

Hearing their voices: The lived experience of recovery from first-episode psychosis in schizophrenia

by

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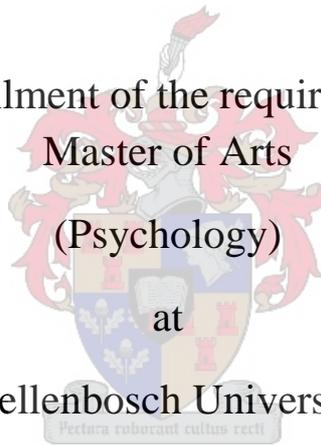
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We cannot change the world by a new plan,
project, or idea. We cannot even change
other people by our convictions, stories,
advice and proposals, but we can offer a
space where people are encouraged to
disarm themselves, lay aside their
occupations and preoccupations and listen
with attention and care to the voices
speaking in their own center.

-Henri Nouwen-

Declaration

By submitting this dissertation electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the owner of the copyright thereof (unless to the extent explicitly otherwise stated) and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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ABSTRACT

Recovery in schizophrenia was regarded, for a very long time, as a somewhat unattainable goal. In addition, the de-emphasis of the subjective experience of the person living with schizophrenia created an environment where studies on the experience of recovery was disregarded. The dawn of the civil rights movement in the 1960s paved the way for the recovery movement in mental health. A new emphasis was placed on the person living with schizophrenia and his or her individual experience. Together with this, the deinstitutionalisation of long-term patients following the introduction of anti-psychotic medication allowed for recovery in schizophrenia to become a more widely accepted concept.

Against this background, this study seemed crucial and focused on how seven participants experienced their recovery from first-episode psychosis in schizophrenia. Each participant was interviewed twice, the interviews transcribed and then analysed with the use of Interpretative Phenomenological Analysis.

It was found that support and its natural corollary, having to care for another, are possibly the greatest contributors to the recovery of persons faced with mental illness. Participants highlighted the important role of spirituality in their recovery, despite it being generally regarded as a controversial topic. Since spirituality has the ability to build resilience, it cannot and should not be overlooked. Stigma was found to be ingrained and pervasive, as it so often is for persons faced with mental illness. It can be a barrier to recovery. The retention or rediscovery of the abilities of those challenged by mental illness was seen as a determining factor for recovery, since it (re)introduces a sense of agency. In conclusion, and without fail, all the participants agreed that talking about their experiences aided them. This points to the fact that there can be no question as to the value of the narrative in the process of recovery.

OPSOMMING

Herstel (*recovery*) in skisofrenie is vir 'n lang tyd beskou as 'n ietwat onbereikbare doel. Hiermee saam is die subjektiewe belewenis van die persoon wat met skisofrenie saamleef al minder van waarde geag. Dit het 'n omgewing geskep waar die studie van die belewenis van herstel geminag is. Die opkoms van die burgerregtebeweging in die 1960s het die weg gebaan vir die herstelbeweging in geestesgesondheid. 'n Hernude klem is geplaas op die persoon wat met skisofrenie saamleef en sy of haar individuele belewenis. Tesame hiermee, het die ontslag van langtermynpasiënte uit institusionele sorg as gevolg van die bekendstelling van anti-psigotiese medikasie daartoe gelei dat herstel in skisofrenie meer algemeen aanvaar is.

Teen hierdie agtergrond is hierdie studie as noodsaaklik beskou en het dit gefokus op hoe sewe deelnemers hul herstel van 'n eerste psigotiese episode beleef. Daar is twee onderhoude met elke deelnemer gevoer. Hierdie onderhoude is getranskribeer en daarna geanaliseer met behulp van *Interpretative Phenomenological Analysis*.

Daar is gevind dat ondersteuning en daarmee saam, om 'n ander te versorg, waarskynlik die grootste bydraende faktore is tot die herstel van persone wat deur geestessiektes uitgedaag word. Die deelnemers het die rol van spiritualiteit, wat dikwels as 'n omstrede onderwerp beskou word, beklemtoon. Aangesien dit kan bydra tot veerkragtigheid, kan en moet dit nie oorgesien word nie. Stigma is diepgewortel en deurdringend bevind, soos dit so dikwels is vir dié wat geestessiektes in die gesig staar. Dit kan 'n hindernis tot herstel wees. Die behoud of herontdekking van die vermoëns van dié wat deur geestessiektes uitgedaag word is 'n bepalende faktor, aangesien dit (weer) 'n gevoel van beheer oor die eie aksies ("sense of agency") inlei, wat so deurslaggewend is tot herstel. Ter afsluiting, en sonder uitsondering, het al die deelnemers saamgestem dat om oor hul belewenisse te praat hulle gehelp het. Derhalwe, kan die waarde van die narratief in die proses van herstel nie betwyfel word nie.

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CHAPTER ONE

INTRODUCTION

Schizophrenia is a serious mental illness which affects about 24 million people worldwide, according to the World Health Organisation (WHO). Of those persons with untreated schizophrenia, about 90% live in developing countries (WHO, 2011).

Historically, schizophrenia was viewed as an illness causing a person to experience an alternative reality. With the advent of the neurobiological view of schizophrenia, schizophrenia came to be regarded as an illness where the person loses touch with reality (Davidson, 2003). The results of the International Pilot Study of Schizophrenia, launched by the World Health Organisation in 1967, dawned the current era where schizophrenia came to be viewed as an illness where the person finds him or herself from time to time in an alternative, albeit extreme, state of reality (Davidson, 2003). Schizophrenia is no longer seen as an illness that leaves no alternative except utter chaos and inevitable death. This new view has brought much needed hope to an illness that is regarded as the most disruptive of mental illnesses (Davidson, 2003). This theoretical shift, together with biological treatments, such as antipsychotic medications, that have played a key role in alleviating symptoms of psychosis, has allowed researchers to consider recovery as a reality. According to Davidson (2003), it has made it possible to have an alternative view from the Kraepelinian view in which it was contended that it is not possible to recover from schizophrenia. A person living with schizophrenia can now be viewed as being a person apart from his or her illness, someone who responds uniquely to the illness and someone who may have the ability to recover from it (Davidson, 2003). From this view, the person is now able to contribute actively and meaningfully to the understanding of the illness.

When adopting the view that the patient is indeed a person apart from his or her illness, someone who responds uniquely to the illness and someone who may have the ability to recover from it, it becomes crucially important to explore recovery in an attempt to understand what the patient experiences when he or she is “seeking to move towards recovery” (Geekie, Randal, Lampshire, & Read, 2012, p. 11) from a psychotic episode in schizophrenia.

The treatment of and recovery from schizophrenia can be approached from different perspectives. From a medical perspective, the focus would be on the alleviation of the symptoms of the illness and the ideal would be the remission of these symptoms. From a psychological perspective the focus would be on the person’s functionality and its status in light of the illness. The ideal would be to improve functionality. Although these approaches are vital in the understanding and treatment of schizophrenia, they neglect a crucial aspect: the person’s lived experience of his or her illness and the fact that the person interacts with his or her illness in an active and pivotal way thus having an impact on the manner in which the illness progresses (Strauss, 1989).

When the focus is on a patient’s lived experience of his or her illness, the attention of the researcher is drawn to fundamental processes that take place within the patient as opposed to merely objectively observing the symptoms of the disorder (Flanagan, Davidson, & Strauss, 2010). In addition, by focusing on lived experience, the manner in which patients experience certain interventions is brought to the fore by the researcher to deepen understanding and broaden knowledge of the illness (Boydell, Stasiulis, Volpe, & Gladstone, 2010).

In a culturally diverse society such as South Africa, focus on persons’ lived experience of their illness should specifically be complemented by a sensitivity to the influence that a person’s culture

has on his or her illness experience. For example, in the context of family therapy as an intervention for schizophrenia, cultural ideologies have an impact on families' belief systems regarding schizophrenia and the culture of a person should be taken into consideration when carrying out family therapy (Asmal et al., 2011). Bewitchment, jealousy, ancestral calling and guilt are some of the themes used to make sense of schizophrenia in the African setting. And, as such, it is possible that persons living with schizophrenia who are of African descent, could view their admission to a psychiatric hospital and the treatment of their illness with medication as purely symptomatic. They may solicit further assistance from traditional healers to deal with what they believe to be the true origin of their illness. The collective nature of African culture, as opposed to the individualism of Western culture, results in the person's position being viewed within the family or society. This may influence the way in which decisions are made regarding treatment of the person (Asmal et al., 2011). All these aspects need to be borne in mind when embarking on a journey to understand the experience of persons living with schizophrenia in Africa, since they indicate a contrast with the traditional western approach, from which most of the existing research in this field is done.

The specific process of recovery from first-episode psychosis in schizophrenia is an integral part of understanding the course of the illness and, ultimately, in treating it. Few studies concentrate on the process of recovery; most studies rather focusing on the symptomatic or functional aspects of recovery (Romano, McCay, Goering, Boydell, & Zipursky, 2010). The primary aim, amongst others, of the present study was to explore the process of recovery and its importance and how it should be understood, taking into account the uniqueness of the person.

The exploration and understanding of a person's lived experience of recovery from a first psychotic episode in schizophrenia is a crucial topic for research and, from this premise, I conducted research

to explore these lived experiences of, and evaluation by, recovering persons after a first psychotic episode in schizophrenia.

The participants currently form part of, or have previously formed part of, a research project, the principal investigator of which is Professor Robin Emsley of the Department of Psychiatry, Faculty of Health Sciences at Stellenbosch University. The project number is N06/08/148. The overall aim of this research project was to conduct a longitudinal study to investigate clinical, socio-demographic, biological and treatment aspects of schizophrenia. My research falls under the Department of Psychiatry's specific research objective of examining the relationships between symptomatic remission and other measures of outcome. The project leader, Dr Bonga Chiliza, identified those participants in their research project who, according to their formal criteria, fared the best in treatment. I then requested the permission of the prospective participants to conduct the intended interviews.

The research problem

Historically, studies of schizophrenia have, to a large extent, discounted the possibility of recovery for a very long time (Andresen, Oades, & Caputi, 2003; Frese III, Knight, & Saks, 2009). This has created a widely held belief that recovery is an idealistic concept and somewhat unattainable. Fortunately, in more recent times and with the work done by the recovery movement to emphasise the importance of recovery, recovery is taken more seriously as a field of study and viewed as a realistic alternative to an inevitable downward spiral.

The main focus of the present study was recovery. Recovery was examined by investigating the lived experience of the participants and approached as being a unique experience for every participant.

The research problem was to examine what the lived experience of recovery from a first psychotic episode in schizophrenia looks like for the group of participants. An attempt was made to limit preconceived ideas about recovery, informed by the literature, to a minimum. This allowed for the uniqueness of experiences of the individual participants to be brought to the fore.

The rationale for the present study

The premise upon which this study is based is that the person is an active agent in their recovery process. The (re)empowerment of the person should be the goal of efforts to study and intervene (Bargenquast & Schweitzer, 2012). Respect for the individuality of the person and their experiences and the belief that the illness is only a part of the whole of the person was the basis from which the research was conducted.

Very often research in this field is conducted without paying enough attention to what the participants experience and how it can contribute to the existing body of knowledge (Karp & Birk, 2013). Loxton (2009) conducted a study to explore the fears of a group of South African pre-school children, as expressed by the pre-schoolers themselves. Pre-school children are, as a group, similarly to the participants in the present study, often marginalised and spoken about and for. Loxton (2009) emphasised that listening to the participants themselves provided much more information and helped to understand their world better than if one were to talk to third parties about them. In the spirit of what Loxton (2009) said, the present study aimed to give a voice to the

participants. The participants were regarded as the experts and the research was seen as a joint effort between the participants and myself.

The term 'lived experience' was used to emphasise the fact that the participants are not only experiencing the illness and their recovery, but are indeed living with those experiences. This lived experience informs their conceptualisation of recovery.

The focus on first-episode psychosis stems from the broader study of which this substudy forms part. First-episode psychosis is an important field of study, since it provides researchers and clinicians with the knowledge to be able to successfully intervene early on in the course of the illness and subsequently increase the chances of a better outcome for the patient.

Interpretative Phenomenological Analysis was chosen as the specific qualitative research approach. Since it is based partly on phenomenology, it was well suited to explore lived experiences. Being an interpretative method, it acknowledges the part that the researcher plays in presenting the experiences of the participants and that such part is not merely a neutral one, but is inevitably informed by the researcher's own opinions (Smith, Flowers, & Larkin, 2009).

The broad aims of the present study

As with all research a general aim of the present study was to attempt to better understand the topic being studied and to contribute to the body of knowledge that exists.

The specific objectives of exploring the lived experience of persons recovering from a first psychotic episode were to highlight the individual patient's experiences and circumstances and possibly to provide some indications as to where practices in the field may improve (Smith, Flowers, & Osborn, 1997). The descriptive process might also contribute to creating a more comprehensive description of the symptoms of the disorder contained in the diagnostic criteria (Flanagan et al., 2010). When considering these objectives, as Strauss (2011) plainly puts it, "a better comprehension of the experiential aspects of subjectivity seems to be really crucial" (p. 12), which, once again, provides a rationale for the present study.

CHAPTER TWO

LITERATURE REVIEW

Introduction

The understanding of recovery from schizophrenia can be approached in one of two ways, from the outside looking in at symptoms and functionality, or from the inside looking out at the experience. Both have merit. This is very similar to how Brown, Rempfer, and Hamera (2008) described outsider and insider perspectives on recovery in persons with psychiatric disabilities. When these two approaches are viewed in isolation from each other, they paint an incomplete picture of the person and their illness.

A selective historical overview of schizophrenia

The study of schizophrenia has its roots in the Kraepelinian-coined phrase, dementia praecox, which was used to distinguish it from what has come to be known as bipolar disorder (Andreasen, 1994b; Davidson, 2003). Schizophrenia is, thankfully, no longer seen as an illness which causes the patient's brain to deteriorate into a state of dementia, as the initial term for it suggested (Andreasen, 1999). Kraepelin placed the emphasis on symptoms characterised by deficits in emotion and cognitive processes and which are now referred to as negative symptoms (Andreasen, 1997). Bleuler renamed the disorder, schizophrenia, because he regarded the illness to be one in which mental functions are split (Andreasen, 1982). He differentiated between the core symptoms, being those that he regarded pathognomonic, and ancillary symptoms, being those that presented similarly in other disorders (Andreasen, 1997). Currently, the former are referred to as negative and the latter referred to as positive symptoms, although neither of the wide variety of symptoms are any longer regarded as pathognomonic (Andreasen, 1995). Schizophrenia was defined according to the core

(negative) symptoms identified by Bleuler for the most part of the twentieth century (Andreasen, 1997).

The plethora of possible signs and symptoms of schizophrenia that were identified early on caused great differences and, consequently, poor reliability in diagnosis (Andreasen, 1995). The International Pilot Study of Schizophrenia and the US-UK study also pointed to an overdiagnosis in mental illnesses and unreliability of diagnosis (Andreasen, 2007). Thus, a need for greater accuracy in diagnosis predominated the 1960s and 1970s and caused positive symptoms such as hallucinations and delusions to be shifted to the fore, since they were simpler to identify as abnormal than negative symptoms. Kurt Schneider played a decisive role in this shift and referred to such symptoms as first-rank symptoms, which, according to him, for the most part, arose from a loss of agency by the patient. Since then, these positive symptoms have found their way into the modern diagnostic instruments as those symptoms that, to a large degree, define schizophrenia (Andreasen, 1997).

However, according to Andreasen (1997) Schneider's approach to schizophrenia was interpreted incorrectly. She asserts that Schneider, in fact, was concerned with the psychological processes that schizophrenia patients experienced internally and was deeply interested in the individual. In light of this, she finds it ironic that Schneider has become the face of the objective and reductionist approach in the field of schizophrenia.

Although certain advantages, such as consistency and having a standardised international measure, came with the diagnostic criteria, having set criteria also desensitised clinicians to the particularities of the individual case. This broad categorical approach became the gold standard for identifying particular cases of schizophrenia (Andreasen, 1997).

It is probably also appropriate at this point to note that with the arrival of the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III), the emphasis was deliberately shifted from viewing mental disorders from the subjective perspective of the mental health professional to an objective perspective offered by the uniform diagnostic criteria contained in the DSM-III (Andreasen, 2007; Flanagan et al., 2010; Karp & Birk, 2013). This led to a simultaneous de-emphasis of the subjective experience of the person living with schizophrenia and subsequently this valuable source of information was mostly regarded as unimportant (Andreasen, 2007; Flanagan et al., 2010). As a further consequence, and one that was not foreseen by the authors of the DSM-III, these diagnostic manuals came to represent the absolute expertise on mental illnesses (Andreasen, 2007). Phenomenology faded into the background and the individual patient perspective was no longer regarded as all important (Andreasen, 2007).

More recently, however, an upsurge in professional interest in studying serious mental illnesses, such as schizophrenia, qualitatively and, specifically, focussing on the lived experience of the patient has surfaced. This has been demonstrated, for example, by a descriptive review of qualitative studies in first-episode psychosis conducted by Boydell et al. (2010) where all but one of the 29 studies included in the review were published since 2000.

Outcome in schizophrenia

Strauss (1996) points out that there is not only one aspect to the concept of outcome in schizophrenia. Depending on one's perspective, one could view outcome in schizophrenia by looking at different aspects of such outcome. In the literature, outcome in schizophrenia is also defined and described in several different ways, which makes the comparison of findings difficult. Emsley, Chiliza, Asmal and Lehloenyha (2011) regard remission as the overarching

term, recovery being an element of this; other authors (Andreasen et al., 2005; Bobes et al., 2009; Harvey & Bellack, 2009; Novick, Haro, Suarez, Vieta, & Naber, 2009; Warner 2009) regard recovery as the umbrella term with remission forming only a part of it. Parise, Balletta, Landolfi, and Manna. (2011) regard recovery to follow on remission, the latter being referred to only as a reduction in symptoms.

Clearly, the aspect of outcome that is of most interest in this thesis is recovery, which will be discussed under the next two headings.

The other important aspect of outcome in schizophrenia is remission or, more specifically, symptomatic remission, which has been one of the focuses of the broader study of which this substudy forms part. The Remission in Schizophrenia Working Group (RSWG) developed a consensus definition for symptomatic remission in 2004 which now allows for better comparison between studies than was possible before (Andreasen et al., 2005; Warner, 2009).

The RSWG defined remission as:

A state in which patients have experienced an improvement in core signs and symptoms to the extent that any remaining symptoms are of such low intensity that they no longer interfere significantly with behaviour and are below the threshold typically utilized in justifying an initial diagnosis of schizophrenia. (Andreasen et al., 2005; p. 442)

This definition emphasises the focus on symptoms, which had been the most prevalent focus in outcome studies.

The RSWG also developed an operational definition of remission, which did not include functional or cognitive outcomes and again focused only on symptoms, since the RSWG was

of the opinion that sufficient knowledge about the course of the former two aspects was not yet known at that stage. They based their definition for symptomatic remission on three dimensions identified in schizophrenia, namely negative symptoms, positive symptoms and psychoticism (Andreasen et al., 2005). Álvarez-Jiménez et al. (2012) conducted research in Australia on the relationship between psychosocial recovery and symptomatic remission in persons after they had experienced a first psychotic episode. The inclusion of negative symptoms in the definition allows scope for the widening of the measurement of outcome, according to them, since, they state, negative symptoms are distinctly related to functional outcomes. According to Emsley et al. (2011), in a South African review of studies to determine the progress that has been made regarding the defining of recovery and remission, the criteria developed by the RSWG have been clearly defined, constructively used as an outcome measure and allowed for much work to be done in this field.

Some authors do not view remission as the end goal in dealing with schizophrenia, but rather as a stage in a continuous process (Harvey & Bellack, 2009; Parise et al., 2011; Pitt, Kilbride, Nothard, Welford, & Morrison, 2007) and believe that remission should, therefore, not be viewed as the only criterion to determine whether persons have been able to successfully overcome or manage their illness. Emsley et al. (2011) join in this view when they refer to recovery as both a process and an outcome, being more complicated to conceptualise and, until lately, investigated less often in outcome studies than remission. In Canada, Windell, Norman and Malla (2012) conducted semi-structured interviews with 33 participants who had experienced their first psychotic episode on the personal meaning of recovery to them. They came to the conclusion that recovery is an end state for some persons and a process for others.

Deegan (1988), in an article in which she discusses the difference between rehabilitation and recovery, does not regard recovery as an outcome in which, when it is achieved, the person is seen as “cured” (p. 14). Rather, she views recovery as a non-linear, individual process in which the person becomes ever more aware of the limitations their illness places on them. However, viewed from within this process of recovery, these limitations are perceived not as a hindrance, but rather as a source of opportunities. As she so aptly puts it, “that in accepting what we cannot do or be, we begin to discover who we can be and what we can do” (p. 15). She refers to this statement as the “paradox of recovery” (p. 15).

In the process of developing their definitions of remission, the RSWG did not define recovery, since they regarded it as falling outside of their mandate. The RSWG stated that they viewed recovery “as a more demanding and longer-term phenomenon than remission” (Andreasen et al., 2005; p. 442). This perspective is in contrast with that of Deegan (1988), who does not require the achievement of remission for recovery to take place. Despite this difference, the RSWG acknowledged the importance of recovery by expressing the hope that the use of the definition of symptomatic remission in practice and research would spark the development of criteria that could be used to define recovery in the future (Andreasen et al., 2005). Emsley et al. (2011) concur by stating that the next step would be to extend the definition of remission to include quality of life and functional outcomes and to develop criteria for recovery.

