

2014

Learning from the experts: Qualitative study of the lived experience of mental illness

Zdenka Bartova
Edith Cowan University

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Learning from the Experts: Qualitative Study of the Lived Experience of Mental Illness

By

Zdenka Bartova, B. A. (Hons)

A thesis submitted in fulfilment of the requirements for the award of the degree

Doctor of Philosophy

School of Psychology and Social Science

Faculty of Health, Engineering and Science

Edith Cowan University

October 2014

Abstract

Severe mental illness has a profound effect on the affected individuals yet it does not necessarily prevent them from leading a meaningful and fulfilling life, and therefore recovering. Recovery has received a great interest in clinical and consumer research yet little is known about how those individuals who do not primarily identify with recovery respond to the concept and come to accept it as something that is personally meaningful. Using a qualitative approach following the principles of Gadamer's (1975) hermeneutics, the present study explored people's subjective experience of mental illness with the aim of identifying factors related to their views of mental illness, their adaptation, coping and recovery, and the subjective meanings they gave to the phenomenon.

In Phase I, 25 adults diagnosed with mental illness participated in unstructured, confidential interviews at the end of which they completed the Recovery Assessment Scale-Revised (RAS-R) (Corrigan et al., 1999). The study identified six main themes related to person-centred and social/relational factors that played a role in the persons' life with mental illness: (a) mental illness as a journey, (b) personal conceptualisations of mental illness, (c) illness management and coping, (d) losses and gains, (e) professional help, and (f) the role of others.

Phase II was completed by 18 participants from the original sample who were provided with feedback on their respective RAS-R (Corrigan et al., 1999) results and who in turn provided their feedback on the scale and their experience of completing it; this was followed by a discussion of recovery. The participant narratives suggested that recovery was conceptualised in two broad ways: as a return to baseline following crisis and as living as best as one can given personal circumstances. The findings further indicated that recovery as a concept had the potential to remain abstract and lack in meaning unless the person's biases and perceptions were explored in an opened, non-directive conversation.

Both the initial interview and the follow-up session were audiotaped, transcribed and consequently subjected to thematic content analysis. Following the analysis, the participants were invited for a third interview during which they were asked to provide feedback on the analysis and add further information. This represented Phase III, which

was completed by 10 participants from the original sample; this phase also served as a reflection on the experience of research participation. Findings indicated that research participation was generally seen as a positive experience that could have potentially therapeutic benefits. The process involved active engagement for both the participants and the researcher, which may have helped foster closeness but that also raised a number of ethical dilemmas, primarily in terms of dual roles and researcher self-disclosure.

Overall, the studies highlighted the complex interplay of both clinical and non-clinical factors that the individuals took into account as they were making sense of their experience. The studies have a number of clinical implications, specifically addressing the role of hospitals in treatment, the relationship between mental illness and trauma, participatory assessment of recovery, and the role of clinical psychology in the treatment of severe mental illness. Furthermore, the studies point out the potential benefits of supplementing clinical work, whether in research or in treatment, with the methods and processes of Gadamerian hermeneutics.

The core principles of the Gadamerian approach (the fusion of the horizons of meaning, the hermeneutic circle and the dialogue) promote viewing of a phenomenon as a contextually embedded experience that is interpreted through the person's pre-existing views and his/her present range of vision. The approach conceptualises interactions between two parties as opened conversations that aim at shared understanding, rather than objective truth. Such conversations are characterised by a back-and-forth movement between the whole and its parts, which eventually leads to improved understanding. Therefore greater appreciation of contextual information and meaning-making processes; treating both sources of expertise (consumer and professional) as equally important; viewing psychopathology as only one part of mental illness and mental illness as one part of the person's life; and finally approaching clinical and research interactions as relational endeavours that test the underlying assumptions of both parties could help influence the way mental health professionals work with individuals with severe mental illness.

Declaration

I certify that this thesis does not, to the best of my knowledge and belief:

- i. incorporate without acknowledgment any material previously submitted for a degree or diploma in any institution of higher education;
- ii. contain any material previously published or written by another person except where due reference is made in the text of this thesis; or
- iii. contain any defamatory material.

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My biggest thanks and gratitude go to the men and women who took their time to participate in my research and generously share their stories. Their courage and willingness to open up has left me determined to do my best as a person and as a professional. I would also like to thank the staff and members of the Lorikeet and June O'Connor centres for their discussions and for always making me feel welcome.

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Chapter 1

Introduction and overview of the thesis

Severe mental illness has long held a widespread fascination and has been subjected to scientific, government and lay scrutiny. The illness can have devastating consequences not only for the person struggling with its symptoms and its functional consequences but also for the person's significant others and for the wider community (Green, 2004), and significant efforts have been put into trying to understand what the illness entails and how it could be treated. However, views on the person's potential to adapt, improve, and to lead a meaningful and productive life vary from pessimistic beliefs that individuals with illnesses such as schizophrenia are destined to "a debased and deficient existence" (Bromley, 2012) to beliefs in partial or full recovery (Davidson, O'Connell, Tondora, Lawless, & Evans, 2005). Stories of the affected individuals themselves point to a huge variation in experiences, with some talking about fear, unpredictability, estrangement, damaged relationships and uncertain future (e.g., Deland, Karlsson, & Fatouros-Bergman, 2011; Jönsson, Wijk, Skärsäter, & Danielson, 2008; McCann & Clark, 2004) and others describing their illness as a transformative experience that resulted in better functioning than before the onset (Tooth, Kalyanasundaram, Glover, & Momenzadah, 2003).

Some of this variability can be accounted for by clinical aspects such as duration of untreated psychosis, initial response to neuroleptics or neurocognitive functioning (Liberman, Kopelowicz, Ventura, & Gutkind, 2002). However, there are clear indications that functioning and wellbeing in mental illness are determined by an interplay of factors related to the person's environmental conditions, personal systems, cognitive appraisals, transitory experiences and coping efforts (Yanos & Moos, 2007). What is less clear is how exactly those factors interact and how they fit into the person's overall experiential world.

People's experience of mental illness has been explored in a range of qualitative studies, which either focused on specific aspects of the illness experience and related issues, such as hospitalisation, diagnosis or homelessness (Hayne, 2003; Kirkpatrick & Byrne, 2009; Lally, 1989; Sayre, 2000), or, less frequently, looked at mental illness in terms of broader contexts and consequences (Barham & Hayward, 1995, 1998). Other studies have focused on stories of recovery. Recovery is a powerful concept, one that

has been receiving increasing attention across settings, from consumer organisations and peer groups to government policies and clinical research. Ever since Anthony (1993) identified recovery as a vision guiding mental health service delivery in the 1990s, studies of recovery have been on the rise, and it has been suggested that no care can be effectively provided unless it is based on recovery principles (Torrey, Rapp, Tosh, McNabb, & Ralph, 2005; Townsend & Glasser, 2003).

In spite of all this attention, recovery remains an elusive concept, one that currently lacks a definition that would be embraced by all invested parties (Silverstein & Bellack, 2008). While quantitative studies have highlighted that recovery is not as rare as was once thought, personal narratives and qualitative studies have provided much needed insight into what is involved in the process of recovering (Davidson et al., 2005b).

Recovery research has been treated as broadly falling into one of two categories: clinical (outcome) and consumer (process). The outcome approach focuses on meeting operationally defined criteria, such as symptomatic or functional remission, and is closely linked to treatment research (Silverstein & Bellack, 2008). The consumer approach treats recovery as a subjective process that occurs over time and that is characterised by the person's efforts to redefine mental illness as only one part of his/her identity (Davidson et al., 2005b). Both approaches have been valuable in advancing our knowledge of recovery but have often been treated as mutually incompatible. In addition, the outcome–process distinction means that different groups of individuals might be studied, depending on the respective approach (Bellack, 2006; Silverstein & Bellack, 2008). Interestingly, even consumer–professionals (i.e. those highly trained mental health professionals who had been treated for severe mental illness and therefore bridge the consumer–professional divide) are at odds with each other as to what recovery is (Frese, Knight, & Saks, 2009). For all its valuable information, recovery research has only accessed small subsections of the population, and is yet to provide an integrated approach that would help bridge the perceived divide between the approaches (Silverstein & Bellack, 2008).

Research suggests that a person's illness experience involves more than the illness itself but rather incorporates a complex interplay of personal, social and

contextual factors that include subjective interpretations and meaning-making processes as well as personal capacities (Davidson, Sells, Sangster, & O'Connell, 2004; Roe & Lachman, 2005). It could therefore be argued that for any new concept to become part of the person's experience it needs to be personally meaningful; the individual is less likely to accept something that he/she cannot relate to and that carries little meaning. If recovery is to become central to mental health care, more needs to be known about how individuals respond to the concept.

The aim of the present studies was not to provide a definition of recovery or to identify its components and mediators. Rather, the focus was on the lived experience of the individual, with recovery introduced as a factor to be examined in terms of how relevant it appeared to be to the person and how it fitted in with the overall experience. The studies also addressed the topic of research participation and its impact on the individuals. The following sections outline the structure of the thesis and provide a brief description of each chapter.

Chapter 2 provides a review of relevant literature. It starts with a brief introduction of qualitative research on the subjective experience of mental illness, followed by a more in-depth discussion of issues related to recovery. It highlights the difficulties associated with attempts to define and conceptualise recovery, and it critically evaluates the two main and distinctive approaches of recovery as an outcome and process. The chapter also includes a section dedicated to the elements, dimensions and stages of recovery, as well as a section outlining the main approaches to assessment. Finally, it turns its attention to recovery-oriented care. Specifically, it briefly discusses interventions and programs; general issues related to recovery-oriented practice and its position with respect to evidence-based treatment; and suggestions that had been made for transformation of mental health care into a person-centred, capabilities-oriented system (Davidson, Ridgway, Wieland, & O'Connell, 2009; Hopper, 2007). The chapter ends with a summary of the literature and with a rationale for the present research in terms of its topic, its qualitative approach and its philosophical framework.

Chapter 3 describes the method used in the present research, starting with the design which was informed by the principles of Gadamer's (1975) hermeneutics.

Specifically, it outlines three philosophical constructs that were relevant to the research endeavour: the fusion of horizons of meaning, the dialogue and the hermeneutic circle. Theoretical and methodological application of these constructs permeated the subsequent data collection and interpretation, and so this chapter also provides an overview of the studies and their aims. The first was an exploratory study which utilised a case study approach to analyse five personal narratives. Its findings pointed out the richness of the topic and therefore inspired the three consequent studies (phases) which involved a total sample of 20 individuals with severe mental illness who were interviewed up to three times. Phase I focused on the lived experience of mental illness while phase II examined the participants' responses to the concept of recovery. Phase III served as a feedback session, both in terms of the researcher's summary of the participant's narrative and the participant's feedback on the summary. In addition, the experience of research participation was explored. The study overview is followed by a brief description of the sample and its recruitment, the study procedures and analysis. The chapter also details the way trustworthiness was established, with an outline of credibility, transferability, dependability and confirmability (Koch, 2006; Nagy & Viney, 1994).

Chapters 4, 5 and 6 report on the findings stemming from the data collected on the lived experience of mental illness (Phase I). Chapters 4 and 5 focus on person-centred factors, which have been organised into four main themes.¹ *Mental illness as a journey* discusses the way the participants traced their journey from illness development to stabilisation and maintenance. The process was characterised by the back-and-forth movement between the past, present and future, and influenced by what the persons learned about their experience and how they learned to negotiate the mental health system and . *Conceptualisation of mental illness* refers to personal models, signs of ill health versus being well, multilayered acceptance, the differentiation between the person and the illness, and the role of trauma in mental illness. The theme titled *illness management and coping* includes subthemes of personal responsibility, self-monitoring, balance and personal limitations, lifestyle adjustments, being productive and having fun,

¹ Due to the amount of information and for easier readability the exploration of those factors has been split into two chapters, with Chapter 4 providing a detailed description of the themes with illustrating quotes and Chapter 5 providing a discussion.

and pulling back. Finally, Chapter 5 provides a discussion of what the participants believed they had lost and what they had reclaimed, gained or planned for the future (*losses and gains*).

Chapter 6 focuses upon the social and relational factors, which were broadly grouped into two themes: *professional help* and *the role of others*. The first theme involves the experience of and views on medication, hospitalisation and professionals. It also highlights those aspects that were found helpful to the participants (diagnosis and medication, good working relationships, fostering hope and having treatment options) and those that were not (difficult access, poor continuity of care, no guidance to address adjustment to hospitalisation and paternalistic system of care). With respect to the role of non-professionals, the chapter focuses on relationships with significant others, the impact of mental illness on others, the individual's view of and relationship with other people with mental illness, and the difficulties associated with disclosure of mental illness to others.

The concept of recovery is explored in Chapter 7. The first part focuses on the *Recovery Assessment Scale* (Corrigan, Giffort, Rashid, Leary, & Okeke, 1999), with discussion of participant scores and their reactions to the scale. The second part relates to *conceptualising recovery*, and the following subthemes are described: talking about recovery, defining personal recovery, returning to baseline following crisis, living as best as one can, starting points, components and facilitators. The chapter highlights that the process of talking about recovery is just as important as what the individual believes the word 'recovery' refers to.

This chapter is important as it describes a reconciliation of the consumer (process) and clinical (outcome) approaches to recovery. The participants' stories demonstrate that aspects of both approaches can be compatible and relevant, and that the specific combination of those aspects is unique to each individual. It is therefore argued that the main distinguishing features of the two approaches are their primary focus (the individual versus the illness) which may instead be understood as two perspectives on the same phenomenon. In a hermeneutic tradition, they represent two horizons of meaning that can be reconciled (or fused) through a dialogical exploration that leads to shared understanding.

Chapters 8, 9 and 10 are based on data that relate to the research process rather than its outcomes (i.e. findings related to the lived experience and recovery). The experiential aspects of research are summarised under three main themes in Chapter 8. The theme titled *being a research participant* describes the participant's reasons for and their experience of participation. The second theme is *relating to the researcher* as a person and as a mental health professional. The final theme (*being a researcher*) describes the researcher's background, her role as an active participant in research and her reflections on being a mental health professional in a research setting.

Chapters 9 and 10 tell the story of two participants to illustrate some of the issues highlighted by the research. Paula and Heather (their names are pseudonyms to protect their privacy) were two female participants whose stories could be differentiated along several dimensions. Heather was further along on her recovery journey than Paula yet their stories do not represent opposite sides of the recovery continuum (the "failure" versus the "success story") as they both did their best to use their existing knowledge and abilities to cope with what had been extremely challenging sets of circumstances. The two women also differed in other aspects, such as their views of their potential roles in treatment or in the degree of their engagement in research. However, their stories are primarily included because of their place with respect to the learning journey undertaken by the researcher and the hermeneutic principles guiding the research.

Paula's story (Chapter 9) highlights the struggles of someone who remains "stuck", in that she has not been able to make much progress since diagnosis, and has not as yet found meaning in her experience. The researcher suggests that the reason for this "stuckness" is that the dialectic Paula has engaged in has been ineffective in challenging her pre-existing assumptions and prejudices in such a way that would promote a shift in understanding. Her own horizon of meaning and the horizon of her treating practitioner(s) had not been reconciled in a way that would lead to shared understanding. The illness, which had become such a large part of her identity therefore continued to lack in meaning.

In comparison with Chapter 9, Heather's story (Chapter 10) illustrates the way the research themes (and therefore experiential aspects) interacted with each other to form a personal narrative. Her story also demonstrates how the opened, non-directive

give-and-take of hermeneutic interviewing promoted the establishment of a close professional relationship which in turn led to greater engagement in the explorative work that resulted in improved and shared understanding. The implications for therapeutic application are discussed later in Chapter 11.

Chapter 11 summarises the overall findings with respect to what was learned about the person-centred and social/relational aspects of the lived experience, about recovery and about research participation. It is argued that the impact of the personal and social factors is mediated by subjective interpretations, the way those factors interact and the way they are embedded in context. Moreover, the chapter presents an argument for the proposition that the term ‘recovery’ refers to two separate yet related processes of episodic and global improvement, both of which may require careful reflection on wellness and normality. Wellness and normality are both described as subjective, fluid states that are created and recreated by the individual and that may change with new experiences and improved understanding. Normality refers to the constructed and reconstructed baseline of the person’s functioning; it also acts as a foundation for wellness, which refers to enhanced state of being and functioning.

The chapter also makes a call for greater appreciation of the way recovery is discussed and assessed. Communicating about recovery is conceptualised as a back-and-forth exchange that aims at reconciling the two horizons of meaning and that should include discussion of short- and long-term expectations. Such communication could also include assessment with special attention not only to what is measured but also how that measure is used. Participatory assessment, in which clients are encouraged to engage with the process and perhaps comment on the questions and their answers, could be used to enhance the therapeutic value of assessment, so that measures are used as tools to help clients tell their story, and to enable and facilitate their meaning-making processes.

Chapter 11 then highlights the findings related to the research process as experienced by the participants and by the researcher. From the participants’ point of view, their engagement with research was motivated by a desire to help and was generally rated as positive and potentially therapeutic. From the researcher’s point of view, being an active participant herself was at times challenging but ultimately

personally enriching. The researcher proposes that hermeneutics be used not only as a methodological guide but also as an approach that treats a phenomenon as contextually embedded and as something that can only be understood through a mutual exploration of the whole and its parts. Hermeneutics can therefore be understood as an approach that sees inquiry as a practical and moral process that places “being with” the other party at its centre.

The final chapter also briefly described some of the difficulties related to the technical aspects of the project, such as participant drop-out and recruitment, as well as the dilemmas regarding the decision to use personal reflections as a source of data. It then turns the reader’s attention to clinical implications associated with the hermeneutic approach. It is argued that incorporating hermeneutics would lead to improved assistance with the adjustment to hospitalisation and greater emphasis on therapeutic processes that would help the person find meaning in his/her experience, as well as greater sensitivity to the complex relationship between mental illness and trauma. Furthermore, incorporation of hermeneutics could improve the way the knowledge and skills possessed by clinical psychologists are utilised in the treatment of individuals with severe mental illness. The chapter then outlines suggestions for future research on the use of the research interview as a learning tool and a therapeutic activity, on the subjective incorporation of recovery and on how the concepts of severe mental illness and recovery are addressed in graduate training.

The way the chapters are structured largely reflects the chronological progress of the research from the summary of the existing literature and rationale for the studies, through the choice of method informing the three phases of data collection, to a discussion of what the research contributed to the existing body of knowledge. However, the structure only alludes to the learning journey that the researcher undertook. The journey was not directly linear, as the outline would suggest, but could rather be characterised as an ebb-and-flow movement between the researcher’s background knowledge and the new experiences and findings. Each new finding and experience became part of the questioning process that challenged what the researcher already knew and that examined the way the parts fitted together as a whole as well as how the whole could help explain the role of the parts. This dialectical process itself describes the hermeneutic process of understanding.

If understanding occurs as a result of the fusion of our background knowledge (pre-understanding) and our present range of vision, as Gadamer (1975) suggested, then each chapter of the thesis should be understood as both a new finding that was interpreted in view of background knowledge while at the same time creating a new pre-understanding for future undertaking (and the chapters that follow). So for instance, as the researcher progressed from learning about the experiential factors of the lived experience her horizon of meaning shifted to create improved understanding which in turn formed the basis for how she interpreted participants' discussions of recovery and so on. Although the questioning process went full circle and back to the beginning as the researcher returned to the participants for feedback and as she reflected on her journey, she is aware that the process will in fact continue with each reader's new interpretation and eventually become part of ongoing learning.

