounds besides where I was staying – no."(…) "I started feeling bad. Loosing memory. Yes. You find that at times I didn't understand the days. If today is Thursday, I think maybe it is Saturday. (…) Most of the time I had to walk. I didn't even feel hungry. No. So I spend most of the time walking, and loosing memory" (…) No, I wasn't feeling well. I was working, as maybe like in a command. I couldn't do things on my own. No. There is something which was operating, like the way you have just switched that stuff there* [nodding to the recorder on the table]. *That is how I was operating. I operated almost like a computer. When I sit, I feel there is something that tells me: No. Don't sit! Stand! I am walking up and down you see. So I could walk even from the morning up to sunset. You find that I go home, and I try to rest. No. I am not supposed to rest. I wake up, and go outside. I sit outside. I feel like something is trying to command me, somewhere, somehow. (…) I go inside my house, I go in my bed, I sleep – I try to sleep. I don't even get a deep sleep. The whole night until it is sunrise. Once it's sunrise I go out of the house. I'm not even supposed to stay with somebody. No. I'm just alone. I move a bit, I find a shelter. I try to sit in the shelter. Maybe it is just a sound of a bird, I have to start off again. It is disturbing. So, my wife she went to the relatives, they talked to me, now, I couldn't even hear them. So I continued on for almost a week".*

This detailed description from Benjamin can inform us about several aspects of how mental illness can be experienced. He describes how his mental stability has been disturbed and that he don't seem to recognize his thoughts and behaviour as part of his 'ordinary self'. Thou seemingly being in a state of confusion and experiencing alienation to the ordinary self, Benjamin is able to talk about this experience with a kind of familiarity and consciousness; almost as if he talks about somebody else, as if he looks at himself from a distance.

They compare the severity of the illness with malaria and TB, which are conditions they are familiar with, and which are also considered as dangerous, sometimes lethal conditions. Eden says about the severity of mental illness: "*…because it affects even the brain, the thinking and the reasoning. So it is a most, most serious issue which can not be compared even to malaria. I know that malaria is a deadly disease, but mental health-, mental aspects are one thing that needs to be taken care of".*

All participants talks about mental illness as an illness that affects both their physical body and their thinking and their sense of self. The bodily ailments seem first and foremost to be located to the vital organs and functions of the body; like the head or the brain, the heart and

the chest and the breathing. Andrew says he had problems with breathing and he experienced chest pains: *"I was just breathing, without coughing. (…) I started breathing, breathing, then started the pain. (…)It's the way my illness started, my mental illness; to brain infection, hearth and this part (pointing at his chest)"*. David also experienced pains in his body: *"I was not feeling well. My body pains. I was shivering. So maybe it can be malaria-? With stomach pain and headache pain."*

Benjamin experienced not recognizing his ordinary self during his illness, saying "I was not myself. This experience about an altered self during illness episodes is shared by others. Eden describes it like this:

> *"It's like the brain has been disturbed, and you can't remember, you can't even control – how to control over yourself. From that moment I couldn't recognise whether this was wrong or this was right. I could hit some people. I could get some fritters[9] from others, for the sake of eating, without me knowing that, that is a wrong thing".*

Charles is also recalling a feeling of an 'altered self' and says about the first time he experienced mental illness and is': *"And then when I woke up next morning; I never felt like myself"*.

It seems like the experience of mental illness are some kinds of entities in their everyday life, which they observe and relate to as a strange phenomenon that happens to them. The unstrained and kind of familiar way they talk about their dramatic experiences, stands in stark contrast to the severity of the content of the experiences.

5.3.3 Mental illness and madness are two different things

Benjamin is asked how he would name his condition and says: *"Mine was -ah- maybe I would say I had a mental illness"*. Though one of the inclusion criteria in this study is that the participants are diagnosed with 'schizophrenia', none of them are naming their condition 'schizophrenia'. They use different terms when talking about their condition, and 'mental illness' is one of the terms more frequently used. They also refer to the condition as 'being mentally disturbed' or having 'lost the mentality'.

Charles is the only one who raises an issue on the term schizophrenia. He comes to the interview, bringing with him an old Oxford Dictionary and he reads aloud from it: *"Schizophrenia. A disorder of the mind, causing the person to draw away from other people, into a life in the imagination world"*. He appears to be a bit upset when he reads this and

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[9] Deep fried buns

makes a comment with a tone of indignation: *"I thought to say; psychiatric patients are still quite somewhat different. It is very assumptious!"*. He obviously disagrees with the description in the dictionary, and indicates that what is written is different from how mental illness may be experienced. Another of the participants, David, says he has a file at the hospital. *"I got myself this document to say I've got a mental illness.(…) I can't – I can't judge myself. But-, I'll be flexible to them"* He may not agree with the statement from the hospital, but he also doesn't seem to want to do something about it. Benjamin on the other hand, acknowledges that he is considered to have a mental illness, but doesn't seem to be preoccupied by the diagnosis: *"I don't know. But it was written on my paper. This diagnosis. It's there – on my card"*. He says that knowing the diagnosis might be useful for him and may assist him to cope better with the illness: *"It is important. Because you may know what you are carrying - and you may know what you are - what you are supposed to do – and what you are not supposed to do. Yes"*. It is only David amongst the participants who seems to be uneasy by being considered as having mental illness. The other participants seem not to be pre-occupied by what their illness is labelled; only that it is a mental illness.

Another issue emerging from the analysis is that all participants also talk about being mad and madness, but none of the participants seem to consider themselves as being 'mad'. On the contrary, they all make clear distinctions between madness and mental illness, and they relate themselves to the latter category. Benjamin describes how he understands the difference between mental illness and madness:

> *"Somebody who is mentally disturbed and somebody who is mad –. I think there are two different things there. A person, who is mad, is somebody who cannot think. (…) That is a different character from somebody with mental illness. Because when you are mentally ill, you can be able to acknowledge some of the things. But when you are mad - you find that they give you a cup like this, the cup is spoiled, but they'll give you to say; 'can you draw water in this cup'? Automatically you'll go and put water in. Because you are mad. You can't reason. Giving you a new cloth, you throw it away. So you find that there are different things. Giving you a clean food, you don't want to eat the clean food. You just want to go and pick in the bin. Yes. You can't even go and sleep in the house. You want to sleep in the streets, under a three. There, I think, now you are mad."*

The participants do not consider themselves to be in this category of being mad thou some of them experience being called mad by others.

5.4 Treatment experiences: Western medicine and African traditions hand in hand

The way the participants explain their mental illness and their treatment experiences, seem to reflect diverse cultural beliefs but also influence from Western medicine. All participants have used both African traditional treatments and western medical treatment. Some have gone to the hospital first, others have seen traditional healers before they have gone to the hospital. Andrew describes how he has tried different treatments in his search for something that helps: "*At first I try to the hospital. Then traditional healer. I didn't go to traditional healer first – I go first to the hospital. Then at the hospital they try. Then the disease still grow. That's when I try to the traditional healers*".

The western medical treatment they refer to in the study is mainly medication in form of tablets; Largactil and Piriton, and sometimes injections. The hospital services mentioned in the study are short admissions in the acute stage, reviews mainly of the medication and an activity centre for outpatients. The African traditional healers mentioned by the participants, are seers, diviners and witch doctors. Andrew explains what a seer is: "*When you have got a problem, he'll tell you;' you've got this problem and this problem. This problem needs to be treated like this, or this problem like this*". Traditional treatment may involve the use different medicine: "*Some medicine is for to drink, some are just boiling and washing, and some are even tattoos*". Eden was treated by a diviner: "*It was just for prayers. What was called - encountering demons. Where they pray to remove demons so that you are de-demoned*". He was also treated with tattoos, believing that his blood also was infected with evil: "*You are declaring that this blood belongs to the enemy; that's the devil*".

The participants have different experiences with the different treatments, and they have different experiences of what has been helpful. Common for all participants is that the family is fully involved in choosing treatment and in organising the treatment. They are also providing care for the participants while recovering.