Shrivastava, Johnston, Shah and Bureau (2010), in a review of literature on outcome measures in schizophrenia, recommend that these measures comprise various dimensions, of which a clinical remission and social outcome dimension should at least be part. They

emphasise that the latter should be defined within the cultural parameters of the particular person whose outcome is being investigated.

The development of the concept of recovery in general

When one looks at the development of the concept of recovery over time, it was, originally (and at a time when the application of the medical model was prevalent in schizophrenia), defined as “an outcome occurring at a discrete point in time after an illness when one’s health is entirely regained” (Resnick, Fontana, Lehman, & Rosenheck, 2005, p. 119). This definition alluded to a strictly symptomatic approach to recovery, where complete symptom absence was regarded as recovery from mental illness. This recovery was viewed as improbable and a diagnosis of schizophrenia painted a bleak future for the patient (Pitt et al., 2007). It certainly did not allow for a continuous process of recovery. Andreasen (1994a) believes that the widening and narrowing of the definition of schizophrenia over time, as alluded to earlier, has contributed to the improvement and deterioration, respectively, of the prognosis of patients with schizophrenia. This may also have had an influence on the development of the concept of recovery, since a positive approach to recovery presupposes a view of the patient’s prognosis as potentially promising.

Since the 1980s greater focus has been placed on the distinctiveness of the experience of recovery with the widespread publication of first person accounts of recovery (Pitt et al., 2007; Tolton, 2004) and the combination of professional perspectives with accounts of lived experiences of schizophrenia (Bock, Buck, & Esterer, 2007; Geekie et al., 2012). This pointed to the acceptance of a new, wider definition of recovery.

Recovery is no longer viewed as simply the absence of symptoms or a full return to being the self that the person was before. It refers to creating a fresh sense of self, transformation and fulfilment regardless of the presence or absence of symptoms (Pitt et al., 2007).

Warner (2009), in his exploration of whether evidence exists in the research literature for optimism regarding outcome in schizophrenia, refers to Liberman's definition of recovery. According to Liberman (as cited in Warner, 2009) there are two parts to such a definition; one being objective and the other subjective. The objective aspect contains elements such as symptom remission, productivity, independence, positive family and peer relationships and engagement in leisurely activities. The subjective aspect entails concepts that are more complex to define, such as empowerment, support from peers, dealing with stigma positively, and hope. Warner (2009) concludes that the optimism regarding outcome in schizophrenia is warranted, because, amongst other things, research has shown that engaging in work activities and increasing patients' insight into their illness while simultaneously empowering them and reducing their sense of stigma, all spurs on recovery.

In an Spanish 1-year follow-up observational study of persons in symptomatic remission, Bobes et al. (2009) regard recovery as comprising both symptomatic remission and psychosocial functioning, the latter measured according to the Global Assessment of Functioning (GAF) scale.

Novick et al. (2009), as part of the EU-SOHO study conducted in 10 European countries, defined recovery as functional and symptomatic remission in the long term as well as a sufficient quality of life for a period of 24 months which had to be maintained for 36 months.

Frese III et al. (2009) refer to the working definition of recovery that was conceptualised at a conference held in December 2004 by the Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration, which is a division of the Department of Health and Human Services in the United States of America, and described as “a journey of healing and transformation enabling a person with a mental health problem to live a meaningful life in a community of his or her choice while striving to achieve his or her full potential” (p. 372).

In a Hong Kong study, Lam et al. (2010) explored the ways in which the participants defined their recovery. They had an overall optimistic approach to recovery and to them recovery did not entail not being ill or a lack of symptoms. It had more to do with displaying and receiving respect, constructive relationships, viewing their selves as positive, learning which aspects of living life are more important than others, and picturing a future for themselves where they play a meaningful role.

One of the first steps identified by participants recovering from a first episode of psychosis and taking part in a study by Windell and Norman (2012) in Canada was acceptance of the fact that they indeed had a mental illness.

According to Geekie et al. (2012), for persons recovering from psychosis, the recovery process often starts at a more elementary level than one would expect. It is often necessary for persons to first regain or even gain, for the first time, a sense of coherence and predictability in their experience of themselves and the world around them (Geekie et al., 2012). According to Saks (2007), this is because the psychosis strikes at the centre of one’s being and leaves the ability to view the world from a sound internal perspective shattered.

Only once the continuity has been (re)established through the person's awareness of their presence in the here and now and their belief in their autonomous ability to have an effect on the world around them, can the person set out to overcome or manage their illness (Geekie et al., 2012).

The Schizophrenia Patient Outcomes Research Team (PORT) study was launched to communicate treatment recommendations regarding schizophrenia. The study commenced in 1992 through funding by the Agency for Health Care Policy and Research and the National Institute for Mental Health in the United States of America. Such treatments, in order to be recommended, needed to be scientifically supported. However, it is noteworthy that in the 2009 Schizophrenia Patient Outcomes Research Team (PORT) psychosocial treatment recommendations and summary statements, Dixon et al. (2010) acknowledge that, although the evidence does not yet warrant the recommendation of peer support and peer-delivered services, a care system for persons with schizophrenia requires the involvement of consumers in various aspects of treatment services when approaching outcome from a recovery perspective. The mere mentioning of the possibility that consumers might be able to contribute specifically "by sharing their lived experiences and serving as role models for one another" (p. 61), is indicative of a shift that has taken place in the research community towards emphasising recovery-oriented practices. It is also encouraging to note that the authors recognise the necessity of further research in this area.

In a special issue of Schizophrenia Bulletin in 2009, attention was placed on functional recovery. In the editorial piece, Philip Harvey, states that since remission is now viewed as attainable, the focus has shifted to functional recovery and the possibilities it holds (Harvey, 2009). He refers to recovery as both "a medical concept and a personal process" (p. 299) and

declares that persons with schizophrenia should have the opportunity to recover from it. It is encouraging and exciting to see this written, since it once again confirms the shift that is taking place regarding the importance of the role that recovery plays in outcome in schizophrenia.

Brown et al. (2008) in their study to determine whether the insider and outsider perspectives on psychiatric illness, as stated in the introduction to this literature review, are related, have taken to describing them as such, rather than as scientific and consumer models of recovery. This is because they believe that both models are open to research and calling the one scientific may create the impression that the consumer model is not. According to them, the insider perspective refers to empowerment and hope and the outsider perspective to symptoms and cognition.

The concept of recovery as a subjective experience

According to Harvey and Bellack (2009) well-being as experienced by the person with schizophrenia does not show a straightforward correlation with the other elements, such as functional and symptomatic remission.

In the semi-structured interviews conducted by Windell et al. (2012), referred to earlier in this chapter, with 33 participants who had experienced their first psychotic episode on the personal meaning of recovery to them, three aspects of recovery came to the fore: illness recovery, personal and psychological recovery, and functional and social recovery. Illness recovery represented the aspects of recovery related to the reduction of symptoms, where participants focussed mostly on positive symptom alleviation. Personal and psychological aspects included once again having a coherent sense of self and a notion of control.

Functional and social recovery meant being included socially, having a positive social identity, being employed, engaging meaningfully in relationships and being competent.

The experience of recovery in the context of symptomatic remission

As stated by other authors (Parise et al., 2011; Pitt et al., 2007), and alluded to earlier in this literature review, Andreasen et al. (2005) refer to remission as a component of recovery.

Álvarez-Jiménez et al. (2012) concluded that recovery in functional and vocational domains early on in the illness played a crucial protective part against disability and chronic negative symptoms. Their opinion is that this supports the necessity for interventions aimed at psychosocial recovery in the early stages of the illness.

Gorwood and Peuskens (2012), in a collaborative French-Belgian literature review of 181 articles selected from the worldwide schizophrenia literature regarding the change in how the term remission in schizophrenia is being used before and after the Andreasen criteria (developed by the RSWG, led by Nancy Andreasen, and referred to earlier in this chapter), remark in their discussion that when persons with schizophrenia achieve symptomatic remission it can have an influence on their functional abilities. They warn, however, that a direct correlation between remission and recovery has not been found across all the studies that came under their review.

In a randomised, double-blind trial involving treatment of 462 persons with a first psychotic episode from 11 countries, Emsley, Rabinowitz, Medori and the Early Psychosis Global Working Group (2007) concluded that by using the criteria proposed by Andreasen et al. (2005), which simply focus on symptom improvement, it is possible to successfully pinpoint

those persons who would also have a better outcome overall, which refers to quality of life and functional outcomes.

Brown et al. (2008) found a relationship between the insider perspective of hope and empowerment, and the outsider perspective of symptoms and cognition. However, a weaker relationship was found between hope and empowerment and positive symptoms than between the former and depression and anxiety. Resnick et al. (2005) also came to a similar conclusion. This, according to Brown et al. (2008), suggests that the emphasis should be placed on the impact of anxiety and depression on people's experience in order to minimise this impact and consequently promote hope and empowerment.

Processes or factors in recovery

Even though recovery is now widely regarded as a unique experience for every person, some universal themes or processes have emerged from research done on this topic.

Andresen et al. (2003) identified certain component processes of recovery from schizophrenia, namely hope, self identity, meaning in life and responsibility. Resnick et al. (2005) identify component processes similar to those identified by Andresen et al. (2003). They regard recovery as based on the principles that all persons, including those living with serious mental illness, have the ability to find hope, take part in activities that are meaningful to them and take charge of their own lives.

In user-led qualitative research conducted on the topic of recovery from psychosis, Pitt et al. (2007) suggested that recovery represents a stage process that is irregular and continuous. Once again the themes that emerged centred around the rebuilding of the self, and life and

hope for a better future. The rebuilding of the self incorporated a growth in the comprehension of the self and empowerment, while the rebuilding of life involved taking part in life and restoration of social support. A desire for change and the fact that change is a process formed part of the theme, hope for a better future.

Eisenstadt, Monteiro, Diniz, and Chaves (2012) conducted qualitative research from a phenomenological perspective in Brazil in an attempt to grasp the factors that contribute to the recovery process following a first psychotic episode. They added to the already existing list of factors by concluding that recovery is an intricate process which is related to the presence of social support, treatment received and the personal characteristics and experiences of the participants.

In the study by Windell and Norman (2012), interviews were carried out with the participants. The aim was to identify the factors that were either supportive of or posed a challenge to the recovery of the participants. The supportive factors that emerged from the study, which echoed some of the factors found in other research, were the type and routine of medication that they used, social support by, amongst others, family and friends, the adaptation of their behaviour, and pursuing interests that they regarded as worthwhile. Certain factors that challenged the recovery process were also determined, namely the adverse effect of medication, the stigma associated with mental illness and the misuse of drugs. Of all these factors, social support and stigma were regarded as the most influential on the recovery process.

Boydell et al. (2010) used some of the generic social processes, which were identified by Prus (1996), to organise their findings of the studies included in their descriptive review.

These processes are the following: *achieving identity*, *acquiring perspectives*, *doing activity*, and *experiencing relationships*. A significant theme in the process of achieving identity is the important role played by the person's search for meaning in his or her experience. Finding meaning helped people maintain hope despite the dire consequences of psychosis (Boydell et al., 2010). In the process of experiencing relationships and, specifically, the importance of peers, loss of friends seemed to be a characteristic of the experience of persons in early psychosis and their recovery. Acquiring perspectives was regarded as a positive relationship between the user and the health care provider in terms of feeling supported, taken care of and being heard. Doing activity as a process emphasised the crucial and positive influence of employment and reaching out for help. Once again factors such as finding meaning, the presence of hope, regaining one's identity and support, or the lack thereof, were highlighted as important in the pursuit of recovery.

Henderson (2010) conducted a study in Western Australia to explore the way in which participants viewed their own recovery from severe mental illness. Amongst the participants were persons diagnosed with schizophrenia and schizoaffective disorder. Loss was considered by the participants to be the fundamental issue at hand. This loss was experienced on three levels, namely socially, in a mental health context and psychologically. Henderson (2010) identified the conquering of the loss as a three-phase process of recovery. Firstly, recuperation, secondly, acceptance and adaptation and, thirdly, adjustment. In addition, participants again regarded having social support, engaging in safe behaviour and being in reciprocal relationships as the factors that assisted them in their recovery.

Macdonald, Sauer, Howie, and Albiston (2005) found that persons who have lived through a first psychotic episode prefer the company of others who have had corresponding

experiences, whom they perceive as understanding them and whom they feel they can trust. This underlines the notion that supportive relationships are a crucial factor in recovery.

At the conference held in December 2004 by the Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration (SAMHSA), which is a division of the Department of Health and Human Services in the United States of America, and referred to by Frese III et al. (2009), a statement was issued regarding the components that recovery programmes should comprise. They argue that the following should be promoted: self-direction; being individualised and person-centered; empowerment; an holistic, nonlinear approach based on strengths, support of peers, respect, responsibility and hope. Frese III et al. (2009) regard the inclusion of components such as hope, being person-centered and self-direction as emphasising the significance of the subjective perspective of the person in recovery and, very importantly, that the ultimate opinion on whether recovery is being achieved is that of the person in recovery.

Davidson and Roe (2007) reviewed the literature on recovery and found that recovery is meant in one of two ways. The first is clinical improvement, referred to as “recovery from” (p.462) and the second is the person’s right to be included in community life and to self-determination, which is referred to as “recovery in” (p.463). They do not regard these two meanings as mutually exclusive and regard them often to even coexist in the same person. Repeating once again that recovery is a multi-faceted phenomenon.

With the proliferation of opinions and findings on the factors and processes in recovery, Whitley and Drake (2010), while referring to the recovery components put forward by the Centre for Mental Health Services of the SAMHSA and several other authors, suggest a five

dimension understanding of recovery. These five dimensions are: clinical recovery, existential recovery, functional recovery, physical recovery and social recovery. According to them this is not yet another attempt at identifying components of recovery, but rather meant as a overarching system to organise the already existing components suggested by various authors. Whitley and Drake (2010) subdivide the different dimensions they put forward into: factors that are included, the roleplayers involved and the outcomes that can be measured in each dimension. According to them, applying these dimensions should aid in the organising of the plethora of factors and processes that recovery can potentially consist of.

To summarise, it is clear from these studies that the main themes in recovery that emerge time and again are: *finding hope* (Resnick et al., 2005), which includes hope for a better future (Pitt et al., 2007) and maintaining hope (Prus, 1996); *social support* (Eisenstadt et al., 2012; Henderson, 2010; Prus, 1996; Windell & Norman, 2012), which also refers to the role of various types of relationships and positive experiences thereof (Boydell et al., 2010; Henderson, 2010; Macdonald et al., 2005; Prus, 1996;); *taking responsibility* (Andresen et al., 2003) or charge of one's own life (Resnick et al., 2005), which also resonates in self-direction (Frese III et al., 2009) and self-determination (Davidson & Roe, 2007); *self identity* (Andresen et al., 2003), which includes rebuilding the self (Pitt et al., 2007) and achieving identity (Boydell et al., 2010); *meaning in life* (Andresen et al., 2003; Boydell et al., 2010; Resnick et al., 2005; Windell & Norman, 2012); *treatment* (Eisenstadt et al., 2012), which includes the type and routine of medication taken (Windell & Norman, 2012) and clinical improvement or recovery (Davidson & Roe, 2007; Whitley & Drake, 2010).

The lived experience

Strauss (1996), when discussing subjectivity, notes that a different, broader perspective than that of traditional medical science is needed. He finds that the objective approach of science creates a remoteness, instead of a much needed experiential perspective when dealing with the topic of subjectivity. He regards much of subjectivity to be common sense. But, a common sense that had taken him years to realise. In his opinion, the questions that trouble persons with schizophrenia when relating their subjective experiences, are the most important life questions, such as whether they will be well or ill. He also emphasises the importance of being specific. In order to relate to and, possibly, understand the experiences of persons with schizophrenia, it is necessary to listen to the specific details of their experiences. This provides the listener with a multitude of facets of the lived experiences of such persons and brings the experience to life, as it were.

Lloyd, King, and Moore (2009) conducted a study to establish whether subjective aspects of recovery, such as empowerment, were related to the self-report of relatively more objective aspects of recovery, such as degree of community participation. According to them, the measurement of an aspect such as empowerment does play an important role in determining the overall recovery of persons with severe mental illnesses, such as schizophrenia and bipolar disorder. This finding supports the current move away from solely focusing on objective signs towards the relevance of the “lived experience” (p. 227) of recovery.

Shapiro (2011), from a perspective of valuing the role that the story of the patient plays in understanding illness, discusses the question of reliability and trustworthiness of the patient’s story, since all narratives are, according to her, created by the narrator and, thus, do not reflect an “objective truth” (p. 68) and, furthermore, are influenced by “meta-narratives” (p.

69). She also warns that narratives in which the main character is expected to somehow find him or herself in a better position at the end of the story than at the start, as well as so-called recovery narratives, may preclude the voice of another person with a different storyline, which may include failure, suffering or anger, in coming to the fore. She advocates an attitude of empathy and respect, which she calls “narrative humility” (p. 70), in the approach to illness narratives. I have attempted, in this study, to bear this warning in mind when exploring the meaning that the participants make of their recovery.

What Shapiro (2011) describes as “narrative humility” (p. 70) echoes what Deegan refers to in her 1996 article, *Recovery as a journey of the heart*. Deegan (1996) emphasises the fact that persons with psychiatric illnesses must be granted the chance to overcome or manage their illness, but they must simultaneously also be granted the chance to fail at doing this. She calls this the “dignity of risk” (p. 97) and she urges clinicians and researchers to accept this risk. I would argue that this is an example of the respect that must be afforded persons with psychiatric illness and the importance of recognising the person’s lived experience of an illness rather than the illness alone.

The rationale for the focus on first-episode psychosis

According to Windell et al. (2012), there are several reasons that make the focus on a first psychotic episode desirable. Firstly, they argue that it is likely to increase the understanding of the experience of such persons, which may help with the design and assessment of interventions that focus on their interests. The latter may, in turn, improve the course of their illness at all stages. Additionally, persons in the early stages of schizophrenia may adopt a perspective which is more positive than that of persons finding themselves in later stages of

the illness. Lastly, how they conceive of their illness may also differ in persons earlier on in their illness as opposed to in the more advanced stages of schizophrenia.

The research team conducting the research project from which my prospective participants were sourced, states in its protocol that in first-episode psychosis great regard should be given by the medical fraternity to effective intervention and the prevention of relapse so that outcomes over the long-term may be improved (Schooler et al., 2005). It further states that this is necessary in view of the fact that relapse rates are high, that, with every relapse, it is less probable that patients will return to their earlier levels of functioning (Keith et al., 2004) and that patients experiencing a first psychotic episode are especially sensitive to the side-effects of antipsychotic medication (Robinson, Woerner, Delman, & Kane, 2005). According to the research team, long-acting injectable atypical antipsychotic medication, which forms the basis of their research project, is the best possible treatment for patients with early psychosis and it is crucial to provide these patients with a treatment that improves compliance by being sustainably delivered. For these reasons they have chosen to focus on early psychosis. And, since research done in the field of first-episode psychosis should focus on different perspectives to bring about not only knowledge but understanding of schizophrenia (Boydell et al., 2010), my focus has been on persons who have lived through a first psychotic episode and are recovering from it. In this respect, the aim of my research was to complement the research that is being done by the broader research team.

Some suggestions from the literature

We need to consider that not all persons use narratives to make sense, or even need to at all make sense, of their experiences. What about people who do not relate to their experiences through storytelling or the narrative? We need to be open to other modes of dealing with

experiences according to Woods (2011), otherwise we are guilty of denying the thing that lies at the very core of this study: that persons differ with regards to their experience and means of expression of such experience. I strove to also be aware of this in my interactions with the participants.

Boydell et al. (2010) suggest not only attending to the lived experience of the person, but also to the subjective experience of those persons who play a significant role in the life of the person living with schizophrenia, especially peers. Although I did not explore this aspect in my research, the possibility of it should be borne in mind in future research projects on the topic of subjective experience in recovery from schizophrenia. In addition, Boydell et al. (2010) emphasised the importance of having a sound theoretical framework for qualitative studies on this topic. In keeping with this and convention, the next chapter will set out the theoretical framework and methodology used in this study.

CHAPTER THREE

THEORETICAL FRAMEWORK AND METHODOLOGY

Theoretical framework

An age-old battle exists between the subjective and objective perspectives on knowledge. The study of schizophrenia did not escape this battle (Strauss, 2011). As mentioned in the introduction, the treatment of and recovery from schizophrenia can be approached from different perspectives. Often, research in the medical arena approaches the study of schizophrenia from a belief that reality is consistent and external and it uses quantitative methods to do so. Its aim is to create objective knowledge about schizophrenia and recovery from it; knowledge which is universally true and correct under any circumstance. As such, its epistemological position is impartial and objective (Terre Blanche & Durrheim, 2010). The researcher interested in the knowledge generated through a lived experience perspective finds himself or herself on the opposite end of the epistemological spectrum, attempting to interpret and understand such human experience, rather than reduce it to generally accepted facts. Such a researcher would adopt an interactional or intersubjective epistemological standpoint. Knowledge generated in this way is, inevitably, subjective and obtained through qualitative methods (Terre Blanche & Durrheim, 2010).

As Strauss (2011) states, it is necessary that we do not engage in this age-old battle that will lead us to choose one of the perspectives as the superior one. Instead, it is important for us to come to the realisation that both have a place and purpose in the generation of knowledge. They both contribute in their own way to a better understanding of schizophrenia and recovery from it. Geekie et al. (2012) also emphasise this when they state, in the introduction

to *Experiencing psychosis: personal and professional perspectives*, that subjective experience is not regarded as the ultimate route that guarantees truth as the destination, however, it is crucial that it be considered. They also agree with Smail (2010)'s insistence that an intersubjective approach needs to be employed when weighing up the value of subjective experiences. The intersubjective approach, according to Smail (2010), requires the data, which is generated through the communication of the subjective experiences of a person, to be analysed by another person. Smail (2010) states that such an approach will bring the subjective experience as close to being objective as is possible.