Chapter 2

Literature review

Severe mental illness has a profound, at times catastrophic, effect on the affected person (McCann & Clark, 2004; Zolnierak, 2011). Apart from the actual symptoms of the illness that may interfere with the person's cognitive functioning and coping, and that may cause significant distress, the illness also influences the person's functioning in other life domains, including relationships with others, occupational functioning or the person's ability to live independently (Silverstein & Bellack, 2008). Mental illness has been associated with feelings of estrangement and alienation (Deland et al., 2011), isolation (Deegan, 1993; Ekeland & Bergen, 2006; Karp, 1994) and loss (Baxter & Diehl, 1998; Henderson, 2010). It has been suggested that the onset of mental illness may challenge the persons' understanding of who they are and therefore affect the very core of their sense of self (Farone & Pickens, 2007; Lally, 1989; Pettie & Triolo, 1999; Roe, 2005; Wisdom, Bruce, Saei, Weis, & Green, 2008). It is partially for these reasons that severe mental disorders, such as schizophrenia or bipolar disorder, have long been believed to have poor prognosis.

These beliefs have been challenged with the emergence of longitudinal studies and first-person narratives that indicate that a large proportion of people diagnosed with severe mental illness can lead successful and fulfilling lives (Davidson & Roe, 2007; Green, 2004). Although some people experience full remission of symptoms, others can lead their lives in spite of having to cope with their symptoms. It would thus seem that the presence or absence of symptoms may not be the sole indicator of people's overall functioning and that studies that focus on psychopathology only may provide useful yet limited information about the person's subjective experience.

The experience of people with severe mental illness has been subject of increasing interest. Traditional outcome-oriented quantitative research continues to play an important role, but there is growing acknowledgment that consumer perspectives are an important source of information, which is why first-person narratives are published not only in popular literature and consumer materials but have also found their way into peer-reviewed journals, such as *Psychiatric Rehabilitation Journal*, *Schizophrenia Bulletin* or *Journal of Clinical Psychology*. It is also one of the reasons for the growing

number of qualitative studies which have addressed the experiential, “person” side, as opposed to clinical, “illness” one, of mental illness.

Qualitative research on the subjective experience of mental illness has addressed a wide range of problem areas in various settings, such as the impact of hospitalisation on the individual’s self-perceptions (Lally, 1989; Sayre, 2000), the experience of mental illness and homelessness (e.g., Kirkpatrick & Byrne, 2009; Thompson, Pollio, Eyrich, Bradbury, & North, 2004; Yanos, Barrow, & Tsemberis, 2004); the experience of mental illness in a forensic setting (Laithwaite & Gumley, 2007), the experience of being diagnosed (Hayne, 2003), people’s identification with their illness (Ekeland & Bergem, 2006; Howard, 2006), mental illness and employment (Gahnström-Strandqvist, Linkko, & Tham, 2003; Honey, 2003, 2004) or coping with the dual demands of parenting and mental illness (Ackerson, 2003; Bassett, Lampe, & Lloyd, 1999; Diaz-Caneja & Johnson, 2004; Nicholson, Sweeney, & Geller, 1998).

While some of the studies have focused on specific aspects of the illness experience, others looked at the experience of illness more broadly. For instance, Barham and Hayward (1995, 1998) explored the personal as well as the social constraints experienced by people with a long history of schizophrenia and found wide-ranging consequences of mental illness, including structural constraints (e.g., in housing), cultural burden of misconceptions or struggle for valued social roles. Estroff, Lachicotte, Illingworth and Johnston (1991) examined the strategies patients used to account for their symptoms, diagnosis and hospitalisation. They found that viewing self as having a mental illness was influenced by the person’s understanding of what the problem was and how the problem was seen to work, rather than a diagnosis, and that the type of illness account was associated with factors, such as race and gender. They concluded that people’s views of their illness were largely influenced by non-clinical factors, including contextual, experiential and sociocultural. Although their focus differed, the studies indicated that a great deal of the illness experience occurred outside the traditionally defined illness criteria.

Overall, reviews of first-person accounts and qualitative, experiential explorations indicate that studies tend to fall into four general categories: (1) subjective experience of illness, which includes responses and attitudes towards illness, the impact

of illness on people's life, studies on insight/awareness and the role of trauma; (2) the person's experience of self; (3) subjective experience as influenced by social contexts, focusing on the person's desire for normalcy and life in the community; and (4) the experience of care and treatment (Roe & Lachman, 2005; Zolnierrek, 2011). It would seem that far from being passive recipients of treatment, many individuals experiencing mental illness, even those hospitalised for severe psychiatric problems, make active attempts to try to understand their illness and its role in their lives; strive to build interpersonal relationships with others, including family/friends, peers and providers; and look for strategies that could help them improve.

Roe and Lachman (2005) warned against oversimplification of mental illness and reducing it to symptoms and pathology, in essence treating individuals as "entirely ill". They concluded that it is not possible to study disorders as separate from the individuals experiencing them, and that more attention needs to be paid to the personal meanings individuals attribute to their illnesses, within their unique contexts. They believe that it is these personal meanings that comprise the person's recovery process, as discussed in detail in the sections that follow.

Similarly, Davidson and colleagues (2004) noted that professional inquiries should focus on the person, rather than the illness, in order to find out how people recover. They believe that researchers and practitioners should be opened to the complexity of each individual's unique experiences, capacities and talents because it is these factors that will help the individual recover. Both arguments point towards experiential and contextual factors, whether in the form of personal strengths or meaning making processes, rather than the clinical ones. It should be not so much what professionals do to the person to treat the disorder but what persons with the illness do to get better. Failure to acknowledge the crucial role of these factors and processes could result in failure to understand, promote and foster recovery.

Recovery

Recovery, or the process of healing, or getting better, has been subject of increasing interest in the past decade. This interest has been apparent not only in research and consumer organisations' services but also in a range of government policy and planning documents published in England, Australia, USA and elsewhere (Piat &

Sabetti, 2009; Ramon, Healy, & Renouf, 2007). For instance, Australia's *Fourth National Mental Health Plan* for 2009-2014 identified social inclusion and recovery as one of its priority areas, with the aim of "adopt[ing] a recovery oriented culture within mental health services, underpinned by appropriate values and service models" (Department of Health and Ageing, 2009, p. 28). Similarly, not-for-profit and consumer organisations, such as Australia's Richmond Fellowship or Mental Illness Fellowship, focus on providing services that promote increased consumer participation and recovery.

Recovery as such is not a new concept; longitudinal studies of symptomatic or functional recovery have been appearing in scientific literature since at least the 1960s (Davidson et al., 2005b). What has changed, however, is the view that recovery is a quantifiable outcome, usually a result of extensive formal treatment. Instead, beginning in the 1990s, there has been a shift towards re-conceptualising recovery as a process that enables individuals with mental illness to lead meaningful lives, whether or not they continue to experience symptoms. The main drive of this shift has been the consumer movement but other factors, including the de-institutionalisation, published first-person accounts of recovery and the influence of the social model of disability are all believed to have played a role (Ramon et al., 2007). In spite of the interest and subsequent research, the concept of recovery remains a problematic issue since there is currently no consensus on what recovery is; whether and how it should be assessed; or how it should be practiced within the mental health field (Silverstein & Bellack, 2008).

Definition and conceptualisation

Although a number of definitions of recovery have been put forward, there is no single description or an operationalisation that would be universally accepted. Some definitions equate recovery with amelioration of symptoms or with other outcome measures, such as treatment effects, symptom remission or restoration of occupational functioning (Silverstein & Bellack, 2008). This clinical model is based on outcome studies that have focused on meeting operationally defined criteria that are predetermined by researchers who assess outcomes such as symptomatic remission which usually refers to absence of major symptoms (or at least low scores on core symptoms as measured by a psychiatric scale), or no hospitalization for a period of time

(e.g., Harrow, Grossman, Jobe, & Herbener, 2005; Torgalsbøen & Rund, 2002; van Os et al., 2006). However, there is an increasing acknowledgment that while symptomatic remission may be important for recovery, it is not sufficient because the illness might have had consequences on the person's daily life and on his/her social and occupational activities (Whitehorn, Brown, Richard, Rui, & Kopala, 2002; Wunderink, Sytema, Nienhuis, & Wiersma, 2009). This sometimes leads to a situation where symptoms have improved but the person continues to struggle with functional consequences or where the individual may have ongoing problems with symptoms but with less severe impact on his/her everyday life (Pachoud, Plagnol, & Leplege, 2010). It is for these reasons that researchers have started to include measures for both symptomatic and functional remission (Wunderink et al., 2009) so that current operational definitions tend to involve three sets of criteria: psychopathology, psychosocial functioning and duration (Lieberman & Kopelowicz, 2005).

One such operational definition is by Liberman and colleagues (2002, 2005) who described four components of recovery from schizophrenia: sustained symptomatic remission (scores of 4 or less on positive and negative symptoms of the Brief Psychiatric Rating Scale); at least part-time engagement in an instrumental role activity, such as work, study or volunteering; independent management of day-to-day needs (e.g., funds, medication); and participation in social and recreational activities (e.g., meeting with a peer at least once a week). All four components need to be met and maintained for a period of two years to meet the criteria of recovery.

Although such a definition could be viewed as a step up from the narrow, single-criterion approach, it represents a clinical perspective where the state of a person's recovery is determined by a clinician/researcher rather than the person with the illness. Liberman and Kopelowicz (2005) themselves commented that their operationalisation, as well as operational definitions in general, should be subject to social validation where they are assessed by a variety of interested parties, including clinicians, persons with mental illness, family members and advocates. Without such validation the construct could be viewed as lacking in social credibility.

Beside lack of social credibility, outcome definitions generally have been criticized for maintaining their focus on the illness, symptoms and other clinical factors.

Apart from the notion that symptomatic remission doesn't necessarily equate good functioning, scientific definitions are usually determined consensually, not empirically, and they include terms such as return to pre-morbid functioning which are consistent with dictionary definitions of recovery and perhaps therefore appealing, but which are nevertheless problematic (Bellack, 2006; Brennaman & Lobo, 2011). Firstly, the term 'pre-morbid levels of functioning' is ambiguous and difficult to determine. Secondly, where the onset of the illness occurred during adolescence or early adulthood, it might have interfered with the establishment of independent functioning and the attainment of social and occupational roles; return to such levels of functioning would have been below what could be considered normal range (Lieberman & Kopelowicz, 2005). Finally, outcome definitions provide useful information about some end state or about the person's functioning at one point in time but they say less about how the person got there, and it has been proposed that recovery should be understood not as an outcome or a destination but as a process that comes from within the individual and that occurs over time in an incremental fashion, with successes and setbacks (Bellack, 2006; Brennaman & Lobo, 2011; Leamy, Bird, Le Boutillier, Williams, & Slade, 2011; Ochocka, Nelson, & Janzen, 2005).

Recovery as a process or a journey is the key element of conceptualisations that originated in consumer literature but that are increasingly considered by researchers, clinicians and government agencies. For example, the *National Mental Health Plan* states that recovery "represents a personal journey toward a new and valued sense of identity, role and purpose together with an understanding and accepting of mental illness with its attendant risks" (Department of Health and Ageing, 2009, p. 26). Another often cited definition describes recovery as a "deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles...[that] involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness" (Anthony, 1993, p. 15). These definitions reflect a view that stresses that recovery does not necessarily mean cure and that the existence of symptoms does not preclude effective functioning in society (Davidson et al., 2005b).

Consumer-oriented conceptualisations do not focus on the illness but rather consider the person experiencing the illness and examine non-clinical factors that could be broadly categorised as person-centred/internal (e.g., hope, self-determination),

social/external (e.g., relationships with others, community integration) or a combination of the two (e.g., empowerment) (Onken, Craig, Ridgway, Ralph, & Cook, 2007; Ralph, 2000a). These conceptualisations are grounded in data generated by individuals with mental illness whose stories seem to point out a discrepancy between a clinical and an experiential perspective of the same phenomenon.

Although the consumer model has been supported by research, its definitions have been criticised for being nonspecific and lacking clarity, which limits their utilisation as criteria for research, for evaluations of clinical programs and for public policy work (Bellack, 2006; Liberman et al., 2002). It could be argued that such criticisms do not just target the actual model in question but also reflect the underlying conflict between positivist and non-positivist approaches. If we are to measure an aspect of someone's experience we need quantifiable constructs. Yet ultimately it is the person, not the illness, who recovers and to whose benefit such constructs should be created. A definition might seem vague and unclear from an outcome perspective while being meaningful for the individual.

Apart from being seen as non-specific, it has also been suggested that consumer definitions often reflect the views of individuals who act as spokespersons and/or are involved in advocacy, some of whom have become mental health professionals, and that research is conducted with participants who have recovered and who may therefore represent a distinct subgroup (Bellack, 2006; Silverstein & Bellack, 2008). Both comments have raised the issue of how characteristic those individuals are of the broad population of persons with mental illness.

It is clear that both models have their critics and proponents, and just as there are disagreements about the definition, there are disagreements about the relationship between the two concepts (Davidson, O'Connell, Tondora, Styron, & Kangas, 2006). Some believe that a person needs to experience significant reduction in symptoms and signs of mental illness before there is any improvement in functioning, whereas others claim that a number of people with mental illness can lead successful and meaningful lives without much change in outcome measures (Davidson, Tondora, & Ridgway, 2010).

The empirical literature suggests that the two conceptual perspectives (i.e.

recovery as an outcome versus recovery as a process) are fluid, can coexist within a person at any given time (Collier, 2010; Davidson & Roe, 2007), and are both involved in consumer definitions (Piat et al., 2009). In addition, there are indications that even those individuals who view recovery as a process describe it in different ways, depending on their explanatory models of mental illness. For instance, in a dimensional analysis of 30 public narratives sourced from various materials (e.g., journals, conference presentations, consumer conference), the way individuals viewed their illness helped determine their understanding of recovery (Jacobson, 2001). Those who saw ‘the problem’ as biologically based identified recovery as a process through which they integrated their illness into the self-concept, whereas those who thought their illness represented a spiritual or philosophical crisis described their recovery as a rebirth. Other researchers have similarly found that persons with mental illness create various explanatory models (illness accounts or narratives) that help them come to some understanding of their experience (Estroff et al., 1991; Sayre, 2000; Thornhill, Clare, & May, 2004). They have also indicated that a number of those individuals can hold mixed models at particular points.

The combined weight of the literature would lend support for the suggestion that the various definitions (including process and outcome ones) are not mutually exclusive but can in fact coexist. People can create different types of explanations, hold two or more types at one time or change them over time; those explanations are then influential in how people view their recovery. Hence individuals with mental illness create their own definitions of recovery that are multifaceted, unique to their circumstances, and that may serve different purposes.

How people recover

Along with attempts to define recovery, researchers have examined both the clinical and non-clinical factors that play a role in recovery. For instance, research on schizophrenia identified factors such as late onset, absence of substance abuse, shorter duration of untreated psychosis, good pre-morbid history or adherence to treatment as associated with better outcomes (Hoffman & Kupper, 2002; Liberman et al., 2002; Rosen & Garety, 2005), whereas variables such as severe symptoms and neurocognitive impairment have been linked with poor functioning (Yanos & Moos, 2007).

In addition to the measurable, objective factors, researchers have identified various subjective dimensions and processes that are repeatedly cited by consumers themselves as important for recovery. Factors such as acceptance and understanding of one's illness (Cunningham, Wolbert, Graziano, & Slocum, 2005; Jensen & Wadkins, 2007), hope and optimism (Bonney & Stickley, 2008, Ridgway, 2001; Roe & Chopra, 2003), determination to get better (Marin et al., 2005; Tooth et al., 2003), responsibility and active engagement (Borg & Davidson, 2008; Davidson & Strauss, 1992; Kartalova-O'Doherty & Doherty, 2010; Ridge & Ziebland, 2006), empowerment (Cohen, 2005; Provencher, Gregg, Mead, & Mueser, 2002), social relationships (Bradshaw, Armour, & Roseborough, 2007; Corrigan & Phelan, 2004; Schön, Denhov, & Topor, 2009; Topor et al., 2006), meaningful activities (Andresen, Oades, & Caputi, 2003; Davidson, Shahar, Lawless, Sells, & Tondora, 2006; Mancini, 2007; Smith, 2000) and spirituality (Sells et al., 2006; Sells, Stayner, & Davidson, 2004; Torgalsbøen, 2001) have been cited as important for recovery.

Another aspect that is consistently discussed across studies is that of "self-identity" (e.g., Baxter & Diehl, 1998; Laithwaite & Gumley, 2007; Mancini, Hardiman, & Lawson, 2005; Sells et al., 2004). According to Davidson and colleagues (2005b), redefining self is the most overarching element of the recovery process. It refers to the process of redefining mental illness as only one dimension of the person's identity. Through the process of redefinition, the person creates an active, functional, positive sense of self (Andresen et al., 2003; Ridgway, 2001; Roe & Chopra, 2003; Tooth et al., 2003; Young & Ensing, 1999).

Several researchers have attempted to identify what was involved in this redefining process. For instance, Davidson and Strauss (1992) described it as a series of four steps where a person starts envisaging a more active sense of self, evaluates his or her strengths and weaknesses, tests this new self in action and finally uses this new sense of self to cope with the adverse effects of mental illness. Andresen and colleagues (2003) identified five stages of recovery through which individuals first experience identity confusion, followed by an increased awareness of the possibility of a new self. They then take stock of their values, strengths and weaknesses in order to start working on their recovery and finally forge a positive identity. In more recent research, Shea (2010) proposed a theory of self-recovery that involved similar processes, namely

losing the self, searching for self, rediscovering and redefining self, testing the new self and recovering self. The final stage involves full development of self-awareness and reconstruction of multidimensional identity that integrates past, present and future views of self. Although the studies differ in their descriptions of the stages, they tend to agree that by the final stage individuals would have reconnected with other people and integrated back into the community (Bradshaw et al., 2007, Schön et al., 2009), and would have experienced improved well-being and quality of life (Andresen et al., 2003; Beeble & Salem, 2009; Young & Ensing, 1999).

While terms such as redefining self or identity (re)development would indicate an internal journey, there is evidence to suggest that external processes are involved as well (e.g., Henderson, 2010; Ochocka et al., 2005). Factors like social support and social interactions, including those with friends/family, peers and professionals (Bonney & Stickley, 2008; Cunningham et al., 2005; Laithwaite & Gumley, 2007; Mancini, 2007; Topor et al., 2006), positive life events (Davidson et al., 2006b), material resources (Borg et al., 2005; Topor, Borg, Di Girolamo, & Davidson, 2011), continuity of care (Green et al., 2008), and trusting, collaborative relationships with professionals (Borg & Kristiansen, 2004; Schön et al., 2009; Young, Green, & Estroff, 2008) have all been identified as important to recovery.

The growing body of knowledge on outcome and process recovery provides valuable information on what is involved in people getting better as well as getting those people better, but there are still many remaining questions. For instance, it has been suggested that some of the concepts (e.g., hope) are vague and therefore complicate practical applications (Green, 2004). Although it is the person with mental illness who “does” recovery, the clinician facilitates it while the system and the community supports it (Townsend & Glasser, 2003). Yet questions such as when and how clinicians should facilitate hope without setting unrealistic expectations still remain unanswered. While there are some suggestions that stories of recovered individuals could be used to promote hope, there is a danger of putting pressure on clients to recover (Davidson et al., 2005b). The client who receives the message that all people can recover yet does not recover him-/herself, may be left feeling that he or she is to blame. Far from being empowering, the recovery language could create feelings of

helplessness, leaving clients to feel that since they are not recovering, they either lack the abilities to do so or their condition must be very serious.

Issues around clinical implications also apply to the stage models. Firstly, models of recovery do not specify at what point recovery starts. Denial, identity confusion and hopelessness (Andresen et al., 2003), demoralisation and feeling overwhelmed (Bradshaw et al., 2007), disconnection and powerlessness (Spaniol, Wewiorski, Gagne, & Anthony, 2002), and losing one's sense of self (Shea, 2010) have been described as initial phases of recovery in different studies. Yet if all people experiencing mental illness go through these phases, it would mean that they are all in recovery, which is clearly not the case. The same issue was raised by Roe, Rudnick and Gill (2007) who questioned whether those patients who are getting worse, whose daily functioning is deteriorating, or who lack awareness of their illness were in recovery, and if they were, then what defines a patient who is not in recovery.