5.4.1 Different explanations of mental illness

The participants explain their mental illness in different ways. Andrew seems to be convinced that his illness is from witchcraft: "*…because my disease has just not come like this – like anyhow. It's a witchcraft case*". He says this was confirmed by a traditional healer specialized in mental health problems and says that the treatment he received was helping him: "*I found a specialist. He was trying. The way I was, it was different. I get well. I get better, than the way I was*". The other participants seem to be more open and suggest that several factors can

contribute to mental illness. Charles relates the onset of his mental illness to a difficult life situation combined with substance abuse: *"I think it was too much thinking. And I had to take some marihuana, for a month or so. I think it was that and too much taking marihuana"*. Eden is also relating his mental illness to difficulties and distress in life: *"When I get cross, and get irritated and so forth; that is one weakness that I have traced. That I need not to be angry at anything, but to be sober always, and handle things the way they are. So that also contributed for me to come into that state"*. Benjamin says he was taking a lot of beer at the time he got sick and says this might have contributed to his illness. But he is also open to the influence of witchcraft on mental illnesses: *"You know, black people, when you get mentally ill, they just tend on witchcraft. (…)Because with witchcraft they can also practice something. 'Cause you'll steal somebody's property; now they go to the witchcrafts, they disturb your brain"*.

Benjamin was admitted in hospital and received medical treatment. His family had also organized some traditional treatment which he was given in secrecy:

> *"You know at the hospital, they don't advice somebody to be taking African herb. But they could hide. They give me some medication to drink. I drink, they hide and then they take home. They were afraid of the nurses to say; 'why are you giving that –that stuff?"*

The analysis shows that the participants are quite clear about what they think is helpful to their mental illness, and what kind of treatment they prefer. Andrew's says that the medical treatment he was given did not help him. On the contrary, he says he felt more sick.

> *"We are getting this Piriton[10] - and other drugs. Because this drug for mental - some are increase the disease. You are not thinking properly, you are just like maybe-sort of like the brain is kind of ceased. There is this kind of drug that is not good. So after I have got that drug starting again sick, mentally - the mental come back again". (…) So it's better, in fact to get to the traditional healer"*.

Eden has also tried different traditional treatments, but seems to have the experienced that medical treatment has been more helpful to him:

> *"Like I have said earlier on, medication plays a very vital role. Because it stabilises the brain. The brain now, it functions well. The mental functions - it functions well. Because there is instability in the brain formation. - when the sickness happens. (…) Had it not been for the medication, maybe I would not be in here. So I change very much on the medication on which I'm receiving. That it puts the situation in order"*.

He doesn't want to take traditional treatment: *"Because it has not yet been proven medically. Neither has it passed through the labs. So that is where the problem is with me in this*

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[10] Sedative drug

especially. I can't opt for traditional medicine. I'd rather go for a proven medical medicine". Another reason for not choosing traditional medicine is his belief in God: *"Because I have seen; one - it is against the will of God, two -the medicine is not proven, they do not know if it is toxic".*

Though some of them relate the illness to factors outside themselves, it seems like they have experienced that they can influence on their wellbeing and to do something to contribute to the recovery process. Andrew says he stopped smoking and drinking and found himself a job: *"I worked just like that to save myself. I'm feeling well. God helped me".*

5.4.2 Control or care? The family's influence in choice of treatment

The analysis shows that all participants have experienced being taken for treatment against their will, and been given treatment forcibly. From the analysis it seems to be two aspects in this; participants have experienced being taken to treatment when they felt they were not in need for any kind of treatment, and that they are given a different treatment than their choice. Andrew says he had behaved violently, and he was then taken for treatment against his will: *"... they catch me, to tie me up and put me in the vehicle and take me to the traditional healer".* But he also says that people who are mentally ill, sometimes can't seek treatment themselves, but need to be taken by others. Benjamin was also taken for treatment against his will, and tried to resist the medication he was given: *"I was put in a sideward there and they had to inject me an injection. It was a war. They tried to inject me. Now, I couldn't allow it. They still had to hold me. Tight".*

Eden's family decided to take him to a church for treatment: *"But the traditional medicine is also where I found conflict with them. I was not for it. But they were forcing it on me. (…) I had not lost my mind during that state. I was able to know everything".* He tried to resist, but was tied with ropes on both his hands and feet: The ropes were tied so hard that he suffered severe injuries. At the time of the interview his wrists and ankles had still deep soars and the some of the fingers on his right hand were injured. But despite the pain inflicted on him, he seems not to angry or upset about the way he was treated. It seems like he could understand the good intentions and care for him behind their hash treatment and that he managed to make meaning out of an otherwise serious and abusive situation:

> *"They were tying me. Just to protect me from going anyhow. Just to try to secure me.(…) Why I think they did this was; one; they were looking at me, if I was left-, untied, -I would either damage some people's property, - or two; I might even bring harm of like beating-. So they were looking at those. That's why they were hand-*

cuffing me".(…) "When one is faced with such a tragedy, they would always want to tell you the solution.(…) And now in some situation where such person is sick, and you are the one-, the next of kin who wants to take responsibility to that person that is sick-. You open to any problem".(…)"From the family background there are those on cultural issues. There are those who believe that this can be cured by African doctors.(…) So there was that misunderstanding in the family. The family wanted that – maybe that way it would work. On my own I looked at it, that that way it couldn't work".

Both Eden and Benjamin say that the traditional approach in mental illness is so strong because it is a vivid part of the culture. Eden says: *"People are very much in tradition. One reason is; this is an inherited thing. It is being passed by our forefathers, and our fathers. Why people opt to traditional healers, it's like they have grown with it. They can't let go".*

They have some critical comments regarding traditional treatment: Eden: *I've come also to assess these churches. You find there are those who are real and there are those who are not real.*" Thou Andrew have found a traditional healer he trusts, he says that many of the traditional healers are not reliable and that they are just after people's money:

> *"We've got a problem with traditional healers-some – they are just crocks, The true traditional healers they are not many. They are few. Because there are specialists in mental health - in mental illness. Yeah. There are some specialists in other illness, in different illness. Some, they want money. You give them money to treat you, but they fail to heal.(…) They are just stealing the patients' money, and even other thing, because it we don't have money, they say you are just paying with which you have, even radio, even TV, and you fail to be cured.(…)It is a problem that we have here in Zambia".*

The family seems often to be the ones to decide <u>that</u> they are going for treatment and <u>what kind</u> of treatment they are taken for. The choice of treatment is sometimes in agreement with the affected person, but all participants have experienced being taken for treatment against their will and being given a different medication than their own choice. Even if some of the participants have experienced being treated with violence, they describe these episodes with a high degree of understanding and without any signs of sourness or anger.

5.5 Mental health services; some reflections and recommendations from the service users point of view

The participants in this study show a keen interest in the welfare for people with mental health problems. They want to use their experience to improve the conditions for the people in need of mental health care. From the material there are three main areas that emerge as important to improve on: provision of care for those who can not take care of themselves, being listened to

by the health care professionals and access to some kinds of occupational services; either as a therapeutic mean or as skills training.

Andrew is a member of the user organisation for people with mental health problems, and he think they should do something to improve the situation for people with mental health problems. "*We are supposed to have a meeting. So that we can see how we can save our mental people here. And to let money for account and shelter and food. And because that is just now what we want to fight for*".

5.5.1 Provision of care for people who can not take care of themselves

One of the major concerns of the participants is that sometimes people with mental health problems are not able to take care of themselves, and are not being taken care of by others, and they lack the most basic things as shelter, clothes and food. The participants see this as a most serious issue, and Andrew is addressing the families as well as the Government to do something:

> "*Because there is no care. Most of the time there is no care. We are just in the streets. In the marked. In town. Everywhere. Even sleeping or not sleeping anyhow. They don't have shelter to sleep, and food to cook. (…) Ah, lack of care-from government, from citizens and families. (…) The families must assist them in medicine, even food, even clothes, even to bath. The government must fight for shelter for them and medication. And help them, like, because in that state, you cannot stay. How to care for people with mental health problems is to give them food, and shelter and try to kit them, to be cured, to be well.*"

Unregarded their own preferences for treatment, they seem to believe that the hospital care and medication should be available when people experience mental illness. They also recommend that families or others should take charge if the person himself is not able to seek help. Andrew says people with mental health problems need to be attended to and given they receive treatment they can recover: "*Because himself can not go to hospital. That's a problem.(…)It's families and even the government to assist them. You can take them to the hospital, the ward and put them there. (…)So the brain can be working. For become normal*".

They are very concerned about the people with mental illness who are not being attended to. They say that these people are in danger to become mad. From the distinctions between mental illness and madness described earlier it seems like madness is seen more as a social category then a medical condition. From the descriptions given by the participants, madness seems to occur when a person are not being taken care of and looses his home and income:

Then we see some can not be well. Some are high, it's forever. So for those...for health, food and clothes and eating well, is better. Then they can change, if he found the support. Cause being alone, causes the things worse, and then when they don't have food, energy, just moving anyhow to find the food, even the bins, you know. So these things are big problems (…) Because when we are sick we must have care. So when we don't have care, that's when we find many people are there (on the streets). Because we no longer have ward to be healed there. Because of lack of energy, they are just a moving anyhow, so the disease is increasing. Some are smoking, some are drinking, that's why the disease is going hell".