Flanagan et al. (2010) regard an inductive approach to the studying of mental illness as important. According to them, an inductive approach attempts to view the experience from the perspective of the patient, as opposed to a deductive approach that fits the patient into a predetermined diagnostic category.

From this it was clear that the research approach required in this study needed to be intersubjective, inductive and qualitative in nature, since the aim was to study the phenomenon of the lived experience of recovery from a first psychotic episode, in depth and in its context in an attempt to grasp what information emerged from the data collected through the interviews (Durrheim, 2010).

It was important to bear in mind at the outset that persons living with schizophrenia may lack the ability to be aware of their illness, which can make researching the lived experience of any aspect of their illness a challenge. However, despite this challenge, such qualitative

research should be undertaken, because it has the potential to allow for greater understanding and better treatment of the illness (Davidson, 2003). Strauss' (2011) point that some persons with schizophrenia who improve regard feeling cared for and taken seriously as the most important influences in their improvement, further emphasises the importance of conducting such qualitative research. By its very nature, conducting qualitative research which focuses on attempting to understand how a participant might be feeling about an aspect of their illness, has the potential to allow for the participant to feel heard, cared for and taken seriously and, thus, could have an important positive influence on the participant's recovery.

Kelly (2010) points out that it is important for the researcher to ensure that both an empathic and distanced perspective on the data is represented in the analysis of it. He describes this as understanding and explaining or description and interpretation of the data. This was one of the aims of this study, namely to offer a voice to the participants, while also attempting to understand the data academically and in the light of theory.

Pauen (2012) adds to this when stating that it is crucial to have a second-person perspective when studying the mental states of others, since it provides a unique way of retrieving such information, especially in social contexts. Davidson (2003) agrees with this when he emphasises that we need to regard experience as intersubjective, because only then are we aware of the fact that we live in a "shared world" (p. 21) and not each in our own separate worlds. Pauen (2012) describes the second-person perspective as drawing upon one's own experiences in order to understand those of others. He states that there are three requirements for second-person perspective taking. Firstly, as already stated, the person must draw on his or her own or similar experience of the state that the other is experiencing. However, this is

not sufficient for this kind of perspective to be present. Secondly, the person must realise that the state being imagined is not his or her own, but rather that of the other. And, thirdly, the person must be able to draw a distinction between his or her own perspective and that of the other. The last requirement enables the researcher to make inferences regarding the participants' state of mind. Pauen (2012) confirms that the second-person perspective does not generate objective knowledge as the third-person perspective would clearly do. But, instead, such knowledge is intersubjective and not first and foremost scientific as the former would be. This links Pauen's (2012) second-person perspective with the research approach taken in this study. Pauen (2012) also highlights that a second-person perspective is only relevant when studying beings that are able to have mental experiences, such as the participants in this study. He adds that, particularly, from the second-person perspective a greater "reflective perspectival awareness" (p. 43) is required than from the first-person or third-person perspective. He explains this by saying that it is necessary to take on another person's perspective, which may not necessarily be explicit from the latter point of view, in order to engage in a second-person perspective. He also describes the second-person perspective as one person's perspective on another person's perspective and, therefore, in terms that are similar to the "double hermeneutic" (p. 35) that Smith et al. (2009) refer to in their description of the features of Interpretative Phenomenological Analysis. This methodological approach is described in detail in the methodological section of this chapter. Pauen (2012) concludes by saying that by using a second-person perspective we can obtain intersubjective information that would not be gained through the other perspectives. Pauen's (2012) explanation of the second-person perspective describes the perspective that has been adopted throughout this study.

When approaching qualitative research, it is absolutely crucial that the researcher examine their being and their way of relating to other persons. This is necessary, because the researcher should be cognisant of the fact that he or she is not impartial to the process and has an influence on the process and the participants involved.

The way that I chose to be while conducting the interviews, and even when analysing the data collected, had an influence on the quality of the research experience for both myself and the participants, the results that were obtained and, ultimately, the contribution that this project makes to the greater body of knowledge. This inevitable influence underscores the responsibility I have before and during the research process to know myself and conduct myself as far as possible in a manner that avoids harm to anyone. My being and conduct should thus be congruent with my ethical principles.

My intention was to conduct myself in a manner that allowed me to be open to the participants and their experiences, in other words to not be closed off by preconceived ideas or theories of what should transpire through the research process. I did this by putting aside the further writing of my thesis for the duration of the interview process. This created a space in which I could focus solely on the participants and the interview process. I also attempted to approach each participant in a way that required me to make the transition into their world and not the other way around (Smith et al., 2009). To this end I interviewed all the participants at the Schizophrenia Research Unit at Stikland Hospital. The research unit is a familiar environment to the participants and aided in putting them at ease at the start of their interviews. I also deliberately used words and phrases that the participants employed during the interviews, without the intention to patronise them, however. This served to make the

interviews flow more smoothly. The qualities that mark what I try to achieve in my being as a person and a researcher and that were relevant to this project are patience, gentleness, humility, respect, being in the pursuit of wisdom, compassion, naivety and a willingness to be adaptable and able to endure uncertainty. Davidson (2003) also adds to this list the necessity of being empathic in order to be able to relate to the participants and their experiences. I agree with this and attempted to imagine what it would be like to have their experiences myself, as Davidson (2003) suggests. The first question in the interview was asking the participants to relate to me something of what they could remember from the time they first became ill or were not feeling themselves. This assisted me in entering their world, since most of them were able to give me an elaborate account of such a time. I also bore in mind that the data would in all likelihood not be neatly packaged and presented by the participants and that I would have to get my hands dirty, as it were (Smith et al., 2009). My experience during the interviews regarding this aspect was that very often I would ask a question to which the participant responded that they did not know the answer, but then they would answer it a few questions later.

By viewing the participant as a person apart from his or her illness, as someone who responds uniquely to the illness and someone who may have the ability to recover from it, as suggested in the introduction, it is inevitable that the theoretical framework for my research was a phenomenological one, that is one which “studies conscious experience as experienced from the subjective or first person point of view” (Smith, 2008; What is phenomenology?, para. 2). In addition and as I have alluded to, I regarded myself as being part of and having an unavoidable influence on the interviews and the research process as a whole. I intended staying aware of this fact throughout my research, so as to ensure that, despite my influence, the voice of the participant still took priority.

My intention with the research was to explore the participants' recovery experiences in order to grasp how they understand these experiences. In this exploration my emphasis was on the way in which the participants made meaning of their experience of recovery, rather than the end result of their recovery process (Smith et al., 2009). I also remained ever aware of the fact that experiences cannot be separated from time. An experience has to be explored within the temporal context in which it occurs and cannot be regarded as separate from the participants' other experiences (Davidson, 2003).

From this theoretical framework, I attempted to explain the narratives and themes that emerged from the data in terms of the component processes identified by Andresen et al. (2003). These component processes were used only as a guide to learn more about the process of recovery in schizophrenia. It was crucial for me to be open to what emerged from the exploration of the personal experience of the participants and I regarded this as distinct in every participant.

In a qualitative study such as this one, it is important to tie the theoretical framework and research methodology together as best the researcher can, and this made it crucial to find a methodological approach that suited the data as close to perfect as possible.

Methodology

Background to the study

The ongoing broader research, conducted by the Schizophrenia Research Unit, which forms part of the Department of Psychiatry at Stellenbosch University and of which the participants to this subproject form part, is quantitative in nature. In light of this it was considered useful to add to the existing body of knowledge that has been created through this research by focusing on qualitative aspects of first-episode psychosis. The focus in the qualitative part of the research was placed on the lived experience of recovery from a first episode of psychosis. Conducting individual interviews was considered the most suitable method for collecting the data from the participants. Its suitability will be evident once the chosen methodological approach has been discussed.

Study design

Qualitative research focuses on what human experience consists of and the way in which it is constructed. As such, its ontology is subjective, rather than objective (Davidson, 2003).

A most suitable approach was sought amongst the many different qualitative methodological approaches that exist. Many of these approaches could be regarded as suitable, because they have, at first glance, only subtle differences in their practical applications. However, the differences that are in fact decisive are those concerning their theoretical underpinnings and, upon closer scrutiny, these differences are often significant.

When considering an approach, it is important to start by paying attention to the topic at hand, not the approach that is being considered (Smith et al., 2009). The topic in this instance is the lived experience of recovery from a first episode of psychosis by a small sample of schizophrenia patients. Grounded theory would require a greater amount of data and time than is available through this research (Smith et al., 2009). Since the focus with this topic is not on the construction of the participants' stories per se, and also not on the way in which the participants interact or communicate their experiences, narrative approaches and discourse analysis are not particularly suited (Smith et al., 2009). Since the lived experience of recovery from a first psychotic episode was being studied, it was decided to use a phenomenological approach, since it was best suited to explore what constitutes such experience and allowed us to gain access to the lived and experiential aspects of the participants' lives (Davidson, 2003).

A suitable approach to analysing the data generated was found in Interpretative Phenomenological Analysis (IPA). It is an inductive approach which was developed specifically for the discipline of psychology by Jonathan Smith of Birkbeck College, University of London in the United Kingdom (Smith et al., 2009), and on this basis alone it is already a well-suited approach to the data. IPA aims to be a tool to assist the researcher in grasping, in great detail, the meaning individuals create from their own and, importantly, significant experiences in life (Smith & Osborn, 2004). It is based on phenomenology, hermeneutics and idiography (Smith et al., 2009).

Using phenomenology as a basis for IPA allows the researcher to place emphasis on the studying of the individual's experience as the individual truly experiences it and not, in the

first instance, on a theoretical or conceptual approach. According to Smith et al. (2009) the most important philosophical contributions in this regard were made by Husserl, Heidegger, Merleau-Ponty and Satre. While Husserl's ideas constitute the point of departure for the other three, and is aimed more at contemplating and generalising the lived experience, the other three philosophers each contribute a more contextual, bodily or relational view of experience, respectively. The experiential aspect of the participant's account is highlighted (Smith et al., 2009).

Even though this methodology is deeply rooted in phenomenology, it does acknowledge the need for the researcher to use his or her skills of interpretation to comprehend what the participant communicates to him or her (Smith & Osborn, 2004). Hermeneutics is the theory that underscores the interpretational aspect of this method of analysis (Smith et al., 2009). The researcher attempts to create meaning from what the participants are creating meaning from, namely, their experiences (Smith et al., 2009). The fact that I, as researcher, live as a human being in this world, will also influence my interpretation of the data (Smith et al., 2009), which makes my being an integral part of relating the participants' experiences. Smith et al. (2009) call this a "double hermeneutic" (p.35). My interpretation of the data as researcher will be informed not only by the individual participant, but by the whole body of data collected. I will also inevitably be informed by psychological theory (Smith et al., 2009).

Ultimately, the knowledge gained through this research can be considered a joint effort by the participants and the researcher (Smith et al., 1997), which assists in narrowing the power imbalance that normally exists between researcher and participant.

The idiographic nature of IPA, firstly, allows the focus to be on the individuality of the participants' particular experiences in a given context and, secondly, pays great attention to the detail contained in such experiences (Smith et al., 2009). The aim is to grasp participants' experiences and not, in the first instance, to be able to generalise to a population. I regard each individual's experiences as unique and, thus, the idiographic nature of this methodology suits this aspect of the theoretical framework, from which I approached the interviews, well.

In order to explore the experiences of the participants in great detail, the number of participants in research employing IPA must be limited to small numbers and the interviews are conducted in a semi-structured manner (Smith et al., 2009). The semi-structured nature of the interviews creates a space in which the participants determined to a large extent the course of the interview (Smith et al., 2009), and this is exactly what I as researcher hoped to achieve. Consistent with Davidson's (2003) approach to qualitative studies of recovery in schizophrenia, the interviews were also conducted in an open-ended way. Davidson (2003) advocates such open-ended interviews because he insists that it brings us closer to the data than we would have come if other methods, such as case studies or autobiographies, were chosen, since the emphasis is on first-hand accounts being related to us directly.

Methods and procedure for data collection

In line with the IPA approach, I conducted two semi-structured interviews, of between 21 minutes and approximately 75 minutes each, with each participant, using some structured questions and some open-ended questions to guide the interview process. This was best suited to the exploration of participants' experiences and perceptions and to eliciting a thick

description. The use of a semi-structured interview allowed for greater flexibility in the questions being asked and the responses being given, which is a defining characteristic of IPA (Smith & Osborn, 2004). The questions included in the interview schedule were based on those aspects of experience of recovery from serious mental illness that emerged from the existing literature. However, and once again, these questions served merely as a guide, since the participants were allowed to direct the course of the interviews.

Participants

Interviews were conducted with seven participants, of whom three were English-speaking and four Afrikaans-speaking. The ages of the participants varied between 28 and 46 years, with a mean age of 35.29 (SD=9.01) years. The diagnoses of the participants, as provided by the Schizophrenia Research Unit, were schizophrenia, paranoid schizophrenia or schizophreniform disorder. All participants were regarded as in symptomatic remission at the time of the interviews. Symptomatic remission was determined using the criteria set by Andreasen et al. (2005). The details of study participants are set out in Table 1 on the next page.

Table 1

Study Participants

Participant	Age	Race	Home Language	Diagnosis
Rachel	46	Coloured	Afrikaans	Paranoid Schizophrenia
Mary	28	Coloured	English	Schizophreniform Disorder
Christine	42	Coloured	English	Schizophrenia
Conrad	45	White	Afrikaans	Schizophrenia
Andrew	32	Coloured	Afrikaans	Paranoid Schizophrenia
Fred	31	Coloured	English	Paranoid Schizophrenia
Steven	23	Coloured	Afrikaans	Schizophreniform Disorder

Note. All names are pseudonyms.

Initially, I set out to conduct two interviews each with between eight and twelve participants. The requirements for participation were that the participants were not actively psychotic, that they were in recovery from their first psychotic episode at the time that the interviews were conducted, and that either Afrikaans or English was their language of preference. Regarding this last requirement, interviews were conducted only in Afrikaans and English with Afrikaans and English-speaking participants, respectively, because I am only able to speak

and understand these two languages. Since the research conducted focussed on eliciting the lived experience of the participants first hand, it was imperative that I was able to grasp the essence of the experiences that each participant was attempting to convey and in a language that he or she was most comfortable engaging in.

All participants were recruited through the Schizophrenia Research Unit at Stikland Hospital. They were either attending there at the time of the interviews or had attended there in the past, as part of the broader study being conducted there and which has been reported on elsewhere in this chapter. Those participants that were still attending at the research unit at the time of the interviews were asked by me to participate at the time that they attended the unit for their two-weekly or monthly appointments. The interview was then conducted either at the same time or at an alternative, mutually convenient time. Those participants who had already concluded their attendance at the research unit were contacted telephonically by me and asked whether they were willing to consider participating. If they were indeed willing, I arranged a mutually convenient time to meet at the research unit to explain the study, request their consent and conduct the first interview.

During the interview process it became evident that not enough participants were available to participate to attain between eight and twelve participants, as a result I finally only managed to recruit and conduct interviews with seven participants. The unavailability of participants was due to the participants either not meeting the criteria of not being actively psychotic, or the language criteria or, simply, not being willing to participate. The limited number of participants was still in line with the goal of IPA, namely to focus on how the participants felt and thought about what they communicated and to consequently give an in-depth account of

their experiences (Smith & Osborn, 2004). Smith et al. (2009) agree that seven participants are still a sufficient number to continue with an analysis of the data generated and obtain meaningful results.

It was pointed out to the participants during the process of consenting to the interview that they were the experts, as it were, and that I was there to learn from them. I also made it clear that there were no right or wrong answers to the questions that I posed and that they could take their time in answering. Participants were encouraged to contribute spontaneously, openly and freely to the interview to maximise the possibility of obtaining an account of their experiences in their own words and to allow the participants to highlight important areas to them, which contributed invaluable data to the research. I practised active listening during the interviews by using encouraging behaviour such as nodding, paraphrasing (so that participants got that I understood what they were saying) and summarising. Despite the open-ended nature of the interviews, interview schedules (see Appendices A and B for the interview schedules in English and Afrikaans, respectively) served as a guide for the interview process, assisting with the wording of questions and removing uncertainty on my part regarding how the interviews would proceed so that I could be as confident as I could be as an inexperienced researcher and not be distracted from what was being related by the participants (Smith & Osborn, 2004).

During the initial interviews participants were asked to describe where they regarded themselves as being in the process of their illness at the time of the interview. They were then asked to explain what that meant to them. My expectation was that this would elicit a possible conversation about recovery with them. This is similar to how Windell et al. (2012)

approached this aspect of their interviews. They, however, took a more direct approach and asked participants to their study to indicate whether they considered themselves recovered or not and what that meant to them. I initially opted for my approach, because I wanted to understand where participants to the present study saw themselves in their illness process, without prompting them, by using the word recovery, to necessarily think in terms of their own preconceived ideas of recovery. However, during the first few interviews it became clear to me that a more direct approach to this part of the interviews was required, since participants did not understand the question. I changed the formulation of the question in the interviews with later participants to take a more direct approach, similar to that of Windell et al. (2012), however, still avoiding the use of the word recovery as far as I could in order not to prompt the participants unnecessarily.

In preparing myself for the interviews, I sought to increase my own understanding of the experiences of persons living with schizophrenia before the start of the interviews in order to create the best possible space for an empathic interaction with the participants, as emphasised by Davidson (2003). I did this by reading first-person accounts of the experience of living with and recovering from schizophrenia (Deegan, 1996; Saks, 2007) and watching podcasts of persons relating their experience of living with and recovering from schizophrenia (Benjamin, 2011; Saks, 2012), since this provided comprehensive, direct and intimate narratives of personal encounters with mental illness (Karp & Birk, 2013).

Data analysis

The interviews were audio-recorded, with the permission of the participants, and transcribed verbatim by me. No coding frame was set prior to conducting the interviews, because of the exploratory nature of the research and the chosen methodology. A systematic search for themes was conducted. This was followed by an exploration of links between the themes and the creation of superordinate themes. This was done for each transcript. Thereafter patterns between the themes in the different transcripts were explored to generate master themes for the group of participants as a whole (Smith & Osborn, 2004).

In addition to the interviews, it was also decided to make use of the case study method of analysing the data. The purpose was to give an in-depth account of the interviews with two of the participants who seemed to have very different experiences of their illness, in order to gain further insight into their particular experience of their illness.

Flyvbjerg (2011) points out that the case study has, for a long time, been dismissed as a substandard methodology. Even though it is still regarded as such in certain circles, in general, the move is toward accepting this methodology as a valuable contributor to the generation of knowledge and this has led to an acknowledgement of its importance in the field of research (Flyvbjerg, 2011).

Terre Blanche and Durrheim (2010) describe the case study as a research method that is ideographic in nature. Yin (1999) emphasises a very important aspect of the case study, namely “its intense focus on a single phenomenon within its real-life context” (p. 1211),

which highlights the significance of the role that context plays in the case study. Despite their warning against generalisation and problems with validity in case studies, Terre Blanche and Durrheim (2010) acknowledge the contribution that this research method can make by providing a thorough insight into a single example of a phenomenon. Yin (1999) furthermore stresses that the focus in case studies is to inform theory rather than be informed by theory. Flyvbjerg (2011) adds to this when he describes the strong points of the case study as “depth-detail, richness, completeness, and within-case variance” (p. 314).

Emphasis was placed in the use of plain language throughout this thesis. Very often academic work is shrouded in language that is inaccessible even to academic persons outside of the specific discipline that the work forms part of. My intention with the use of plain language was to make this thesis as accessible as possible to persons outside of the discipline of psychology. This is to echo the approach in the interviews to use plain language that did not create a barrier or power imbalance between the participants and me. The insistence upon plain language is rooted in the belief that the participants are the experts and should not be made to feel otherwise, particularly by the use of language.

I kept my research questions fairly general as opposed to being based on any strict hypotheses. This allowed me to be led by the data. I was open to allow the experience of the participants to come to the fore, to be aware of any preconceived ideas I might have about the results of my research and to mitigate the effect of these ideas as far as possible. Bracketing is the term used in the literature to describe this stance and it entails letting go of preconceived ideas when describing and attempting to understand experiences (Smith et al., 2009).

Ethical considerations

Ethical considerations are, first and foremost, crucial for the protection of participants. But, it is also essential to protect the researcher.

My research proposal was submitted to the Health Research Ethics Committee (HREC) of the Stellenbosch University for approval, which approval was obtained on 17 April 2012. It is a substudy of research project number N06/08/148, which is titled: A prospective study of clinical, biological and functional aspects of outcome in first-episode psychosis in South Africa, and of which Professor Robin Emsley is the principal investigator and Dr Bonga Chiliza is the project leader.