Secondly, little is known about the type of strategies used at different stages. Models such as the one proposed by Andresen and colleagues (2003) are useful as an outline of the type of problems people with mental illness face along their illness journey but so far there is little research as to what sort of assistance they need at different stages or how they get from one stage to the next. Silverstein and Bellack (2008) pointed out similar problems in terms of treatment choices, suggesting that little is known about what choices clients make at what stage, what determines those choices and what the outcomes were.

Assessing recovery

As noted earlier, recovery has been traditionally assessed in clinical terms, typically as some outcome, such as reduction in or absence of symptoms, no rehospitalisation during the follow-up period, or full employment. These outcome studies have shown that contrary to what was once believed, recovery is possible even for individuals with severe disorders such as schizophrenia. Estimates of recovered people vary across studies and closer inspection reveals the complexity of the concept. For instance, a review of longitudinal studies of people with schizophrenia showed a great heterogeneity in long-term outcome, with the proportion of samples demonstrating good outcome ranging from 21 to 57% (Jobe & Harrow, 2005). Studies further show

that a significant proportion of people with schizophrenia and other psychoses have an episodic, rather than chronic, illness (Harrison et al., 2001; Harrow et al., 2005; Modestin, Huber, Satirli, Malti, & Hell, 2003), that there were significant individual differences in functioning at baseline which may have influenced recovery (Liu, Choi, Reddy, & Spaulding, 2011) and that recovery occurred in different dimensions (Whitehorn et al., 2002; Wunderlin et al., 2009). Hence, the labelling of individuals as either recovered or non-recovered is neither simple nor uni-dimensional.

Some of the aforementioned complexity reflects the true heterogeneous course of schizophrenia and other severe disorders but also reflects the heterogeneity of assessment methods and tools that are used. Furthermore, outcomes are predetermined by researchers and assessed with measures that have been developed by researchers therefore reflecting a clinical, rather than consumer, perspective. Collecting information about patients might be useful for some research purposes but if that information is of little relevance to that patient, the assessment itself might be disempowering to him/her.

Similar criticisms have been made regarding the use of routine standardised outcome measures in clinical settings. For example, it has been suggested that clinician-rated tools, such as the HoNOS, are limited in their use when it comes to the recovery process as they don't assess concepts that are most relevant to the consumer (Dickens, 2009; Lakeman, 2004). This has been supported by a study that found little relationship between traditional clinical outcome measures and measures that are grounded in consumer experience (Andresen, Caputi, & Oades, 2010). In that study, 281 participants diagnosed with a psychotic disorder were assessed with self-rated and clinician-rated scales measuring recovery, symptoms and levels of functioning. Results showed that there were poor correlations between summary recovery scores and clinical scores which would suggest a qualitative difference between what the authors called personal recovery and clinical recovery.

It is not clear whether Andresen et al.'s (2010) results are evidence for two distinct types of recovery, or whether recovery involves multiple components and different studies emphasise different components. Moreover, it is not clear whether questions of perceived usefulness relate to the tools themselves or to how they are used. Andresen and colleagues recommended that recovery measures be used in clinical work,

because a person's subscale scores could provide areas for discussion and help nurture the therapeutic relationship. Incorporating consumer recovery measures could therefore change what is assessed as well as how that assessment is used.

Consumer-oriented assessment of recovery has a considerably shorter history than outcome assessment. Although a number of such measures have been developed, many of them appear to be still in their early stages of development and are yet to undergo psychometric evaluation (Burges et al., 2011; Campbell-Orde, Chamberlin, Carpenter, & Leff, 2005). The tool development has been marred by a number of obstacles, some of them relating to the lack of consensus on the definition of recovery and its stages. For instance, the Stages of Recovery Instrument was based on Andresen et al.'s (2003) model of recovery. The model outlines five stages of psychological recovery which the authors termed moratorium, awareness, preparation, rebuilding and growth. The 50-item scale (10 items per stage) was shown to be valid and reliable, and correlated with measures of hope, resilience and other variables of psychological health. However, cluster analysis revealed only three clusters, which raised the question of whether the scale was a valid measure of the model or whether recovery consisted of three, not five, stages. Furthermore, it was suggested that the measure may not sufficiently capture the complexity of a process that is believed to involve four psychological component processes (hope, self identity, meaning in life and responsibility) and that is described as non-linear where individuals may return to earlier stages before progressing to later ones (Andresen, Caputi, & Oades, 2006; Weeks, Slade, & Hayward, 2010).

The consumer-oriented measures can be broadly divided into two groups: measures of individual recovery and its related components, and measures of recovery-promoting environments and systems (Campbell-Orde et al., 2005). The first group involves measures that either yield a single score of recovery where the higher the score the higher the person's recovery (e.g., Recovery Assessment Scale, Mental Health Recovery Measure), or subscores that represent different stages of recovery (e.g., Stages of Recovery Instrument) or dimensions of recovery (e.g., Recovery Process Inventory).

An example of a measure of individual recovery is the Recovery Assessment Scale (RAS). It consists of 41 items, each rated on a 5-point Likert scale ranging from

1= “strongly disagree” to 5= “strongly agree” (Corrigan et al., 1999; Corrigan, Salzer, Ralph, Sangster, & Keck, 2004). The scale has been used in a number of versions, including a revised, 24-item version (e.g., Chiba, Miyamoto, & Kawakami, 2010; McNaught, Caputi, Oakes, & Deane, 2007) and a brief, 20-item version (Roe, Mashiach-Eizenberg, & Corrigan, 2012). The two most commonly used versions of the scale are the original RAS-41 and the revised RAS-24 (also RAS-R), which assess five domains: personal confidence and hope, willingness to ask for help, goal and success orientation, reliance on others, and not dominated by symptoms (Corrigan et al., 2004). Overall, the measure has been shown to have good internal consistency (Cronbach α range = 0.76-0.97) and validity (positive correlations with measures of empowerment, hope, self-esteem, resilience and quality of life) (Salzer & Brusilovskiy, 2014).

The second group of consumer-oriented measures addresses the degree to which mental health services incorporate recovery-supporting practices, such as patient involvement or diversity of treatment options. For instance, the Recovery Oriented Systems Indicators measure utilizes two sources of data (consumer self-report and review of administrative data) to assess a total of 65 items (42 in self-report and 23 in administrative data profile) measuring domains such as access, invalidated personhood, person-centred decision-making and choice, or system culture and orientation (Dumont, Ridgway, Onken, Dornan, & Ralph, 2006; Onken, Dumont, Ridgway, Dornan, & Ralph, 2007). The measures were largely developed as quality improvement tools so that they could be used for organizational planning and change efforts. They could help identify areas for improvement, evaluate change of programs/systems over time or compare interventions in terms of their recovery orientation (Campbell-Orde et al., 2005). However, the measures have been criticized for not matching the conceptual framework of recovery (i.e. not addressing concepts such as hope or identity) and for lacking extensive psychometric evaluation (Williams et al., 2012).

Researchers have also considered a third approach to assessment which would use existing scales to assess three core concepts of recovery: hope (e.g., Beck Hopelessness Scale), taking personal responsibility (e.g., Illness Focus of Control Scale) and getting on with life beyond illness (assessment of identity, meaningful relationships, meaningful structured activity and recreation) (Noordsy et al., 2002; Torrey & Wyzik, 2000). The three concepts have been derived from cumulative experiences of treatment

research and from information from consumers, consumer-professionals and family advocates, and reflect subjective, behavioural, interpersonal and environmental aspects of recovery. For instance hope can be facilitated by the person's spirituality as well as support and encouragement from professionals and peers (Noordsy et al., 2002; Mead & Copeland, 2000). A periodical assessment of the client's sense of hope prior to and throughout an intervention could therefore provide information about potential change in the client's feelings about future, motivation and expectations.

While the proponents of this third approach believe that it could help generate research on recovery and establish recovery as a standard of mental health care (Noordsy et al., 2002), it could be argued that the potential direct benefit to the person with mental illness remains unclear. The authors point out that the proposed assessment would need to be supplemented by collateral information, a longitudinal perspective as well as measures of personal relevance. However, without bringing the collected data into the client-practitioner setting the assessment results would remain the practitioner's "property", ultimately guiding what the practitioner does rather than what the two parties might work on in collaboration.

Issues surrounding assessment of recovery are as complex as attempts to conceptualise it. Outcome studies may underestimate the actual prevalence of recovery, as prevalence is based on clinical samples that may not include those individuals who have good outcomes but who were not treated in the health system, whereas rates of consumer-defined recovery are largely unknown (Bellack, 2006). Scales used in clinical research tend to focus on deficits and narrowly defined criteria. Consumer-oriented scales focus more on psychological factors but a number of them have undergone only minimal or no psychometric testing and contain items that are ambiguous in concept and wording (Burgess, Pirkis, Coombs, & Rosen, 2011; Williams et al., 2012). What is not disputed is that recovery is possible for a large number of individuals with severe psychiatric problems.

Recovery-oriented care

Despite differences in the conceptualisation of recovery and its measurement, there is a growing recognition of the role recovery should play in care provision. The importance of recovery in the area of mental health is reflected in a range of initiatives,

scientific publications and policy documents. For instance, in Australia the *Fourth National Mental Health Plan* for 2009-2014 cites recovery and social inclusion as Priority area I (Department of Health and Ageing, 2009). According to the plan, mental health services should adopt a recovery-oriented culture that is “underpinned by appropriate values and service models” and that acknowledges “best practice and policy” (p. 28). It is also noted in the plan that the recovery focus should be promoted not only by non-government organisations and consumer advocacy bodies, as is currently the case, but also by clinical staff in public and private areas of practice.

The attempts to address the question of how to make service delivery more recovery-oriented has so far taken the form of specific recovery interventions, outlines of how recovery should be practiced and discussions on a more systemic level. These will now be described in the following section.

Recovery-oriented interventions and programs.

Recovery programs, such as the Wellness Recovery Action Plan or the Pathways to Recovery program, aim at educating participants about mental illness and mental health systems as well as about recovery and self-care. They also help individuals build a support network, set personal goals and develop stress management strategies (e.g., Barbic, Krupa, & Armstrong, 2009; Fukui, Davidson, Holter, & Rapp, 2010; Fukui et al., 2011). One such intervention, the Illness Management and Recovery program, uses a mix of educational, motivational and cognitive-behavioural strategies to help people improve their coping and self-management while providing them with knowledge and skills to achieve personal goals. Empirical evaluations of the program showed that apart from improvements in self-reported knowledge about illness, distress related to symptoms, hope and goal orientation and clinician-rated global functioning, participants reported high satisfaction with the program (Mueser et al., 2006) and one year after its completion still viewed it as effective (Roe, Hasson-Ohayon, Salyers, & Kravetz, 2009). Other studies indicated decrease in suicidal ideation (Färdig, Lewander, Melin, Folke, & Fredriksson, 2011) and reduction in hospitalisation and emergency room use over time (Salyers, Rollins, Clendenning, McGuire, & Kim, 2011).

So far, studies on the effectiveness of recovery programs have shown promising results, with improvements in recovery and hope (Barbic et al., 2009; Starnino et al.,

2010), self-esteem, self-efficacy, social support and spiritual well-being (Fukui et al., 2010) or self-reported effectiveness in coping with symptoms (Mueser et al., 2006). However, the studies tend to have small samples and often lack control groups and follow-up assessments. In addition, some programs showed reduction in symptoms but no effect on recovery (Fukui et al., 2011) whereas others demonstrated improvement in recovery orientation but no significant improvement in symptoms (Starnino et al., 2010). Kidd and colleagues (2011) asked a large sample of clients, support persons, staff members and team coordinators (N=2226) to complete the Recovery Self-Assessment, and concluded that although there were indications that recovery-oriented service provision was associated with better client outcomes, the findings were not consistent across the various stakeholders.

More work needs to be done to better understand how recovery should be incorporated into mainstream mental health and consumer services. Apart from possible inconsistencies in the way programs are set up and delivered, program developers need to be aware of possible barriers to implementation. Whitley, Gingerich, Lutz and Mueser (2009) examined the way 12 community mental health centres implemented the Illness Management and Recovery programs over a two-year period, and found differences in leadership, organizational culture, training and staff/ supervision that helped determine how well the program performed in each centre. Issues such as staff scepticism of the new program or organisational preference for the status quo could act as barriers to implementation. Therefore, an effective program isn't sufficient to bring about desired changes.

Recovery-oriented treatment.

The barriers identified by Whitley and colleagues (2009) exemplify some of the concerns that are commonly associated with recovery. Worries about extra resources and additional burden on the providers, beliefs that recovery is rare and only follows professional treatment, suggestions that it sets unrealistic expectations or even viewing recovery as an “irresponsible fad” could all potentially impact on mental health transformation (Davidson et al., 2006a; Roe et al., 2007). On the other hand, current interest in recovery could lead to re-branding existing services as recovery-oriented yet providing care as per usual with practices still rooted in a custodial, paternalistic

approach to care (Smith & Bartholomew, 2006, Sowers, 2005). In addition, using the term ‘recovery’ without engaging individuals (and their families) in discussions about its meaning could be counterproductive (Meehan, King, Beavis, & Robinson, 2008).

Recovery-oriented treatment is often described as treatment that is person-centred and strengths-based, one that focuses on individually defined goals and that requires collaboration and active engagement between the individual with mental illness and the professional (Chopra et al., 2009; Davidson, Drake, Schmutte, Dinzeo, & Andres-Hyman, 2009; Kidd et al., 2011; Mezzina et al., 2006). It represents a holistic approach that inspires hope and enhances the person’s autonomy, self-worth and dignity (Sowers, 2005; Townsend & Glasser, 2003), while also engaging community understanding and support (Meehan et al., 2008). The clinician’s role in such an environment is not directive but rather facilitative: it is less about what sort of treatment is offered but rather about what options are available, how they are delivered and how service providers relate to clients (Bellack, 2006; Davidson et al., 2009a; Solomon & Stanhope, 2004; Townsend & Glasser, 2003).

There are further indications that an intervention in itself may not be sufficient to support recovery and that it is the nature of the helping relationship that plays a role. Studies show that to help in the process of recovery, it is important that professionals show empathy, respect and general interest in the person’s everyday life; treat the professional relationship as an equal partnership; demonstrate flexibility; show humanity and do more than what is routinely expected (Borg & Kristiansen, 2004; Denhov & Topor, 2011). Understanding, caring and compassion, together with mutual trust and collaboration, reciprocity, creativity and continuity of care all play a role in recovery (Green et al., 2008; Topor & Denhov, 2012; Torgalsbøen, 2001; Young et al., 2008).

Together with attempts to outline how to practice recovery, there are also discussions on how to combine the recovery concept with evidence-based practice. Evidence-based practice represents a medical model approach to treatment, whereas recovery is centred in consumer experience, which raises a question of whether those two approaches are compatible (Solomon & Stanhope, 2004). Many now consider that the two approaches are complementary as they are both needed for high-quality care

(Davidson et al., 2009a; Rodgers, Norell, Roll, & Dyck, 2007; Sowers, 2005; Torrey et al., 2005).

Effective treatments such as pharmacotherapy, psychoeducation, cognitive-behavioural strategies or coping skills training should be part of routine clinical practice but, in line with recovery principles, should form only a part of the decision-making process (Mueser et al, 2002; Solomon & Stanhope, 2004; Torrey et al., 2005). Individuals should also receive information about their illness and treatment options (including discussions of possible side effects of medication), and only then make their choice and consent to treatment (Davidson et al., 2009a). Evidence-based interventions are thus delivered in the context of collaborative partnerships that instil hope.

Recovery-oriented treatment therefore needs to be holistic in nature. Although a person is classified as having a mental illness, the symptoms and impairments are not the only areas of functioning that need attention. The person's needs are complex and require collaborative efforts that involve numerous parties and that address both clinical and contextual factors. While a recovery-oriented intervention may improve the person's hope and ability to manage his/her illness, these improvements may be only short-lived if other providers within the mental health system the person comes across retain a paternalistic approach. Similarly, the individual may develop a trusting, respectful relationship with one practitioner yet be exposed to non-recovery practices in other treatment settings, such as when hospitalized for an acute episode. In other words, the way recovery is promoted, practiced and supported needs to be consistent across all levels of treatment, which would require a systemic transformation.

System transformation.

The concept of recovery should not only apply to specific interventions or clinician attitudes but should be implemented across the whole mental health system. This means that recovery principles should be evident across all levels and dimensions of the system, from the mission, policies and procedures to program design and evaluation; the selection, training and supervision of staff; as well as management and leadership dedicated to the concept (Anthony, 2000; Farkas, Gagne, Anthony, & Chamberlin, 2005). The system should demonstrate person, not illness, orientation by treating consumers as unique, multidimensional individuals who are involved in the

planning and delivery of services and who have the potential to grow and achieve personal goals (Farkas et al., 2005; Smith & Bartholomew, 2006). The focus should be on autonomy support, collaborative goal setting and collaborative exploration of the person's strengths, values and life vision (Oades & Anderson, 2012; Oades et al., 2005). It has also been suggested that the mental health should be transformed into a capabilities-oriented system of care (Davidson et al., 2009b; Hopper, 2007).

A capabilities-oriented system incorporates an agent-centred approach that suggests that human beings need the freedom to make their own choices from a range of valued options (Davidson et al., 2009b; Hopper, 2007). This approach would mean shifting the focus from what mental health practitioners do to treat the illness to what the person with mental illness values and what capabilities he/she has. Such system of care would be about working with the individual in order to help him/her pursue, achieve and sustain whatever outcome matters to him/her the most. A recovery oriented system within such paradigm would be characterized by respect and support of the person's capabilities, agency and self-determination, by treatment options and flexibility and by the acknowledgement that there is a diversity of outcomes (Davidson et al., 2009b; Hopper, 2007).

Summary and rationale for the present studies

Research shows that a large proportion of people diagnosed with severe mental illness like schizophrenia are able to develop coping strategies that allow them to lead a meaningful life. Whether it is because of effective treatment, self-management or social support, they defy the traditional notion of poor prognosis. A growing body of evidence supports this notion of recovery, whether measured by various outcomes (e.g., symptom severity levels) or conceptualised as a journey towards wellness. In spite of these efforts, there are still numerous individuals who continue to struggle with mental illness, and who appear to be 'stuck', seemingly unable to move on in life. It would be difficult to ascertain why; it may be because they do not have access to services that researchers have found to be effective (Solomon & Stanhope, 2004; Torrey et al., 2005), their treatment may have failed to offer hope or promote active involvement, or there may be other clinical and contextual factors. It is these individuals who might benefit from information gathered from participants who are willing to share their story.

It has been argued in this chapter that the consumer conceptualisation of recovery is important for two reasons. First, it broadens the scope of clinical research to include client perspectives. Second, it promotes the idea of adaptation and growth. However, both the clinical and the consumer models of recovery bring in a number of pre-defined concepts. Studies guided by the clinical model tend to focus on psychopathology and other clinical criteria usually applied to the illness, as opposed to the person with mental illness. In comparison, studies guided by the consumer model are largely built around the experiences of people who have recovered or are in recovery and who therefore may represent only a subsection of the mental health population (“the success stories”). Moreover, examining the lived experience through studies that are from the outset promoted as studies of recovery may bias the type of descriptions participants use to talk about their experience.

Research on recovery has certainly shed some light on what is involved in the process of getting better. However, methodological issues, lack of consensus on the definition of recovery and vague descriptions of some of the factors believed to be important for recovery make the translation of research into practice somewhat difficult. It has been suggested that the word itself (recovery) might be problematic as it is not value neutral, and that perhaps substitutes, such as healing, overcoming or transformation should be used instead (Ralph, 2000b). This problem was illustrated in Tooth et al.’s (2003) study in which many participants said that they were uncomfortable with the word ‘recovery’ and instead preferred terms, such as “getting on with their lives”. Similarly, Adame and Knudson (2008) commented that the term recovery suggests that people are recovering from something, which creates a dichotomy of either health or illness without taking into account the context and meaning. Based on their interviews with individuals with mental illness, they reconceptualised recovery as living a good life.