Benjamin shares the same concerns as Andrew and says that people with mental health problems can recover, and should be taken care of:

"To say now, instead of roaming in the streets, doing what, even if he's mad, but he's up to learn. But instead of trying to do that-, just leave them, just because they are mad they should just go like that. It should be something for them as well".

Benjamin also mentions the importance of reviews after being discharged from the hospital. He says it is important that the health care workers are informed about the progress:

"But now, you see. it seems, by the time of discharge, by the time I got well, they can't even recall to say, that I'm was such and such a patient. Is he still alive, is he dead? How is he living? What is he doing in his lifetime?"

They seem to have a concern on those who are regarded to be mad, and what can be done to prevent people from ending up in madness. They say it is a responsibility of the government and the families, but they also seem to take a responsibility upon themselves to contribute to a better mental health service. He seems to have an idea about not only meeting the health workers, but meeting with other patients to share experience: *"It'll be very easy for me- to attend to a patient who is suffering from this stuff. Because I'm talking out of experience. And I would know how to go about it".*

5.5.2 People with experience of mental health problems should be listened to

The relationship and communication with health workers seem to be another concern shared by the participants. They have diverse experiences on how they are met by the health workers in the mental health services. One of the things that appear to be a significant experience is the issue of not being listened to. They also mention that they don't feel they are met as individual unique persons, with different needs and different experiences. Eden says:

"They should spend more time to listen from us. We are created differently. The way we approach issues are also differently. There are those who speak slowly, there are those who speaks very fast – there are those who are on the moderate and so forth"

Eden says he doesn't feel he is understood and taken seriously by the health care professionals, and that they don't listen to his views. He says they should pay more attention

to his point of view and to take notice of how he experiences his situation and the impact illness and treatment have on his everyday life:

> "Medical tradition should at least spend more time in listening to us – what we want. Although it may not make sense-, but sense can be extracted from what is spoke. Because it is me taking the track".(…)"If I say I get drowsy, they should listen to me. Because it is making me drowsy. If it's making me sleep, they should listen to me, that there is an overdose. Because, there could also be an overdose in the drugs. So the medical practitioner should listen more to us. It is us to bring the problems to them. And then they need to look at the problems and how they could help us. (…) "…because it's us who is taken the drugs, not the doctors. Maybe the drugs are making me sleepy during the day, which means I have to communicate with my doctor. Because one, during the day, that is when I need to work. Now, if I 'm drowsy, which means I can't do my work properly. So it's either they change, or the way I take them or so forth".

But the experience is not unambigous. Some health workers are different. Eden praises one of the health workers he has met as being a helpful relation. He says that the encouragement and guidance he gets from him means a lot to him:

> "So I really thank God for him. He has been a tremendous health worker. He's always here with us. He is always here to give us the encouragement. He's always here to get our petition. He's here to take our cares and so forth. He would guide you; 'don't stop on taking medicine, you should always –. This place is open' –and so forth".

Eden closes his statements by saying: *"Medical practitioners should be friendly to us, because we have a lot of needs, more than they can think they have"*.

5.5.3 Being occupied

Another issue emerging from the analysis is the issue of being occupied when suffering from mental illness. All participants say that occupation is important for people with mental health problems; either as skills training or incomegenerating purposes or as a therapeutic approach.

Eden calls it survival skills: "*Why I call them survival skills is because you need to do something to earn a living. Survival skills - it would help us very much*". He is sometimes attending the activity centre at the hospital where they are taught different skills and produce items for sale. They also receive a meal during the day from the hospital. He says it is important that the mental health services provide opportunities to learn skills in income generating activities:

> "To do something. And that can generate income. And not just to come and wait for meals. Meals should not be the first priority. Because even those meals- we take them at home. But it should be something that would benefit a person. After making a stool, he sells that stool and have something.(…) So if we are helped in survival skills, those skills can be turned into income – after doing the work. After all, the end part is income. Then income brings in food and stability in a home.

Being occupied is also seen as being therapeutic. Andrew says that being occupied can improve the mental health:

> *"That time they had a workshop for making papers. You must try to doing something. So, once you are feeling better-, must train them for job, working, and to keep them busy so that the mind can starting work properly".*

6. Discussion. What can we learn about recovery from the experience of 5 men living with severe mental illness in Zambia?

My intention with this study has been to explore how living with severe mental illness in the context of everyday life in Zambia can be experienced, and to try to understand these experiences in a recovery perspective. In this chapter I will discuss the findings described in the previous chapter in light of theory presented in chapter 2and 3. I have chosen to pursue the findings I have found to be more significant in order to promote recovery in the context of everyday life based on literature and my own experience.

6.1 Participation in everyday life (activities).

"*Every personal journey towards recovery is punctuated by a critical negotiation on how, where and when to be what with others*" (Sells, Stayner et al. 2004:95).

The participants in this study are involved in a variety of activities that take place on different arenas; at home, at work, in social venues like bars or in church, just to mention a few. They are all living in a home together with or near by other family members. They have access to daily work or other income generating activities. They are also involved in church and different social activities. They describe an everyday life that consisted of a variety of activities and social relations. A considerable amount of recent research on recovery in mental health emphasise the contextual aspect and the importance of being in an ordinary environment performing everyday life activities with others. (Sullivan 1994b; Ridgway 2001; Sells, Stayner et al. 2004; Davidson, Borg et al. 2005; Deegan 2005; Marin, Mezzina et al. 2005; Sells, Andrés-Hyman et al. 2005; Sells, Borg et al. 2006; Topor, Borg et al. 2006; Mezzina, Borg et al. 2006a; Mezzina, Davidson et al. 2006b; Borg 2007; Borg and Davidson 2008; Borg and Kristiansen 2008; Topor, Borg et al. 2009).

The activities the participants are performing in their everyday life may be seen as trivial activities; e.g. going for work, helping children with their homework or chatting with friends, but it is these trivial activities that provide the opportunities for the participants to perform interests, skills and expertise and to interact with others (Marin, Mezzina et al. 2005; Borg 2007; Borg and Kristiansen 2008). Performing everyday life activities also comprises interaction with others and with the material environment. It is through this interactions with one develops as a person, and realize potentials to reach life goals. (Deegan 2001; Sells, Stayner et al. 2004; Borg 2007). Research shows that experiences of interpersonal acceptance, mutuality and a sense of belonging promote recovery (Sells, Stayner et al. 2004; Deegan

2005; Borg 2007). For most people recovery appears to develop from participation in work and to live with supportive others (Sells, Stayner et al. 2004; Borg and Kristiansen 2008). Participation in various contexts and performing everyday life activities with others can provide that.

6.1.1 Access to work roles (and participation in different social arenas)

As already mentioned, all participants in my study have access to in work or other activities which could generate some income. In Zambia more than 80 % of the population live under the poverty line (CIA 2008), and the little public welfare available is reserved targeted groups of the population (Mayeya, Chazulwa et al. 2004). Since most families live under extreme marginalised living conditions, this necessitates that all family members contributes in one way or the other to the household. The man as head of the family is expected to be the main breadwinner and as it came out in my study the access to work enable them to have some income and secondly to contribute to the welfare of the family.

Eden calls it 'survival skills'. He says: "*After all, the end part is income. Then income brings in food and stability in a home*". Since the role as head of the family and being the main breadwinner is the most, or one of the most important roles of a man in Zambia, being able to maintain these roles are crucial in recovery. The unemployment rate in Zambia is very high, and formal employment is difficult to find. But fortunately the use of manual labour and informal services gives opportunities to find income for people with different levels of education and different skills.

Research on recovery describes work and the work setting of significant importance to the recovery process. Work and the work setting offer a variety of opportunities to work on the recovery (Borg and Kristiansen 2008). The findings in my study indicate that work might be the most important everyday life activity for the participants.

Work also contribute to the persons self esteem. The participants talk about their work with obvious pride and confidence and it is obvious that their participation in work and their contribution to the family's subsistence empower them as persons and valued participants in their community. Borg and Kristiansen (2008) found that work is associated with a positive identity and status as being an adult and a contributing member of society; to be and become someone". The work role might provide a positive status and identity, respect from others and a feeling of inclusion in the community. Work as an arena may provide a sense of belonging and a sense of community and collective positive identity as socially valued workers (Borg

2007; Borg and Kristiansen 2008). These aspects of work were quite evident for the participants in my study.