General ethical considerations

Participants were informed of the nature and aim of the research. This was done as part of the process of informing the participants of various aspects of the research before obtaining written consent from them. The study was explained in plain language and participants were encouraged to ask questions before being formally asked to sign the consent form. After signing the consent form, they were once again reminded that they could ask questions at any time and could also withdraw from the research or end an interview at any stage without any adverse consequences to them. Permission was also asked of the participants to audio-record and transcribe the interviews. They were assured that I would be the only person listening to the audio-recordings and that only my supervisor, Professor Leslie Swartz, and I would be reading the transcripts. The identities of the participants remain confidential and they were advised of this. Their names will not be known to anyone except my supervisor, the staff at

the Schizophrenia Research Unit and me. The anonymity (as it is referred to by Smith et al. (2009)) of the information shared during the interview was also communicated to the participants and ensured through the secure storage of the interview recordings and transcriptions on my private computer. The participants consented to the results of the research forming part of this thesis, being published in the professional literature and made available to the members of the Schizophrenia Research Unit at Stikland Hospital. The privacy of participants was ensured by conducting the interviews in a closed room. No compensation was paid to participants, except for a contribution towards their travelling expenses, and they were informed of this. Written, informed consent was obtained from participants before commencement of the interviews. Each participant was given a signed original consent to take with them. I offered the participants the opportunity of reporting back to them with the results of my research. Several participants indicated their interest. I will arrange a joint opportunity for all of those participants who indicated their interest once this thesis has been finalised.

Specific ethical considerations

I attempted to minimise my expectations of participants' answers. I did not rush the interviews or the participants and was very aware of only asking one question at a time, so as not to overwhelm the participants. I paid close attention to the effect of the interview on the participants. Some participants felt emotional during the interviews and I offered them a break from the interview and also asked whether they wanted to continue.

In those interviews that were conducted in one of the psychiatrists' offices at the research unit I made a point of sitting on the same side of the table as the participant so as to indicate with my physical presence that I was not taking on the role of the expert in the interviews. Some of the interviews were conducted in the tea room of the research unit and in these interviews I made sure that the participant and I sat at one corner of a long table to once again even out the power imbalance as far as I could. During the interviews I ensured that my body language conveyed a message of being open by not crossing my legs or arms.

As the interview progressed and I became more familiar with a specific participant, I adapted the terms and language that I used to that of the participant without the intention of patronising the participant, so as to put the participant at ease, improve the power imbalance that may have existed between us, as far as possible, build rapport with him or her, and allow him or her to feel heard. The questions in the interview schedule were also formulated in such a way as to follow terms that I anticipated the participants themselves might use. I refrained from the use of terms such as schizophrenia, recovery, first psychotic episode and lived experience (Windell et al., 2012) as far as possible.

Even though only low or minimal risks were expected to be associated with participants' participation in this research, I assured participants of the availability of professional support in cases of distress. Some participants became emotional in the interviews. In such cases I asked the participant whether he or she wanted to stop for a while. Every time, however, they declined and we continued. Fortunately, it was not necessary to call on such support.

CHAPTER FOUR

RESULTS

Introduction

During analysis of the transcripts of the interviews several themes emerged. An overview of the super-ordinate themes is given in Table 2. Thereafter each of the themes will be reported on and attention will be drawn to the meaning of recovery for each participant through excerpts from the transcripts. In the last part of the chapter the interviews with two of the participants will be presented as case studies.

Table 2

Themes Emerging from the Transcripts

Keeping Busy or Having a Job

Support

Taking Responsibility for Themselves or Independence

Insight Into the Illness and Knowing What to Expect in Future

The Importance of the Participants' Positive Attitude and Their Belief in Their Own Abilities

Awareness of Limitations

The Role of Having To Care for Another

Adapting To and Accepting Circumstances

Stigma

The Role of Spirituality

Themes

Keeping busy or having a job. Many of the participants felt that keeping busy, having a job, or feeling that they have a purpose helped them with their recovery. Rachel managed to articulate this very well in our first interview:

Rachel: And, then when I started to work again, got a job, a casual job, then all that thinking when you sit at home, a lot of things go through you, through your brain. Especially, if you worked all those years and all of a sudden you do not work. I think that being busy and working is very much part of my recovery.

She repeated the important role having a job played in her recovery in our second interview:

Rachel: And the time that, uh, that I kept myself busy and got myself a job, a little something to do and I think it also helped me much more than sitting still.

Rachel aptly and succinctly described it again in the second interview:

Rachel: ...but I believe if you are busy, it helps you to recover.

Andrew explained in his first interview that he felt better at the time of the interview than he did even two years before his illness started. He elaborated on what helped him feel so much better:

Andrew: Because I started working, so to say, again recently and that is, so to say, a bonus, because I received, so to say, treatment at home for the past three years and did no...nothing, but be, so to say, on the treatment and, and yes.

Immediately after stating that he did nothing for three years, it was very important for Andrew to qualify to me that:

Andrew: Well, not that I'm saying I did nothing and I mean I lay in front of the TV and, and did nothing. There was, so to say, time that I, so to say, how can I say, um, that I discovered myself, if I can call it that. That I discovered myself, that's now your purpose, because what, so to say, what you live for, yes.

Fred described his desire to work, which he already expressed to the psychologist he went to see before he came to Stikland, as follows:

Fred: And, I went to private psychologist and the psychologist told me about this [the study at the Schizophrenia Research Unit]. I told her I'm looking for work and I'm desperate, and I got matric and drivers and N6 electrical and I'm looking...I want to be part of society. I want to become a productive part of society. And, she told me, no you can come here to Stikland Hospital, here's a, a section 14 where they do work rehabilitation and that's where I started off there.

In this extract from my first interview with Fred it is clear what role work plays in the participants' lives:

Fred: And, I must say my, my, my work...also gave me another positive, because I was working and earning a salary. I felt part of society. That was the main thing, ja.

ADW: So, you would say that work is...had a good influence on your illness and your recovery in your illness?

Fred: Ja, ja.

Steven, although he has not been in full-time employment again since he became ill, has had a job on a building site for a few weeks. He described working again as:

Steven: ...Feels normal. Feels like...you can do it again. It feels, I was happy those three weeks that I worked on the building. I was like, wow, now I can work again.

On being prompted about the role of his work, Conrad added :

Conrad: Yes, it's almost like someone contributing to something.

ADW: Ok, ok. So, you also contribute?

Conrad: Yes.

ADW: You also do your part?

Conrad: Yes.

Support. The theme of support encompasses both the aspects of support and the lack of support, possibly resulting in loneliness or isolation.

Fred explained the lack of support he received at home compared to that which he received at work very touchingly as follows:

Fred: So ja, but I would say that the situation at home hasn't changed that much. I still seclude myself and that, but when I come to work it's like I'm in heaven. You know, like I feel like I'm free, I can do anything.

In his description of the positive aspects of his circumstances in the first interview, Conrad highlighted:

Conrad: Yes, the, my girlfriend supports me by cooking meals for me.

Later in the same interview, Conrad added that:

Conrad: So, she's[his girlfriend] actually a great help to me. I cannot imagine myself without her.

Throughout the two interviews Rachel emphasised the support she received from her son. In the second interview she specifically said:

Rachel: Uh, my family didn't support me that much, but my son support me very much.

Rachel also referred to the support she received from her two close friends:

Rachel: Yes, they [friends] supported me. They came to see what I was doing, what I was doing in the hospital, always asking my son, how is mom? And, when I was discharged, they came, because they stayed close by.

ADW: Yes, and how did it feel to have those people around you?

Rachel: It felt good. At least they did not reject me or anything. They came regularly. Or, I went to their place, went and sat and watched TV. Did their hair sometimes. They asked me. Kept myself busy that way.

Christine's experience was that she had no support:

Christine: Because, I mean, there's no friends or no anything that support me... You know so, but there's no like, um, no one discusses it with me,

*no one talks to me about it, I mean, unless I'm here [at the hospital].
So, um, like I say, I think it's just me and...*

However, Christine put up a brave front when asked how it felt to have no support:

Christine: Well, I'm used to having no one there to support me and ever, in a lot of things, a lot of things I deal with myself. So, it's no real biggy. So, it's just another obstacle.

Mary emphasised the important role the support of the nursing staff at the research unit played in her recovery:

Mary: I feel like Sister Irene is like a mother to me, another mother, the way she care for me and gentle and [cries]. I always appreciate it. [Cries] They're very sympathetic and they made you feel normal, that you can do normal things again.

The important positive role of Mary's husband in supporting her is clear from her first interview:

Mary: So, it's just my husband treats me as normal. He doesn't see me as schizophrenia. He says that's normal... [Quoting her mother] You have to be aware that if Mary has a relapse because of her medication, you must be able to handle it. And, that's why he also keeps a calendar on the wall, so I can see this, that 28 days from when I took my injection, that I must take my next injection, he reminds me also. So, that we don't forget.

And, again in the second interview:

Mary: If I didn't have his support and his understanding and I don't think I would be able to cope.

Mary's parents also played an important role by supporting her:

Mary: My parents as well...Giving, encouraging me not to go off the trial, off the medication...So, they're always telling me, you stay on your medication and you'll be fine. So, their support as well.

The aspect of loneliness or isolation notably emerged in the interview with Rachel. She became very emotional, at times, when she spoke about it. Her loneliness is also linked to taking responsibility for herself and that nobody else is there to do so. She referred to being alone regularly throughout both interviews. The first time was:

Rachel: ...But he's [her son] married now. Yes, now I am staying alone again. And, otherwise I am very well.

Later on in the first interview she became tearful when she said:

Rachel: ...But, he [her son] supported me until last year, then he got married.

In the second interview she referred to it again when she said:

Rachel: But, my son supported me all the way until he got married. Now I am alone. On my own, living alone and now I must just stay positive. I can't think of wrong things.

Further on in the second interview Rachel was emotional once again when answering the question of how the experience made her stronger:

Rachel: Yes, everyone must do their bit for themselves.

ADW: Uh, Uh, uh. Ok, ok. And that has made you stronger?

Rachel: That made me stronger. [Cries]

Another aspect that could be included under this theme is noticing an improvement, since it displays support given by others. Andrew said that others noticing that he had improved, helped him:

Andrew: ...then he said, Andrew the day when I still saw you, you looked terrible, man! Now, definitely, you are looking good, man. So that, so to say, boosted me a little.

Taking responsibility for themselves or independence. Closely linked to the theme of support is taking responsibility for themselves. Participants indicated that through their illness and recovery they learnt that they needed to take responsibility for themselves and learn to be independent. This is how Rachel summed it up:

Rachel: Nobody is going to look after me. Even if I am ill. And family each head in their own direction and if I live alone, aside, then I can look after myself. This is what I have learned in this time. And, family keep to themselves.

Later on in the same interview Rachel also emphasised the importance for her of not being dependent on others, which implied taking responsibility for herself once again:

Rachel: What I have learned now is not to be dependent on others.

Fred also indicated that he aspires to be independent one day and how that would make him feel:

Fred: ...I wanna buy my own house and so, you know.

ADW: Provide for yourself?

Fred: Provide for myself. I wanna be totally independent. I don't wanna be dependent on anybody.

ADW: What would that mean to you, if you can do that?

Fred: [Smiles] I'll be very happy, I'll be very happy.

Fred often, throughout the interviews, referred to the cognitive strategies he employed to aid him in his recovery. This can be regarded as a form of taking responsibility for himself. An example of such a strategy is:

Fred: ...Like my mother and brother went to go watch a movie at Tyger Valley and I, I was feeling depressed and I didn't wanted to go with, but I thought to myself, no if I just come out a little maybe it might, it might aid in my recovery as well, ja. But, seclusion.

ADW: And, did you do it then?

Fred: Ja, I did go watch a movie with them.

Christine was adamant throughout the interviews that she was wary of romantic relationships, because she feared that the possible rejection could bring on another episode. This consequently brought about a strong sense of responsibility and independence, as is evident in this extract:

Christine: Like I say, I've always grown up with this thing, whatever I love is gonna be taken away from me. So, um, it's very difficult for me to actually get close to someone, because I'm always, when it ends or when it's finished, uh, I don't, you know, want that. So, rather not get involved in the first place, so.

ADW: Ja, ja. Keep yourself safe?

Christine: Ja.

ADW: ...And, maybe you can explain to me what, what from the whole experience of this illness, what has helped you that you take with you in the future?

Christine: I don't know. I honestly don't know. Um, basically, just don't go, you know, look out and be careful, don't let it happen again, so. But other than that...

Insight into the illness and knowing what to expect in future. Several participants reported that they were unsure of what was happening to them when they initially experienced the first-psychotic episode. As Rachel pointed out:

Rachel: I did, I did not know what was happening.

Fred also explained that:

Fred: I didn't even know what schizophrenia was. I don't know...my mother just told me I'm acting silly and there wasn't...it's just all in my head.

In Fred's case the topic of knowledge about his illness came across very strongly in the interviews; he referred to it repeatedly throughout both interviews. He regarded it as very

important to know and understand his illness. He explained the following to me within the first few seconds of our first interview, possibly indicating the importance thereof for him:

Fred: I's...at the time I didn't know what the word schizophrenia meant, but now I've...now that I'm equipped with the knowledge, I know the symptoms and I can compare them with the symptoms I had be...earlier on. So, if I do suffer from that, I make a note of it and I get back to the doctor and I tell him I was feeling so and so on such a day.

In the following extract from our conversation in his first interview, he also emphasised the anxiety-relieving effect that this knowledge about his illness had on him and that, once he had the knowledge, his recovery could start:

Fred: I felt a little bit alleviated, because I could...there's a word for it now, it's an illness. It's not something I dreamt of or anything like that or something that I just keep in my mind.

ADW: Yes, yes. So, one can almost say you felt more normal, you know that, that...

Fred: Yes, that's when the healing began. Once I knew my illness and I knew the symptoms and I knew what...I got the knowledge, they say mos knowledge is power...

ADW: Yes...

Fred: So, once I knew about that I could start tackling the problems one by one, one by one, day at a time, day at a time. And that...then I tried...then I became positive and then my negative, my anxiety went away and I started feeling less depressed, because I knew what my

illness was. Ja, and so I feel...I feel for the people out there that is...many of them that do suffer from their illness. I do come from, I'm not actually from the Cape Town, but I'm actually from Eastern Cape, in a small town called Grahamstown, where the university is there, and I know of pe...guys that do suffer, they're sitting with ten, eleven years at home and they are suffering and they don't know about their illness. And, I'm the one who's knows about this illness.

Fred also compared the fear of not knowing to knowing when he said:

Fred: The fear of not knowing is more...that's more traumatising than...more stressful on a person, than knowing. You must know what your illness is, what...how your body works.

In the last part of his second interview, Fred described the benefit of his knowledge about schizophrenia very touchingly, when he said:

Fred: ...I still have the illness, yes, it won't go away. It will stay with me till I die. But, the knowledge of having, of what can be done to overcome it, it's, it's priceless. You can't put a price on it.

Andrew, when asked what he could remember about his feelings when he first became ill, replied:

Andrew: Feelings? I would say maybe a bit anxious I was, very anxious. I got anxious quickly.

In the second interview Andrew, when asked about what recovery meant to him, said:

Andrew: So, ...if I now look at the anxiety that I had, that I am not so anxious or get so anxious anymore. Or, that I know how, so to say, when I get anxious and what anxiety actually is too, so yes.

This underscores the importance to the participants of having knowledge about their illness and its symptoms. Andrew also added, further on in the second interview, when asked what he thinks lies ahead in terms of his illness:

Andrew: ...I think it is almost like I say, just take it as it comes. If it comes again, then like I know where to come, how it happened and that there are helping hands, so to say, to save me from the ditch, if it, if it happens again, if I go downhill again.

Christine highlighted that, according to her, the doctors or nurses had not explained to her what was happening to her. She said that the first she knew of her diagnosis was when she received her hospital bill. Once she knew what her illness was called, she said:

Christine: I mean once my head connects with the paranoid schizophrenia, then I sort of started dealing with it, you know in other words, you know, yes, dealing with it.

Mary's brother also has schizophrenia and she explained that having the illness herself gave her a better understanding of what her brother endures:

Mary: So, that's learned me to be patient with him and to hear what he has to say and not just shut him down and say, hey you're talking nonsense now, go take your tablets. Because, now I understand what schizophrenia is about, which I didn't.

The importance of the participants' positive attitude and their belief in their own abilities. Fred described the attitude that he felt was needed when he said:

Fred: You need to, need to be productive part in society and, how can I say, do positive things for...to help other...do something for someone else for a change. Not always be self-centered, you know.

Rachel explained how she remains positive:

Rachel: ...I don't really like people who are negative. If people say something negative to me, I believe I stay positive. I keep believing that it will come right. And, I pray about it and I firmly believe and I try to do it right. I try to do it right and then it does come right, yes. I am such a person.

Upon being asked what helped her, Christine said:

Christine: ...my own willingness to, to be, to stay better...

Also:

Christine: ...I think it just my own, um, drive and perseverance and strength that, that is keeping me healthy, so to say.

And:

Christine: ...I try and look at it positively, you know, that I'm, that I'm better and cured and, um it's not gonna happen again [laughs], I'm not gonna have that relapse again. So, I try and stay positive and focused and just, um, take it one day at a time and in, in that sense.

Mary described herself as:

Mary: ...very determined person. I wasn't going to let my schizophrenia influence me. After the noises went away, um, sounds and Doctor Chiliza said I must start going back to my normal life. And, Tech started, I went back.

Mary's attitude about having schizophrenia is very clear:

Mary: ...I don't feel I have an illness. I'm living normal, like I say. I don't have schizophrenia. I don't tell myself I'm schizophrenia. As long as I take the injection, I don't have it. So, schizophrenia is not part of me. Unless, I come to the doctor and they tell me you're schizophrenia. I haven't had a relapse or anything, so for me I don't have schizophrenia. As long as I take that Fluensol [probably a reference to Fluanxol]. And, that is keeping me normal. So, for me I don't have it.

The restoration of the participants' belief in their own abilities may also centre on the overcoming of the onset of an episode. An example is when Rachel explained why she did not tell the doctor about hearing voices again:

Rachel: ...I didn't tell the doctor, because I didn't feel that it was necessary. Because I can overcome it.

ADW: I understand. On your own?

Rachel: On my own.

Christine's belief in her own strength helped her:

Christine: So, I think from mentally, physically, n...mentally, ja I think I'm much, um, stronger frame of mind than, than some people and that has led me to be more, um, adaptable, or to, to, recover.

Awareness of limitations. Throughout the interviews it was clear that the experience of a first psychotic episode made the participants aware of their limitations. This awareness was not inevitably negative. Often the awareness brought them more certainty of what they were capable of and what they were not. This gave them the choice of staying away from activities that were not beneficial to them. Many of the participants had active social lives and were very busy and stressed before the illness. In recovery, they professed that they did not go out as often anymore, did not keep the same friends they had before and did not engage in as many activities as they used to.

Andrew displayed an awareness of his limitations when he explained things he stayed away from since the illness:

Andrew: The earpiece that I had, the music and the light. The music of the machines, the people calling, the people speaking. So, so it was, it is so to say, if I am perhaps in a few stores now and the speaker is directly under [sic] me while I am busy with the shelves, then I feel it has a little bit of an effect on me, so to say, that, something that doesn't help. So.

ADW: Ok. Then you realise you have to move away from it?

Andrew: Move away a bit or as quick as possible, or maybe get done as quick as possible with what I am busy with on the shelves, yes...

Conrad was patently aware of his limitations throughout his interviews and made this clear, especially when he described how he felt after receiving treatment for his illness:

ADW: *Ok, and does it feel to you that you, um, does it feel to you that you are the same as you were before that time, when you were feeling healthy?*

Conrad: *No, not actually.*

ADW: *Or, does it feel different?*

Conrad: *I feel a...I feel almost like someone who is a, uh, someone who is a little handicapped.*

ADW: *Ok, explain a little more to me about that?*

Conrad: *Yes, I mean I am not as outgoing as other people and sometimes it seems to me as if I almost just want to sleep. Yes, it almost feels to me I can't get enough sleep.*

ADW: *Ok, ok. So, you are very tired?*

Conrad: *I could say that. I am actually, yes.*

ADW: *Or, it is just sleepiness?*

Conrad: *Yes, I have.*

ADW: *That your eyes just want to close?*

Conrad: *The brain is a bit lazy.*

ADW: *Ok, ok. And, is that different to how it was before?*

Conrad: *To concentrate, yes.*

At the start of his second interview, Fred also emphasised a limitation he experienced by stating that his memory had deteriorated:

Fred: The other thing is, I want to talk about is the schizophrenia affects you when you don't, you can't like, you don't have flat, you don't have, um, recall memory. You can't, you can't memorise things very easily. You tend to become forgetful also. So, you forget things.

As has been referred to earlier in this chapter, knowledge of the illness was a very important recovery tool to Fred. He made it evident how this knowledge of his limitations in terms of the illness could help him, when he said:

Fred: ...And, I don't know if I will become ill again or, or, or I'll be recovering, but my process through my, my, my day-to-day working..., I, I try and build up knowledge of my illness, so that when that problem or that day arrives when I think I'm losing my mind or I suffer from schizophrenia, then I will say, no so and so day I did this and that and it helped me. So, I can, I'm gonna do that again and see if it helps me again, ja.

Steven often, throughout his interviews, referred to not overdoing things in his life. He had, by his own admission, a very busy life before his psychotic episode and was aware of the limitations that he experienced afterwards:

Steven: I hope it [studying] doesn't make me stressed again. Uh, then I collapse again or something. Again. But, I believe I won't, I believe I won't.

Elsewhere in his first interview he went on to say:

Steven: I am recovering nicely. It's, it's very, I feel very good, like in I, I, it's almost like I don't have worries anymore. I'm going to work again some day. And, I feel I can, I can do it again.

ADW: Ok, you can do what?

Steven: ...and like in, I can work again, I am playing rugby again, like I can tackle things I tackled before. But, I won't go about like I did before. It was too much.

Mary emphasised the fact that she could not deal with too much conversation after her first psychotic episode:

Mary: ...Then, after the illness, getting better, I didn't feel like going out with people and socialising, we're talking, I couldn't handle too much talking. I couldn't take it. And...

ADW: Why is that?

Mary: I, if it's too much people in the room and they're talking loud and I just got stressful, it got, I couldn't handle the noise.