Although both the clinical and consumer perspectives have provided important information about what is involved in adjustment to and coping with mental illness, the existing knowledge appears to be insufficient to guide interventions and promote support systems that would be effective if not for all than at least for a majority of people with severe mental illness. In an era that is marked by conflicting agendas with a push to make service delivery more recovery-oriented on one hand and doubts about the

concept of recovery itself on the other, it is clear that attempts to resolve this conflict will only be successful as long as they take into account all possible perspectives from various invested parties, as they explore individual components and their interactions as well as their position within the whole, as they no longer just point out inconsistencies in findings but also try to account for those inconsistencies, and they do so on a systemic level.

In spite of what is known of the recovery process, it is not clear how it starts and unfolds over time, and therefore what mental health professionals, including clinical psychologists, could do to promote it while working with a client. It further raises a question of how best to combine recovery-oriented care with evidence-based practices (Silverstein & Bellack, 2008). If factors such as hope, optimism and agency are important for recovery, both researchers and practitioners need to learn more about how and when they should be addressed in treatment (Green, 2004). Similarly, Lysaker and Buck (2006) pointed out that if the goal of psychotherapy in severe mental illness such as schizophrenia is to include recovery, then researchers should turn their attention to what exactly is involved in this type of therapy. However, a more holistic approach to care goes beyond the immediate therapeutic relationships to other support systems and non-treatment aspects that could have healing affects and that therefore need to be appreciated (Silverstein and Bellack, 2008). It is all these individual aspects of care as well as the most effective interplay of these factors that need clarification, one that could benefit from the rich information provided by the ultimate experts: the people living with mental illness.

The current series of studies were designed to investigate the lived experience of people who had been diagnosed with mental illness. The project is a qualitative inquiry based on the principle that individuals who have a direct experience of a phenomenon, such as mental illness, may have important information about that experience as they are in the best position to determine what they need, what works for them and what would help them foster their own recovery (Davidson et al., 2004). Unlike quantitative conceptualisations that frame questions and response options from the position of the researcher rather than the participant, qualitative research tends to be more sensitive to user-led agenda as it gives participants more freedom to express what they really think and thus provides for depth of insight (Edwards & Staniszevska, 2000).

Qualitative approaches also allow better access to the context of a phenomenon in all its complexity. They place participants in their life worlds and treat them as intentional agents with reflexive and meaning-making capabilities (Marecek, 2003). It is these capabilities that help the person make sense of, adapt to and cope with their experience. According to Gadamer (1975), each person makes sense of his/her experience through a process that incorporates the person's interpretation of his/her experience, as well as general presuppositions that are formed within the person's social, political and cultural contexts. Applied to the phenomenon under investigation in the present studies, such approach would suggest that what constitutes mental illness is not the actual illness itself but the illness as embedded within the relevant contexts and as interpreted by the person experiencing it.

Individuals with mental illness have been traditionally treated as subjects that were studied and assessed or as illnesses that needed to be treated. Contrary to this, a Gadamerian approach considers those individuals to be agents who hold their own assumptions and presuppositions that they use to interpret their symptoms and other aspects of their illness experience. They may use professional knowledge but only if it helps them make sense of their experience and if it increases their understanding in a way that is personally meaningful. Gadamer himself addressed this point in his book *The enigma of illness* (1996) in which he wrote that clinicians usually see their patients (clients) in the clinical stage which tends to focus their attention on the illness, rather than the whole person. However, looking at (mental) illness from the point of scientific or professional expertise only, treating it as if it reflected the clients' own self-understanding, would misrepresent the true experience of the client (Gadamer, 1996).

The Gadamerian approach outlines a process through which an individual comes to an understanding of his/her experience which is conceptualised as a fusion of personal interpretations and context-bound general presuppositions. The same processes operate when two parties are having a conversation: both draw on their own experience and their presuppositions which they bring into the process and which, through an opened, back-and-forth exchange, lead to improved understanding. The Gadamerian methodology is highly suited to the research topic as its open and non-directive interview style allows participants to set agenda and guide the interview with their own selection of topics; it was the topics raised by the participants, rather than a pre-selected

set of questions, that were the focus of the interviews. Both the participants and the researcher had complementary roles in generating and understanding information, which promoted reflection and allowed for better understanding.

The aim was to obtain rich, detailed, in-depth information about their journey, about their meaning making processes, and the steps they took to adapt to their illness. The assumed perspective was not how people in recovery reflect on their lived experience but how people with the lived experience of mental illness reflect on recovery. The concept of recovery was not the primary focus; rather it was one aspect of the overall experience that was brought into a conversation and examined with respect of how it fitted in with the whole illness journey. Gadamer (1975) wrote about the hermeneutic circle which can be understood as a back-and-forth movement between the whole and the part; individual components cannot be understood without reference to the whole and vice versa. Applied to this concept, recovery did not represent the whole but one of the individual components.

Since it has been proposed that recovery is not a value-neutral term and that promoting a study as an investigation of recovery may bias participants' descriptions and self-selection of topics, it was important to ensure that all the initial steps of the research process, including the invitation to participate and the type of questions asked by the researcher, were couched in terms that were as neutral as possible until such time when the topic of recovery was introduced. This was either when the participants spontaneously raised the topic or when it was introduced by the researcher.

In summary, the aim of the present research was to explore the ways people with mental illness described their experience, what sense they made of their experience, how they adapted to it, the decisions they made and the steps they took along their journey. Further, the research was designed to help answer the question of how the experience fitted in with recovery and what happens when the concept of recovery is introduced in a conversation, for some individuals perhaps for the first time.

Chapter 3

Method

Design

The present study used a qualitative methodology based on Gadamer's (1975) hermeneutics. Hermeneutic tradition posits that every phenomenon has many possible perspectives and that understanding is not about accurately describing a pre-existing meaning but that meaning is created through the act of understanding (Hein & Austin, 2001; Smith, 1993). The emphasis is on situatedness and contextuality. According to Gadamer (1975), every person experiences the world in a way that is unique and personally meaningful, and that is embedded within the contexts of his or her individual history. Gadamerian approach to this process of personal experiencing was based on his concept of horizons of meaning.

Gadamer defined horizon as "the range of vision that includes everything that can be seen from a particular vantage point" (1975, p. 269). He believed that to reach understanding of their experience, individuals need to draw on two perspectives, or horizons of meaning: the so-called universality, which is the persons' historically transmitted pre-understanding (i.e. knowledge based on their historical, cultural and social contexts), and their personal experience seen from their present range of vision (Polkinghorne, 2000). It is through a fusion of these two horizons, universal and particular, that a person can reach understanding (Lebech, 2006). Thus viewing the experience of mental illness as a fusion of pre-understanding and present viewpoints offers a new perspective and a move away from the traditional empirical approaches that tend to focus on the measurement and exploration of the present experience, often to the exclusion of the historical perspective, within pre-determined parameters. Such an approach could provide for a holistic, more systemic understanding of a phenomenon that is intrinsically complex.

While the background knowledge is formed from the persons' culturally given understanding and their personal experience, it doesn't bind knowledge. Instead, the background is dynamic and loosely textured and therefore allows for a number of solutions and advanced understanding (Polkinghorne, 2000). It is through a process of reflection that individuals can examine their pre-understanding and broaden their

knowledge (Lebech, 2006). For that, the individual needs to be willing to relinquish those personal pre-conceptions that are no longer productive for understanding so as to make space in which new subject matter may be presented. The person has to apply the subject matter (e.g., mental illness) to his/her situation in order to be able to interpret it (Lebech, 2006). It is through a process of forming, posing and testing questions that a person can enlarge or shift one's background, although full understanding can never be achieved (Polkinghorne, 2000).

Just as Gadamer (1975) viewed understanding as an ongoing process, he also believed that experience was a dialectic of question and answer, and therefore should not be judged in terms of its results (Gonzales, 2006). When individuals experience a phenomenon, such as mental illness, they already hold a number of generalisations and assumptions about it that are confronted through that experience. Therefore, rather than just living with symptoms or acting as passive recipients of professional knowledge, individuals who experience mental illness are actively engaged in meaning making processes. They interpret symptoms in view of their own pre-understanding and experience of those symptoms, and they use clinical explanations and interpretations to self-reflect. Thus professional knowledge may be used to broaden knowledge and increase understanding where the individuals find it personally meaningful.

The Gadamerian approach as a research methodology is based on three philosophical constructs: the fusion of horizons of meaning, the dialogue and the hermeneutic circle (Koch, 1996; Whitehead, 2004). On an individual level, the concept of the fusion of the horizons of meaning helps explain the subjective process of understanding and knowledge formation. However, the process of fusion also operates when an experience of a phenomenon is examined in a dialogue between two people. In that case, the conversation involves the fusion of two perspectives: that of the person who expresses himself (i.e. participant) and that of the person who understands (i.e. researcher) where each party draws on his/her own pre-judgment and present range of vision. This process requires the researcher's own involvement in the dialogue with the participants.

Hermeneutic dialogue and interviewing approach are characterised by openness and non-directiveness where it is the answers provided by the participants that guide the

course of the interview (Koch, 1996). Therefore, rather than simply posing questions, throughout the interview process, the researcher actively participates in opened conversations where it was the actual topics raised by the participants that guided the interviews, rather than a pre-set list of questions. In addition, just as researchers do not just ask questions and record answers, they also bring in their own understanding and presuppositions. Roe and Lachman (2005) noted that researchers need “the humility to admit that there is more than one kind of knowledge” (p. 227). The Gadamerian methodology treats both parties as equal partners and therefore promotes the interplay between two sources of expert knowledge: that of the researcher and that of the person with mental illness. Both parties have complementary roles in generating and understanding information.

The researcher’s active participation is related to the third philosophical construct: the hermeneutic circle which can be understood as the analytical, back-and-forth movement between the whole and the part. It refers to the principle of questions and answers, which represents a movement between the expressions used in the dialogue and the meanings within which these expressions are embedded (Smith, 1993). This process does not have clear starting or ending points, and its aim is mutual understanding, rather than objective interpretation. The process also presupposes that the researcher becomes a part of the circle, which leads to the final key aspect of the hermeneutic approach: the representation of the researcher.

It has been pointed out that in qualitative (non-positivistic) inquiry, researchers play a key role as writers and creators who influence what and how data are collected, selected and interpreted and who are therefore responsible for constructing the researched world (Finlay, 2002; Mantzoukas, 2004). It is because of this active involvement in the research process that their presence cannot be excluded from the study. The issue of representation of the researcher has been addressed by many authors who propose that researchers engage in the practice of reflexivity (e.g., Davies & Dodd, 2002; Jasper, 2005; Koch & Harrington, 1998).

Finlay (2002) described reflexivity as thoughtful, conscious self-awareness that is dynamic and subjective. Within the research process it has been identified as a valuable tool that could not only contribute to the study’s trustworthiness but that could

also facilitate creativity and critical thinking as well as promote rich insight (Finlay, 2002; Jasper, 2005). Although there have been suggestions that researchers can become preoccupied with their own experience which could then block out the participants' position and skew findings (Finlay, 2002), the researcher ensured that at all stages of the research process there were clear boundaries between data generated by the participant and data provided by the researcher. The primary focus always remained on the participants' stories.

The researcher's reflexive writing took the form of an electronic journal in which she recorded her journey. The journal data included not only the actual events of the research process and her responses to them but also observations, personal reflections on her own experience, her expectations prior to interviews, as well as thoughts and comments related to the formation of her understanding. In addition, she kept a hand-written journal that was used for notes, ideas and reminders related to the emerging themes. The journal data allowed her to reflect on how her own horizon of meaning was developing throughout the process and thus helped her understand her own role in the research and its possible impact on the interviews and data analysis.

In the present study, using Gadamerian hermeneutics as a philosophical approach served two main functions. Firstly, it helped conceptualise the phenomenon of mental illness as an experience that was embedded in each participant's unique context and interpreted through the person's background knowledge and pre-existing views. Traditionally, the scientific approach to the study of mental illness has been largely framed by the professional knowledge, viewing clients' contextual factors and personal interpretations as secondary to the "objective" data, such as symptoms, diagnosis or treatment adherence. However, trying to treat such scientific viewpoints as reflective of the individuals' own understanding of their experience would not provide a true representation of the phenomenon. Thus broadening the scope away from the narrow focus on mental illness as characterised by its symptoms or diagnostic criteria (i.e. taking the experience out of the person's context) toward looking at mental illness in its entire complexity meant that potentially vital secondary information was retained. This provided a unique opportunity to help create better understanding and improved knowledge of mental illness within the psychological sciences.

Secondly, the Gadamerian approach was applied as a paradigm guiding the research process. The underlying assumptions that both the participant and the researcher draw on their background knowledge and that understanding is advanced through self-reflection promoted active engagement of both parties. Therefore, the researcher acted also as a participant, while the participants became co-researchers. Through that process knowledge was not created by the researcher; rather, it was the result of a joint, meaningful construction based on an opened dialogue between the two parties.

Overview

Pilot study: Case studies.

The pilot, exploratory study used a collective (or multiple) case study approach based on Gadamer's (1975) hermeneutics to explore the lived experience of mental illness. Collective case study focuses on a selected issue and uses multiple bounded cases for illustration. It consists of a detailed data collection based on several sources of data, including interviews, observations, archival reports and other documents (Creswell, Hanson, Clark, & Morales, 2007). The aim is to reach in-depth understanding of each case as it interacts with or is set within its context (Verschuren, 2003).

Five participants (three male and two female) were recruited via GROW WA, a voluntary organisation that provides support for people with mental illness, and via Internet postings on Gumtree Perth which serves as an online community noticeboard. Each participant completed an unstructured, in-depth interview that functioned as an opened conversation and that was guided by the participants' own answers, in line with Gadamerian principles. The aim of the interviews was to obtain rich descriptions of the lived experience of mental illness and to gain understanding of the processes the participants utilised while trying to make sense of the experience.

The five case studies produced five unique narratives. Although those narratives differed from each other, they also shared some similarities. They all indicated that the way individuals incorporate their illness into their lives, with their unique context as a mediator, represents a complex process that goes beyond symptom description, diagnosis and treatment. The participants differed in the way they created their own

personalised models of mental illness that were meaningful to them and that helped explain their experience. However, for all five there seemed to be a link between the conceptualisations of their illness and their coping and adaptation. There were also a number of mediating factors, including stressors and triggers believed to play a role in the onset and prognosis of the illness; the role of significant others; and the place of professional help in the person's coping and illness management.

All five participants focused more on the impact of their illness on their lives than the actual symptoms. Instead they talked about a journey that was characterised by search for meaning, by their own way of conceptualising their illness and by the context within which their illness occurred. In this way, the participants demonstrated the depths and complexity of issues that are closely linked to their illness yet would not be traditionally considered as crucial to illness management. In addition, their stories indicated that it was not so much the clinical aspects of their experience (e.g., type of mental disorder, symptom severity) that determined how well the person was doing. Rather it was their ability to interpret events and make sense of their experience in a personally meaningful way that helped determine their perceived recovery.

The pilot project not only demonstrated the effectiveness of the Gadamerian approach as a research paradigm but also identified the need for further exploration of mental illness, as experienced and interpreted by the affected individuals. Furthermore, the findings contributed to the development of the researcher's horizon of meaning and helped shift her background knowledge.

Phase I: Exploration of the lived experience of people diagnosed with mental illness.

The first phase of the main study aimed to build on the preliminary findings of the pilot study and to further explore how people respond and adapt to the experience of mental illness and how they incorporate it into their lives. The study involved in-depth, unstructured interviews with individuals who identified themselves as having had mental illness. Although the researcher helped guide the interviews, the agenda was set by the participants themselves. The interviews were thus characterised by non-directive questioning, openness and joint contribution. It was this process of constructive dialogue that helped create an improved understanding of the participants' journey.

To supplement the qualitative data, the participants also completed the Recovery Assessment Scale (Corrigan et al., 1999). This 24-item self-report measure was developed in order to assess factors that consumers previously found important for their recovery and therefore reflects consumer conceptualisation of recovery. Yet as a tool that assesses certain aspects of individual functioning at one point in time (i.e. an outcome) it also represents the clinical frame of reference. In the age of evidence-based practice, outcome data are routinely collected as part of the clients' assessment (e.g., Health of the Nation Outcome Scales), and there have been calls for inclusion of recovery measures (Dickens, 2009; Lakeman, 2004).

The main aim of the RAS-R (Corrigan et al., 1999), as used in the study, was to gain additional information about the participants' experience and to see how their experience compared to their RAS-R scores. However, the scale was not used simply as a source of data that sat aside the participant narratives. Although it provided another horizon of meaning, the researcher wanted the scale itself (not just the results) to become part of the hermeneutic circle where both the researcher and the participant could engage with it and use it to possibly improve their understanding. The other aims, therefore, were to see whether the scale could be used as part of a dialogue about the person's illness-to-wellness journey and whether it could be used in a way that was useful for the participant/client.

It was decided to leave the surveys until the end of the interview because the main focus was on the description of the lived experience with participant-driven agenda. It was also felt that the openness of the interview process was better suited for the establishment of rapport than could be achieved with a survey. Furthermore, the term 'recovery' is not value-neutral. Priming the participants with the concept of recovery at the beginning might have biased the selection of topics they discussed during the interview. Finally, closing the first interview with a recovery scale provided a transition for interview II, which focused on recovery.

Phase II: Feedback on the Recovery Assessment Scale and exploration of recovery.

Shortly after the first interview, a second meeting was arranged. In the first part of the interview, participants had an opportunity to talk about their experience of

completing the scale and their perception of the items. A 2003 report on outcome measures used throughout Australia indicated that consumers (individuals with mental illness) believed that measures should be useful to them in that they should help them make sense of, and cope with, their illness (Siggins Miller, 2003). Therefore, participants were also provided with an oral feedback on their results on the scale. This process didn't involve the actual scores but rather a broad discussion of the five domains the scale is measuring as well as any items that either stood out for the participant (they were perhaps difficult to answer) or that stood out in terms of how they fit with the rest of the answers. The aim was to present the RAS-R (Corrigan et al., 1999) as measuring only one area of coping and functioning as well as something that the participants could contribute to in terms of their own feedback and that they could incorporate into their journey but only if they found it meaningful.

In the second part of the interview, the participants were asked to discuss their view of and response to the concept of recovery, as introduced by the RAS-R (Corrigan et al., 1999). Participants were asked about their definition of recovery in general and about their views on their personal recovery. Even though the primary topic of the interview was pre-selected by the researcher (RAS-R and recovery) the choice of what to talk about and explore was up to the participant.

Phase III: Follow-up interview.

Six months after their initial interviews, the participants were invited for a third interview. The aim of the interview was to present the researcher's summary and analysis to ensure that it correctly represented the participants' stories. The interview also provided the participants with an opportunity to provide feedback on the researcher's analysis. Because the Gadamerian approach is based on the principle of active participation of both the researcher and the participant, the process of providing and receiving feedback was an important part of the hermeneutic circle.

The second aim of the follow-up interview was to ask participants further questions that may have arisen during the process of transcription and analysis, as well as to allow participants to reflect on the preceding six months to add an update on their lived experience and possible new meanings. Yanos and Hopper (2008) noted that due to self-censorship and performance expectations qualitative research participants

sometimes present ready-made stories, instead of authentic, reflective accounts of their experience. They cited recovery research as an illustration of how perceived pressure to provide a ‘model’ story which is in line with available ‘success’ stories of recovery can produce interviews that are characterised by contradictions and inconsistencies and that are not true to the actual experience in question. The authors suggest supplementing interview data with informal conversations and casual observations, conducting repeated interviews where issues are revisited, and being attentive to one’s own biases as some of the ways to deal with what they call ‘false, collusive objectification’. Thus apart from forming a part of the hermeneutic circle, repeated interviewing was also used to enhance interview authenticity.