Other aspects of work that came out in my study, was that work provided an arena for making friendship and partnership with others and a chance to be in reciprocal relations. Andrew is exchanging favour with his landlord; he looks after the house, while he stays for free. David is helping his friends ferrying passengers by taxi and trading on the streets. In return he is given some payment which enables him to contribute to his sister's household. The importance of participating in teamwork, the experience of partnership and being in reciprocal relationships is found to be significant importance in recovery (Mauss 2002). These kind of experiences may also provide feelings of being part of the ordinary, collective 'real life' (Deegan 2005; Borg and Kristiansen 2008).

Work environment is also an important arena for the individual to experience mastery and competence (Deegan 2005; Borg and Kristiansen 2008). The participants in my study talk about their work in a confident way and with obvious pride. They present themselves as competent and skilled in their work activities. Some of them also talk about plans they have for the future to develop their skills or work opportunities. By engaging in work activities they seem to have experienced their capacity to perform different activities and explored potentials for further development. Participation in different work activities might have provided them an experience of competence and mastery which gives them confidence to pursue the potentials they see in themselves and in the environment for developing their work situation. The feeling of success and enhanced mastery may also provide positive feedback from others and this again may impact on their sense of self and their self presentation. In this way participating in work may contribute to important experiences to the individual, but also opportunities to perform activities which are well recognised and valued by others (Borg and Kristiansen 2008). My previous experience from work in Zambia has shown that this process can be seen as a 'good circle' where each element is enforcing the other and may be a major contributing factor in recovery.

A last aspect of work or rather occupation being brought up by the participants is the value of using occupations as a therapeutic means. They say that mental health services should include occupation as therapy or skills training for patients. They do not exhaust this in detail, but Eden says that being kept busy 'helps the mind to work properly'. This may be related to work as structured and usually a quite predictable activity (Borg and Kristiansen 2008), which

may be an important contribution if the everyday life otherwise appear as disorganised and chaotic.

To conclude on the topic of work, it seems that both empirical data from my study and other research seems to be quite unison regarding the significant importance of work in recovery.

6.1.2 Being active participants in the community

Another finding which seems to be of importance in relation to recovery is the participation in church activities and other voluntary activities. Andrew, Benjamin and Eden are active church members. They were involved in a number of church activities as participants, leaders or volunteers. Andrew use to visit people at the hospital and sometime assist church members in funerals. Andrew is also a member of a group for keeping the environment clean. Eden is a member of a trade union, and they are all involved in activities with the local association for mental health. Their involvement in different activities shows that they see themselves as persons who have something to contribute to others and as committed citizens. Research shows that the opportunity to contribute something to others as volunteers or as members of peer groups are of importance in recovery in mental health (Deegan 2001; Borg and Kristiansen 2008).

The participants show sincere concerns about the situation for people with mental health problems and become upset when they talk about those who are not taken care of ; and those who are mad. They show sympathy with them, but also anger towards the families and the government who were supposed to provide care. They talk with engagement and commitment about improved services and better rights for people with mental health problems. They have a number of suggestions for how the situation for people with mental health problems can be improved, especially for the group that have no care, and they want to contribute with their experience and their commitment. Knowing that they have their own adversities and distress in everyday life, they still have this degree of commitment and drive be concerned about the I believe that these concern and commitment are important opportunities to meet expectations and demands from the community and also from themselves about balance and mutuality. In periods of illness they are often in the position of receiving care and support from others, and the opportunity to contribute to others may provide another role than as a recipient (Deegan 2001) and a balanced relationship to the environment (Mauss 2002). To be able to give or to be something to others are also important for a maintaining a sense of self as a resourceful and valued person (Borg and Kristiansen 2008).

Their active involvement in different volunteer or peer activities may also reflect values they share with their community or expectations from the community. They are all members of different Christian church communities and participation in church activities and practicing religion is an integrated and important part of everyday life. Doing good deeds and sharing with others are important Christian values and may promote participation and contribution. It may also be important to do good to avoid wrath or punishment (Sells, Stayner et al. 2004; Teuton, Bentall et al. 2007).

6.2 Sense of self. Being a person; being competent, active and contributing

The social context where the everyday life activities takes place has proved to have tremendous influence in recovery in general, but is also of significant importance on the person's sense of self. We interact with our environment; we change and we are changed. We become who we are as persons in the encounter with the environment (1989; Sells, Stayner et al. 2004; Mezzina, Davidson et al. 2006b; Borg and Kristiansen 2008).

Inclusion and participation in valued ways and settings enhances the competence of activities in everyday life (Borg and Kristiansen 2008). A sense of self as active and effective has been found to be crucial in recovery (Davidson and Strauss 1992; Sells, Stayner et al. 2004). One of the main findings in my study is that the participants see themselves as *competent, active and contributing* members of their community.

6.2.1 A sense of self beyond the illness

It is quite apparent in my study that the participants perceive themselves as persons who *have* an illness and the mental illness does not seem to be part of their identity. They talk about their illness as episodic incidents that occur more or less often. They name their condition 'mental illness' and they make a clear distinction between having mental illness and being mad.

Some of them say 'I was not myself' and describe how they felt differently and did things they otherwise would not have done. 'Not being oneself' indicates that there is a known, durable sense self as a reference. I understand this statement from the participants as if they have a continuous and embodied knowledge of their own uniqueness as persons beyond the illness; a sense of self that is recognized as 'I' before, during and after illness episodes. The self seems to be experienced as durable and persisting, only with some new features or new capacities or incapacities.

This may also contribute to the familiar way the participants talk about their illness. It is like the illness is an entity in their life, but not part of their 'self'. They have a high degree of consciousness even in periods of severe distress; e.g. Benjamin's detailed description in a previous chapter.

The self is changing in an interaction where the inner self is negotiating with the social world (Estroff 1989). My study shows that despite living with severe mental illness, the participants manage to perform different everyday life activities which they are proud of and which benefit their families and communities. This may contribute to a sense of self as confident, competent and able. Thou there are periods where they are unable to perform the expected roles and responsibilities, this does not seem to affect their sense of self profoundly and is experienced as episodes and as a temporary state.

A substantial amount of research (Estroff 1989; Davidson and Strauss 1992; Deegan 2001; Ridgway 2001; Estroff 2004; Sells, Stayner et al. 2004; Deegan 2005; Borg 2007) from the last two decades underpin the assumption that having a sense of self that is durable and characterized with unique personal qualities rather than characterized with pathological labels is one of the most important factors in a recovery process. As mentioned above the sense of self develops in interaction with the social environment (Estroff 1989; Christiansen 1999). My study is merely based on the participant's presentations of themselves, and the picture would probably be more differentiated if I also talked to 'the others' on how they perceived the participants. Sense of self is the self as known to ourselves, but our self can also be known to and identified by others. If the gap becomes too big between the self as we know it ourselves and how we are seen by others, this may be experienced as radical estrangement or hyper-alienation (Estroff 1989). The participants in my study say they experience being perceived as mad, while they define themselves as ordinary persons suffering from mental illness. But this does not seem to threaten their sense of self. Despite being called 'mad' and experiencing discrimination and social exclusion, they claim to be treated as respected persons and granted their rights as citizens in the society. I think this represents a great potential for recovery in severe mental illness.

6.3 Social support and interdependency.

As a society with a sociocentric structure, the family and the community plays a significant role in recovery in Zambia. The social environment may represent barriers in forms of public

attitudes and stigma, but it is also where the resources can be found and released (Borg and Kristiansen 2008).

One of the significant findings in this study is the tremendous support from families, neighbours and others during periods of illness. The participants in this study are sons, brothers, fathers, husbands and friends and they describe the love and concern they receive from their dear ones. They feel loved and cared for. Significant and intimate relationships are important for everyone (Davidson, Borg et al. 2005; Deegan 2005; Topor, Borg et al. 2006; Mezzina, Davidson et al. 2006b; Borg 2007), but even more when one is faced with adversities and distress of severe mental illness. The findings from the study also suggest that there is a dependency on the participants from the families. The participants are the main bread winner in the family and the family will suffer severely if they loose this income. The already strained resources and the marginalised living conditions make the families extremely vulnerable for any extra challenges, such as mental illness and loss of income. The findings in my study show how the participants and their families, not only looses sources of income for shorter or longer time, they also have extra expenses for food and treatment during illness. The association between poverty and mental health problems are well acknowledged and the way direct and in-direct costs of mental illness worsen the economic situation is described by Patel and Kleinman (2003) and they call it a vicious cycle of mental illness and poverty.