The role of having to care for another. Repeatedly, throughout his interviews, Fred emphasised the gain for him in helping others. He stated it very clearly when he said:

Fred: ...and I give it to them and it makes me feel better inside, because I am helping another person and helping myself as well.

Elsewhere Fred touched on this theme again when he said:

Fred: ...I see there's people sitting in the street and don't have something to eat and I buy them a loaf of bread and this penny polonies and something and I watch them how they eat and I feel very happy and then they ask me when am I gonna come again and something like that, you know. Then I feel very happy inside, because I know I did something, I did something for someone else.

Fred also stressed that a reciprocal relationship with others is helpful to him when he said:

Fred: I'm also getting therapy by myself also, because sometimes they share their problems with me, I share my problems with them.

Andrew explained to me that he was not able to express his emotions as a child. During the interviews it became clear to me that it was important for him to create a space where this was possible for children. This led him to pursue a part-time career as a clown. He explained what his experience as a clown around children meant to him:

Andrew: For me that means because there was not, because I could not, so to say, express my emotional needs, or rather not needs but could not express myself emotionally, it helps me to give it to them [the children]. So, that is how I see it, how I can help them. Or help myself.

Conrad also expressed how helping his girlfriend to buy stock for her tuckshop made him feel:

Conrad: Yes, like my girlfriend has a tuckshop. So, I also feel in a way I am a help to her. She helps me and I help her...

ADW: How do you help her?

Conrad: By buying her things for her, taking her to the warehouse, wholesalers.

ADW: Yes? Ok, ok.

Conrad: ...

ADW: Ok, ok. But, by helping her with her tuckshop, it makes you feel better too?

Conrad: Yes, it makes me feel I am, someone needs me. Contributing to something, yes.

ADW: That's a good feeling?

Conrad: Yes, yes, it makes me feel I am not worthless.

Christine took a slightly different approach to this theme and regarded having to care for her daughters as a motivation to do what she could to avoid another psychotic episode:

Christine: You know, it's, it's, it's I try not to dwell on it [becoming ill again] too much, but obviously it is there and I think the biggest part is I don't want to put my children through that again. So, I don't want to get sick again, cause of that. So, um, I try not to let it rule my life, but you know, I'm conscious of it.

Adapting to and accepting circumstances. The importance of being able to deal with the illness as it arises was raised by several of the participants. Andrew said:

Andrew: ...I think it is almost like I say, just take it as it comes.

And Fred said:

Fred: But, what I've noticed is, you can't always pinpoint what's going to happen. And you, and you just have to deal with it as it comes along.

Steven also referred to this when he explained that he saw himself as a guide to others:

Steven: ...Take it as it comes, ...

Stigma. In the second interview it became evident that Rachel experienced stigma, even if she did not name it:

*Rachel: ...I didn't go to people anymore. I just stayed at my place, where I....
If they see you coming to Stikland, then they think, all kinds of things
they say to you. And I kept myself away from people.*

A few lines further, Rachel said:

*Rachel: People don't understand it. They think only mad people come here.
They don't understand it...*

Mary explained her non-disclosure at work, because of the possibility of stigma:

*Mary: But, I still, um, don't tell my work doesn't know I'm schizophrenia,
because I don't want to be discriminated or they know I have diabetes
and rheumatoid, but I don't want them to think that I'm, I am not
normal, that I can't do my job. So, I don't disclose that, that I'm
schizophrenia.*

Elsewhere she described it very succinctly when she said:

*Mary: ...I didn't want to tell people about my illness. I was shy over it. I'm
still shy over it today. I don't want people to judge me or treat me
differently. Because I'm thinking that's like a stigma, I've got a mental
illness, you're not totally there.*

In the second interview Mary once again brought up the subject of possible stigma at her workplace:

*Mary: ...unless they [work colleagues] go through it themselves. Or, they
have a family member with it, that that they understand it. But, if they
don't know nothing about it, it's just a condition that they hear about
and they judge you on that...I don't think they would understand what*

schizophrenia. If I must come to, if I have a relapse and it has to come out that I have it at work or something, but that I would rather keep private. I'll say it's depression or something. I wouldn't disclose it, because then they will treat you completely different. I don't know how they would treat you, but they will be judgementals and....

Interestingly and in contrast to the other participants who touched on the topic of stigma, Steven, although he admitted being weary of others' reactions to his illness, claimed that he did not experience stigma and was not fearful of it:

Steven: ...and then I walked [in the neighbourhood] and everybody greeted me and people were still the same. They don't talk behind my back, nothing. Like in, I have never heard, like someone say to me, you crazy thing or some, nothing like that.

The role of spirituality. For many of the participants spirituality played an important role in various ways in their recovery. Mary was very emotional in the first interview when she made a possible connection between her illnesses and God:

Mary: ...So, it just, I don't know if it's God giving me these challenges, if I strayed away from him, but every time I get over it, he gives me an illness...

When asked about alternative treatments, Mary added:

Mary: People prayed for me and I know that church would pray for me, friends and family prayed for me. But that was it. My mommy and them don't really, they believed in the doctor's medication and they just prayed.

When Mary answered the question about what helped her in the second interview, she said, amongst others:

Mary: ...the church, um, going to church and also, um, prayers. I think they're also important.

Christine contributed a very touching piece when she said:

Christine: I keep thinking about this quote, um, apparently Mother Theresa said it, um. She says, she said, um, God is supposed to not give you more than you can handle. But, sometimes I wish he didn't trust me so much. [Laughs] So, ja, sometimes I feel there's stuff that I can't handle, but I always end up handling it, you know. Not always the way I want it to, but, ja, so. Um, that's basically all I can say is, um, I mean, through God's strength and giving me the strength to cope with every day, so.

In Steven's interviews the role of spirituality in his recovery was repeatedly evident. The first indication was in the first few minutes of the first interview:

Steven: I can, I don't want to blame man. I'd rather just say that it's an illness given to me by God.

Later on in the first interview Steven also said, similarly to what Christine and Mary had said:

Steven: I believe in the man above. He would not put something in my path that I can't handle or so.

Steven believed that prayer was stronger in helping him recover than the medication given to him by the doctors:

Steven: ...we always believe to pray is the best way. You must, medicine helps too, but prayer has the most power. It carries power.

Rachel also added:

Rachel: I learnt that if I go on my knees every night and pray to God, then I say to God to help me. And, in the mornings it makes me a stronger person every day.

The meaning of recovery

Fred said that recovery meant:

Fred: Being totally, being totally normal, like the normal people, like sister Retha and Irene. They can work under pressure, you know, they can do many things, they can multi-task. But, I can't multi-task yet, I used to do that, but I can't do that anymore, because pressure is too much for me.

Fred also referred to recovery being a process and described the course it took for him very clearly:

Fred: ...So, by coming to, by acknowledging first. First acknowledging that I have the illness and learning about my illness from the doctors here and then coming for my therapy, my talking to the psychologist or the doctor about my problems and also taking my medication, as

prescribed. That will help. But, also finding a distance for yourself, a me-time...

At the end of his last interview, when asked to explain how he thought recovery worked, Fred said:

Fred: I won't, I won't really recover from it. But, there are ways of overcoming it. By becoming practical, ja.

Rachel, when asked how one knows that you are recovering, said:

Rachel: ...because you do things again like you used to, before you became ill. Then you can see, you're looking after yourself and you're doing things. You're independent of others. Then you're busy recovering.

Just a few lines on, Rachel added:

Rachel: To stay positive is, is part of recovering.

Andrew uses an image, which he also drew as steps on a piece of paper:

Andrew: So, recovery I see as someone climbing a ladder. Climbing stairs, if one can put it that way....

ADW: Yes...?

Andrew: ...put that way. Where I, so to say, took it slowly step-by-step to get, so to say, where, where I am now or, like I say, step-by-step climbing up to improvement, to recovery.

Upon being asked what it meant for him to be recovering, Steven said:

Steven: It means a lot to me, because why I didn't think that I would recover. I thought that I would be like that for the rest of my life. It means a lot to me and I thought, hey, I'm not going to have a wife one day. Because a woman would not put up with a person like me or I thought I would stay at my sister's all my life and they would probably look

after me. And, look, I am healthy today. I am grateful to the man above. That's all I said. And, I am still healthy and I can once again my life...pattern...It's, it's, it's it's almost like it's nicer than before, because why, I feel again like I can work again, I can do everything...

Conrad said that to him recovery meant:

Conrad: It's just, it's almost like a pro...process. Yes, you get better and...day-by-day.

Christine explained that recovery for her was:

Christine: Well, I think it's a, it's a everyday thing, you know, because like I say, with the, even with the study there's so many people that had a relapse. So, um, the possibility is always there and I think one day at a time thing. I mean, I don't want to get too cocky and think, but now I'm cured now, there's nothing wrong with me and then two days later I have a relapse. So, I think recovery is an ongoing process.

Christine also proclaimed that she was uncertain if one could completely recover from mental illness when she said:

Christine: Is there such a thing as complete recovery from a mental illness?...I mean, obviously you can get better and that, but it's like a drug addiction, you're always going to be a drug addict and anything can put you back there. So, I think a mental illness is the same...

ADW: So, what you're saying is you don't think that one, one always has something of that, that stays behind or something that you keep or

something that you have, it's something that you have to bear in mind in your life?

Christine: I think so, if you're, I think you have to bear in mind, I mean not let it overwhelm you, but you have to, I feel I have to live basically knowing that anytime I could, you know...

Christine said at the start of the second interview that:

Christine: Recovery means that I don't have the same, um, problem as I did last time...That you're not going to get again, you know, something like that.

She also reiterated what she said in the first interview:

Christine: ...but the recovery is obviously an ongoing process, because I, you know, I think every day, every day that you take is a step closer to recovery, but I don't know from a mental illness, if you can ever be fully recovered, because I mean, that's, you know, something that can easily, very easily happen again.

Mary described recovery as:

Mary: ...becoming better...

And:

Mary: Your normal life, living life as normal.

And also:

Mary: But, things has changed for me dramatically and recovery, I don't know how to say, but I think I recovered well and I'm to a point where

I'm healthier and I know my whereabouts and I know where I'm coming and I'm going and not delusional. And, that to me is that I recovered completely.

At the start of the second interview Mary gave a summary of what recovery meant to her:

Mary: Ok, for me recovery is, um, becoming more stable and normal, into a healthier stage to a normal person. Not having the delusions and the noises, the voices. You, um, totally stable. That's what recovery means to me.

Case studies

Introduction. My intentions with these case studies are to gain a depth of insight into the particular experience of recovery from a first psychotic episode, which would not be possible without doing a study of particular cases, and to provide an analysis of these specific cases as a whole. I chose to focus on the experiences of Steven and Conrad, because they presented themselves and their experiences in very different ways. My reason for stating this will emerge from the analysis that follows, suffice to say at this point that Steven displayed a very positive approach in dealing with schizophrenia and his recovery from it, while, in contrast, Conrad sketched a rather dismal picture of his experience.

Steven. From the moment Steven walked into the first of our interviews he exuded an air of positivity, friendliness, openness and eagerness. As I explained the details of the study to him, he seemed rather impatient, wanting to start telling me about his experience. He answered questions in great detail and could give me the precise date on which, according to him, he first became ill:

Steven: ...November. Was the 23rd of October 2010. November...about November the 1st, the 2nd I was here. It was then that I arrived here.

My first question to all the participants was whether they could tell me a little bit about the first time they became ill or were not feeling themselves. Steven did not hesitate at all before starting to tell me about it. He took me into his world by referring to people as if I knew who they were. Within the first minute of the interview, Steven already displayed this tendency:

Steven: And, the whole week to hospitals...different hospitals. They didn't know anything and then the following week I went there to Mr Van Niekerk. I told my mother, I always drop by the school. Then I went to Mr Van Niekerk at the school. And, he got me the help to...

ADW: Is he one of the teachers at the school?

Steven: He's the principal.

It made me feel very much included in his world and experiences and helped me to grasp what he was trying to relate to me, better. During the course of the second interview, he said that he would like me to meet his best friend, Aiden, and he seemed very disappointed when he realised that it was our last interview and that it was unlikely that I would meet Aiden. Also, at the end of the second interview he was clearly eager for me to meet his fiancée, Shirley. She was sitting in the waiting room and I followed him there and met her.

Steven: ...But, can you meet my girlfriend quickly? Can I go and call her? So...

ADW: Yes, I will walk out with you just now. Then I will meet her.

Steven: Yes, ok.

Steven had strong religious ties. He spent a great deal of the time in the interviews describing his experience of his illness and recovery in terms of his religion. In the second interview he spent a great deal of the time explaining to me how marriages in his faith work, since he and

his girlfriend had decided, the week before the interview, to get married. And, he displayed a sense of satisfaction, after doing this, because he had educated me on something that I had no knowledge of before. This possibly also emphasised my point at the start of the interviews that the participants are the experts and I seek to learn from them.

Steven also explained the alternative healing methods, that he tried, in-depth. These methods mostly consisted of very specific prayers by religious elders, the drinking of “holy water”, the use of prayer oils and the burning of incense. He, in contrast to most of the other participants, still believed at the time of the interviews that the alternative healing methods contributed significantly to his recovery. He stated this in the first interview when he said,

Steven: Like I think a little bit...I think the medicine of the doctors helped and that [prayer] helped, because why, when you believe in it, it will help you.

In the second interview he reiterated the above statement by saying,

Steven: ...we always believe that to pray is the best way. You must, medicine helps too, but to pray has the most power. It carries power. That's what we believe.

Two important contributing factors to his belief that he had the ability to continue with a meaningful life after having been diagnosed with schizophrenia were having a job and playing rugby. Referring to a part-time job he had for three weeks, doing manual labour, he explained how it made him feel by saying,

Steven: Is ok. Feels normal. Feels again like, you can do this now. It feels, I was happy how I, that I just worked those three weeks there at the building. I was like, wow, now I can work again...

The significance of playing rugby is clear from the following excerpt from the second interview:

Steven: It's almost like they talk to you and tell you how good you play and then you feel good and you feel, hey you're home again and you feel like a, like a human being.

In addition to having a job and playing rugby, Steven also emphasised the importance of talking to somebody:

Steven: Yes, I come from the doctor and go straight there, then we perhaps go there, then he [religious elder] prays for me, then...I already feel good after I have been here [at the Schizophrenia Research Unit], because I always spoke to someone. I had...am...was necessary to talk to someone. About how you feel, because why, it's not something nice to talk about, because one tends to bottle it up and you keep things inside...

ADW: Yes, yes, I understand. Yes, yes. That you...it must come out.

Steven: It must come out...

Steven's belief in his ability to attempt something new is also clear when he explains how he came to study at a college at the time of the interviews:

ADW: And, how did you decide to, to go and study?

Steven: Ummm

ADW: What made you...decide on it?

Steven: I told myself I can do it.

ADW: Yes?

Steven: I can get over it and I can do it...

During the course of the interviews, Steven also spoke about some of his disappointments. These centred on his not finishing his school career and having to give up his job, a job that he indicated he enjoyed very much, because he fell ill with schizophrenia. The fact that he did not finish his school career was a great disappointment to him. He regarded it as a contributing factor to his illness:

Steven: I am, I don't know, but I was very disappointed when I didn't finish school. I think tha...it has something to do with that thing, when I became so ill, I think, because I talked a lot about school.

Having to give up his job because of the illness also came as a great disappointment to him. However, in this instance, his attitude most certainly contributed to his recovery. He described it as follows:

Steven: Only, it would have only been seven days...November month I would have become junior controller. I am very sad about it, but it is over, it's part of life as...[laughs].

From the interviews it was clear that Steven had become aware of his limitations, especially because he had pushed himself, by his own admission, excessively before he became ill:

Steven: Ummm, how I, I don't feel like walking around like I used to anymore. I think I did too much. I had too, I don't know, it was just too, the activities I did were too much.

Elsewhere Steven added to this when he said:

Steven: ...But, I won't walk around like that again, like I walked around previously. That was too much.

Together with the realisation of his limitations, he also indicated that he became more aware of his activities and consequently more careful:

Steven: Then I played there [a university]. But, you get home too late, when you finished practising. And, then I decided that I was going back to our club in Rondebosch.

Elsewhere he reiterated this:

Steven: I'm just going to make salah [pray] and then I go to my girlfriend, play rugby and if I get a job again, then I'll work again, so. But, I will not, if I work on a Saturday again, play rugby again on a Saturday. Because it will exhaust me.

Steven recalled many sources of support that had helped him and continue to help him. These sources include his family, his girlfriend, his friends, his rugby teammates, his community and his relationship with God.

A very touching excerpt was when he shared his gratitude towards his girlfriend with me:

Steven: ...I told her, I spoke nicely to her. If I get ill again, will you stay with me like you did before? She said yes, she will stay with me. And, I said to her, shukran, it means...thank you.

Regarding the community he lives in, Steven was adamant that he never experienced any stigma.

Steven: Yes, there I started walking. And, then I heard he [a friend] had died and then I walked and everybody greeted me and people were still the same. They don't talk behind my back, nothing. Like in, I have never heard, like in someone say to me you mad thing or some...nothing like that.

Steven regarded the death of his friend as an event that caused him to overcome his fear of people and leave the safety of the house again:

Steven: ...I can say thanks to...I can't actually, I know he's not there anymore, but I can thank him. That made me walk again. After that, I walked again.

Steven also regarded himself as a guide to others:

Steven: ...I always thought, hey what will the people say to me. Everybody knows me. Many people know now that I was ill. But now I am, I don't worry anymore. I tell them openly. Because like, I am almost like a guide to them. That's what I think.

These extracts give a clear impression of Steven's experience of his illness and recovery from it. His positivity, attention to detail, his eagerness to include me and the important role of his religion, is evident. He highlighted important protective factors, such as the role of a job and playing rugby, as well as the support he experienced from several sources.

Steven's openness about the disappointments he experienced and his limitations was noticeable. His attitude of being able to move on from and accepting these disappointments and limitations seemed to have stood him in good stead. After completing the interviews with him, I felt inspired by his positive attitude and openness.

Conrad. From the moment we started the interviews, Conrad displayed a lethargy or sluggishness (which could be due to negative symptoms of schizophrenia or to medication). His speech was slow; he needed much prompting and gave mostly short answers. This resulted in many close-ended questions being asked. An example of this is:

ADW: I understand, I understand. Ok. And, this is different for you to how it was earlier when, say, you were feeling healthy?

Conrad: Yes.

ADW: What was it like then?

Conrad: Then of, course I felt nor...normal.

ADW: Yes. Did you go out often then and?

Conrad: Yes.

ADW: Slept less than you do these days?

Conrad: Yes, slept less.

ADW: Yes? You went out more?

Conrad: Mmm.

As a result, the descriptions by Conrad of his experiences are not as thick as those of the other participants. Nevertheless, he provided me with a perspective on the experience of recovery from schizophrenia that allowed me to, once again, realise that every participant's experience is unique and should be respected and appreciated as such.

In the first lines of the first interview, I detected a helplessness in Conrad's approach to his illness.

Conrad: Ummm, usually the people that are sick, they don't realise that they...there's something wrong with them. It's the family who realise and reach out to those who help. Yes, my sister actually brought me to the clinic in Mitchell's Plain. Then that nurse referred me here.

Conrad also displayed a tendency to please others, such as his sister. This could be linked to the helplessness and which are both, in turn, possibly indications of an inability to accept responsibility for the illness.

ADW: Ok. So, you just agreed because she wanted very much for you to go [to the clinic]?

Conrad: Yes, to please her too.

Despite his clear sluggishness and need to be prompted, Conrad succeeded in describing quite aptly his fear when he first became ill:

Conrad: Yes, I was just panic-stricken, yes. Yes. I was almost like, they can hurt me.

Conrad spent some time in jail for a crime he felt he did not commit. He felt that this contributed to his illness:

Conrad: Yes, my, my ex-wife actually put me in jail for a crime I did not commit. I was convicted and I appealed and was released again. And, that also maybe gave me a knock. And, there at the jail also, maybe just go to the toilet, but make sure my locker is locked.

Another example in the theme of feeling at the mercy of others emerged when Conrad explained how long he had been part of the research program:

Conrad: I am now already, I have now finished two years already and then they said I must stay on for another year. So, I agreed to stay on another year.

The formulation of his answer indicated a feeling of almost being forced into staying on for another year.

In the same vein, Conrad also displayed a resignation, which was evident from his answer to my question about where he saw himself in the course of the illness:

Conrad: Yes, I am in the acceptance process, because I am accepting things. It must just be like this.

ADW: The illness?

Conrad: Yes.

ADW: Ok. Or, what is it that you are accepting?

Conrad: Yes, I accept the circumstances, my illness.

When asked about recovery from schizophrenia, Conrad indicated an uncertainty:

ADW: And, do you think you're busy recovering at the moment?

Conrad: Yes, yes.

ADW: Does one recover from something like this, from such an illness?

Conrad: I don't know, but I feel satisfied with myself.

Conrad also acknowledged that the fact that his energy levels had decreased made him worried, but that he just had to deal with it.

Conrad reiterated what many of the other participants also remembered upon being asked how their illness was explained to them by the doctors and nurses:

Conrad: Yes, they didn't give me an explanation.

In contrast to Steven, Conrad did not experiment with any alternative treatment methods. He made it very clear when he said:

Conrad: No, I did not use anything.

I tried to prompt him after this initial answer, thinking that he may not have understood the question correctly, but he kept to his initial answer of no.