Sample

The recruitment method involved a combination of community announcements, personal visits, Internet postings and snowballing. Community announcements were carried out with the help of three consumer organisations: GROW WA; Mental Illness Fellowship of WA; and the June O’Connor Centre. GROW WA, which was used for the pilot study, is a peer support organisation developed by and for individuals who have experienced mental illness or emotional distress, and who share their experience and coping strategies in order to help and support other members while participating in weekly meetings, social activities and other events (“About GROW”, n.d.). Group notices and email messages with a description of the study were distributed through the GROW network.

Mental Illness Fellowship of WA (MIFWA) is a support, advice and advocacy organization for West Australians with a mental illness, as well as significant others (“About MIFWA”, n.d.). The researcher arranged personal visits to the Lorikeet Centre, MIFWA’s psycho-social rehabilitation centre for people with mental illness. The first three weekly visits were pre-arranged so that all attending members had prior knowledge of the researcher’s attendance. Following this initial stage, the visits occurred approximately fortnightly and in the follow-up stage monthly or as requested. These visits enabled the researcher to meet the centre’s members and explain the project so that all potential participants had an opportunity to ask any questions about what participation would entail. The visits also provided a unique platform for informal

observations and discussions that added another dimension to the learning process and another source of data, as recorded in the journal. While a number of participants were recruited following a direct conversation with the researcher, others volunteered to participate once they learned of the research from other members (snowballing).

The repeated visits also had the advantage of presenting the researcher as a fellow individual who had a genuine interest in getting to know the participants and hearing their stories. This helped to break the professional barrier and somewhat lessen the power imbalance that might have otherwise existed between a person of authority (the researcher) and the studied subject (the participant). It also might have promoted better rapport and therefore increased openness in the interviews. In total, 23 visits were made to the Lorikeet over a period of 13 months.

The June O'Connor Centre provides non-government services that allow people diagnosed with mental illness to meet, socialize and learn from each other. Six centers operating under the organisation offer social and recreational activities and a number of group programs ("June O'Connor Centre", n.d.). Flyers with information about the research and the researcher's contact details were distributed throughout the centres. In addition, similarly to the Lorikeet, the researcher made personal visits to one of the centers during which she met members, promoted her research and interviewed interested members. A total of 10 visits were made over a period of 9 months.

Internet postings appeared on the Gumtree website. Gumtree Perth is an open online medium where community members are free to post classified advertisements and community notices ("What is Gumtree", n.d.). An ad with a brief description of the research and contact details was posted on the website and subsequently reposted so that it was available for public viewing for a period of 10 months.

The participants were English speaking adults aged 18 years or older who had been diagnosed with severe mental illness². A total of 25 participants, 11 female and 14

² There is a lack of consensus on the definition of severe mental illness. Although there have been arguments that the definition should take into account diagnosis, degree of impairment and degree of service utilisation, such criteria remain problematic due to the episodic nature of mental illness, severity and impairment fluctuations and variability in service use (Parabiaghi, Bonetto, Ruggeri, Lasalvia, & Leese, 2006; Schinnar, Rothbard, Kanter, & Jung, 1990). In the present study, all participants were diagnosed with either a psychotic or affective disorder and had had experience with professional services. Furthermore, their narratives indicated that at some stage the illness had interfered with the

male, were interviewed, five for the pilot study and 20 for the main study; four participants each were recruited via GROW and the June O'Connor centres, six via internet postings and 11 via Lorikeet. In terms of clinical presentation, 10 participants received a primary diagnosis of bipolar disorder; eight of depression; four of schizoaffective disorder; and three of schizophrenia. Furthermore, 16 of the participants had more than one diagnosis and/or have had their diagnosis changed in the past.

Although attempts were made to ensure that all 20 participants of the main study completed the three interviews, this was not always possible for a number of reasons, including repeated hospitalisations, participants no longer attending the centres or no response to emailed or voice-mailed invitations. Out of all the participants who the researcher was able to contact only one communicated his wish to no longer participate (interview III)³. This resulted in a total of 52 interviews: 5 interviews in Pilot study; 20 interviews in Phase I; 17 interviews in Phase II; and 10 interviews in Phase III. The interviews added up to more than 43 hours of recorded data. Evaluation of the quality and the value of the emergent data determined that further recruitment was not needed as collected data provided sufficiently rich and varied information.

Procedure

The interviews took place at mutually agreed locations which included psychosocial centres, libraries, a cafe, and a church meeting room. One interview was conducted in participant's home and one in a psychiatric hospital. The process involved face-to-face communication as well as a number of email and/or telephone exchanges, followed by an in-depth interview. All interviews were conducted by the researcher who followed the Gadamerian construct of a dialogue so that each interview functioned as an

person's functioning to a degree that was perceived to be personally significant. However, the participants themselves indicated that the role of mental illness in their lives tended to fluctuate and for the research purpose it was more important to hear their stories than to ensure whether or not they could be formally classified as having a severe mental illness.

³ Upon being invited for the third interview, the participant commented that "I have done all that", meaning that he had shared his story. Although he had been informed of the full process and agreed to participate, he seemed to find the interviews more difficult than some of the other participants. He shared his story initially (interview 1) but seemed less interested in discussing the topic of recovery and furthermore asked not to be recorded (interview 2). Informal chats and observations at a centre he visited indicated that he was a very private person and it could be argued that he wished to no longer participate in order to prevent further disclosure and to protect his privacy.

opened conversation. Pilot interviews and Phase I interviews started with an opening question: "What can you tell me about your experience of mental illness?" Depending on the emerging data, this question was supplemented by questions about clinical aspects, such as diagnosis (e.g., "What were some of your thoughts when you were told your diagnosis?") and non-clinical factors, such as future plans (e.g., "Where do you see yourself heading in the future?"), plus other prompts and clarifying questions.

Phase II interviews started with a brief description of the RAS-R (Corrigan et al., 1999) and its five domains, followed by a discussion around perceived relevance of the domains to the participant, based on their scores. In addition, exploration of the concept of recovery was prompted by questions such as "How would you define recovery?" Phase III interviews started with questions around possible new developments in the preceding six months after which the researcher presented her summary/analysis of the first two interviews. This was carried out in a conversational manner, with the discussion structured around themes that emerged for that particular participant but presented in a way so that the participant had an opportunity to correct and clarify misunderstandings, or offer further comments. The participants were also asked to reflect on their experience of being research participants.

The whole data collection process was fluid and interactive so that for instance if a topic emerged repeatedly in the later part of Phase I, the topic was addressed with early participants in follow-up interviews. The process of checking and cross-checking for each participant across interviews as well as between overall themes and individual participants was important in order to achieve mutual understanding and complete the hermeneutic circle.

The data collection took place between July and November 2009 (pilot study) and January 2011 and April 2012 (main study). All but four interviews were audio-recorded and transcribed verbatim. Of those four, two were lost due to malfunction of the digital recorder and two were not recorded upon participants' request. In all four cases, the researcher wrote notes shortly following the interview. In addition to transcripts, journal data were entered after each interview, phone conversation or centre visit.

Establishing trustworthiness

Trustworthiness (or rigour) involved four aspects: credibility, transferability, dependability and confirmability (Koch, 2006; Nagy & Viney, 1994). Credibility can be established when participants are presented with the outcome of the analysis and are thus able to comment on it. (Koch, 2006). Because the Gadamerian approach is based on the assumption of two horizons of meaning, the analysis must function on both levels. As Polkinghorne (2000) suggested, interpretation is linked with understanding and to ensure that the participants' experience of mental illness was correctly understood, each participant who completed the Phase III interviews was provided with an oral feedback of the key themes for final evaluation. They were thus able to provide feedback on the analysis which was then incorporated into final interpretation of the interview data.

An additional layer of credibility was added with the use of the Recovery Assessment Scale (Corrigan et al., 1999), a validated and reliable measure. Another method for increasing credibility is via researcher's description and interpretation of his/her experience (Whitehead, 2004). This was sought with the help of the journal data which acknowledged the researcher's active role in the whole research process.

In terms of transferability, readers should be able to determine whether the study findings can be applied to other settings (Whitehead, 2004). According to Koch (1994), transferability depends on similarity of contexts. Therefore, readers should have sufficient information regarding the context. The contextual information in the present study consisted of the content of the interviews and relevant literature, together with description of the events, email correspondence and journal entries. The contextual data also helped establish dependability and confirmability by forming an audit trail which allows readers to follow the way data were collected, analysed and interpreted. The cross-member checking provided by the RAS-R (Corrigan et al., 1999) feedback served as a further test of confirmability.

Ethics

Both the pilot study and the three-phase research received approval from ECU Human Research Ethics Committee prior to their commencement. All potential participants received information about the research from a third party or via publicly

available information. Even in the case of personal visits, individuals were informed of the visits beforehand and those who were interested then approached the researcher; the researcher was introduced by staff members working in the relevant centres or, in later stages, by other members attending the centres.

Upon receiving the initial information participants had a choice to decide whether they wanted to participate and make a contact with the researcher. They were made aware that they could withdraw from the study at any time and were then asked to sign the consent form. Analysis was carried out with the use of transcripts which were de-identified. All names appearing in this paper are fictional.

Analysis

The data were analysed through thematic content analysis, following Gadamerian principles. Firstly, all transcribed interviews were treated as texts (Koch, 1996). Secondly, the analysis was carried out in accordance with the principles of the hermeneutic circle which proposes that the analysis should function on two levels: the descriptive one relating to the individual parts of the phenomenon and the interpretative one that places the parts within the whole of the experience (Whitehead, 2004). In other words, if we want to understand each part of a text, we need to understand the whole text but in order to understand the whole text we need to have an understanding of the individual parts. It is this back and forth movement between the parts and the whole that characterises hermeneutic interpretation (Smith, 1993). Thirdly, the analysis followed the principle of the temporality of data. According to Gadamer, each individual reaches his/her understanding in the light of existing pre-suppositions, and therefore the meaning of the text is not a matter of accurate representation that is set once and for all (Lebech, 2006). There can be no final analysis because the readers of the text continue the questioning (Hein & Austin, 2001). By bringing their own presuppositions into the process, readers themselves become interpreters as they interact with the text. Therefore, the emergent themes may differ for the researcher and for individual readers. However, readers should be able to follow the researcher's interpretative process (Koch, 2006). Thus it is the researcher's task to show that her interpretation is plausible when compared to other possible meanings.

The analysis was carried out in four stages. In the first stage, the transcripts were

read and re-read repeatedly to gain an overall impression of the data (Wertz, 2005). In the second stage, individual transcripts were analysed for key themes or concepts that emerged from the data. The third stage involved reflection on the themes as part of the whole, that is in relation with each other and with the overall experience of the phenomenon, as well as in relation with relevant literature and personal reflections, as recorded in the researcher's journal. The results of the Recovery Assessment Scale (Corrigan et al., 1999) were also used to examine what the assessment of recovery and/or the five domains measured by the RAS-R could add to each individual story. In the final stage, the themes identified for each participant were synthesised into a coherent picture of the phenomenon, including quotations to illustrate each theme.

Chapter 4

The lived experience of mental illness

Part I: Person-centred factors

Overview

A total of 25 participants (pilot study and Phase I participants) completed unstructured interviews in which they were asked about their experience of living with mental illness. Each interview started with the same question: “What can you tell me about your experience of mental illness?” and was then primarily guided by the participants’ answers. Clarifying questions were used, together with other relevant questions related to the topics of illness management and coping, current status and future directions, the experience of help (from professionals, peers, friends and family as well as self-help) and meaning-making processes. At the end of the interview, the 20 participants of the main study were asked to complete the RAS-R (Corrigan et al., 1999); all but two participants agreed. Of the two remaining ones, one chose not to complete it because of language difficulties (English was his second language) and one couldn’t complete it because of time constraints and was lost to follow-up so couldn’t complete the survey at a later stage.

Chapters 4 and 5 present those themes that could be broadly categorised as person-centred ones while Chapter 6 will focus on social and relational factors. The decision to divide the themes was partially made for practical reasons. The amount of information included in one chapter would have made reading the document more difficult. It was also considered that the themes naturally fell into two broad categories although it should be noted that those categories are not exclusive. For instance, the way a participant conceptualised his/her illness was a subjective process that could be viewed as person-centred yet the same process could be strongly influenced by professional explanation of the illness which could be categorized as a social factor. Similarly, although the individual themes and subthemes are presented separately, they were not distinct domains but rather factors that overlapped and interacted with one another. Finally, it should be noted that all participant names appearing throughout this document are fictitious.

Findings

Theme 1: Mental illness as journey.

The experience of mental illness was not seen as a linear process but rather as a journey of setbacks, adjustments and learning. Whereas clinical discourse usually follows the timeline of onset of symptoms, diagnosis, treatment and clinical improvement, participants were able to put together a story that was chronological but that was nonetheless marked by a constant back-and-forth movement between the past and the present as well as the future and the present, and that consisted mostly of rich contextual information. They were trying to understand why they became ill, what their illness signified, how it should be managed and how it should fit into their lives. With each episode the understanding was deepened or perhaps changed but it usually involved learning that there is a relationship between having an illness and living that could not be ignored.

Clinical information was rarely mentioned in its own right. Participants didn't just talk about symptoms but about what it was like living with them; they didn't just mention a diagnosis but also described their response to it. Treatment effectiveness was not seen as a yes/no dichotomy but rather as 'it works for me because...' or 'it works but...' For some participants, the learning process was a deliberate effort to try and understand and may have involved reading, research or attendance of seminars; for others, learning was more incidental.

Illness development.

All participants were given an opportunity to start their story where they wanted. While some talked about their diagnosis, most commenced their stories by talking about their childhoods and/or some other past experiences, in a way paving the way for what they perceived as an evolution of, or journey with, their illness. This journey usually started with what they understood as triggers or other factors somehow contributing to the development of illness. Some participants, usually those whose onset occurred at an early age, mentioned feeling "different" all their lives or they mentioned early pathological signs, which to them signified that the illness has always been there.

I knew I'd been different to other people but never knew why. And then when he diagnosed that things sort of fell into place, things that had happened and things that I felt or did and things like, you know, insomnia and talking too much. My dad always said I was vaccinated with a gramophone needle. And this was when I was really young and I would talk. And sometimes I get excited and I'm talking and I'm burbling like a brook. And I can see your eyes glazing over but I can't stop it. That's also part of it. And I can be way up there and then the very next day I'm in a hole and don't want to get out of bed, maybe don't want to cope with things... I could be crying, whatever (Elisabeth).

Others talked about difficult childhood characterised by strict upbringing, abuse, bullying, and/or familiar instability. Yet others mentioned experiencing a breakdown that was triggered by an event that was if not traumatic, then highly distressing. Not all participants made the link between predisposing/environmental factors and mental illness explicit but they seemed to agree that the development was gradual and that it involved a complex interplay of factors.

Once my wife and I had started a family, we have five children, um, I found myself increasingly disturbed by memories that I'd deliberately chosen not to think about or remember, so there was no element of restored memory or anything like that, it was simply realising what I'd chosen not to remember (Bill).

Stabilisation and maintenance.

With the exception of one participant from the pilot study who did confirm that he was psychologically unwell for a period of time (following a series of very stressful events) but disagreed with the clinical explanation of his experience and believed himself to be fully recovered, all participants saw their illness as something that will always be with them, with possible future episodes. Even those who could be described as being well saw their present state as temporary and used words such as maintenance or being stable. Such state was tentative with the underlying understanding that relapse was possible. However, such understanding was rarely associated with passive resignation or pessimistic outlook. Rather, participants accepted the episodic nature of their illness as part of life and either talked about active attempts to prevent future relapse and/or about their determination to manage such episodes if and when they

arise. Some of them communicated their belief that focusing too much on what could happen could be anxiety-provoking and ineffective. The point was not to dwell on the danger of possible relapse but rather on accepting the possibility and just focusing on the present with the hope that they will be prepared if another episode occurs.

I don't care less about that [future episodes]. I just think if it happens it happens. But I'm very cautious to try and make sure that it doesn't happen. Because I've got a lot of good belongings. I've probably got, I don't know, 50,000 dollars worth of stuff, you know, instruments and other things, furniture, stuff like that and I don't want to lose that. You know, that's like stuff from my family and all this, other things, you know and I don't want to lose that. And if I ended up with a really bad episode maybe I could lose that. Or even emotional things or you lose parts of your memory. If you have an episode you lose things, things go by the wayside, you know, it's not to worry about it, though, I mean, that's probably what's gonna send you there anyway, worrying about it...(Isaac).

Lessons learned.

Relapse and recurrent episodes were generally seen as setbacks but not necessarily as failures. For some participants, they were understood as opportunities to learn. For instance, they sometimes served as reminders for participants to slow down and focus on their wellbeing. At other times, a new episode led to a realisation that in order to be well the person needed to make some lifestyle or social changes (e.g., stop/reduce drug and alcohol use; break up relationships that were unhealthy). For Isaac, one such lesson involved him learning that he may relapse if he abruptly ceases medication and that medication plays part in his wellness:

I don't know, it was just, just some little slice of mania, you know, like I'm gonna improve, I'm gonna get better, I'm gonna get well and I don't need this stuff and that sort of thing and that's what ultimately taught me the lesson to, um, respect it as medicine and stay on it, you know, for the better.

Some participants recalled having had long periods of feeling unwell with very little distinct memories of those times, whereas others were able to describe each episode and what they learned from it. Making sense of individual episodes and learning from them contributed to the person's evolving knowledge, but this process

could not occur or only with great difficulties if the episodes were frequent or there were other ongoing problems that presented a strain on the person's personal resources. The individual usually needed time between episodes to reflect and make sense of what happened.

I think one of the other things as well as is they talk to you when you first come in [hospital] but they don't talk to you later down, later downstream when you've got a chance to recollect and realise what was going on, so... You need that space of time to come to your senses, so to speak, this is what's been happening, yeah...(David).

There were rarely any mentions of breakthroughs or turning points, even though certain events may have stood out (e.g., some psychotic experiences, first hospitalisation, being an involuntary patient); rather the experience was viewed as a gradual learning journey that consisted of gathering new information, creating new meaning and acquiring knowledge that helped them navigate through various obstacles.

In spite of individual differences, there were certain lessons that seemed to be common across participants. One of them was the realisation that their problems were classified as mental illness. For some individuals this was preceded by a feeling that something was not quite right, sometimes accompanied by a quest to find answers. For instance, Alice recalled:

It was frustrating. I used to go to my doctor and I used to say to him, I'm not sick but there's something wrong with me, I need some help with something but I don't know what it is because I'm not sick. And he used to say, oh, you work too hard and you smoke too much, go away (Alice).

For others the lesson was learned more abruptly, following an acute episode that perhaps required hospitalisation. Those participants were able to learn only in hindsight that there were signs prior to the episode that indicated that they were becoming unwell.

Participants also learned about the role the illness played in their lives. There were a few individuals who seemed to be consumed by their illness as if their illness was their lives. However, the general understanding was that the impact of illness tended to fluctuate. There were times that the illness seemed to almost take over whereas at other times it was just something that stayed in the background but

nevertheless never went away. Rachel described the phenomenon in the following way:

I mean it's probably, at this point in time in my life if I'd like to sort of sum it up in percentages or something, it's probably a 30% issue. I only say that because obviously I'm in a new emotional area so obviously it's a teething time and I'll see how I go and that sort of thing but in other times in my life it's been about 90% an issue because I've been so unwell but yeah. It's not a big thing at the moment because, you know, I'm taking the medication, I'm compliant with that, I'm realising when I'm getting off, you know, the keel, when the scales are tipping, I realise when that happens so yeah, it's not really, it's part of my life but it's not like Rachel equals bipolar lady, you know, like it's Rachel has bipolar but then I could just as much have an amputated leg or you know what I mean? It's there but it doesn't mean that you can't continue with your life.

Negotiating the system.

Together with learning about themselves and their illness, and the role the illness played in their lives, participants had to learn how to navigate the mental health system.