The findings in my study suggest that this situation creates a state of interdependency between the person who suffer from mental illness and the family and others in the social network. The person who is sick needs the support from the family and others to recover, while they need the participation and contribution from the one who has fallen sick. This state of interdependency might be seen as conducive to recovery and a motivation for releasing resources for support.

But – there seems to be a limit for how much strain the families can endure. Based on the findings in my study it seems like the end of support from the family is where madness begins. This shows how the whole family's welfare and social position is at stake, and how much it means for everyone that the person who suffers from mental illness recovers.

A person who is considered to be mad, has far less opportunities than someone who has a mental illness. They have little support from the community since they are not regarded to be able to contribute to the community, and most people fear them. According to Mayeya, Chazulwa et al. (2004) say they are scorned, humiliated and condemned. Even their families

are stigmatized. Avoiding ending up with this situation must be an urgent issue for the person and the family, and indirect a vital agent for recovery.

6.4 Creating meaning through future goals, purpose in life, faith and spirituality

All of the participants presents hopes and plans they have for their futures. Despite the adversities and the distress they experience related to the mental illness, they seem to hold strong hopes for a better life in the future.

6.4.1 The power of hope

Hope is a future-oriented concept, it may be seen as anticipation and about something to be realised sometime in the future. The hopes of the participants in my study are closely related to their everyday life. They talk about better accommodation, expanding the business, developing new skills, getting married to mention some. According to Noh, Choe et al. (2008) hope is about human possibility; to discover meaning in life and to discover the possibilities beyond the adversities. Hope is also seen as the energy that enables people to try to achieve what they hope for. The participants in my study seem to pursue their hopes with vigour and some of them have developed their hopes into more concrete plans and strategies for how to achieve what they hope for in the future.

This study shows that the participants seem to have a strong sense of confidence, pride and self-esteem, which has been found to be important internal sources of hope (Noh, Choe et al. 2008). They also seem to have access to important external sources such as love from others, family relations, spiritual relationship with God, involvement in activities, nature. They seem to be proud of their previous achievements and this may give them confidence in their abilities and the courage to take measures to improve their future everyday life. Research suggests that hope is one of the most critical determinants of recovery. In mental illness hope play an essential role in overcoming distress and promote positive changes in life.

6.4.2 Purpose, meaning and sense of coherence

Antonovsky (2000) says there is a positive association between optimism, hope, learned resourcefullness and constructive thinking. The participants in my study seem to possess these capacities which enable them to organise and to utilise available resources in society, the social context and self. E.g. Eden had bought a piece of land where he could develop farming and Charles had started to build the first room of his future house, Andrew had developed a

strategy for expanding his business. Efforts to achieve what is hoped for are seen as the first step for a better future, and this is not only the nature of hope, but also the real meaning of recovery (Noh, Choe et al. 2008).

Hope is also connected to having purpose and meaning in life (Antonovsky 2000; Noh, Choe et al. 2008). The findings in my study indicate that the participants seem to experience a multitude of purpose and meaning in life through their participation in everyday life, where relations to others and relation to God is important. The participants present themselves as integrated members of a community where social expectations are pronounced and where everybody is aware of and usually able to perform according to social norms and cultural traditions. I believe this contributes to a sense of meaningfulness for the participants, which is another issue that appears to be of significant importance in recovery (Deegan 2005; Borg 2007). Antonovsky's theory (2000) about salutogenesis might be helpful to explore what enables the participants in my study to maintain their sense of purposefulness and meaningfulness, despite the adversities and distress they experience.

One of the interesting findings in my study is the way the participants seem to relate to having a severe mental illness. When they describe their experiences during times of illness, they do it with a high degree of consciousness and clarity. Despite experiencing oneself as different from the 'ordinary self' and despite of the dramatic incidents they have gone through, they don't seem to feel any fear or anxiety, which could be a natural reaction to the dramatic events. I haven't found this phenomenon described in any literature, but based on my previous experience and my intuition, my suggestion is that this position they have towards their illness experience is related to a sense of coherence; they interprete their illness within a meaningful and understandable context, and perceive their challenges as relatively manageable. The findings in my study indicate that the everyday life of the participants have a high degree of consistency and meaningfulness which make them more equipped to deal with adversities which is promoting health according to Antonovsky (2000).

Another aspect of how they relate to the illness and distress, is a kind of indulgence or tolerance. All of them had experienced episodes where they had been socially devalued, excluded, called names, tied with ropes and given medication against their will. They talk about his without any sourness, bitterness or anger. On the contrary, they say that they understand and believe that these things were not done out of evil, but out of despair or lack of knowledge. As sense of coherence meaning can be derived from situations from the

situations, while resilience is seen as the effective adjustment and adaption to challenges in life (Geanellos 2005).

6.4.3 Faith and spirituality

Religion and spirituality are important aspects of everyday life in Zambia (Mayeya, Chazulwa et al. 2004; CIA 2008). The participants in my study are members of different Christian churches and participate in a wide range of activities. These activities seem to be an integrated part of their everyday life. The church seems to be an important social arena for social interaction and community with others.

The participants express that their faith in God is an important source of support and safety in life. Eden says that God will never disappoint him, and that God is able to provide for him what he needs. They say God gives them guidance and the knowledge they need to live a good life. They say the belief in God also gives them comfort and strength, especially during times of distress. Eden says that God is the stability in his life, and gives him hope and assurance for a bright future.

Though the material in my study does not give many details on the participant's relation to faith and spirituality, the findings suggest that even if the Christian faith is presented as dominant, it seems that some of them are open to the traditional beliefs ways that include influence of spirits as well. It is very common in many African societies that the Christian churches also incorporate elements of indigenous beliefs in their practices (Mayeya, Chazulwa et al. 2004; Teuton, Bentall et al. 2007). Faith and spirituality are seen as powerful forces for creating a sense of purpose and meaning in life (Christiansen 1999; Teuton, Bentall et al. 2007).

In a traditional perspective, the individual is integrated in the social, natural and supernatural world. Health and a good life are achieved when the individual is in harmony with their environment (Mayeya, Chazulwa et al. 2004; Teuton, Bentall et al. 2007). In this perspective mental illness does not come just like anyhow, as Andrew says about his illness. The cause of the illness is often explained at two levels (Ingstad 2007); the immediate cause which some of the participants explain as abuse of alcohol, smoking dagga[11], the brain is not working properly or stressful events in life. The other level is the explanation for why this would happen to that person, at this time. In this understanding it is important to treat the immediate symptoms, but there is need to find the origin to the illness and find adequate ways of

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[11] Cannabis

restoring the balance with the social and spiritual world. In everyday life context the origin of problems can be immoral behaviour, offending ancestral spirits or jealous neighbours. (Ingstad 2007).

This way of understanding mental illness might induce a lesser strain on the individual, since the reason for illness and the purpose and meaning in life lie in the relation with the social and the spiritual world, and the individual are not to blame alone, and not the one who has to be repaired – as in a western biomedical understanding. Borg (2007) says that an individualised perspective of recovery which pays little attention to environmental factors are adding to the burden of responsibility to the individual.

Mental illness can also be explained as manifestation of evil or punishment from God. To have faith in God may also lessen the strain on the individual and provide purpose and meaning to a difficult situation (Mayeya, Chazulwa et al. 2004; Teuton, Bentall et al. 2007).

The material in my study shows that the participants have different understandings of their mental illness. It is quite obvious that faith and spirituality is vivid in their understanding and their different ways of coping with their illness. Antonovsky (2000) says that religious or spiritual values contribute to people's mental health. It seems like spirituality and faith as part of peoples everyday life provides a sense of coherence and contributes to make sense of otherwise adverse and challenging events in life, and promote recovery.

6.5 The importance of transcending mental health services

The material from my study shows that the participants have different understanding of their illness, and that they have used both different African traditional treatment and western medical treatment. They also describe what they do for themselves to avoid or reduce the illness. They also have different experiences about what has been helpful and they have different preferences to the kind of treatment they want to use. According to Kleinman's model (in Ingstad 2007) the African traditional treatment belongs to the traditional sector, the western medical treatment to the professional sector and their own approaches and interventions to the private sector which is basically situated at home and in the household and to some degree in the community. The consequences of mental illness seem to a large degree to be dealt with in the private sector. Only when the problems become insurmountable for the family to handle, they search help in any of the other two sectors. Research shows that 70-80% of people with mental health problems in Zambia consult African traditional healers before they seek medical treatment from the professional sector(Mayeya, Chazulwa et al.