Conrad also acknowledged his sluggishness in his answer to the question of how he felt after the treatment compared to before:

Conrad: Yes, I feel as if I have more energy now, but I'm a bit more sluggish. I don't go out a lot. It's just for the sake of my girlfriend that I get up on weekends. If I didn't have her, then I would stay in bed. When Fridays came, I used to just lie down or perhaps I got up, went to the shebeen and drank two or three beers and just came back home.

He added to this by saying:

Conrad: I feel a...I feel almost like someone that, uh, someone who is a bit handicapped.

And:

Conrad: Yes, she's [his girlfriend], she, uh, ummm, I am, I feel almost like someone...like a small child who cannot do anything for myself...

He also said that he cannot get enough sleep and his “brain is a bit lazy.”

In response to my attempt to elicit more of the positive aspects of his circumstances, Conrad stated that:

Conrad: Um, yes, the fact that I still have a job, and that's one of the positive aspects, because why, ummm, if I perhaps lose my job, then my situation might deteriorate, I might neglect myself, not care for myself as I should.

However, Conrad soon returned to his negative perception when he described his doubts about his participation in the study:

Conrad: I am not someone who communicates much. I, I was a bit uncertain whether I should agree to this [the study].

This was linked to a feeling of inferiority regarding his competence to take part in the study:

Conrad: Because why, I don't speak a lot and I read very little. And, I left school when I was still in one of the lower classes.

Conrad explained that his lethargy and unwillingness to interact with others was linked to:

Conrad: ...because why, I cannot listen very well. I am not a good listener.

He also added:

Conrad: It's, they speak to me, but I can't actually, I cannot hear what they say. I do not follow.

Conrad also thought of himself as limited because of his illness:

Conrad: Yes, I'm now just, how should I say, limited to...

ADW: And, how's that different for you? How? You just said that it's limited.

Conrad: Yes, I'm am not so, how should I say, how should I say, uh, um, not so, uh, so energetic as I used to be anymore.

From these extracts, it is clear that Conrad had trouble being positive about his situation. He displayed a sluggishness, helplessness and resignation. He regarded himself as inferior to others and thought of himself as limited and like a small child. He required my encouragement to focus on a positive aspect of his experience. However, he returned to his negative point of view immediately after answering the question. Conrad also clearly lacked a solid support base. Except for his girlfriend, who cooked and cleaned for him on weekends, he did not identify anybody who supported him. This surely had an influence on his negative perception of his situation and circumstances. After my interviews with him, I was left wondering how things could have been different for him if he had more support and his attitude was more positive.

In the next chapter, the focus will be on the exploration and explication of the themes that emerged from the results in this chapter.

CHAPTER FIVE

DISCUSSION

Introduction

As has been discussed in Chapter Two, outcome in schizophrenia is viewed either as the remission of symptoms or as recovery or, even, a combination of the two. Whereas symptomatic remission criteria have been set by Andreasen et al. (2005), which makes the comparison across such studies and subsequent discussion more meaningful from a scientific perspective, such criteria have not been set with regard to recovery. This makes the comparison between recovery studies more challenging. Emsley et al. (2011) acknowledge that recovery is more complicated to conceptualise than remission. In addition, it must be borne in mind that recovery always contains an element of personal experience (Harvey, 2009) and can never be evaluated by objective standards or criteria alone. As such, the setting of universally accepted criteria for recovery, and using these criteria as a gold standard for the determination of recovery in specific instances, could be problematic (Davidson, 2003). Should this be done, the uniqueness of the experience of the individual will be lost.

For purposes of this study the focal point was recovery and specifically the unique experience of the patient recovering from schizophrenia.

This chapter will focus on the exploration and explication of some of the themes that emerged from the results. It is necessary to start by making a link between the facets of

recovery, as discussed in the literature review, and the themes that emerged from the present study. Many of the themes that emerged relate to themes that have been identified in previous research with similar participants.

Spirituality is a theme that is often avoided, perhaps because spirituality is a topic that is often shrouded in controversy and regarding which many wide-ranging opinions exist. To overlook spirituality in this discussion, however, would be tantamount to silencing a crucial part of the voice of some of the participants. Support in its various forms is possibly one of the most important contributors to the recovery of persons faced with mental illness. It is a theme that cannot be excluded from this discussion, especially since the majority of participants referred to it. Lack of support is also acknowledged and explored in the discussion. The role of having to care for another is a natural corollary to support and is a theme that emerged from the present data and is investigated in more detail.

No discussion on any study done on personal experience would be complete without a reference to the role of stigma. Stigma is an ever-present, ever-pervasive theme that must be addressed time and time again. The highly criticised and contentious theory on elaborated and restricted codes by Basil Bernstein is revisited in the light of the present data.

The abilities of persons challenged by mental illnesses are often and sometimes unintentionally disregarded and discounted, even by themselves. It is fundamental to highlight the role that the retention or rediscovery of these abilities played for participants in the present study. Having insight into their illness can be essential in the recovery process for

some persons. The role of insight in recovery and the importance of a degree of certainty about the future is explored.

Before the limitations of the study are pointed out and recommendations are made for future studies, the discussion is concluded with an elaboration on the meaning that the narratives had for each of the participants. Though this is unusual in the discussion, I feel that this is necessary in order to respect one of the key tenets of this study: to allow the voices of the participants to be heard.

The description of recovery and its various facets

Many of the participants viewed recovery as a continuous process. However, some participants saw recovery as an end goal to be achieved. This is in line with findings in other studies (Emsley et al., 2011; Windell et al., 2012) and also in accordance with the development of the concept of recovery over time (Andreasen, 1994a).

Apart from illness recovery, Windell et al. (2012) also identified two other areas in which recovery took place. These were psychological and personal recovery, and social and functional recovery. These three areas correlate, according to Windell et al. (2012), with four of the six areas identified by Whitley and Drake (2010), namely clinical, existential, social and functional areas. The two other areas identified by Whitley and Drake (2010) were the spiritual and physical health dimensions. In the present study, the spiritual domain played an important role in recovery for most of the participants.

Andresen et al. (2003) distinguished between four aspects in the process of recovery. These are meaning in life, hope, self identity and responsibility. As has been identified in the present study, keeping busy or having a job, the importance of the participants' positive attitude and their belief in their own abilities, awareness of limitations and taking responsibility for themselves or independence correspond with the aspects identified by Andresen et al. (2003).

Resnick et al. (2005) identified certain principles on which recovery is based. Amongst others these are taking charge of their own lives, and taking part in activities that are meaningful to them. Once again the themes identified in the present study, namely taking responsibility for themselves or independence and keeping busy or having a job correspond with these principles.

The most influential factors in the recovery process, according to Windell and Norman (2012), are social support and stigma. In the present study these were also recognised as themes.

Both Henderson (2010) and Windell and Norman (2012) noted that participants in their studies opted for safer, recovery-conducive behaviour following a psychotic episode. In the present study most of the participants reported refraining from busy social lives and stress and engaging in more spiritual activities such as prayer in order to support them in their recovery.

Several of the participants referred to their ability to deal with uncertainty as an aspect of their recovery. The theme identified in this regard was described as adapting to and accepting circumstances.

Another important theme that emerged from the present study was the participants' knowledge about the illness and knowing what to expect in future. They acknowledged that this equipped them with the tools to deal with, firstly, what had happened in their first psychotic episode and, secondly, what might lie ahead for them in terms of their illness in the future.

The role of having to care for another is another theme that emerged from the present study. As an example, Rachel doing her friends' hair made her feel that that she kept busy and meant something to others. The role that having someone to give something to played in her recovery cannot and should not be overlooked.

The experience of recovery in the context of symptomatic remission

The criteria set for symptomatic remission by the Remission in Schizophrenia Working Group (RSWG) and published in Andreasen et al. (2005) were used to determine the level of symptomatic remission achieved by the participants in the larger study of which this is a part. Being bound by these criteria, symptomatic remission in the larger study was measured using only certain of the Positive and Negative Syndrome Scale (PANSS) scores. As such, symptomatic remission is determined by taking only the scores for the core symptoms of schizophrenia into account. The scores of the PANSS that were used are those for delusions,

conceptual disorganisation, hallucinations, blunted affect, social withdrawal, lack of spontaneity, mannerisms and posturing, and unusual thought content (Andreasen et al., 2005).

According to the Schizophrenia Research Unit, all of the participants in the present study were regarded to be in symptomatic remission at the time of the study.

As has been stated repeatedly, the criteria for symptomatic remission have, after their determination by the RSWG and publication in Andreasen et al. (2005), been clearly and uniformly set. As has also been pointed out, this greatly improved the ability to draw comparisons between remission studies which used the RSWG criteria. The important contribution that this has made to the study of schizophrenia and recovery from it can never be underestimated.

During the interviews in the present study, it became clear that many of the participants regarded the remission of symptoms as an important, although not the only, indicator of recovery. This is consistent with the findings by Windell et al. (2012), who conducted a similar study to the present one, and referred to symptomatic remission as illness recovery. As this indicates, it is crucial to bear in mind that, in recovery from schizophrenia, symptomatic remission can possibly be regarded as only one aspect of recovery. Interestingly enough, one of the findings by Boyer et al. (2013) in their cohort study carried out in France, Germany and the United States of America, is that Quality of Life (referred to in their study as “subjective recovery” (Discussion section, para. 5) as opposed to functioning and clinical symptoms, which is referred as “objective recovery” (Discussion section, para. 5)) is a greater predictor of relapse than symptoms and functioning. They do acknowledge that Quality of Life is not the only aspect of recovery and that research needs to be done on

the other aspects of recovery and their ability to predict relapse. They are also of the opinion that their conclusions may back the expansion and inclusion of approaches that are based in recovery in the prevention of relapse.

Recovery is a complex, multi-faceted concept. Arguably, this does not make it uniformly definable as is the case with symptomatic remission. This can be ascribed to the fact that each person is unique and, as a consequence, their experience is unique (one of the key tenets of the present study). Various aspects of recovery have been pointed out throughout this thesis. From the present study alone it is clear that not all persons experience all the aspects of recovery in the same way. It is even so that not all persons experience all the aspects of recovery. It is also important to bear in mind that what might be a positive and constructive experience of one aspect of recovery for one person, might not be as positive or constructive for another person. Each person's uniqueness and unique circumstances must be taken into account when determining recovery in their specific case. This makes a comparison of the experience of recovery between different persons and studies virtually impossible and, in some way, unnecessary. This makes the study of recovery a very challenging field of study, but as Strauss (2011) pointed out, "It is not good science to ignore data simply because you do not know how to measure them" (p. 10). Limitations with regard to methodology cannot be an excuse to not study such data (Strauss, 2011). It is possible that one of the reasons that the topic of recovery has, for a long time, been sidelined is because it is such a difficult topic to justify and study by scientific methods. This, however, is no reason to discount the topic.

The role of spirituality

Spirituality can build resilience in persons experiencing psychosis by providing them with an effective, alternative explanation to the traditional psychological or medical explanations for their experiences. Spirituality has been found to play a significant part in the process of recovery from serious mental illness, because the presence of mental health issues does not obliterate the age-old human need to make meaning of experiences (Luckoff, 2012). During the interviews, six of the seven participants mentioned some aspect of spirituality or such based activity, which they or persons close to them engaged in and which contributed to their recovery. One of the participants, Steven, even went as far as to insist that prayer had more power to aid in his recovery than medication.

For purposes of this discussion, the word spirituality is used in its broadest sense. It means some form of relationship or connectedness with a higher being, which may be personal or organisational. Since fragmentation of the self is a part of the experience of psychosis, questions regarding the meaning of life, which is linked to spirituality, often arise for persons afflicted by psychosis (Walsh, 2012).

The approach, from the outset, in the present study has been to be inclusive of all aspects of recovery. Thus, the role of faith in the experience of recovery must be explored and seen as an important one. This is despite some authors' warning against it being a controversial topic to address (Chidarikire, 2012; Weskamp & Ramugondo, 2004). As Weskamp and Ramugondo (2004) put it, a complete impression of a person cannot be formed if the role of spirituality is not taken into account. They emphasise that spirituality can assist people in

gaining an understanding, transformation and achieving hope in their lives. Furthermore, they see two additional, significant functions of spirituality, its ability to assist people in reaching what they are capable of and helping people in finding purpose in their lives.

Many of the participants in the present study referred to prayer as supporting them in recovery. Luckoff (2012) confirms this when he states that practices such as prayer seem to shield against the severity of symptoms. In the present study, participants referred either to their own prayers or the prayers of people close to them or in their spiritual community. Fallot (as cited in Fallot, 2007) underscores the importance of a spiritual community for persons who find themselves discriminated against or outcast, as persons suffering from schizophrenia often do. He states further that such a community often creates a sense of belonging for those who are stigmatised.

Many of the participants professed that their belief in a higher being gave them the strength to face the illness and to recover from it. This is in accordance with the findings by Chidarikire (2012) and Fallot (2007). Chidarikire (2012), who wrote an article based on his experiences in Tasmania as a mental health care nurse, highlights the importance of mental health care professionals paying attention to the spiritual needs of patients by suggesting that they should explore the spiritual background of patients during assessment. The reason for emphasising this lies in the fact that good psychological well-being and few symptoms of the illness were reported by patients who acknowledged that they were spiritual (Fallot, 2007).

Fallot (2007) and Hadzic (2011), however, also warn against the negative role that spirituality can play in the improvement of patients. Fallot (2007) states, for example, that patients might regard their illness as a punishment by God. In the present study Mary regarded her illness as a punishment for having been unsympathetic and judgemental towards her brother, who also suffered from schizophrenia. She displayed guilt about her negative behaviour towards her brother and made a direct link between her behaviour, God and her illness. She said that God gave her the illness to teach her patience with her brother. This may be part of an attempt at making sense of the experience of the illness and finding a reason for it. In this way she may also have protected herself from a more adverse outcome by helping herself to cope with the illness. She also came across in the interviews as being very strict about adhering to her medication, almost as if she needed to be the obedient child (in contrast to her brother, who was a long term inpatient at a psychiatric hospital), to her parents, and perhaps God. She often referred to keeping a precise record of when she receives her injections and when the next injection was due. She also refused to take part in a further study at the Schizophrenia Research Unit where participants were taken off Fluanxol and given omega 3 tablets instead. She regarded the risk of suffering a further psychotic episode as too high. Of those participants whom I interviewed and who had already completed the first study, she was the only one who had refused to participate in the omega 3 study. According to her, she was also diagnosed with diabetes and rheumatoid arthritis. She attributed her illnesses to having “strayed away” from God. She was very emotional when she related this. This is an indication of the close connection she has made between her illness and its possible source, according to her, namely God. Group therapy has been used as a means to address anger towards God and mitigate feelings of guilt, such as Mary displayed about the illness (Kehoe as cited in Luckoff, 2012).

Support

In the present study six of the seven participants said that support was a contributing factor in their recovery. Some of the participants stressed the importance of it more than others.

Steven felt safe and secure, because his mother was not scared of him when he was actively psychotic and because of the kind way in which his girlfriend spoke to him during his psychotic episode, even though he could remember very little of what anybody else said to him during that time. Mary found the courage to face the illness through her husband who shared the responsibility of the illness by reminding her to take her medication on time and her parents who were always by her side. Conrad's girlfriend came to his home to clean and cook for him on weekends and thereby motivated him to get up in the mornings. Fred's work colleagues provided him with the encouragement, which he did not receive at home. Andrew's friend suggested he appreciate himself more by going out and spending a day at an amusement park with another friend. Talking to people at her church and the solace of her son carried Rachel through the challenges of the illness.

Davidson (2003) echoes what the participants discovered, that support is a crucial component of the recovery process for most patients. Davidson (2003) states that with the loss of agency that people who suffer of schizophrenia experience, comes a loss of identity. According to him, this leaves a "vacuum" (p. 164) and creates a vulnerability in the person, which puts them at the mercy of how others react to them. If others ignore or ostracise them or are afraid of them, this may leave them even more frightened than the illness has already made them and cause them to succumb to feelings of despair. To return from where this leaves the

person can be impossible for them to do on their own. Davidson (2003) indicates how the support of others can be the mechanism by which a person can escape from such despair. To extend the theme of support, Davidson (2003) also stresses the importance of true friendship for people suffering from schizophrenia. True friendship can allow the patient to feel like a person again, to feel part of society, and allows them the freedom to decide whether they would like to engage in typical and customary behaviours associated with friendship, as opposed to not having such choice at all. Davidson (2003) refers to a study of friendship he conducted in 1997 in which a group of reserved outpatients with serious mental illnesses, who had few friends, if at all, were invited to participate. He reports that most of the patients were keen to take part and, ultimately, they contributed enthusiastically from their side to develop the friendship that was presented to them.

In the present study the other side of taking responsibility for themselves or support was found to be feeling alone in the illness. Christine was the only participant who declared that she received no support. She acted very bravely and regarded it as “just another obstacle.” To Rachel the lack of support and the subsequent burden of responsibility she had to carry for herself since her son married, made her very emotional during the interviews. She clearly felt alone and fairly isolated.

The role of having to care for another

A closely linked theme to the previous one and one that emerged in the present study is how caring for another plays a role in recovery.

Davidson (2003) emphasises the importance for patients not only to receive care or attention, but also to give care or attention. He states that for the patient to be allowed to care for another made them realise that they were still capable of doing so even in the face of an illness.

In the present study Fred emphasised the reciprocal nature of having to care for another and having the other care for him. Conrad also pointed out how his girlfriend helped him and, in turn, he helped her.

The importance of the realisation of the ability to care for another lies in the fact that the person discovers that certain aspects of themselves, that they thought were lost through the illness, together with their identity, were still available to them and are of value to others (Davidson, 2003). This assists in restoring the identity of the person and their sense of agency in the world.

As in the case of Fred in the present study, Davidson (2003) found in his study of friendship in 1997 that participants who were part of the control group and not matched with a partner, were more likely to spend the amount of money they received as part of the study on others than on themselves, as they were instructed to do. Davidson (2003) comes to the conclusion that any form of giving by the participants to his study, and which requires a willing recipient, allows them to discover that there is more to them than their illness. Once this realisation dawns, recovery can begin, because it seems that the illness' influence in the

person's life is more contained and they can focus on the aspects of the self that have been neglected in the face of the onslaught of the psychosis and illness (Davidson, 2003).

Stigma

Stigma is seen as a barrier to recovery (Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001).

Mary: But, I still, um, don't tell my work doesn't know I'm schizophrenia, because I don't want to be discriminated or they know I have diabetes and rheumatoid, but I don't want them to think that I'm, I am not normal, that I can't do my job. So, I don't disclose that, that I'm schizophrenia.

The above quotation is from the transcript of the first interview with Mary. She evidently exhibits a fear of stigmatisation at her workplace. She made it clear that she was comfortable with her work colleagues knowing about the diabetes and the rheumatoid arthritis, but not with them knowing she had schizophrenia. She added that she feared them thinking that she could not “do my job”. A possible explanation for this could also be a judgement she perceives from God, which was discussed under the previous heading and which she might be projecting onto her work colleagues. Ultimately, however, this points to stigma in some form.

Scambler and Hopkins (1986) researched stigma as it relates to patients with epilepsy in Britain. They made a distinction between felt and enacted stigma. According to them, enacted stigma refers to the actual prejudice against persons who are different to the norm on

the basis that they are not acceptable or worthy because of such difference. This form of stigma is something that few of their participants could recall. Felt stigma, on the other hand, is “the fear of enacted stigma” (p. 33) as well as the feeling of indignity experienced by a person (Scambler & Hopkins, 1986). The research by Scambler and Hopkins (1986) suggests that felt stigma, in the case of epilepsy, frequently originates from the attitudes of the person’s family towards the illness. The stigma referred to by Mary in the quotation can be described as felt stigma. She had not yet experienced stigma by her work colleagues, because they were unaware of the fact that she suffered from schizophrenia. However, she displayed a fear of their behaviour and what they would think of her should they find out about the schizophrenia. Quite possibly she is also ashamed of suffering from schizophrenia, as Scambler and Hopkins (1986) suggest. In their study, Scambler and Hopkins (1986) also noticed a reluctance by their participants to disclose their illness at work. Those participants who had disclosed their epilepsy were the ones who were having frequent seizures. Scambler and Hopkins (1986) refer to the fact the participants to their study who did not disclose their epilepsy, lived with the risk of being discovered should they experience a seizure at work or be overheard talking about it or taking their medication, for instance. This is similar to Mary’s experience. She referred to the possibility of having a psychotic episode at work and being forced to reveal her illness in such circumstances. Scambler and Hopkins (1986) concluded that felt stigma caused more disruption than enacted stigma, since the bulk of participants chose not to disclose their illness status and as such they could not be exposed to enacted stigma.

An interesting phenomenon is that Mary regularly referred to herself throughout both interviews as “I’m schizophrenia”. This might refer to a manner of speaking about the illness in her community, as well as the fact that she perceives the illness as an integral part of her

identity; something that defines her. It may also be an indication of self-stigma and how she has come to conceptualise schizophrenia through familial and peer perceptions, her own experiences with her brother and her community's impressions of people with schizophrenia (Link et al., 2001). Mary's life might be seen as one of hiding herself. Sally French, a writer with disability, states very simply that "When people deny our impairments and disabilities, they deny who we really are" (French, 2004, p.84). French's quote offers a possible explanation for Mary's approach in dealing with schizophrenia. It is possible that she is no longer able to be herself, but has to be who others expect her to be. Davidson (2003), in a reference to stigma, adds to this when he states that "some people internalise their community's notions of serious mental illness, and withdraw into a 'mental patient' role and identity" (p. 46). This may also be true of how Mary deals with schizophrenia. The possibility exists that she made the notions that her community has of her illness, her own and is accordingly living up to such notions.