It [first hospitalization] is scary. You step into the unknown. You don't know anything about mental illness until you're in the system yourself. The average person that you speak to on the street if you ask them about the mental health system, they'll say the what? You know, so you don't know anything about the system until you're in it (Alice).

Although there was a great variation in the degree of utilisation of professional services, all participants had some experience with the system, ranging from a brief psychotherapy to involuntary hospitalisation. Aside from treatment options and their perceived effectiveness, the understanding of how the system works, what roles various practitioners play in it, what role the individual plays in it and how best to utilise what is available, were all important. Such understanding helped the individuals accept the system as one form of help that could be incorporated into his/her overall toolkit of management strategies.

One of the difficulties encountered by the participants as they learned about the system was the realisation that there were in fact two different systems (public and private) each with its own rules and ways of operating, and each with its own benefits and drawbacks.

I decided I didn't want to continue with private... it's too expensive and the private hospitals I thought were a bit corrupt, they kept me in one called [...], you've probably heard of it... and I was there for six months and I wasn't... I was just really a bit depressed when I went in there and to stay there for six months, and they were claiming full benefits from [healthcare funds] I think, and I thought that's just corruption... (Eric).

Although some participants were aware of mental health services, true learning only came with direct experience. The lessons collected along the way varied, relating to anything from rights and entitlements through clearly stated preference for certain types of treatment to careful selection of what to disclose at the time of assessment. Especially those participants who had been involuntarily admitted in the past were worried about being “locked up”; they were aware of the power the system could hold over them and they learned to self-monitor and censor their responses:

And he asked me a question, you know, off his list, do you believe in spirits? Have you ever heard, have you heard spirits, or something like that. Well, excuse me, I've hung out with medicine men, I know there are spirits, I've experienced them, right? That's my perception. You know what I said to him? I said no, of course not. So they give me the tick because I don't believe in spirits. If I had said yes, god knows what would have happened. He had the power to refer me to whoever, right? ...So I gotta lie to keep functioning, that's what they taught me, this society. And I try not to because I've always believed in being straight up but if you are, it counts against you sometimes, and sometimes you do have to play with the truth (Andrew).

Past – Present – Future.

At some stage, all participants either raised or were asked about their view of their future. All were able to identify something they aimed, hoped or wished for. The goals could be specific, such as becoming a guitar teacher, or general, such as becoming more confident. Most participants also communicated their hope for getting better in the future. However, the outline of plans and goals came with the caveat that it will all depend on the state of their illness at the time. While they generally needed to have something to look forward to and something to strive for, the participants tended to talk about being grounded in the present.

Staying in the present was not linked only with the future but also with the past. As discussed later in the chapter, past losses could have had a negative impact on the person's ability to function and manage their illness and therefore needed to be at least acknowledged (but possibly also grieved, worked through or reclaimed).

...if you dwell on something, like everyone's got something bad that they often dwell on or think about, everyone, everyone and I think the only way to deal with this sort of things is directly confronting them and then trying to let go. Or maybe let go off the past as well completely because some people have such terrible pasts that if they hang onto it all the time, that's a terrible burden. I wouldn't kind of just, just completely letting go of everything that's happened in the past and then just hanging onto the present and creating a new future instead of dwelling on the past because the past is often what, it's like the past, present and future, that makes up yourself (Liam).

However, one's personal history was not necessarily limited to negative experiences; the person's past also involved achievements and successes. It was the combination of both positive and negative experiences that the person would reflect on.

Being grounded in the present therefore involved movement between the past, present and future with strong emphasis on what was happening now. Going back was useful when the individual was trying to make sense of his/her experience, while having goals and plans for the future provided a direction, something to strive for, but it was the present focus that was the most important. Well-being seemed to be linked with a sense of contentment with the present.

Theme 2: Conceptualisation of mental illness.

Personal models of illness.

The participants varied in the way they tried to explain their illness. Although they were not always able to clearly define how they conceptualised the illness their narratives indicated at least an attempt to try and understand, whether in the form of a "mind-body-environment type model" (Christopher) or the belief that "some people have become unwell because of circumstances in their life" (Heather). However, not everyone has been able to create a model and this inability to do so was accepted with varying results. Some participants kept asking the question of why they became ill and

what their illness represented whereas others felt that they will probably never know why but that it did not matter as long as they knew how to cope. Therefore, finding a satisfying answer (whether in the form of a model or the belief that finding the cause did not matter) was more important than what particular model the person held.

Although some conceptualisations were unique, such as Oliver's assertion that he volunteered for schizophrenia, the most commonly described concepts could be summarised as falling into one of three categories: biopsychosocial, medical and trauma.

I mean I don't know that I know what causes it. I think in some ways for me it is very much a chemical internal issue but I also think a lot of my environment and my response to my environment it definitely magnifies my feelings and my reactions and different things (Janet).

I think it's obviously, if there is bipolar in the family I've got receptors to it, so receptors to stress, anxiety and depression and obviously receptors, they work when something triggers it, so, well, usually it's stress (Tina).

... it [hearing voices] started, um, quite suddenly. I think it was because I was really, really scared from my dad hitting me and I was trying to... and my mind went a bit crazy in an attempt to escape because I'd had a hard life and was trying to escape it (Vanessa).

The first of the three aforementioned explanatory models, the biopsychosocial model, recognized the complex interplay of genetic, psychological and environmental factors. Proponents of the medical model tended to compare mental illness to chronic physical illnesses, such as high blood pressure or asthma, illnesses that were biological in nature and needed to be treated with medication. Those who believed that their illness was the result of a trauma could generally identify the event or series of events, such as childhood abuse, that they believed was responsible for them becoming unwell.

The three models do not represent all the individual explanations but the ones that were most commonly mentioned. They were not necessarily mutually exclusive and one participant could hold more than one explanation, especially when they were diagnosed with multiple disorders or with a mental disorder and a disability (e.g.,

schizophrenia and Asperger's). For instance, Alice saw her depression and bipolar disorder as two distinct illnesses:

I know it comes from the sexual abuse I know that's where it stems from but it doesn't explain the manic or the lows, it doesn't explain those. Those are just illnesses that I've accumulated as I've got older, yeah, because the depression is the sexual abuse. The bipolar is just an illness that's helped itself to me as I've grown older.

The personal model sometimes took into account what the person learned from clinical resources but it was not always the case. Professional explanations were examined to see whether they made sense to the person. Where they clashed with the person's beliefs or where they were seen as providing only an insufficient answer, they were rejected, especially when there was no dialogue about the potential personal-professional discrepancy.

And another thing about that whole experience was, there was no solution, right? Solution, other than the chemical one, right? And there was no recognition of interconnectedness of the physical body and the spirit and the external stuff, and all that sort of thing. All he was looking at was some so called, and I've never actually seen it written down, proved on paper, chemical reaction in there that didn't balance, like... sounds like a fairy-tale to me (Andrew).

Once every two or three months I went to see a psychiatrist in [town], it was always a different one, but all they wanted to do was draw pictures of your brain and your endorphins and how the brain worked. Hello, I don't want to know how my brain works, I just want to know why it's doing what it is doing and it's really in more self-help, reading, talking to other people that have sort of done it and to me psychiatric help was no help at all because it was just too clinical (Bridget).

Just as professional explanations did not necessarily determine how the person viewed his/her illness, the type of illness model did not seem to be linked with a specific style of coping or illness management. The medical model, which is typically associated with reliance on medication and passive coping, could be viewed in a way that allowed for personal responsibility and active participation. For instance, Gwen who was diagnosed with bipolar disorder, which she conceptualised in a similar way to asthma, believed that it was her responsibility to go to appointments, ask questions, take

medication as prescribed but voice concerns if the medication was not working as expected, plus just like with asthma, there were lifestyle adjustments that could prevent exacerbation of symptoms. It appears that it is not the model/explanation people create or adopt that determines the person's response to their illness and their coping, but rather how the model is used and whether or not it allows room for action and personal responsibility.

Signs of ill health vs. being well.

All participants were able to describe their symptoms, using both clinical jargon and lay descriptions, at times including rather vivid metaphors. However, not everyone was able to link the two and there was confusion about technical terminology. Furthermore, the participants described parts of their illness that would not qualify as symptoms in clinical terms but that were nonetheless disabling.

I can remember when I was really unwell that things were too much in my chest that I couldn't even open the door, say like that door there because it was too heavy. I would wait for someone to open the door and I would hold it with my foot, like that, you know, that's, there's a lot of things involved. And jumpers. I couldn't wear jumpers. If it was cold and it was too much for me, I had to take my jumper off because I couldn't function, you know what I mean? I had to use plastic spoons, plastic cups because I found crockery very heavy (Heather).

What I can describe it as is when you have a whiteboard and you know the splatter hands that you have, so these splatter hands of blackness just keep coming over on the whiteboard and they splatter and slowly, slowly they eat the whiteboard up until it's all black. That's what depression is to me (Alice).

At the height of being ill, if the phone rang suddenly I would become incontinent, if a dog barked as I was walking past the house I would become incontinent, it became impossible for me to go anywhere (Bill).

Unlike talking about being ill, when it came to describing wellness (or 'doing OK') a number of participants seemed to struggle. Wellness was not always seen as a distinct state of being but rather in relation to the person's illness, usually as an absence of symptoms. It seemed that for some individuals with chronic problems and frequent

episodes, being unwell was almost seen as the norm and therefore represented a baseline; deviations from the baseline were understood as improvement but not necessarily wellness. Other participants understood wellness as their baseline but were aware that some adjustments may be necessary so that what they understood as wellness prior to onset was not the same as wellness experienced following episodes.

Acceptance: mental illness, diagnosis and episodic nature of the illness.

Accepting that the person was suffering from mental illness was one layer of acceptance. Some participants spent years knowing that something was not right before being diagnosed. Acceptance might have been preceded by denial or by having to face one's own preconceived ideas of mental illness but was eventually associated with a sense of relief. Diagnosis legitimised the person's experience. Worries about going crazy were replaced by a realisation that they suffered from a real, legitimate illness that had a name.

...having had a diagnosis explained a lot of the way I felt earlier in my life and different behaviours and things like that. It explains to me that, you know, this is something that was there for a very long time. It just wasn't being addressed (Gwen).

It's weird but I've never actually had a period of mourning becoming mentally ill, I actually almost celebrated it because, not because it was a convenient peg to hang things on but it helped me... As soon as someone said, actually, you're not very well that was certainly committing to not be well for a while and fix myself up instead of just skating along the surface. I never felt I had a permission to be ill or to be tired or to be stressed so you end up ill, tired and stressed (Bill).

People used to say you're mad, you're crazy, you know, you're this, you're that. For a while I did believe it. But I knew I wasn't that mad, you know what I mean? It's just an illness (Heather).

Most participants also accepted their diagnosis. It gave a name to what they were experiencing and helped explain what they at times found as puzzling or scary. Unpredictable mood swings could now be named bipolar disorder; extremely low mood states were termed depression. The individuals tended to accept the diagnosis and then move on. The actual label did not seem to be important even though a few participants

believed they were misdiagnosed, others had their diagnosis changed and yet others expressed their confusion about what their particular label represented. One participant recalled having received up to 9 different diagnoses by the time he was 22 years old. He found the diagnostic process unreliable which made him question the whole mental health system.

Although the participants generally accepted that they were mentally ill and they generally accepted their diagnosis, the process of acceptance differed. Some participants seemed satisfied with the answers provided by their treating practitioners: they suffered from mental illness that had a certain name and that needed to be treated with certain medication. Others, however, had to grapple with the idea that they were not “normal”. Diagnosis provided answers but they also sought to understand how it related to what they were experiencing. They might have done research (library, internet) on their particular diagnosis, joined a support group or even sought to share their story and educate others. They attempted to work out what caused their illness or why they became ill in the first place. The diagnosis was not used to define them but was assessed and examined, which helped the individual incorporate the illness into their lives.

I think it's, I'm glad I had though time without it, if that makes sense, and I'm glad I had a time when I didn't have that extra label. I know that sounds a bit bizarre but I'm glad I sort of had, you know, for 20 years of my life I didn't feel like I was any different from anyone else and I'm actually very glad for that only because of the way society puts us, I guess is the reason I'm glad (Rachel).

It could be argued that mental illness and diagnosis are two different concepts. Mental illness refers to the nature of the person's experience/problems whereas diagnosis is a name given to the person's particular type of mental illness. Having a diagnosis means that a person is classed as being mentally ill whereas having mental illness does not necessarily mean the person has been diagnosed. Yet those two concepts are intertwined. When people start experiencing psychological difficulties they could be seen as mentally ill yet the participants indicated that they didn't start seeing themselves as mentally ill until they were diagnosed (or self-diagnosed in one case). When talking about their experience they were more likely to say they had depression or they suffered from schizoaffective disorder than that they were mentally ill.

The third level of acceptance related to the episodic nature of the illness. This type of acceptance developed over time, following ongoing problems and repeated episodes when the person came to realise that although he/she may be well there was always the possibility of future episodes. For instance, Isaac reported that he hadn't been sick for 14 years yet acknowledged that he had an illness that didn't present major obstacles or didn't interfere with his functioning because he had learned to manage it.

I just think I'm always gonna have it [depression]. I don't want to have it, I don't think I have to have it, I don't want to keep hold of it but I just think, well, I'm always gonna be right-handed, I'm always gonna be myopic to some degree so I'll probably always have episodes of depression (Keith).

When it [psychosis] just happened once I thought, oh, it might never happen again and I was a bit wrong in thinking that it may never happen again... so I thought I was off the hook almost and I was a bit too no worries about it. Having had it a second time it's really drilled in. It's like I'm a bit... I draw a link between saying, you know, I think I was a bit dense the first time, a bit stupid, and I was a bit, oh, a slow learner and then it happened again so I got the message, you know. And so the message is obviously there is that ability... I've definitely got bipolar for one. Secondly, I am susceptible to this psychosis and I guess the conclusions are that the stress probably was a cause, the major cause (Rachel).

My overall goal is not to necessarily be permanently on medication but I realise that it's something through the course of my life that I will have to cope with, that it's not going to hundred percent just disappear even if it goes into remission for a while. It can easily just come up again so if I can do things to try and set myself up where, you know, it's less likely to be an issue then that's what I'll try and do (Janet).

Describing someone as a person who has mental illness or talking about chronic illness could create the perception that the person is ill all the time. Yet people actually experiencing mental illness generally accept the illness as something that is with them, part of who they are and part of their existence but they do not consider themselves ill unless they have an actual episode. Therefore a person who is mentally ill can in fact be a person feeling and functioning very well.

MI (mental illness) and Me.

Participants reported that it was sometimes difficult to differentiate when what they experienced was due to illness (e.g., low mood as a sign of depression and therefore a possible warning sign of relapse) and when it was a normal reaction to events (e.g., low mood as a normal, temporary reaction to stressful events).

I don't want to get into the blame game of I'm having a bad day so it must be the depression versus no, I'm having a bad day because I'm human and I'm having a bad day. And the thought of because I'm struggling with such and such, well, that's because I've got depression versus I'm just struggling (Janet).

The participants engaged in self-monitoring and used their knowledge of their illness to try and separate the two, but it was a balancing act that required self-awareness. Being able to tell when they could still cope and when it was time for an intervention, whether in the form of increased medication, voluntary hospitalisation or a visit to a psychologist, was an important skill.

Similarly to the illness/normal response dilemma, there seemed to be a fine line between a specific characteristic as part of the person's nature and its link to illness.

You will know when I'm in one of my high periods. I'm talkative all the time. I've been talking since before I was twelve months old and I'll probably talk until the day I die, you know, that's because I'm a Gemini, not because I've got bipolar, yeah, that's just a personality trait for me, you know. But there is a difference between me talking in a conversation and being overly talkative. It can be very quick and quite erratic (Gwen).

Trauma.

The schizophrenia symptoms are random, they come and go when they choose to. Or sometimes when I think about something and a memory comes back, that can be a bit upsetting but you just have to work through it and not let it disturb you too much. But if you've been through trauma you're always going to have the memories of whatever it is that has happened to you and you never entirely forget it (Vanessa).

A large number of participants disclosed having experienced trauma. Those who believed that the trauma contributed to them becoming ill usually found that working

through their trauma was important, whether through counselling, self-help, spiritual guidance or another form of help. However, they also acknowledged that such healing was not always a permanent achievement. Even where they believed that they had worked through the distressing experience, certain events or circumstances could cause for memories of the trauma to come up throughout the person's life. When that occurred, the trauma and its consequences may have needed to be revisited in view of the relevant circumstances. For instance, Heather who was severely abused as a child by her parent received counselling to learn about trust, to gain self-esteem and to learn about how to set boundaries in relationships. The abuse was then revisited when she struggled with intimacy in her relationship with her partner and again later when she was thinking about having children and feared that she would become like her abusive mother.

Trauma could come in different forms. It could have been a specific event, such as death of a loved one, or a series of events, as was the case of all of the participants who disclosed having been abused as children. However, it could also be the actual symptoms of their illness, particularly in the case of psychosis.

It's a very scary thing when your own mind is like your enemy. It's not someone physically or psychologically attacking you, it's you own mind, like, it's like attached to you so you can't escape it. Yeah, so that was hell, but I got through that... (Liam)

Trauma also related to treatment. Involuntary hospitalisations or treatments (heavy medication or ECT) have been mentioned. Some participants had strong objections to being treated without consent but others, who were able to acknowledge the necessity of such treatment in hindsight, nonetheless described their hospitalisation as a frightening and bewildering experience. This was particularly pronounced in first hospitalisations. Not only did the individuals experience acute symptoms that were highly distressing but then found themselves in an unfamiliar place without a clear understanding of where they were, why they were there and what was going to happen to them. Heather who was admitted by her mother (the same person who had been subjecting her to severe abuse for years), had no understanding of mental illness and no knowledge of psychiatric hospitals. She described her first hospitalisation with the following quote:

I just, I don't know, things fell apart and I ended up in this hospital over here [hospital]... .. And in actual fact it was my mother that took me there, she dumped the suitcase at the front door, the nurse went up to her and before the nurse got a chance to talk to her, my mother said to her, 'get rid of her'. 'Get rid of her'. And I thought, oh, shit, what's all this about? It didn't click and they took me to my room upstairs ,before the night was up a priest came in and he said to me, would you like me to say a few words, and I thought, what's all this, what's going on here? And I said no, and I was confused. There was no one else coming in to talk to me, I didn't even know what I was in there for. I knew that I wasn't well but I just didn't know what it was and then in what seemed like a half an hour later a nurse came in and she said to me 'we're going to give you your injection'. And I said, no, I don't want any injection, and they didn't say what it was for or nothing. Anyway, I'm on the bed and she was trying to give me the injection and I was pulling away from her because I thought she was killing me, I thought she was injecting me with something because I'd heard my mother downstairs say 'get rid of her', so I became paranoid, 'get rid of her'. Anyway, she ended up giving me the injection and I was lying on the bed and thinking, that's it, I'm going now, I'm dying. Oh, it was horrible, Zdenka, it was scary. And I woke up the next day and I was all bruised because I tried to stop her from giving me the injection.

While her fear could be inscribed to paranoid thinking, the combination of being unwell, history of abuse, no knowledge of mental illness and the system, and reportedly lack of communication on the part of practitioners combined to create a traumatic experience. Whether or not Heather's recall of the events was accurate is less important than her interpretation of what happened, as it was this interpretation that consequently guided her views of her difficulties and of treatment. It was such lack of communication (explaining what the professionals thought the problem was and explaining each step of the treatment AND asking Heather for her explanation of what was happening) that magnified what was already a highly distressing situation. It was also an example of missed opportunities: an opportunity to help Heather integrate what was happening with her life experience in a way that made sense to her.

Theme 3: Illness management and coping.

A number of participants were experiencing symptoms of mental illness for a long time prior to being diagnosed and they had developed coping strategies without

fully realising what it was they were trying to cope with. The early attempts were not always effective and were therefore at some stage re-evaluated and replaced. Self-medicating with alcohol or illicit substances; keeping busy with work to the exclusion of anything else; or self-blame were all reported as examples of early coping.