2004). The traditional healing practices has been found to promote a more integrative approach in treatment of mental health problems and is seen as one of the factors that may contribute to the difference in recovery between developing and developed countries (Sullivan 1994a; Rosen 2003; Hopper, Harrison et al. 2007; Luhrmann 2007; Teuton, Bentall et al. 2007).

Mental health services in Zambia are mainly institutional. Due to severe shortage of trained mental health workers the mental health services in the community are scarce, and even at hospital level there is severe shortage of trained staff. The infrastructure in mental health services are described as being in a deplorable state (Mayeya, Chazulwa et al. 2004). The access to mental health services is therefore limited, and as it is shown in my study that the participants have only short admissions in the hospital and the treatment is mainly medication.

Institutionalisation of people with mental illness has been criticised for decades in western countries for conserving mental illness rather than curing (Deegan 1988; Deegan 2005; Borg 2007; Luhrmann 2007). The participants in my study have been admitted in hospital several times, but not for long periods. But they have some experience to share, and they have opinions about how mental health care should be delivered. Some of them praise the health workers for their commitment and encouragement. They say it is important that the health workers care about how they are doing even after discharge and that they are called for review. Some of them talk about situations where they feel have been met with disrespect and a negligent attitude. They say that it is very important that health workers are listening to them, and acknowledge their experience and perception of the situation. They say that they are the ones to feel the effect and the consequences of treatment and should be listened to.

As this study shows, the participants have valuable experience and their own opinion about what kind of treatment they would like to have and they want to have influence on their situation. It seems like the choice of treatment is often made by the family, and they might sometimes have a different opinion than the participant. The participants say that the family's choice are mainly based on traditional beliefs and their first choice is often a traditional approach. To promote recovery there may be need for more knowledge about different treatment approaches and a diverse health services transcending existing traditions and different sectors.

7. Reflections and closing remarks

In this final chapter of the thesis I want to link back to the starting point for this study, reflect on possible implications of the findings and finally to suggest some possible areas for further research.

Both the research process and my own learning process has been 'a long and winding road'(McCartney and Lennon 1969); from the initial idea to the completion of the thesis. The observations that triggered my curiosity in the first place was that despite that people with severe mental illness lived under quite marginal living conditions and the health services they had access to were limited (Mayeya, Chazulwa et al. 2004) many of those who came to the hospital for treatment still lived active lives in the community with others. My initial research question was about participation in everyday life activities in the local community described by people living with severe mental illness. The findings in the material were rich and as I worked on the analysis I found that many of the findings corresponded well with the findings from a large number of studies about recovery in western settings. I realized that several aspects of everyday life in Zambia, as it was described by the participants in the study, seemed to promote recovery. I was not so familiar with the recovery literature before I started on this long and winding road, but the more I read, the more meaning it gave to my previous experiences from my work in Zambia. Recovery as a concept and a practice also fitted well with and embraced many of the beliefs and assumptions underpinning occupational therapy practice. Occupational therapy is concerned with enabling people to engage in occupations and participate in the society (Rebeiro 2005). Occupational therapists are working to lower environmental barriers as stigma and poverty and to encourage people to develop their occupational capabilities for community participation (Christiansen and Townsend 2010). This 'discovery' of recovery might have biased the balance between the contribution from the medical field and the field of recovery in my presentation. In retrospect I can see that the role of the medical perspective might have been under-communicated. I believe that medical science and treatment has a role to play in mental health care, but I also agree with the criticism of psychiatric practices which not always have contributed to recovery for people with mental health problems (Deegan 2005; Kristiansen 2005; Borg 2007).

Recovery as it is described in this study is about process in a continuum over time. Recovery is taking place in the context of everyday life together with family, friends and colleagues. Everyday life represents a context with opportunities, hope and support, but it may also

represent challenges and barriers. One of the main findings in this study is the significance of interaction between the participants and their social environment. The participants in this study present themselves as active, contributing and competent members of society. They become 'ill' when they are not able to maintain their roles and responsibilities and they receive substantial support from families and others. The release of support may not only be an expression of love and care, but also an expression of expectations and need from the community about everybody's contribution. On one hand this may be a challenge for people with mental health problems, but on the other hand it offers opportunities to participate in everyday life activities and social relations. Having access to roles and activities in everyday life enable people with mental health problems to develop their competences, increase their participation and sense of belonging (Rebeiro 2005). This again seems to enhance meaning and purpose in life which promote recovery.

A recovery perspective brings a long some challenges to current health policies, mental health services and the role and practice of health professionals. Recovery is embedded in everyday life, and implies community involvement. Mental health services in Zambia are still mainly hospital based offering symptom reduction and stabilization. Extended community based services with a focus on peoples own abilities to find solutions and ways to cope with the situation would improve the services for people with mental health problems. The study shows that the potential for self help, social support and inclusion is there. I believe that the professionals have an important role to play in supporting the users to realise these potentials. I believe the professionals also have a role to play in the work against barriers in the environment like stigma and poverty. Recovery from the perspective of service users requires health professionals that are willing to share power and listen to their experience and opinions. It means that health professionals must share knowledge and responsibility with the user and his family. I believe this is already happening, and I believe the growing awareness among users about their influence and rights are going to promote a more user-oriented and community based practice.

During my work with this study I have asked myself about the relevance of western literature to the Zambian context. When I worked in Zambia I experienced the lack of theories and literature based on the local context as problematic. The available textbooks in psychiatry often described phenomena and situations I couldn't recognise in my practical work. I have had this in mind when using mainly western literature in this study. But I have found the literature useful despite the different context. I believe recovery is about universal issues such

as citizen rights, human worth, dignity, meaning and purpose in life, hope and prospects for a better life and spirituality.

Work and income generating activities seem to be of significant importance in recovery. In Zambia where the majority of the population live under the poverty line (Patel and Kleinman 2003) and public welfare is lacking for most people, work and income generating activities are closely linked to survival and life sustainability. I believe the existentialistic role of work and income generating activities also adds meaning and purpose in life and that work and income generating activities is a source for recovery. In western societies many people are excluded from participation in work due to high demands of specialized skills and efficiency. The Zambian society is also part of the modern world with high developed technologies, but there are still areas based on manual manpower and a relatively big informal sector where activities like trades allow people without specialized skills to participate.

This study has given a picture of people living with severe mental illness, all of them engaged in work or other income-generating activities and to various degrees involved in activities in the community. The findings in this study differs from the description from Mayeya, Chazulwa et al. (2004) who says that people with mental illness… "*to a large extent are stigmatized, feared, scorned at, humiliated and condemned*". There may be many reasons for this difference. One possibility is that there is no contradiction but rather a distinction between people who are considered to be mentally ill and those who are considered to be mad. Those who are mad are not considered to be able to contribute and are not welcomed as part of the community. My study suggests that those who are mad are those who have lost support from family and community due to material and social marginalisation; financial resources are exhausted, relapses or prolonged illness periods exhausts the sources of hope and social support. The person with mental illness is protected by the system of the extended family, but when this system brakes down, the person are in danger to become mad.

The study has left me with new questions about living in recovery. As this study has shown recovery is not only an individual process, it is highly a social process. I believe that the experience of family members and other significant persons could make a important contribution to the understanding of recovery in a Zambian context. Further the experience from women living with severe mental illness. From my work at the hospital in Zambia women with mental health problems rarely came for treatment. I believe women's recovery differs from men's recovery since they have different roles in the family and different everyday life activities. Another issue it would be interesting to follow up is the development

of user participation. My study shows that the participants have valuable experience and knowledge about their recovery, but they are not always heard. Being an occupational therapy I would also have liked to further explore how occupation can create meaning and be used as a mean to cope with everyday life for people with mental health problems.

I hope this study can serve as an inspiration to understand and know more about living with severe mental illness and about recovery. I hope the study may contribute to the development of services for people with mental health problems. I also hope it serves as an acknowledgement for the efforts and endurance of people living with mental health problems, their families and friends and others involved.

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INTERVIEW GUIDE

How do persons with the diagnosis schizophrenia describe their participation in daily life activities in their local community?