Steven had a very different perception of stigma. After his first psychotic episode, he spent a long time at home before he ventured out again. He admitted that during this time he feared what people might think of him. He explained that he was quite well-known in his community and subsequently many people knew of his illness. However, he said in the interviews that he was surprised that people "were still the same", nobody spoke of him behind his back, they still greeted him and they did not call him names. This may indicate that Steven perceived a small amount of felt stigma, but no enacted stigma. One can only speculate on the protective factors that contributed to him not perceiving enacted stigma. These may include that he seemed to have a good self-esteem, his positivity, the fact that he and his illness were known within his community and the fact that he had a good support base within his immediate family, but also within his circle of friends. Also, from the

interviews it was evident that he felt accepted in his community. He described his circle of friends as very protective of him and he said his mother was not fearful of him during his psychotic episode, which made him feel secure. He also described himself as someone who is respected by others in his community.

Once again, the description of the experience of stigma by two of the participants varies widely and is indicative of their uniqueness.

Elaborated and restricted codes

Steven was probably the most enthusiastic participant in the study. He exuded this enthusiasm from the first moment of the first interview and this was evident in his hurry to start the interview and in the fast speed of his speech. Together with this enthusiasm he had a way of including me. He related his experiences to me as if I were a part of his day-to-day milieu.

When viewing Steven's inclusive manner of speaking based on the restricted and elaborated codes described by Bernstein (1964), it would seem that Steven engages in a form of restricted linguistic code.

It is necessary, when relying on Bernstein's theory on linguistic codes, to acknowledge and elaborate somewhat on the controversy that surrounds the theory. Bernstein (1964) made certain links between linguistic codes and social structures, but did not necessarily regard the

codes as an indication of the speaker's intelligence or disadvantaged background. In time, Bernstein's theories came to be known as the verbal deficit view, although, more recently, Bolander and Watts (2009) point out that Bernstein did not refer to it in these terms himself or even associate himself with the view (Bolander & Watts, 2009). Bernstein's work on students' linguistic challenges, its possible link to social class and its association with the verbal deficit view was criticised by Labov (as cited in Bolander & Watts, 2009) in 1970. Labov even refuted Bernstein's theory. Bolander and Watts (2009) made considerable effort to counter the arguments formulated by Labov (as cited in Bolander & Watts, 2009) against Bernstein's theory. They came to the conclusion that these two theorists should not be regarded as polar opposites, since both argue for the dissimilarity between different linguistic forms without regarding one as superior to others. Ironically, it would seem that the use of language and the interpretation of it has been the cause of the misunderstanding of and amongst these two theorists.

When returning to the discussion of Steven's manner of speaking, it is necessary to explain that, according to Bernstein (1964), restricted linguistic codes refer to a limited range of options in terms of syntax in such speech. A limited vocabulary and preceding organisation are also often displayed in restricted codes (Bernstein, 1964). Restricted codes of the structural prediction type are representative of closed communities and the sharedness between parties to conversations in such communities. Much is taken for granted in this type of code.

The use of *we* by Steven as an indication of community, as is evident from the following extract, might also be an indication that he engages in such restricted code:

Steven: ...we always believe that to pray is the best way. You must, medicine helps too, but to pray has the most power. It carries power. That's what we believe.

As referred to earlier, Steven also spoke about people in his milieu as if I knew them. He only explained who they were when I asked him to do so. This is also an indication of the restrictedness of his speech. He assumed that I knew things and people in his milieu. At the time of our second interview he had just become engaged to his girlfriend. He was very excited about this fact. Because I was unaware of the customs in his religion, I was unaware of how they concluded marriages. As soon as he realised this, he elaborated on it in great detail so as to seize the opportunity to inform and educate me. If I had not explained to him that I did not understand, he might have possibly continued to describe his experiences without any explanation. The fact that he insisted on explaining their customs to me in detail, may be indicative of the very tight-knit community he forms part of and the restricted codes they engage in.

The role that the retention or rediscovery of participants' abilities played in recovery

“I have learned to *hurry slowly*” (Davidson, 2012, p. 23). Davidson (2012) emphasises the destructive effect that psychosis has on the sense of self of the person. Quoting Saks (2007), amongst others, he describes it as a feeling of being “tossed to and fro on the waves of this turbulent ocean of stimulation” (Davidson, 2012, p. 26). He points out that a person needs to

“reclaim...a sense of agency” (Davidson, 2012, p. 26). In order to do this, a person needs to feel secure enough and not at the mercy of forces outside of his or her control.

In the present study, for Steven his ability to work again came as a surprise. He admitted that, before he started work, he thought that he would give up at some point. Clearly the experience of psychosis left him with the inability to believe that he could persevere in his work. The rediscovery of his ability to work supported him in his recovery. In addition, the discovery by Steven that he retained his talent in sport, despite the illness, seemed to have formed part of his recovery. He was evidently excited whenever he spoke about playing rugby, although he quickly and repeatedly admitted that he could not play to the extent and as often as he did before. These limitations in his abilities did not seem to dampen his enthusiasm.

Another important theme that emerged in the present study, and which is closely linked to a restoration of one's belief in one's own abilities, was the ability to adapt to and accept one's circumstances. This theme emerged in several of the interviews, most notably those of Fred, Andrew and Steven. They all declared that they learned to be open to new experiences and that they needed to be able to adapt to what was required in such circumstances. These declarations predispose a sense of agency and belief in their own abilities as well as diminished feelings of anxiety about what the future holds. This points to a sense of recovery.

The importance in recovery of insight into the illness and knowing what to expect in future

During his interviews, Fred valued knowledge of the illness above all else. He equated knowledge about his illness to “power”. He also underscored the ability knowledge about his illness gave him to determine whether he needed to seek medical attention when experiencing certain symptoms. These aspects can be regarded as part of the topic of insight into one’s illness. From a clinical perspective, people who are challenged by schizophrenia often lack insight into their illness (Davidson, 2003). It would seem from Davidson’s account (2003), that from a clinical perspective insight into equates to knowledge about the illness. Davidson (2003) continues by saying that he does not agree with this clinical perspective. His experience of the participants in his research was that they were well aware of their illness and the effect it had on their lives. Galasiński and Opaliński (2012), in a study on how Polish psychiatrists conceptualise insight into schizophrenia, identified three aspects of such conceptualisation, namely that patients had knowledge of their illness, that they were able to understand their illness to such an extent that they were able to assess their own experiences and that they ultimately sought treatment because of the knowledge and understanding that they had. This conceptualisation of insight would seem to open it up to a wider definition, which includes not only knowledge, but also an awareness, as Davidson (2003) believes his participants had. Although Galasiński and Opaliński (2012) criticise the participating psychiatrists for emphasising the medical aspects of insight and, in the process, marginalising the experiential aspects, it can be said that knowledge of the illness is one of the core aspects of insight into the illness. This is clear from Fred’s emphasis on the knowledge aspect of insight. For him knowledge is the most crucial aspect and he made a point of gaining as much knowledge about his illness as he could.

Once again, however, it is necessary to stress the importance of taking the uniqueness of the person experiencing the illness into account when attributing value to having insight into the illness.

For some persons, like Fred, having knowledge of his illness is important, in fact, it is crucial to him. In such cases, having the knowledge can aid in the person's recovery, as Fred attested. It made him feel in control of the illness, which is a sense that is lacking when psychosis is experienced. Others, however, may choose not to gain such knowledge or only gain a limited amount of knowledge or insight for a variety of reasons, of which one could be that it may bring about additional anxiety, which may hamper their recovery. Another reason might be that the symptoms and conceptualisation of schizophrenia is not an easily understood topic and an attempt to understand it may create more confusion for the person than the illness has already brought on. And, persons may tend to shy away from such additional confusion, which leaves them feeling even less in control of the illness. One participant in the present study, who displayed such behaviour, is Conrad. Throughout the interviews he disclosed very little about his illness and mostly only answered when prompted to do so by closed-ended questions. An explanation for his behaviour could be that he wished to avoid an already confusing experience and that he found schizophrenia and psychosis complicated concepts to understand.

Insight into the illness can also be associated with acceptance of the illness. Acceptance has often been cited as one of the key dimensions of recovery (Davidson, 2003). In order to be open to insight into his or her own illness, the person has to be accepting of the fact that they have the illness. All the participants in the present study accepted their illness, albeit to

varying degrees. For a person to be labelled as denying their illness, they should have had their illness explained to them and rejected it completely (Davidson, 2003). However, as Davidson (2003) continues to explain, one should not be blinded by such denial, since the denial does not negate the experience that the person has internally of their illness. Such experience is still very much real and was borne in mind during the interviews in the present study.

Davidson (2003) brings a vital aspect of insight to the fore when he asserts that awareness of the illness does not necessarily imply that the person is prepared to divulge his or her illness status to others. This aspect of insight can be associated with stigma that the person may experience. As Davidson (2003) states further, it might also be because the person is aware that something is amiss, but is not sure whether they understand it.

Insight, it can be seen, can be a vital aspect of recovery. It is, however, possible that it can take a number of different forms, depending on the unique experience and approach of the person.

The function and value of narratives

Pederson (2013) suggests that if the researcher lets go of a pre-conceived interview structure, is open and flexible and sees him or herself and the participant as partners in the interview process, the interview can result in the mutual construction of a narrative by the participant and the researcher. By doing this, the researcher approaches the meeting rather as a conversation than an interview. This creates a space in which the unexpected and richer story

of the participant can come to the fore (Pederson, 2013). Steven's interview was such an example. I entered our second interview with a certain expectation of what was to happen. What followed, however, was not planned at all. Steven had just become engaged a few days before and he went on to explain to me in great detail how marriages worked in his faith. At first I was eager for him to finish his explanation so that I could get on with the interview. But, I soon realised that a thick description was developing in a very unexpected way and I relaxed into it. Only once I started analysing the transcribed interview, did I learn that the unintentional stumbling upon a haphazard narrative interviewing technique (with help by my participant) allowed for a richness of data, that I might have missed out on otherwise.

The way in which participants view the story of themselves may be linked to the hope they have for the future and their perception of their own abilities (Geekie et al., 2012). This supports the contention that narratives contribute to and may be seen as a unique and vital aspect of recovery. However, Geekie et al. (2012) warn that the absence of hope and a disbelief in one's own abilities should not be construed as an indication of a lack of narrative. Conrad's narrative is such an example. In his narrative he often referred to having little hope and aspiration for the future, yet he still told me a great deal about his life. What he did tell me enabled me to gain a better insight to his specific circumstances and the challenges that he faced and how he managed, in his way, to address them.

Christine's narrative was one where there is seemingly no support and she is reliant only upon herself. Geekie et al. (2012) describe "a disconnected narrative" (p. 11), which is a narrative in which the person's experience is that of a self under threat; a self that no longer feels like a self. According to Geekie et al. (2012) this may be a means of protecting the self.

The recently developed therapeutic treatment model of Metacognitive Narrative Psychotherapy by Bargenquast and Schweitzer (2012) in Australia bears further testimony to the fact that narratives must be given prominence and that the (re)construction of the stories by the person facing schizophrenia themselves serves as an invaluable tool in the process of recovery.

Geekie et al. (2012) emphasise that, however the story seems, the telling of the story provides the narrator with a sense of agency and “with the opportunity to renegotiate the meaning, sequence and connection between past and present life events and accept[ing] themselves and their personal histories” (p. 9). This once again confirms the recovery value of narratives. Further to this, I reiterate what was mentioned in chapter three:

Strauss (2011) states that some persons with schizophrenia who improve regard feeling cared for and taken seriously as the most important influences in their improvement. By its very nature, conducting qualitative research which focuses on attempting to understand how a participant might be feeling about an aspect of their illness, has the potential to allow for the participant to be heard, feel cared for and taken seriously and, thus, could have a important positive influence on the participant’s recovery.

The second last question in the second interview of the present study addressed how the person felt after the interviews were concluded. My initial intentions with the question was, firstly, to provide the participants with an opportunity to find closure after having made

Andrew's answer to the last question added to this:

ADW: O, um, if there's something you would still like to say to me or share?

Andrew: Thank you. Just want to thank you.

Consistent with her matter-of-fact manner, Christine contributed the following touching comment:

Christine: It was a nice, getting, you know, some things off my chest, talk about things, well, ja.

Conrad phoned one of the nurses at the schizophrenia unit the night before our last interview and said that he would not be able to attend the following day, because of commitments at work. However the following day Conrad did attend and we had our last interview. Bearing this in mind and although Conrad answered "No" to the question, right at the end of the interview he said:

Conrad: Yes, yes, now I am also glad I could make it in the end today.

Given his very restricted narrative throughout both interviews, I accepted this to be quite a profound statement.

The importance Fred attached to knowledge once again came out in his answer to the question:

Fred: I feel a little bit better and I feel closure in a sense, because it give me knowledge about myself as well. And, I can identify some points where I can then try and improve. Ja.

Mary, much like Andrew, articulated the insight she gained:

Mary: Um, it's given me a understanding and questions and the questions made me think more a bit, I never thought of these things and it made me think more about it. I just took, I never realised that I was, I don't

know, how can I say, um, I just saw that I was different than my brother, but I now that has over the time, I'm open with him, because I understand him more because of what happened to me. And, I wouldn't have realised that, I just, just assumed I was different with them, but I didn't, couldn't put a finger, why and now it's have clarity to be what. And, realising I am close with my parents, which I didn't think, uh, from that time, thinking from that time I wasn't close with them and now I'm close with them. So, it has opened my eyes to things that was just, we were just living normally.

Rachel expressed her relief at having been heard:

Rachel: I feel good, because, how can I say, I could never speak to someone so openly like I spoke now. It feels like a relief to speak about it.

Steven, unlike his elaborate manner throughout the interview, provided a very short answer to the question:

Steven: No, I am alright. I feel good...

However, his answer to my final question explained it in more detail:

ADW: ...And then, is there something else that you would like to ask or say or so?

Steven: Um, not actually, but it was nice to talk about it, to talk it through. And, I feel better when I talk about it than to keep it. Like I have kept it, but I haven't spoken about it. I talk about it now and then, but not like I did now, getting it all out and what my plans are going to be. Nobody has ever asked me what my plan is for the future. Like that was something that was really nice for me. [Laughs]

Limitations of the study

The study was conducted with only a very small number of participants, which is consistent with the IPA method of analysis, at one specific research unit and at a particular point in time. Thus, generalisation of the findings is out of the question. It is also not possible to examine changes in how recovery is understood by the participants over time (Windell et al, 2012). Furthermore, it might also be that the experiences of these participants do not represent the greater population of persons recovering from a first psychotic episode in schizophrenia. Fortunately, these were never the purposes of this study. The purpose was rather to explore the individual experiences of participants to understand these better and add to the already existing body of studies conducted in the field. And, this was achieved.

Another limitation of the present study is the way in which I formulated some of my questions. It caused the participants to misinterpret what I meant. In particular, when I asked what did not help them. Almost all of them felt the need to voice their gratitude towards the doctors and nurses at the research unit. I had the sense that they were fearful that I would come to the conclusion that they thought the study at the research unit was not helpful.

A fair criticism of the present study may be that the participants were all, to a greater or lesser degree, doing well in recovery from their first psychotic episode. In this respect the study is not inclusive in that it does not represent a broader spectrum of both positive outcomes and outcomes that are less so. This limits the generalisability of the study results. However, what can be gained from this focus on the experiences of so-called successful mental health consumers, is to identify and examine those dimensions of recovery that aided these

participants and to use them to help those who are struggling or do not have access to such strategies to recover.

Recommendations

An important question that requires consideration in the field of recovery in schizophrenia, is whether recovery criteria should be set at all? Symptomatic remission is a far less complex concept to reduce to criteria than recovery. Symptomatic remission requires a knowledge of the symptoms that lead to the person's diagnosis in the first place and whether these symptoms have, since then, subsided or remitted completely. It is a matter of checking the boxes and coming to a conclusion: yes or no. Recovery is never as simple as remission. It is not possible to simply check boxes and come to a conclusion. Symptomatic remission is merely one aspect of recovery. Recovery consists of several aspects or dimensions and the presence of these aspects or dimensions varies from person to person. This is indicative of the uniqueness of the experience of recovery.

The present study has indeed succeeded in confirming that each participant's experience of their recovery is unique. No two participants chose to highlight the same aspects of their recovery in the interviews and not all aspects of recovery found in the literature were necessarily experienced by the participants. This does not imply that the participants are not in recovery or have not successfully managed to cope with their illness. It only serves to emphasise their uniqueness and the resultant uniqueness of their experiences.

It is recommended that future studies be conducted to focus on the question of whether the setting of recovery criteria will indeed be helpful in assisting persons recovering from schizophrenia. A consideration in this regard could be to identify and elaborate on dimensions or aspects of recovery, as has already been done in the literature, and use this body of knowledge to assist other persons to merely understand their recovery more fully. However, caution must be exercised to never attempt to fit a specific person's experiences into only the existing dimensions. The possibility of new, unexplored and previously unidentified aspects or dimensions must always be left open.

The participants in this study all spoke Afrikaans or English as their home language, since that was one of the criteria set initially. While this criterion did limit the number of participants that were eligible to take part in the study, its purpose was to enable me to conduct the interviews myself and to hopefully be aware of more subtle nuances in their use of language. I believe this important goal was achieved. In future, a study could be conducted that includes participants who have home languages other than English or Afrikaans. This would broaden the scope of such a study and make the results more generalisable.

Conclusion

Recovery is a dynamic, evolving and unique process within the life of each person faced with its challenges. Recovery is not an end in itself. It is not an achievement. Rather, it is a way of living and a constant choice that persons in pursuit of it have to make.

Studying recovery requires one to break down barriers, inside and outside of yourself. It also requires an engagement with real-life issues with less distance from the subject matter than in other approaches to schizophrenia. The present study was conducted in this spirit.

The participants in the present study each found their particular way of living, which creates the space and opportunity for them to be who they are, completely. The particular challenges that they face every day are huge and disruptive, but at the same time challenges, in all their forms and guises, are universal to all human beings. And, the universalness of challenges is part of the wisdom gained from this study. The result of such a realisation, is that it is never a matter of us and them. It is necessary for us to acknowledge, embrace and celebrate it.

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Appendix A

Interview schedule – English

Participant: _____

Date of interview: _____

Length of interview: _____

Introduction

Good day, thank you for participating in this interview. My name is Anneliese de Wet. I am busy studying for a master's degree in psychology at Stellenbosch University. As part of this, I have to do research and write down what I find in a thesis. The information that I will collect from you in this interview as well as the second interview will be used as part of my research. I will need your consent to do this. I will explain this to you in more detail shortly. My research focuses on how persons experience how they recover from a first-psychotic episode. Since you are or have been part of a research project by the Schizophrenia Research Unit here at Stikland Hospital, Dr Bonga Chiliza identified you as a possible candidate for me to conduct these interviews with. Once I have gathered the information from you and the other participants, I will try to work out how your experiences fit together with what Dr Chiliza and the other researchers found in their project.

I would like to record the interviews with your permission, to write down every word from the recordings and then try to understand what you and the other participants have said. I will then write about it in my thesis.

Do you understand what I have said so far?

[Allow the participant time to answer; if yes, move on to the next question; if no, ask:

What it is that you do not understand?

and answer all the participant's questions in an unhurried way until the participant is able to answer yes, when asked again.]

Before I ask you to consent to this interview and the second one, it is important that you understand that you are free to choose to take part in this research or not. And also, once you have chosen to take part, you are also free to choose to not take part anymore at any time before, during or after the interviews. Any information that I would have already received from you then will not be used in the research.

Also, I will not share any part of what you have told me with anyone but my lecturer, those persons who will evaluate my thesis, the researchers at the Schizophrenia Research Unit at Stikland Hospital and through publication in professional journals. I will not reveal your name to anyone except my supervisor.

If you feel uncomfortable at any stage during or directly after the interviews, you are welcome to tell me and I will ensure that a professional person is available to talk to you about what is bothering you. I also need to inform you that you will not receive any money or anything, except R100.00 for travel expenses, for participating in this research project.

Do you understand this?

[Allow the participant time to answer; if yes, move on to the next question; if no, ask:

What it is that you do not understand?

and answer all the participant's questions in an unhurried way until the participant is able to answer yes, when asked again.]

Do you consent to all these things that I have explained to you?

[Allow the participant time to answer; if yes, move on to the next question; if no, say:

Thank you for your time and I wish you all the best in the future.]

Could you please sign both copies of this consent form?

[Allow the participant time to answer; If yes, hand the consent forms to the participant for signature. Allow the participant time to read the consent form and sign them, or ask questions. Answer these questions and ask the participant again:

Would you like to sign the consent forms now?

[If the participant answers no at any stage, say:

Thank you for your time and I wish you all the best in the future.]

[Once the consent forms have been signed and one copy handed back to me]

If you wish, I can also report back to you on the results of my research. Would you like me to do that?

[Make a note of the participant's answer on the consent form]

The interview should take about an hour to an hour and a half. Will this be in order?

[Bear in mind that this might have been communicated to the participant already upon making the appointment; Allow the participant time to answer; if yes, move on to the next question; if no, ask:

How much time do you have available?

and then decide whether it would make sense to continue with the interview or reschedule it.]

Of course, once again, you are free to end the interview at any time, should you not wish to continue with it.

Are you ready to start the interview?

[Allow the participant time to answer; if yes, start the interview; if no, ask:

What it is that is bothering you?

and answer all the participant's questions in an unhurried way until the participant is able to answer yes, when asked again or, if the answer is finally no, say:

Thank you for your time and I wish you all the best in the future.]

Questions

1. I was wondering whether you could tell me a bit about when you first noticed that you were not feeling yourself/feeling ill?

That is interesting / understandable, could you tell me a bit more about that?