Some participants carried on with these strategies even once diagnosed and treated within the mental health system, but generally individuals reported a large number of skills and strategies they utilised to manage their illness and improve their coping. Overall, however, it was not just about collecting strategies for a toolkit. Rather, it was an ongoing process of increasing knowledge of self and the illness through each new episode and other life experiences, and about consolidating that knowledge.

It should be noted that the concept of coping was not limited to dealing with the actual symptoms. Well over half of the participants reported having been diagnosed with more than one disorder and/or co-morbid mental disorder and substance abuse. For instance, Vanessa talked about having strategies for her mental illnesses (schizophrenia, depression and OCD) and for her disability (Asperger's).

Further, the coping didn't simply involve addressing the actual symptoms of the relevant mental illness but also consequences of the illness and its treatment, such as loss of relationships because of mental illness or memory loss due to ECT. Finally, participants also developed strategies to help them cope with trauma which they associated with their illness. These participants needed extra resources because instead of coping "only" with mental illness they had the additional work of having to face the memories and the consequences of their trauma.

Personal responsibility.

The quest for effective management was often accompanied by the understanding that looking after one's health had to become a priority; it was important that the individuals learned to put their wellness first without feeling guilty. This was further linked to the concept of personal responsibility. The vast majority of the participants had learned that they had certain responsibility for how their illness was managed. At the minimum level of responsibility, participants talked about attending appointments, listening to their practitioners and taking medication as prescribed. Those with more advanced understanding of personal responsibility also mentioned more

active strategies, such as asking questions if they didn't understand something and speaking up if they struggled with an issue, such as side effects of medication.

While more active, this type of responsibility was still closely linked to professional care. However, personal responsibility at its highest level was a holistic approach where the person accessed a variety of resources (professional treatment, peer support, the support of significant others, self-help) and demonstrated a very good understanding of their particular illness, not just the clinical diagnosis but the way the illness manifested itself in their particular case. It included an understanding of warning signs, understanding of conditions and events that could trigger an episode or exacerbate the symptoms, and having a large toolkit of coping strategies. It also involved knowing when the person was still able to cope and when it was time to ask others for help. Finally, it involved knowing where and how to seek help in case of an acute situation.

For most participants, learning about responsibility was a gradual learning journey. Some participants mentioned being naturally self-reliant, while others talked about having had physical health problems and therefore some experience with health management. For others, learning that getting and staying well was primarily their responsibility came as a shocking lesson, although there were resources they could access for help. For example, Molly was diagnosed with bipolar disorder as an adolescent. Her parents assumed responsibility for her health and she learned to rely on their assessment of the type of help she needed, usually hospital admissions: *"my dad used to force me in there for any reason, happy, sad, anything like that, and I ended up staying in there because that was it"*. Following a period of rebellion and her psychiatrist's intervention in her early 20s, she started making her own decisions regarding her care. However, by then she was becoming more and more reliant on hospital treatment afforded by the private health system. When she was becoming unwell she didn't try to access her personal resources but instead asked to be admitted.

After more than 20 years of following the same patterns she switched from private to public care. Whether because of its philosophy of community treatment or because of external constraints (limited funding, insufficient number of acute beds), Molly realised that access to hospital treatment had suddenly become more difficult.

She struggled with the transition but at the same time admitted that under the private system she became institutionalised and she generally waited for others to “pick up the pieces”: *“I have been hospitalised and I would say institutionalised since I was 15 and I’m just weaning off it if that, well I’m trying, because it’s been a revolving door syndrome”*. While she came to understand the importance of personal responsibility she knew that looking after herself was hard work.

...it’s always been other people’s responsibility to run after me and do it all but the private, what am I saying, the public sector has made me think, my god, no one’s gonna do this, no one’s gonna do this anymore. They can come as a case manager to my house to check on me, do things for me but I’ve been through all that and you know, it’s hard, it is hard.

Self-monitoring.

Participants reported that self-monitoring played an important role. Successful self-monitoring required that the person knew how their illness presented itself and were attuned to changes in their functioning and wellbeing. It also involved knowing the difference between natural fluctuations and warning signs of possible episode.

It’s a constant self-check and as kind of anal as it sounds I guess that’s just my condition and I just have to be more aware whereas someone they can be in a grumpy mood and they can snap out of it quicker or they can, it’s not a big deal because they compensate in an easier way or in a different way but I know that potentially it can get worse for me whereas the other person on the street it might be just for half an hour and no big deal. So I just have to constantly check because I guess what I know at the back of my mind is that I never want to be or if I can help it I never want to get sick again, if I can really help it, so obviously if there’s an external stressor like a death or something that comes up I’m not gonna be able to help that but at least if I can control as much as I can that’s what I try to do (Tina).

Some participants talked about general awareness of what was happening while others used specific tools, such as diaries. A number of participants said that they listened to feedback from other people (significant others, friends, peers) who knew them well and who could sometimes notice subtle changes in behaviour before the individual did. Those who had a good working relationship with their treating

professional also valued their feedback.

Understanding their illness and self-monitoring represented only one step; knowing what to do once they became aware that they were becoming unwell was another. The participants, especially those who had a strong sense of responsibility, had to walk the fine line between self-management and external help. Knowing one's limits to coping was important but those limits were not clearly delineated and could shift depending on context. Some situations required only minor adjustments, such as easing one's work or social commitments, whereas other situations called for a more acute intervention. A number of participants reported having increased their medication dosage temporarily or asking for more frequent psychotherapy sessions. Others used their support network, such as Alice who promised to tell her husband if she was becoming suicidal and perhaps needed to be hospitalised so that things didn't escalate to an actual attempt. Hospital admission was usually seen as a last but nonetheless valid option.

Balance and personal limitations.

Finding the right balance refers to a number of lifestyle and relational issues. What could be seen as a normal adult lifestyle – family commitments, full-time work or study or some combination of the three – was difficult to achieve for a majority of the participants. While they may have done so in the past, they came to realise that their illness made such arrangements no longer possible. Some participants saw such a state as temporary and planned to return to work or study at some time in the future but the majority saw that some adjustments were necessary so that full-time employment was replaced by part-time or casual work, and a university degree was replaced by a college certificate.

Such adjustments grew out of necessity but at times were welcomed as an opportunity to re-evaluate the person's priorities. For instance, Heather who was forced out of her home at the age of 14 and had to work to look after herself since then used, the onset of illness as an opportunity to take some time out and ended up pursuing her interests in art and languages. Molly talked about her love of children, and described the excitement she felt when she volunteered as a Girl Guide. Overall, at least part-time work or study, volunteering, community work or peer support were mentioned by more

than half of the sample.

In addition to adjustments, there was the ever-present understanding that the illness might end up interfering with goal achievement. Alice had to quit her studies because of depression relapse but hoped to do more study once she became well again. Simon loved his work but seasonal affective disorder, on top of his bipolar disorder, meant that he was unable to work for a portion of each year. Bill held a part-time job and while being able to handle it at the time of the first two interviews, he described a growing awareness that the job was becoming too much and quit not long after that.

What I have found was that it is too exhausting and too challenging, not in a physical sense, for me to work too much, um, so I had a variety of part-time jobs that I might do for three or four months and then I could tell that it was, it was wearing me out or I was wearing me out, so in some way self-monitoring myself.

What Bill demonstrated was his awareness of personal limitations. While he had tertiary education and a career in the past and was proud of his achievements he knew that his mental illness placed limitations on what he could do. Awareness of such limitations was necessary for wellbeing. If looking at what they did in the past or what they thought they should be doing, whether because of personal beliefs or some societal expectations, it would be easy to overcommit. Not taking on too much, therefore, was crucial to ensure wellbeing and prevent relapse. Too much work; too many social commitments; too many errands scheduled for one day could be overwhelming. It was important to strike the right balance between social withdrawal and lack of activities on one hand and too much to do on the other, as Rachel reported:

There was probably about a year ago when I was getting too involved and I was planning all these things and I was getting a bit carried away, so obviously it's a fine line. So although it was really good that I got involved and it shows that I'm healthy and it shows that I'm confident and shows that I'm back to myself and I'm meeting new people and things, if that tips too far though then it becomes as a warning sign. So it's a tenuous balance between healthiness or not, or potential illness, not necessarily illness but potential (Rachel).

Lifestyle adjustments.

This subtheme is closely related to the preceding topic. Adjustments in terms of work or study played a role but they were not the only changes participants reported. Some talked about learning that while occasional drinking and recreational drug use may be OK for other people they had to abstain because of the impact of those substances on their illness or their interference with medication. Similarly, while some participants talked about having been able to work hard and function even with a lack of sleep in the past, this was no longer possible. Balanced lifestyle, primarily in terms of at least reduced intake of drugs and alcohol, good diet and nutrition, exercise and regular sleep was not simply a choice because it was healthy but it became a necessary part of illness management.

I'm slowly working on like trying to eat well or better, you know, trying to always eat and trying to hang out with good company, make sure I don't take any drugs, or drink alcohol or smoke cigarettes or anything, yeah, trying to keep myself healthy (Liam).

Being productive and having fun.

A large proportion of the sample was recruited via psychosocial centres. When talking about their experience of the centre, participants often talked about having something to do. Some were regular attendees while others came only sporadically. However, they seemed to agree that without activities, days were difficult to fill, and with nothing to do it would be easy to slip into a cycle of withdrawal and rumination. Some participants were able to find meaningful activities within the community but for others the psychosocial centres filled that role (and certainly a number of individuals engaged in both). Whether just coming for a chat, to use the internet, to ask for practical help or to take part in the variety of scheduled activities (ranging from reflexology sessions, yoga classes, going to a café to day trips), the centres helped keep them occupied.

...a mind that's empty this [past trauma] stays on it and if you fill your mind like I did with [the centre] and school, at least the bad thoughts aren't taking a big part of your life because there's not as much room for them so it's much better when you keep busy (Alice).

It's wonderful, it's given me a social life. I have friends for the first time in years... I was never allowed to really have close friendships, even when I was married, why do you need friends, you've got me, that kind of thing, typical controlling behaviour, so yeah, I've got a circle of friends and I've got things to do, there's plenty of activities to do, the staff are great friends, they're not just the people who work at a place I go (Gwen).

Having something to do helped fill the day, give it a structure and keep negative or obsessive thoughts at bay. It also created the feeling of being productive. For a majority of participants, activities were not random day fillers but they had a function. For instance, sitting around a table and talking to other people was done because the person enjoyed the other people's company, because it gave him sense of belonging or perhaps because it helped combat loneliness. Whatever the reason, the act of being with others was meaningful.

...it is somewhere that you can go to when you are feeling unwell. There's not that many places you can go to when you hear from your doctor, Gwen, you aren't well, where if you are having a really bad anxiety attack, nobody's going to look at you like you're strange, you know. You're accepted the way you are.

While being productive was important, it was equally important to have fun. Participants cited a wide array of hobbies (e.g., exercise, movies, pets or arts and craft) that were pursued for a variety reasons but mostly because they were enjoyable. Acute episodes of mental illness may temporarily disrupt the person's ability to enjoy pleasurable activities but simply being diagnosed with mental illness does not preclude fun. In fact, a sense of humour could be detected right across all interviews. Some participants cited humour as a coping strategy or used a humorous remark as an example of their way of handling past experiences but they were also demonstrating their sense of humour during the interview process.

Socialising.

Socialising and the role of other people in the participants' life played a crucial role. It is included as a subheading because it was used as a coping strategy. However, it was such a large part of the overall experience that it was felt it deserved its own section and is discussed in detail in the subsequent theme in Chapter 6.

Pulling back.

Several participants talked about pulling back from situations, whether in a physical sense or mentally. Physically pulling back refers to walking away from situations that are distressing and that could trigger an episode or exacerbate existing symptoms. For instance, some individuals with paranoid thinking grappled with the idea of whether their thoughts were real or not but learned to walk away from situations that gave rise to such thoughts.

Mentally pulling back refers to strategies that prevented the individuals from immediately reacting to a situation that is found to be potentially distressing. Participants used descriptions such as waiting things out, stepping back, taking time or deliberately slowing down.

And... like the talking too much. I've learned to watch that, usually, step back a bit from it. And also, I get very emotionally involved with people's problems and then I'm walking around like a little old lady with all their problems, so I've learned over the years to step back a bit (Elisabeth).

And one of the things really to help me not just manage the depression but manage my life overall is giving myself time and allowing myself to, I suppose, have some downtime without thinking, without that negative thought process that goes with it (Janet).

Sometimes I've been at a friend's place and I haven't really enjoyed being there, you know, friends are there or relatives of theirs are there or something and it's not really... it's not really an idealist situation for me so I come home and I might be a bit uncomfortable and I've sort of got memories of things being said or stuff that didn't really excite me or didn't make me feel good, you know. And then I just sort of think, ah, it's all gonna disappear, you know. An hour from now, two hours from now, whatever, it's all gonna be gone. And I just let it drift away, you know. If I'm really bad and I can't sleep, um, I'll meditate, you know. I'll just meditate with a mantra until I fall asleep (Isaac).

Other: religion/spirituality; meditation; music; cognitive strategies.

Strategies developed by the participants were unique to each individual and it

showed great creativity. One aspect mentioned by a few participants was religion and spirituality.

And I'd been thinking because as a child growing up mum used to take us to Sunday school and I was thinking maybe I should go back to church, I find it's a good place of solitude and I think it's helped me to reflect back and now I can be accepting of [ex-partner's] decisions and forgiving (Tina).

Another commonly mentioned strategy was meditation and mindfulness.

And you know you can have a really mindfulness type of meditation where you're focusing on something that makes you feel good or nice and relaxed like I do with my garden, so that works for me so that's what I do. When I feel the need for, you know, some calmness and peacefulness, that's what I do. Even if it involves me holding my house and watering the garden, I'm watching, you know, the world as it just goes around my garden, it still counts. See, whereas at one time I didn't know that. People would start talking about meditation and I mean, I would feel too vulnerable, a bit like that being alone. And I wouldn't want to do it (Gwen).

Many participants also mentioned music, whether pursued actively (several participants played instruments and/or sang) or as listeners. Finally, participants didn't rely only on doing things a certain way but also thinking a certain way. Cognitive strategies, such as restructuring or looking at things from a different perspective, were employed. A few participants talked about trying to "think positive". While some failed to elaborate, others expressed their confusion about what that concept entailed. For instance Frank asked whether it was possible to think positive all the time. Nonetheless the notion of positive thinking was evident in many narratives.

Theme 4: Losses and gains.

The journey with mental illness entailed a number of losses. While experiencing loss is an inevitable part of human experience, when it came to mental illness those losses seemed to be either more pronounced or had more severe consequences. All participants mentioned what they had lost but they varied in their response to those losses. Some dwelt on them and seemed to be lost in depressive rumination while others were able to acknowledge them and move on. Some losses were reclaimed, some

needed to be mourned. Sometimes, where a person lost something he/she was able to gain something new. Finally, past losses didn't prevent the person from planning for the future.

What has been lost.

The relationship between mental illness and loss was complex. There were losses that could be directly attributed to mental illness. At the height of an acute episode, the person could have experienced anything from a loss of self or loss of one's ability to look after self and carry out basic daily tasks, such as grooming, to a loss of custody of her children. Those losses were acknowledged and examined in terms of their potential to be claimed back. Sometimes, once the person became better following an episode, their lost skills or abilities returned. At other times, some adjustment was necessary. It should be noted that such losses, while not generally understood as part of the illness, were sometimes at least as debilitating as the actual symptoms.

I had success studying electronic engineering in the 80s but I didn't complete it but I passed all the exams that I sat for the first time I attempted them so I could have completed it. But I had something wrong in my psyche that doesn't let me complete something like that. That could have led to a good outcome for me (Eric).

Aside from losses that occurred as a result of illness, there were losses that caused or at least contributed to the development of mental illness or that exacerbated the symptoms and made coping more difficult. Two participants recalled losing a loved one as a trigger of their illness. Others were convinced that their illness was a direct result of being abused as children. Abuse as such is traumatic and could be interpreted as a constellation of losses, at the very least involving the loss of an opportunity to have a normal childhood with secure relationships. Another participant who grew up in children's home talked about him not having had a mother as a lifelong regret that played some role in his depression.

Finally, loss affected the person's future goals. Being unable to complete a tertiary degree one was hoping for, not being able to work full time or a decision to not have children because of fears of being unable cope all caused distress. Bridget struggled with severe depression which managed to alienate her from her two adult children. With her relational role primarily as a mother and grandmother at the core of

her identity, the loss of her relationships acted as a perpetuating factor. Bridget believed her illness prevented any chance of future reconciliation, which she found extremely difficult to accept.

Regardless of the type of loss experienced, there were various responses to it, including but not limited to acknowledgment, suppression, grief or acceptance. Without understanding its significance and its impact on the person's wellbeing, the loss could interfere with the person's ability to function. Acknowledgment seemed to represent the first step in the effective management of the loss. Acknowledgment, however, didn't necessarily involve rumination. Although for some people the loss was always present to some degree or it kept coming up throughout their lives, it didn't mean that the persons remained fixated on it. The loss may have needed to be revisited and worked through in light of present circumstances but it didn't need to take over the person's life.

I do meet a number of people here who are very much, they're very preoccupied with what they've lost as opposed to what they've got... and I'm reasonably content with what I've got (Bill).

I had big aspirations, you know, but I'm not gonna be sorry for not getting any further with those things than I did because I achieved an awful lot of things that I wanted to (Gwen).

What has been reclaimed/ gained/ planned for future.

Some losses were temporary and were reclaimed once the person's wellbeing improved. In her first interview, Alice talked about no longer being able to go grocery shopping and cooking for her family as a result of her illness. By interview three she reported having gone shopping on a number of occasions. Although shorter in duration, the shopping trips demonstrated that she was able to get some of her old ability back.

I haven't been able to do the shopping until probably the last six months, I haven't been able to do the shopping. Then all of a sudden one day I went into the shop and I bought something small. And then I went back and did the grocery shop. And now I do the groceries again so I've taken back a little piece of who I am, you know (Alice).

In spite of the number of distressing experiences, it would not be accurate to portray the participants' narratives as characterized by loss. In some cases, the

experience of mental illness involved gains. Some gains represented typical goals (or normal developmental milestones) that were acquired in spite of the illness. The participants clearly demonstrated that starting a family or completing their studies was possible even following an onset of severe mental illness. Some gains were old goals that have been modified. However, some things were achieved not in spite of mental illness but because of it.

I've learned a lot about myself and I'm certainly much more tolerant and compassionate towards other people (Rachel).

I found it really valuable in retrospect because it's made me think about what's important to me as a person in life, and it's also made me really, I'm very confident now in my own abilities (Andrew).

A number of participants reported that the onset of illness presented an opportunity to slow down, re-evaluate priorities and start addressing their problems. It was also a reminder to start putting their health first. Other participants talked about taking the opportunity to re-evaluate their relationships. Some had relationships that were unhealthy and that interfered with their coping. Those participants looked at those relationships in terms of whether new boundaries needed to be set or whether perhaps the relationships needed to be terminated. Finally, some participants talked about their illness forcing them to examine their lifestyle. Excessive drinking, irregular sleep or poor diet were found to impact on coping and were therefore changed.

Participants also talked about testing themselves. When describing new activities, they at times mentioned that the activity was a test to see if they can take on new challenges without becoming overwhelmed and unwell. It seemed that the isolation that sometimes came with mental illness had the potential advantage of insulating them from the stresses and demands of the real world. Venturing into the real world required taking small steps to test how well the person could cope. This was also true for those participants who spent significant amounts of time in the psychosocial centres. While the centres played an important role because they allowed their members to experience acceptance, security and sense of belonging, they served as a buffer from the outside. Alice summarized the dilemma in the following quote:

Well, I've got a very big test coming up with starting TAFE [college]. And once I've been doing that for six months, then I'll have a good idea of where I'm at on my road to recovery. Because I will either bum out or I will continue and that will give me an idea of where I'm at on my road to recovery. Because at the moment I'm like in limbo because I'm taking a big step from being protected by the [name] centre to getting out there in the big wide world, you know. I mean, just the thought of getting on the train without anybody with me is daunting enough and so if I can make it through my first six months of study then I know that I'm on the road to recovery.