Topics	Optional questions
Opening question	Is there anything about your current situation you would like to tell about? Could you describe your home environment, and your community?
Participation – present time Description of current participation in daily life activities	Could you describe how an ordinary day during the week looks like for you? What about the week-end? Which activities do you perform now? Can you tell me about this?
Recent changes in participation? What does it mean to them to participate in these activities?	Have you engaged in any new activity lately, or are there activities you have stopped recently?
Interests	Which activities do you like to do? What is it about the activities that make you like them?
Values	Which of these activities are more important to you? What is it about the activities that make them important to you?
Possible obstacles or hindrances	Are there any activities you would like to participate in, which you are currently not? Do you experience any hindrances or obstacles that restrain you from participating in any activities? How do you relate to that?
Possible support / motivation	Are you free to participate in any activities? Who or what encourages you to participate in activities?
Participation in the past Has there been any changes in participation	Are there any activities you used to participate in, which you are not participating in any more? What were the circumstances to make you stop doing these activities? How did you experience stopping participating in these activities? Can you tell me about some of those activities? What did these activities mean to you?

Participation in the future	Have the illness caused any changes in you plans and wishes for the future?
Effect of illness on future hopes and plans.	Are there situations or activities in the future you expect you can not participate in due to the illness?
Hopes and anticipations for future participation.	Are there activities from the past you would like to start participating in again?
	Are there other activities you would like to take part in – which you are not doing now?
	What must be done or changed for you to participate in that/those activities?
	Which activities do you think you will participate in one year? – five years?
Perception of self How do they describe their own health condition, and health related problems?	How would you describe your current health condition? Has it been changed lately? Can you tell me about the time when you first got sick? Did the illness cause any changes in your daily life? Does the illness cause you any problems for you now? In what way? Do you need help to perform any of your daily life activities?
How do they perceive locus of control in their daily life?	Who should influence or make decisions on your participation in daily life activities? Are you satisfied with the way it is today?
How do they look at their occupational competence	Are you satisfied with the way you participate in different activities?
Social environment Which roles does the person perform, and how do they accomplish these roles? Do they perform the roles they are expected to perform according to the cultural norms? How do they perceive other's perception of them?	What is your position in the main activities you participate in? Which expectations do you think others have to you in these activities? Do you think they think that you meet these expectations? Do you feel you can meet these expectations? Do they know about your diagnosis? How do you think they think about you – having this diagnosis?

The interview guide is based on topics from different occupational therapy literature on participation: (Hasselkus 2006; Kielhofner 2002; Law 2002)

ENQUIRY ABOUT PARTICIPATION IN A RESEARCH PROJECT:
"Participation in Daily Life Activities for persons with the diagnosis schizophrenia in Zambia"

We hereby ask if you would like to participate in the research project "Participation in daily life activities".

The research project aims at acquiring more knowledge about how people, who have the diagnosis schizophrenia, experience their own participation in daily life activities. We know from other studies that participation in daily life activities promote recovery and improvements for people with the diagnosis schizophrenia. We want to ask what factors are important for participation, which restrains are experienced, and what can be done to improve the situation. The intention is to elaborate the understanding of the significance of participation and how participation is supported or restrained by the attitudes from the environment. It is important for planning and providing mental health services to know more about how participation in daily life activities supports recovery from schizophrenia. The project will start in September 2007 and completed in August 2008.

We are interested in contact with male persons between 25 – 35 years old who has had the diagnosis schizophrenia for more than 3 years. We are looking for persons who live together with their family within Livingstone city. We want to ask about your experiences and perceptions about your life situation particularly with regard to participation in daily life activities - like work, domestic and social activities.

Participation in this project entails one personal interview in a conversational form. The interview will take place in your home if other has not been agreed on. Present during the interview will be the researcher ms Marianne Olsen, and one assistant; ms Loveness Moonde. Ms Moonde will assist with linguistic and cultural clarifications during the interview. There is also an opportunity for you to bring someone of your own choice as a companion.

Talking about participation in daily life activities will involve talking about your private life. It involves talking about how you perceive you own health and limitations in everyday life activities. It involves talking about your relation to family and friends; it involves talking about your thoughts, hopes and disappointments in life. These kinds of questions may also bring up feelings that may be difficult to handle. As therapists we will be able to relate to the situation at the moment and if needed for further assistance, we will be able to refer you to the hospital.

1

The duration of the interview will be approximately 1 ½ hours. The interviews will be recorded on tape, and the interviewer will take notes during the interview. All information given during the interviews is regarded as confidential. The material will be kept locked-up. Only the project manager and co-workers will have access to this information. All participants in the project have an obligation of confidentiality. All the gathered information will be handled by confidentiality.

The material will be kept in anonymous form, and only Ms Marianne Olsen will have access to the namelist. After the completion of the study, the material will be kept, in case of a follow up study, in anonymous form, meaning that no single person can be identified. The namelist will be destroyed and the background information will be kept in gross categories. After completion of the study, you will receive a paper with a summary of the results. The results from the study will also be presented in a journal article and a paper (essay) in English. All information from the interview will be made anonymous when published, that means that name and other features that can be recognised will be changed. This will be made available for you.

The participation in this study is on fully voluntarily basis. That means that you are free to withdraw from the project at any given time in the process and to leave the study without giving any explanation. If you choose to withdraw you are also free to require that all the information supplied by you will be deleted. There will not be given any form of grants or salary for your contribution.

This enquiry has been forwarded to you from Livingstone Hospital Board of Management by the head of Mental Unit. They have picked your name by random from their register of patients fitting the criteria for participation. The project manager in Norway will not be informed about who or how many who has been asked to participate in this project. If you decide to participate please contact ms Moonde (see below).She will forward the information to the project manager, who will get in touch with you again.

Livingstone Hospital Board of Management will not receive any information about who has accepted to participate and who has not. The choice to participate or not, will not have any influence on your future relations to the hospital. Livingstone Hospital will not have access to any other information than the published material (journal article and paper).

The study has been recommended from The Regional Committees for Medical Research cs, Norway and the Norwegian Social Science Data Services, Eres Converge, Zambia.

For any questions regarding the study, please contact the Project manager:

Geir Lorem, Associate Professor and Project Manager, Institute of Clinical Medicine, University of Tromsø, Tromsø, Norway, Phone: 0047 77 64 65 33 or mobile: 0047 97 77 34 53, e-mail: geir.lorem@fagmed.uit.no

or Edaward Mbewe, local supervisor, Chainama Hills College Hospital, Lusaka, Zambia. Phone: +260 97 7420775, e-mail: embewe2001@yahoo.com

or **Loveness Moonde**, Regional Health Office, Livingstone, Phone: 095 83 84 90 or e-mail: lavuzambia@yahoo.com.

If you are willing to participate, please fill inn one of the Statement of Consent and give it to Ms. Moonde in the enclosed envelop. She will forward the envelope to the project manager. The other copy of the form is yours. You will then be contacted for making the appointment for the interview.

STATEMENT OF CONSENT

I have received oral and written information about the research project. Based on this information I give my consent to participate in this project.

Date:

Name:

Address:

Phone:

Signature:_____

Geir Lorem
IKMASH
Universitetet i Tromsø
9037 TROMSØ

Deres ref.:   Vår ref.: 200702459-3/MRO/400   Dato: 23.05.2007

P REK NORD 85/2007 DELTAKELSE I DAGLIGE AKTIVITETER FOR PERSONER MED DIAGNOSEN SCHIZOFRENI I ZAMBIA - SLUTTVURDERING

Prosjektet ble lagt fram for Regional komité for medisinsk forskningsetikk, Nord-Norge (REK NORD) i møtet 10.05.2007. I referatet heter det:

Mastergradsoppgaveoppgave ved norsk ergoterapeut som tidligere har arbeidet i den psykiatriske helsetjenesten i Zambia. Det vises til forskningsresultater som tyder på at prognosen ved sykdommen schizofreni er bedre i utviklingsland enn i industrialiserte land. Større grad av deltakelse og sosial integrering kan være av betydning. Prosjektets forskningsspørsmål er: Hvordan erfarer personer med diagnosen schizofreni at stigmatisering påvirker deres deltakelse i daglige aktiviteter? Det stilles underspørsmål innen områdene selvoppfatning, deltakelse og sosialt miljø. Problemstillingene skal belyses ved semistrukturerte kvalitative intervjuer av fem hjemmeboende menn i alderen i alderen 25-35 år som har hatt diagnosen schizofreni i minst tre år, og som er i stand til å gi et informert samtykke. En lokal fagperson deltar i intervjuene, som skal analyseres innenfor en fenomenologisk hermeneutisk referanseramme. Informantene rekrutteres fra Livingstone Hospitals pasientregister (Livingstone er en by i Sør-Zambia). Prosjektet er søkt godkjent (meldt) både i Zambia og i Norge. Norge står for prosjektledelse og finansiering.