2. Can you remember how you felt about it?
3. What happened in your life just before you noticed that you were not feeling yourself/feeling ill?

That is interesting / understandable, could you tell me a bit more about that?

4. How did the nurses or doctors explain what was happening to you?
5. Do you or did you use other treatments, than those you received in hospital or as part of the research project by the Schizophrenia Research Unit?

(Possible examples are faith-based treatments, exercise, indigenous treatments, herbs or teas)

6. Could you describe to me how the treatment works or worked?
7. How does or did it make a difference to you and how you are or were feeling?
8. Do you feel different now after being treated in hospital or as part of the research project?
9. Could you describe how this feels?
10. How would you describe where you are now, after having not felt yourself/felt ill, but having received treatment?

[Use term/s that the participant proposes further in the interview.]

11. I would like to understand why you describe it like that, could you explain this to me?
12. Do you feel the same way you did before all this started?

[If yes, just say:

Ok

and move on to the next question]

[If no, ask:

How do you feel different?]

That is interesting / understandable, could you tell me a bit more about that?

13. How do you understand where you are and what is happening to you now?
14. What does it mean to you to be where you are now?
15. How does it feel?
16. What do you think about it?

17. What does recovery mean to you?
18. Why do you think that things are happening the way they are now?
19. What or who helps you to handle your situation at the moment?
20. How does/do help you?
21. What or who helps you the most?

[If it is a person, ask:

22. Would you allow me to speak to them, as part of a possible future project, on how they experience their influence on you in this process?
23. What or who has not helped you in this process?
24. How does/do not help you?
25. Could you perhaps tell me what you do to help yourself?
26. Could you give me an example of that?
27. What do you think you have learned about yourself that makes you stronger?

That is interesting / understandable, could you tell me a bit more about that?

28. How has this experience impacted your work?
29. And, you family/partner/children?
30. And, your social life?
31. Who do you enjoy spending time with at the moment?
32. Is that different than before?
33. Why do you think that is?
34. What have you learned from this experience that will help you in future?
35. What do you hope for in the future?
36. As a second last question: How do you feel right now?

Conclusion

I think this concludes this interview.

37. Is there anything that you would still like to say, share or ask me?

[If the answer is yes, say:

Please do.]

[If the answer is no, move on to the following paragraph.]

By sharing your experiences and feelings, you have made it possible for me to have a better understanding of how what has happened in your life, has had an impact on your life.

Thank you very much for your time and for taking part in these interviews and my research project. I hope that it has also been a good experience for you.

*Arrange a date for a next appointment:

Appendix B

Interview schedule – Afrikaans

Deelnemer: _____

Datum van onderhoud: _____

Lengte van onderhoud: _____

Introduction

Goeie dag, dankie dat u bereid is om aan hierdie onderhoud deel te neem. My naam is Anneliese de Wet. Ek is tans besig met my meestersgraad in sielkunde aan die Universiteit van Stellenbosch. Om die graad te behaal, moet ek navorsing doen en 'n tesis skryf oor wat ek uitvind. Die inligting wat ek van u in hierdie onderhoud en die volgende een sal kry, sal deel vorm van my navorsing. Hiervoor sal ek net-nou u toestemming vra. Ek sal dit als binnekort mooi aan u verduidelik. My navorsing fokus op mense se ervaring van hoe hulle herstel na 'n eerste psigotiese episode. Aangesien u deel is of deel was van die navorsingsprojek deur die Skisofrenie Navorsingseenheid by Stikland Hospitaal, het Dr Bonga Chiliza u geïdentifiseer as 'n moontlike kandidaat met wie ek hierdie onderhoud kan voer. Nadat ek klaar is met die onderhoude met u en die ander deelnemers, sal ek probeer uitwerk hoe dit wat julle ervaar of ervaar het inpas by wat Dr Chiliza en die ander navorsers gevind het in hulle projek.

Ek sal graag die onderhoude met u toestemming wil opneem. Daarna wil ek graag na die opnames luister en elke woord uittik en mooi probeer verstaan wat u en die ander deelnemers vir my vertel het. Ek sal dan daarvoor in my tesis skryf.

Verstaan u wat ek sover verduidelik het?

[Allow the participant time to answer; if yes, move on to the next question; if no, ask:

Wat is dit wat u nie verstaan nie?

and answer all the participant's questions in an unhurried way until the participant is able to answer yes, when asked again.]

Voor ek u vra om toestemming te gee vir hierdie onderhoud en die tweede een, is dit belangrik dat u verstaan dat u vry is om te kies of u aan hierdie navorsing wil deelneem of nie. En, indien u besluit om wel deel te neem, is u steeds vry om te kies om nie meer deel te neem aan hierdie navorsing en te onttrek op enige stadium voor, tydens of na die onderhoude. Enige inligting wat ek op daardie stadium reeds van u verkry het sal nie in die navorsing gebruik word nie.

Ek sal ook nie enige iets, wat u tydens die onderhoude met my gedeel het, bekendmaak aan enige ander persone, behalwe my studieleier, die persone wat my tesis evalueer, die persone by die Skisofrenie Navorsingseenheid by Stikland Hospitaal en deur publikasie in professionele joernale nie. Ek sal nie u naam aan enige ander persoon behalwe my studieleier bekendmaak nie.

Indien u enigsins ongemak ervaar op enige stadium gedurende of direk na die onderhoude, is u welkom om my daarvan te sê en ek sal seker maak dat 'n professionele persoon beskikbaar is om met u te praat oor dit wat u pla. Ek moet u ook inlig dat ek geen vergoeding of enige

iets anders, behalwe R100.00 vir vervoregeld, aan u sal gee vir u deelname aan hierdie navorsingsprojek nie.

Verstaan u dit?

[Allow the participant time to answer; if yes, move on to the next question; if no, ask:

Wat is dit wat u nie verstaan nie?

and answer all the participant's questions in an unhurried way until the participant is able to answer yes, when asked again.]

Stem u toe tot al hierdie dinge wat ek nou aan u verduidelik het?

[Allow the participant time to answer; if yes, move on to the next question; if no, say:

Dankie vir u tyd en ek wens u alles van die beste in die toekoms.]

Kan u asseblief albei afskrifte van die toestemmingsvorm teken?

[Allow the participant time to answer; if yes, hand the consent forms to the participant for signature. Allow the participant time to read the consent form and sign it, or ask questions. Answer these questions and ask the participant again:

Is u nou tevrede om die vorms te teken?

[If the participant answers no at any stage, say:

Dankie vir u tyd en ek wens u alles van die beste in die toekoms.]

[Once the consent forms have been signed and one copy handed back to me]

Indien u dit verkies, kan ek aan u terugrapporteer met die resultate van my navorsing. Wil u graag hê dat ek dit doen?

[Make a note of the participant's answer on the consent form]

Die onderhoud behoort ongeveer 'n uur na 'n uur en 'n half te duur. Sal dit in orde wees?

[Bear in mind that this might have been communicated to the participant already upon making the appointment; Allow the participant time to answer; if yes, move on to the next question; if no, ask:

Hoeveel tyd het u beskikbaar?

and decide whether it would make sense to continue with the interview or reschedule it.]

Natuurlik is u, weereens, vry om my op enige stadium te laat weet dat u besluit het om nie meer voort te gaan met die onderhoud nie.

Is u gereed om met die onderhoud te begin?

[Allow the participant time to answer; if yes, start the interview; if no, ask:

Wat is dit wat u pla?

and answer all the participant's questions in an unhurried way until the participant is able to answer yes, when asked again or, if the answer is finally no, say:

Dankie vir u tyd en ek wens u alles van die beste in die toekoms.]

Questions

1. Ek wonder of u my 'n bietjie kan vertel van toe u die eerste maal agtergekom het dat u anders as normaalweg of siek voel?

Dit is interessant / verstaanbaar, kan u my 'n bietjie meer daarvan vertel?

2. Kan u onthou hoe u daarvoor gevoel het?
3. Wat het in u lewe gebeur net voor u die eerste maal agtergekom het dat u anders as normaalweg of siek voel?

Dit is interessant / verstaanbaar, kan u my 'n bietjie meer daarvan vertel?

4. Hoe het die susters of dokters aan u verduidelik wat met u aan die gebeur is?
5. Het u enige behandeling, anders as dit wat u in die hospitaal of as deel van die navorsingsprojek deur die Skisofrenie Navorsingseenheid, gebruik?

(Moontlike voorbeelde is geloofsgebaseerde-behandelings, oefening, inheemse handelings, kruie of tee)

6. Kan u vir my beskryf hoe die behandeling werk of gewerk het?
7. Hoe het of maak dit 'n verskil aan u en aan hoe u voel of gevoel het?
8. Voel u anders nou nadat u behandeling in die hospitaal of as deel van die navorsingprojek ontvang het?
9. Kan u dalk beskryf hoe dit voel?
10. Watter woord of woorde sou u gebruik om te beskryf waar u uself nou bevind, na u anders as normaalweg of siek gevoel het, maar behandeling ontvang het?

[Gebruik dié begrippe wat die deelnemer voorstel voortaan in die onderhoud.]

11. Ek sal graag wil verstaan hoekom u dit só beskryf, kan u dit dalk aan my verduidelik?
12. Voel u dieselfde as wat u gevoel het voor dit als begin het?

[If yes, just say:

Ok

and move on to the next question]

[If no, ask:

Hoe voel u anders?]

Dit is interessant / verstaanbaar, kan u my 'n bietjie meer daarvan vertel?

13. Hoe verstaan u waar u nou is en wat nou met u gebeur?
14. Wat beteken dit vir u om te wees waar u nou is?
15. Hoe voel dit?
16. Wat dink u daaromtrent?
17. Wat beteken herstel vir u?
18. Hoekom dink u gebeur die dinge op die manier wat hulle nou gebeur?
19. Wie of wat help u op die oomblik om u situasie te hanteer?
20. Hoe help hy/sy/dit u?
21. Wie of wat help u die meeste?

[If it is a person, ask:

22. Sal u toelaat dat ek met praat, as deel van 'n moontlike toekomstige projek, oor hoe die persoon sy of haar invloed op u in hierdie proses ervaar?]
23. Wie of wat het u nie in hierdie proses gehelp nie?
24. Hoe hethy/sy/dit u nie gehelp nie?
25. Kan u my dalk vertel wat u doen om uself help?
26. Kan u vir my 'n voorbeeld hiervan gee?
27. Wat dink u het u omtrent uself geleer wat u sterker maak?

Dit is interessant / verstaanbaar, kan u my 'n bietjie meer daarvan vertel?

28. Hoe het hierdie ervaring 'n impak op u werk gehad?
29. En, op u familie/man of vrou/kinders?

30. En, u sosiale lewe?
31. Met wie spandeer u deesdae graag tyd?
32. Is dit anders as wat dit voorheen was?
33. Hoekom dink u is dit so?
34. Wat het u geleer deur hierdie ervaring wat u in die toekoms kan help?
35. Wat hoop u vir die toekoms?
36. En, 'n tweede laaste vraag: hoe voel u nou?

Conclusion

Ek dink ons het aan die einde van hierdie onderhoud gekom.

37. Is daar dalk enige iets wat u nog wil sê, vra of deel?

[If the answer is yes, say:

Gaan gerus voort.]

[If the answer is no, move on to the following paragraph.]

Die feit dat u u ervarings en gedagtes met my gedeel het, het dit vir my moontlik gemaak om 'n beter begrip te hê van hoe dit, wat met u gebeur het, 'n impak op u lewe het.

Baie dankie vir u tyd en deename aan hierdie onderhoude en die navorsing. Ek hoop dat dit ook vir u 'n goeie ervaring was.

***Reël 'n datum vir 'n volgende afspraak:**

Appendix C

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT:

The lived experience of recovery from first-episode psychosis and its relationship with symptomatic remission in schizophrenia.

REFERENCE NUMBER: N06/08/148

PRINCIPAL INVESTIGATOR: Anneliese de Wet

ADDRESS: 59 Rhodes Avenue, Stellenbosch, 7600.

CONTACT NUMBER: 083 564 3471

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

The aim of this study is to understand more about people's own experience of the process of recovering from schizophrenia. The study will be conducted at Stikland Hospital and approximately ten to twelve participants will be recruited.

I will conduct two interviews with each participant. During the interviews you, as participant will be asked to explain how you experience different aspects of your recovery from schizophrenia.

Why have you been invited to participate?

You have been invited to participate, because you were part or are currently still part of the research project by the Schizophrenia Research Unit under Professor Robin Emsley and because this project is a sub-project of it.

What will your responsibilities be?

As participant you are requested to share as openly and freely, as you possibly can, your experiences according to the questions that I will ask.

Will you benefit from taking part in this research?

As participant you stand to benefit a clearer understanding of your own experiences.

Are there in risks involved in your taking part in this research?

It is possible that you might experience feelings of discomfort when talking about your experience of recovering from schizophrenia. However, I will ensure that a professional person is available to talk to you about these feelings, should you wish to do so.

If you do not agree to take part, what alternatives do you have?

If you do not agree to take part it will have no influence on the treatment that you receive in the other research projects which you are part of and which are conducted by the Schizophrenia Research Unit.

Who will have access to your medical records?

I do not need any access to your medical records to conduct this research.

Will you be paid to take part in this study and are there any costs involved?

No, you will not be paid to take part in the study but your transport costs will be covered for each study visit. There will be no costs involved for you, if you do take part.

Is there anything else that you should know or do?

You should inform your family practitioner or usual doctor that you are taking part in a research study.

You should also inform your medical insurance company that you are participating in a research study.

You can contact Professor Leslie Swartz at telephone number 021 – 808-3461 if you have any further queries or encounter any problems.

You can contact the Health Research Ethics Committee at 021 – 938-9207 if you have any concerns or complaints that have not been adequately addressed by the researcher.

You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I, _____, agree to take part in a research study entitled, The lived experience of recovery from first-episode psychosis and its relationship with symptomatic remission in schizophrenia.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at _____ on _____ 2012.

Signature of participant

Signature of witness

Declaration by investigator

I, Anneliese de Wet, declare that:

- I explained the information in this document to _____.
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter.

Signed at _____ on _____ 2012.

Signature of investigator

Signature of witness

Appendix D

DEELNEMERINLIGTINGSBLAD EN –TOESTEMMINGSVORM

TITEL VAN DIE NAVORSINGSPROJEK:

Die geleefde ervaring van die herstel van 'n eerste psigotiese episode en die verhouding daarvan met simptomevermindering in skisofrenie.

VERWYSINGSNOMMER: N06/08/148

HOOFNAVORSER: Anneliese de Wet

ADRES: Rhodeslaan 59, Stellenbosch, 7600.

KONTAKNOMMER: 083 564 3471

U word genooi om deel te neem aan 'n navorsingsprojek. Lees asseblief hierdie inligtingsblad op u tyd deur aangesien die besonderhede van die navorsingsprojek daarin verduidelik word. Indien daar enige deel van die navorsingsprojek is wat u nie ten volle verstaan nie, is u welkom om die navorsingspersoneel of dokter daarvoor uit te vra. Dit is baie belangrik dat u ten volle moet verstaan wat die navorsingsprojek behels en hoe u daarby betrokke kan wees. U deelname is ook **volkome vrywillig** en dit staan u vry om deelname te weier. U sal op geen wyse hoegenaamd negatief beïnvloed word indien u sou weier om deel te neem nie. U mag ook te eniger tyd aan die navorsingsprojek onttrek, selfs al het u ingestem om deel te neem.

Hierdie navorsingsprojek is deur die **Gesondheidsnavorsingsetiekkomitee (GNEK) van die Universiteit Stellenbosch** goedgekeur en sal uitgevoer word volgens die etiese riglyne en beginsels van die Internasionale Verklaring van Helsinki en die Etiese Riglyne vir Navorsing van die Mediese Navorsingsraad (MNR).

Wat behels hierdie navorsingsprojek?

Die doel van hierdie studie is om meer te verstaan van mense se eie ervaring van die herstelproses van skisofrenie. Die studie sal by Stikland Hospitaal uitgevoer word en ongeveer tien na twaalf deelnemers sal gewerf word. Ek sal twee onderhoude met elke deelnemer voer. Tydens die onderhoude sal u as deelnemer gevra word om te beskryf hoe u verskillende aspekte van u herstel van skisofrenie ervaar.

Waarom is u genooi om deel te neem?

U is genooi om aan hierdie studie deel te neem aangesien u deel is of deel was van die navorsingsprojek deur die Skisofrenie Navorsingseenheid onder leiding van professor Robin Emsley and omdat hierdie 'n subprojek daarvan is.

Wat sal u verantwoordelikhede wees?

As deelnemer word u versoek om so openlik en vrylik, as wat u kan, u ervaringe met my te deel na aanleiding van die vrae wat ek sal vra.

Sal u voordeel trek deur deel te neem aan hierdie navorsingsprojek?

As deelnemer mag u 'n duideliker en helderder begrip van u eie ervaringe beleef.

Is daar enige risiko's verbonde aan u deelname aan hierdie navorsingsprojek?

Die moontlikheid bestaan dat u ongemak mag ervaar terwyl u u ervaring van u herstel van skisofrenie met my deel. Ek sal egter sekermaak dat daar 'n professionele persoon beskikbaar is om met u oor hierdie gevoelens te praat, indien u sou wou.

Watter alternatiewe is daar indien u nie instem om deel te neem nie?

Indien u besluit om nie aan die studie deel te neem nie, sal dit geen invloed hê op die behandeling wat u in die ander navorsingsprojekte, waarvan u deel is en wat deur die Skisofrenie Navorsingseenheid uitgevoer word, ontvang nie.

Wie sal toegang hê tot u mediese rekords?

Ek het nie toegang tot u mediese rekords vir doeleindes van hierdie studie nodig nie.

Sal u betaal word vir deelname aan die navorsingsprojek en is daar enige koste verbonde aan deelname?

Nee, u sal nie betaal word vir deelname aan die navorsingsprojek nie, maar u vervoer ten opsigte van elke besoek vir die navorsingsprojek sal betaal word. Deelname aan die navorsingsprojek sal u niks kos nie.

Is daar enigiets anders wat u moet weet of doen?

U moet u huisarts of gereelde algemene praktisyn in kennis stel van u deelname aan die navorsingsprojek.

U moet ook u mediese fonds in kennis stel van u deelname aan die navorsingsprojek.

U kan professor Leslie Swartz kontak by telefoonnommer 021 – 808-3461 indien u enige verdere vrae het of enige probleme ondervind.

U kan die Gesondheidsnavorsingsetiek-administrasie kontak by 021 – 938-9207 indien u enige bekommernis of klagte het wat nie bevredigend deur die navorser hanteer is nie.

U sal 'n afskrif van hierdie inligtings- en toestemmingsvorm ontvang vir u eie rekords.

Verklaring deur deelnemer

Met die ondertekening van hierdie dokument onderneem ek, _____, om deel te neem aan 'n navorsingsprojek getiteld, Die geleefde ervaring van die herstel van 'n eerste psigotiese episode en die verhouding daarvan met simptomevermindering in skisofrenie.

Ek verklaar dat:

- Ek hierdie inligtings- en toestemmingsvorm gelees het of aan my laat voorlees het en dat dit in 'n taal geskryf is waarin ek vaardig en gemaklik mee is.
- Ek geleentheid gehad het om vrae te stel en dat al my vrae bevredigend beantwoord is.
- Ek verstaan dat deelname aan hierdie navorsingsprojek **vrywillig** is en dat daar geen druk op my geplaas is om deel te neem nie.
- Ek te eniger tyd aan die navorsingsprojek mag onttrek en dat ek nie op enige wyse daardeur benadeel sal word nie.
- Ek gevra mag word om van die navorsingsprojek te onttrek voordat dit afgehandel is indien die studiedokter of navorser van oordeel is dat dit in my beste belang is, of indien ek nie die ooreengekome navorsingsplan volg nie.

Geteken te _____ op _____ 2012.

Handtekening van deelnemer

Handtekening van getuie

Verklaring deur navorsers

Ek, Anneliese de Wet, verklaar dat:

- Ek die inligting in hierdie dokument verduidelik het aan _____.
- Ek hom/haar aangemoedig het om vrae te vra en voldoende tyd gebruik het om dit te beantwoord.
- Ek tevrede is dat hy/sy al die aspekte van die navorsingsprojek soos hierbo bespreek, voldoende verstaan.
- Ek nie 'n tolk gebruik het nie.

Geteken te _____ op _____ 2012.

Handtekening van navorsers

Handtekening van getuie

Appendix E



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY
Jou kennisvenoot • your knowledge partner.

17 April 2012

MAILED

Prof RA Emsley
Department of Psychiatry
2nd Floor, Clinical Building
Faculty of Health Sciences
7500

Dear Prof Emsley

"A prospective study of clinical, biological and functional aspects of outcome in first-episode psychosis South Africa"

ETHICS REFERENCE NO: N06/08/148

RE : THE LIVED EXPERIENCE OF RECOVERY FROM FIRST-EPISODE PSYCHOSIS AND ITS RELATIONSHIP WITH SYMPTOMATIC REMISSION IN SCHIZOPHRENIA

Your letter dated 28 March 2012 refers.

The Chairperson of the Health Research Ethics Committee approved the amended documentation in accordance with the authority given to him by the Committee.

The following sub study was approved:
'The lived experience of recovery from first-episode psychosis and its relationship with symptomatic remission in schizophrenia.'

Yours faithfully

MRS MERTRUDE DAVIDS
RESEARCH DEVELOPMENT AND SUPPORT
Tel: 021 938 9207 / E-mail: mertrude@sun.ac.za
Fax: 021 931 3352

17 April 2012 11:56

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