Komiteen klassifiserer prosjektet som ikke-terapeutisk annen helsefaglig forskning i utviklingsland på voksne, syke menn. Studentprosjekt

Komiteen har følgende merknader:

Forespørselen
Hele tittelen på prosjektet bør fremkomme i overskriften.
Ordet "not" er antagelig falt ut i første linje i nest siste avsnitt s. 2.

Vedtak:
Regional komité for medisinsk forskningsetikk, Nord-Norge (REK Nord) har ingen innvendinger mot at prosjektet gjennomføres.

Vennlig hilsen

May Britt Rossvoll
Rådgiver
Tlf.dir. 77644876

Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

APPENDIX 4

(NSD)

Harald Hårfagres gate 29
N-5007 Bergen
Norway
Tel: +47-55 58 21 17
Fax: +47-55 58 96 50
nsd@nsd.uib.no
www.nsd.uib.no
Org.nr. 985 321 884

Geir Fagerjord Lorem
Avdeling for sykepleie og helsefag
Institutt for klinisk medisin
Universitetet i Tromsø
Breivika
9037 TROMSØ

Vår dato: 13.07.2007   Vår ref: 17072/SF   Deres dato: Deres ref:

TILRÅDING AV BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 08.06.2007. Meldingen gjelder prosjektet:

17072	*Participation in every day life activities – experiences from men with schizophrenia in Zambia*
Behandlingsansvarlig	*Universitetet i Tromsø, ved institusjonens øverste leder*
Daglig ansvarlig	*Geir Fagerjord Lorem*
Student	*Marianne Olsen*

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, eventuelle kommentarer samt personopplysningsloven/- helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.
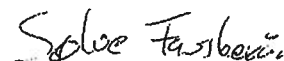
Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/endringsskjema. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, http://www.nsd.uib.no/personvern/register/

Personvernombudet vil ved prosjektets avslutning, 31.08.2008, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Vigdis Namtvedt Kvalheim   Sølve Fauskevåg

Kontaktperson: Sølve Fauskevåg   tlf: 55 58 25 83

Vedlegg: Prosjektvurdering

Kopi: Marianne Olsen, Synnavinden 35, 9015 TROMSØ

Avdelingskontorer / District Offices:
OSLO: NSD. Universitetet i Oslo, Postboks 1055 Blindern, 0316 Oslo. Tel: +47-22 85 52 11. nsd@uio.no
TRONDHEIM: NSD. Norges teknisk-naturvitenskapelige universitet, 7491 Trondheim. Tel: +47-73 59 19 07. kyrre.svarva@svt.ntnu.no
TROMSØ: NSD. SVF, Universitetet i Tromsø, 9037 Tromsø. Tel: +47-77 64 43 36. nsdmaa@sv.uit.no

Personvernombudet for forskning

Prosjektvurdering - Kommentar

Personvernombudet har vurdert prosjektet og finner at behandlingen kan hjemles i personopplysningsloven (pol) §§ 8, første ledd og 9 a.

Det behandles sensitive personopplysninger om etnisk bakgrunn og helseforhold, jf. pol § 2 punkt 8 a og c.

Ombudet minner om at datamaterialet ikke er anonymt all den tid det finnes en koblingsnøkkel, eller at enkeltpersoner indirekte vil kunne identifiseres gjennom bakgrunnsvariabler. Den riktige betegnelsen er i så fall at datamaterialet er avidentifisert. Opplysningen om at "The material will be kept in anonymous form..." i informasjonsskrivet er dermed ikke helt riktig, og må omformuleres. Personvernombudet finner informasjonsskrivet tilfredsstillende forutsatt at opplysningen om anonymitet korrigeres som forklart her. Vi ber om at revidert skriv sendes til personvernombudet før utvalget kontaktes.

Ved prosjektslutt 31.08.2008 skal datamaterialet anonymiseres. Anonymisering innebærer at koblingsnøkkel eller direkte personidentifiserende opplysninger slettes, samt at indirekte identifiserende personopplysninger slettes eller omkategoriseres (grovkategoriseres).

Personvernombudet registrer at prosjektet er meldt til Ethical Committee at University of Zambia, Lusaka. Vi forutsetter at det innhentes nødvendige tillatelser fra Zambiske institusjoner.

Prosjektet er godkjent av Regional komité for medisinsk forskningsetikk.

All correspondence should be addressed
To the Provincial Health Director
Telephone 324435/323516
Fax: 323391

In reply please quote:

No:

REPUBLIC OF ZAMBIA

MINISTRY OF HEALTH

PROVINCIAL HEALTH OFFICE
P.O BOX 60206
LIVINGSTONE

3rd October, 2007,

The Chair person

Ethical Committee.

Lusaka.

Dear DR E.M.Nkandu,

RE; RESEARCH BY MARIAN OSLEN ON "PARTICIPATION IN DAILY LIFE ACTIVITIES
FOR PEOPLE LIVING WITH SCHIZOPHERIA"

Reference is made to the above subject.

Marian Olsen has been allowed by the Provincial Health Office to carry out her
research, which at the end of it all will help the Province improve in this functional
area.

She is to start her research as soon as possible.

By copy of this letter, The Executive Director, Livingstone General Hospital is informed
of the activity and is requested to help Olsen carry out her research successfully.

Your usual co-operation will be highly appreciated.

Thank You,

Dr L. Alisheke

Provincial Health Director.

SOUTHERN PROVINCE.

CC: The Executive Director,

LIVINGSTONE GENERAL HOSPITAL.

29th October 2007
Ref.: 001-10-07

Ms Marrianna Olsen
C/O Livingstone General Hospital
LIVINGSTONE

Dear Ms Olsen,

RE: Approval Letter

During the IRB meeting held on 11th October 2007, the members resolved to approve this study and your participation as principal investigator for a period of one year. The study was approved after receiving minor corrections recommended by the IRB.

Study title: **Participation in daily activities for people living with Schizophrenia**

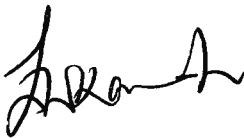| Review Type	Expedited	Approval No. 001-10-07
Approval and Expiry Date	Approval Date: 29th October, 2007	Expiry Date: 28th October, 2008
Protocol Version and Date	Version - Nil	October 2007
Information Sheet, Consent Forms and/or Dates	• One in English	October, 2007
Consent form ID and Date	Version - Nil	October, 2007
Recruitment Materials	• Recruitment letter	October, 2007
Other Study Documents	• Questionnaire	October, 2007
Number of participants approved for study	5	

Specific conditions will apply to this approval. As Principal Investigator it is your responsibility to ensure that the contents of this letter are adhered to. If these are not adhered to, the approval may be suspended. Should the study be suspended, study sponsors and other regulatory authorities will be informed.

Conditions of Approval

- No participant may be involved in any study procedure prior to the study approval or after the expiration date.
- All unanticipated or Serious Adverse Events (SAEs) must be reported to the IRB within 5 days.
- All protocol modifications must be IRB approved prior to implementation unless they are intended to reduce risk (but must still be reported for approval). Modifications will include any change of investor/s list or site address.
- All protocol deviations must be reported to the IRB within 5 working days.
- All recruitment materials must be approved by the IRB prior to being used.
- Principal investigators are responsible for initiating Continuing Review proceedings. Documents must be received by the IRB at least 30 days before the expiry date. This is for the purpose of facilitating the review process. Any documents received less than 30 days before expiry will be labeled "late submissions" and will incur a penalty.
- ERES Converge IRB does not "stamp" approval letters, consent forms or study documents unless requested in writing. This is because the approval letter clearly indicates the documents approved by the IRB as well as other elements and conditions of approval.
- At the end of the study a final report will need to be submitted.

Should you have any questions regarding anything indicated in this letter please do not hesitate to get in touch with us at the above indicated address.

On behalf of ERES Converge IRB, we would like to wish you all the success as you carry out your study.

Prof. J. T. Karashani, MB, ChB, PhD
CHAIRMAN

AGREEMENT BETWEEN

MARIANNE OLSEN

AND

EDWARD MBEWE

FOR

SUPERVISION OF RESEARECH

*"PARTICIPATION IN DAILY LIFE ACTIVITIES FOR
PEOPLE LIVING WITH SCHIZOPHRENIA"*

FROM 8 OCTOBER, 2007 TO 30 DECEMBER, 2007

Sign:...

Date:.......16...1..11...2007...........................

Sign:...16/11-2007...............................

Date:..

2007