Chapter 5

Person-centred factors

Discussion

Introduction

This chapter comprises a detailed discussion of themes and subthemes representing the person-centred factors of the lived experience, reported as results in the previous chapter. Exploration of the person-centred factors involved a large amount of information, which has been divided into one chapter dedicated to a description of the themes and another chapter dedicated to a discussion of those themes. A separate chapter has therefore been created primarily to aid readability.

The findings presented in Chapter 4 are the result of hermeneutic methodology which assumes active participation from both the participant and the researcher, with each party drawing on his/her background knowledge and present range of vision, and with each party therefore acting as a co-creator of meaning. The hermeneutic interviewing process was opened, non-directive and conversational, examining the phenomenon as embedded in context and interpreted through the analytical back-and-forth movement between the whole and the parts (Koch, 1996; Whitehead, 2004).

In this chapter, the findings are discussed with respect to how they fitted together as parts of the whole and with respect to their position in the context of existing literature. In addition, the findings are discussed in view of the philosophical constructs of Gadamer's (1975) hermeneutics. This position – using a philosophical approach to improve understanding of psychiatric conditions – is not entirely novel, with some authors proposing to use a phenomenological-hermeneutic approach to explore hallucinations (voices) as intrinsically meaningful experiences (Thomas & Bracken, 2004) and others suggesting the use of a social constructionist theoretical framework to examine the way individuals make sense of their delusions (Harper, 2004). However, to the researcher's knowledge, this is the first time that Gadamerian hermeneutic principles have been used both as a scientific method and a philosophical approach to understanding mental illness.

Mental illness as a journey.

Living with mental illness was described as a complex journey, characterised by setbacks, adjustments and learning processes. Unlike a clinical understanding of illness experience as a process of onset, diagnosis and treatment, participants' understanding of illness experience was that of a life journey in which mental illness could not be separated from historical and contextual factors. It was these factors that helped determine the development and course of the illness from potential predispositions and triggers to stabilisation and maintenance. Along the way, the participants learned a number of lessons about themselves, about their illness, about the role of illness in their lives and about their role in their own care. They also had to learn how to negotiate the mental health system; understanding how the system works, what roles individual practitioners play in it and what role they (the patients) play helped them utilise the system in a way that was personally beneficial.

The mental illness journey can thus be viewed as characterised by hermeneutic processes that placed the person's experience of the illness not as a distinct entity but rather as something that was embedded in the person's context and that was interpreted in view of past experiences and background knowledge. While a person cannot remove him-/herself from such embeddedness he/she can use it to broaden his/her knowledge (Lebech, 2006). The person's past did not stay in the past but continued to exist within the present as the person's pre-understanding. The person used this pre-understanding to make sense of what was happening; where the pre-understanding was insufficient to help explain the experience the person began to question the limits and adequacy of his/her assumptions and gained knowledge. Hermeneutic processes do not have an end-point, just as the participants' journey did not have a point where all learning ceased. Even where they believed that they were stabilised or knew their illness well, what they believed they knew and understood (about themselves, about their illness, about others or the system) was constantly challenged, or could be challenged in the future; the learning was ongoing.

Learning about illness and learning about self were identified by the present study as two primary processes involved in a journey toward wellness. This is similar to Pettie and Triolo's (1999) concept of recovery which is believed to involve two

developmental processes: struggle for meaning and reconstruction of a positive identity. The authors claimed that the onset of mental illness could lead to an identity crisis in which individuals were faced with two different versions of themselves: a former (pre-illness) self that served as a reference point to which the person wanted to return, and a present self that was perceived in a negative light as sick and unsuccessful. It was through the two processes that the individuals could conceive the possibility of, and eventually find, a future self, one that they could live with and respect. In a similar vein, Wisdom and colleagues (2008) wrote about the loss of a previously held identity caused by the onset of illness and about the duality of self where real, authentic selves were seen as separate from alternative selves during episodes of ill health.

Redefining self was identified as crucial to recovery by many other authors (e.g., Baxter & Diehl, 1998; Laithwaite & Gumley, 2007; Mancini et al., 2005; Sells et al., 2004). It is seen as a process that helps redefine mental illness as only one aspect of a multidimensional identity and that helps the person create an active, functional, positive sense of self (Davidson & Strauss, 1992; Ridgway, 2001; Roe & Chopra, 2003; Shea, 2010; Tooth et al., 2003). By the end of the process the person would have achieved social reconnection and community integration (Bradshaw et al., 2007; Schön et al., 2009) as well as improved well-being and quality of life (Andresen et al., 2003; Beeble & Salem, 2009; Young & Ensing, 1999).

The present study provides support to these findings but also adds further dimensions. Social reconnection and community integration were certainly evident in participants' narratives, but as discussed in detail in the next chapter, they had to occur on the person's terms. It was he/she who decided who to reconnect with, when, how and under what conditions, and he/she who had to resolve a number of dilemmas related to community integration, such as whether or not to disclose his/her illness to others, or whether to integrate as part of the peer (marginalised) versus normal community. Improved wellbeing and quality of life were something the participants aimed for and many achieved. Yet even narratives of those participants who could be described as in recovery indicated that wellness was a state that was seen as temporary and tentative, whether it lasted weeks or 14 years, as was the case of one participant.

One of the lessons the participants learned over the course of their illness

journey was that their illness was episodic and relapse was possible. Rather than with passive acceptance and resignation, this notion was accepted as part of life and could in fact motivate the person toward more active coping and management. If the aim was to remain stabilised and retain wellness, then the person needed to minimise the likelihood of episodes occurring or to minimise their impact once they occurred, which was achieved when the person self-monitored, made a number of lifestyle and goal adjustments and created a toolkit of coping strategies.

The episodic nature also meant that the impact of mental illness on the person's life tended to fluctuate. On one hand, there were times of acute ill health where the illness seemed to take over the person's life so that the individual needed to devote a significant portion of personal resources just to attend to basic daily functioning. At the other end of the continuum, the person could experience periods of wellness that allowed him/her to retain normal functioning with no or only minimal interference from the illness. Both states, and all possible variations in between, challenged the person to re-examine what they thought they had learned previously from their experience. If recovery is about meaning making and identity redefinition, it would seem that each episode of illness, provided that it was followed by a period of relative wellbeing, provided an opportunity to reflect and re-assess their understanding of who they were, what their illness meant to them and how it fit into their lives.

Conceptualisation of mental illness.

The participants varied in the way they tried to account for their problems. Although not all of them were able to articulate a specific model of mental illness, the majority at some stage tried to come to some understanding of why they became ill, or became hospitalised, and what that illness signified. A number of researchers have addressed the topic and similarly identified several explanatory models/illness accounts. Although some models appeared to be unique to the respective findings, a number of them seemed to be common across studies. Medical (also clinical, biological or disease) model; social (also environmental or crisis) model; religious (spiritual or philosophical) model and emotional (trauma) model can be identified in several papers in which it was also pointed out that an individual could use aspects of various account types or mixed models at particular points (Estroff et al., 1991; Jacobson, 2001; Sayre, 2000).

The present study identified similar conceptualisations, with the most commonly described ones being the medical, biopsychosocial and trauma models. It is unlike previous studies that suggested that the type of illness account people create or accept is linked to their understanding of recovery, their views of formal treatment as well as their views of the type of help they would find most beneficial (e.g., Jacobson, 2001; Thornhill et al., 2004). Instead, the present study indicated that the type of model does not necessarily determine the person's coping and illness management styles. It was not the model as such but rather the way it was used, whether it provided the individual with a satisfying answer and whether, and to what extent, it allowed room for action and personal responsibility.

The type of model also did not seem to be linked to the way participants talked about their illness. When talking about signs of ill health, they all used a mixture of clinical terminology, lay descriptions and metaphors. Clinical terminology was part of each narrative although individuals varied in their use of it. Some incorporated it into their stories and seemed to have good understanding of it; some mentioned it as something that was imposed on them externally; while others communicated their confusion, treating their descriptions and formal terms as almost two separate categories. In addition, the participants did not talk just about symptoms but also about other experiences that they believed to be directly associated with their illness yet that would not be considered illness criteria in clinical terms. The narratives clearly demonstrated that what participants viewed as their illness, and what researchers and clinicians viewed as mental illness were not necessarily the same thing.

Contrary to the discourse of ill health, participants' understanding of wellbeing was not always clear. For some, being well was closely linked to being ill; that is, wellness was understood as absence of or improvement in symptoms. Wellness was not always a distinct state or a clearly differentiated baseline to which the person wanted to return. It seemed that many individuals, especially those who had experienced frequent episodes, prolonged periods of ill health or whose problems started early in their lives, experienced mental illness as fluctuations of functioning. Even when a person talked about being well, the wellness was usually described in terms such as maintenance, stabilisation or balance. The person was doing well not because the illness was no longer there but because they had learned to manage it. In addition, wellness was not a

constant state but rather something that often needed to be renegotiated as the person continued on his/her journey; pre-episode (pre-illness) wellness was therefore different from post-episode wellness.

Although there was one participant who believed that he only experienced one period of sickness, believed to be caused by external stressors, the majority saw their illness as episodic. Awareness and acceptance of this episodic nature was one layer of acceptance that seemed to be important for doing well. Others included awareness and acceptance of the illness itself, its diagnosis, the type of limitations it placed on the person and the idea that the illness is something that will need to be managed. Lysaker and Buck (2007) identified five dimensions of awareness: of mental illness and its social consequences, of symptoms and their attribution to the disorder and of their need for treatment. They believe that both awareness and unawareness can have negative consequences; for instance individuals who are unaware of their illness are less likely to see the need for treatment and therefore reject their medication which can lead to more frequent hospital admissions. On the other hand, individuals who are aware of their illness might perceive events as being outside their control which could lead to feelings of hopelessness and low self-esteem. The authors indicated that the effect of (un)awareness might be moderated by subjective meaning of the illness and its perceived impact on the life narrative.

Acceptance of mental illness has been repeatedly identified as important for the way people adapt to their experience and ultimately recover (e.g., Davidson et al., 2004; Jensen & Wadkins, 2007; Jönsson et al., 2008; Ridgway, 2001; Smith, 2000). However, research also indicates that acceptance can contribute to a passive stance of being a chronic patient unable to function (Kartalova-O'Doherty & Doherty, 2010), lower levels of functioning (Warner, Taylor, Powers, & Hyman, 1989) and engulfment (Lally, 1989). Yanos, Roe and Lysaker (2010) proposed that acceptance of having mental illness can affect one's hope and self-esteem, which can then influence a range of factors, including the risk of suicide, social interactions or coping. Warner and colleagues (1989) suggested that to prevent the negative impact of acceptance, the individual needs to develop an internal locus of control, while Lally (1989) found that the person should maintain a self-image of being competent while acknowledging the reality of having a mental illness.

The present study found mostly positive effects of acceptance while also emphasising agency and personal responsibility. It also suggested that given the multilayered nature of the concept, ‘failure to accept’ mental illness can refer to many things. Saying that a client is resistant or non-compliant because of denial or lack of insight is not necessarily correct; they may acknowledge that they have mental illness yet struggle with acceptance of some other aspect, whether the actual diagnosis or its formal explanation, or the idea that their illness is episodic and may require ongoing treatment with medication.

One further aspect that was linked to awareness and acceptance was the role of trauma. Well over half of the participants recalled an event or series of events that were highly distressing and that were believed to have lasting consequences, whether in their role in the development of illness or in their interference with the person’s ability to cope. Coping with mental illness on its own required sustained effort; having to cope with trauma as well added an extra layer of difficulties that called for additional personal resources. Trauma was a broad category that included more than just a life event (such as childhood abuse). Some symptoms were described as traumatic, especially when they led to a loss of self, as was the case of severe psychosis. However, participants also talked about aspects of treatment that were traumatising, particularly involuntary hospitalisation and some interventions (e.g., ECT). There was a variety of responses to the trauma, including suppression, denial and grief. The participants generally agreed that they could not heal unless they somehow worked through the trauma. However, they also suggested that healing was not necessarily a permanent achievement. Rather, it was described as an ongoing process that, even if stable for a period of time, might have required additional work from time to time.

Individuals’ own understanding of health and ill health, their descriptions of the “problem”, multilayered acceptance or the role of trauma are not necessarily addressed in treatment and yet they played such a large role in the individuals’ experience. They represented past experiences and components of background knowledge that served as the basis for interpretation of what was currently happening.

The Gadamerian approach posits that where a person is faced with limitations of his/her background understanding he/she engages in a questioning process that either

leads to a shift in understanding or that is submitted to further tests until the person gains greater appreciation of the topic (Polkinghorne, 2000). It could therefore be argued that some individuals' "failure to improve" is partially due to their difficulty to progress beyond their present understanding; they either were not able to enlarge their background knowledge through their own questioning process or their interpretation stood in contrast to the perspective presented by their clinician. Where such personal–professional discrepancy was not addressed through a mutual exploration, where the clinical perspective was presented as the only viable perspective (or horizon of meaning), it may have interfered with the person's ability to make sense of his/her experience and accept it in a way that would promote effective coping.

Illness management and coping.

All participants were able to identify some coping strategies they utilised to look after their health. Those strategies were not limited to coping with the actual symptoms of mental illness but also their consequences (such as loss of relationships), treatment consequences (e.g., memory loss due to ECT) and trauma. At some stage the participants realised that their health should be a priority and that they are responsible to a great degree for maintaining it. Personal responsibility has been identified in previous literature as important for recovery (e.g. Leamy et al., 2011; Smith, 2000; Resnick, Fontana, Lehman, & Rosenheck, 2005; Tooth et al., 2003). It has been linked with autonomy, empowerment and self-determination (Andresen et al., 2003), power and control (Bonney & Stickley, 2008), agency and efficacy (Davidson et al., 2004) and active coping (Onken et al., 2007; Ridgway, 2001).

Personal responsibility, however, did not represent a dichotomy of responsible/not responsible or active/passive. Rather, it seemed to occur on a continuum, from passive compliance, to active compliance and holistic self-care. The lower levels were closely linked to formal treatment with professionals seen as the primary agents of care. Yet even in passive compliance it was the person's responsibility to for instance attend (versus not attend) appointments and take (or not take) medication as prescribed. At the other end of the continuum, the person used professional help as only one of many strategies. He/she also had a good understanding of his/her illness within its context, and was able to access and use a variety of

resources.

Personal responsibility was also closely linked with self-monitoring. In order to take responsibility and actively cope, the person needed to know what they were coping with and when it was time to utilise what coping or management strategy. Whether they had general awareness, used a diary or looked to others for feedback, the person needed to monitor his/her functioning to be able to identify fluctuations. Once those were identified, the person had to decide whether those fluctuations represented normal changes (possibly a normal response to a stressful event) or whether they were warning signs of potential relapse. They also needed to be able to tell when they could still rely on their own toolkit of strategies and when it was time to access external resources.

The balance between self-reliance and external help was one that had to be handled very carefully. The line between the two was unclear and always shifting, depending on what was happening in the person's life at the time. However, that was not the only aspect of living that the participants needed to keep in balance. A number of them indicated that their mental illness placed limitations on what they could do or achieve. Whereas their pre-illness selves may have been able to manage a large number of commitments or high levels of stress, this was not necessarily true for their present selves. It seemed that the subjective thresholds for busyness and stress have changed following the onset of illness and therefore knowing one's new personal limitations was crucial to effective coping. This knowledge often led to adjustment of previously held goals or to adoption of new goals, in place of the old ones. Although some participants spoke of their awareness of what successful living should look like, either because of societal expectations, their own beliefs or their reflection on what they used to be able to do or strive for, generally there was acceptance of the current state. Some individuals in fact acknowledged that this forced re-adjustment sometimes led to a healthier, more balanced lifestyle with priorities set by them, not a third party.

Seeing something as placing limitations of one's life could be easily construed as having an external party exerting a negative influence and thus affecting the person's prospects of personal growth. Yet the language used in the participant narratives did not reflect that. While some participants seemed to ruminate about the negative consequences of mental illness and of being seemingly singled out ('why me'), others

accepted the limitations simply as part of their lives. Ridgway (2001) suggested that viewing mental illness as a fact of life but not the core of life could help the person move away from a focus on being primarily a person with mental illness. Ochocka and colleagues (2005) identified acceptance of limits, as well as capacities, together with realistic goal-setting and balance as accommodation-oriented negotiations that help the person move forward. Similarly, Marin and colleagues (2005) wrote that being aware of one's fragility and knowing one's limits could in fact contribute to the person's development of sense of power and control.

Having an awareness of the impact mental illness has on one's life was important for the person's ability to self-monitor, plan and set goals. It also helped the person structure his/her day and negotiate various commitments; it did not mean being negative but rather being realistic. Far from sentencing the person to reduced possibilities and limited quality of life, it became an important life skill.

Overall, the individual coping strategies showed individuality and creativity, with participants citing anything from singing, spirituality and humour to positive thinking and mindfulness as helpful approaches to illness management. However, there were certain approaches that were common across participants, including being productive, having fun, being surrounded by supportive people and pulling back during distressing times. Doing something that was meaningful, that gave the individual a sense of being worthy because of his/her individual contribution, that helped fill a day and provide it with a structure, or something that was simply enjoyable were all cited as the reasons for choosing a particular strategy. The strategy also depended on the person's individual traits, likes and preferences.

The choice of strategies identified in the present research mirrored that of previous studies that found being productive (Gahnström-Strandqvist et al., 2003; Onken et al., 2007; Spaniol et al., 2002), engaging in challenging and meaningful activities that provided the person with mastery experiences (Mancinin, 2007; McKay, 2010); as well as spirituality (Leamy et al., 2011; Sells et al., 2004; Torgalsbøen, 2001), positive thinking/self-talk (Marin et al., 2005; Ochocka et al., 2005), self-care (Borg & Davidson, 2008; Smith, 2000), or pleasure and play (Davidson et al., 2006b) as part of coping. Yet as previously indicated, coping was a broad category that, apart from the

actual symptoms, included dealing with the broader consequences of the illness and its treatment, as well as coping with trauma.

The participants were able to identify specific strategies that dealt with a specific problem. For instance, some participants talked about writing things down to help with treatment- or illness-related memory difficulties; one participant mentioned washing her face and imagining a bad thought going down the drain. But a number of strategies were discussed as general strategies that helped them feel better at difficult times, regardless of whether those were caused by the illness or daily living stress. In addition, coping strategies were used to bring participants into the realm of normal living.

It has been suggested that individuals with mental illness are identified by others in a vocabulary of difference and end up having doubts about their own worth (Barham & Hayward, 1998). The individuals themselves may be acutely aware of being different, no longer normal, experiencing a diminished sense of self (Roe, 2005). Return to normalcy can therefore be viewed as a sign that the illness is under control and the person is doing well. Regaining normal life, or maintaining normal lifestyle, may involve doing ordinary activities and spending time in ordinary environments (Davidson et al., 2005a; Marin et al., 2005). One ordinary activity, however, had the potential to satisfy several needs and promote wellbeing in a number of ways. For instance, music could be listened to because it calmed the person or it lifted his/her mood and therefore functioned as an illness management strategy. Listening to music in a company of friends (e.g., going to a concert) could provide a sense of belonging; with that activity the individual became just another person with a love of music which helped emphasise what was shared (healthy/normal) while re-delegating mental illness (the thing that made the person different) into a minority role in the person's life.

As indicated, the use of illness management and coping strategies was highly subjective; a single strategy was used by different people in different ways for different purposes and was closely linked to the persons' interpretation of what it was they were coping with. A clinician may be concerned with his patient's hallucinations and may prescribe medication to help treat them, whereas the person may actually find the voices less distressing than for instance dealing with difficult social interactions. These two viewpoints represent two horizons of meaning that may or may not be reconciled

(fused). It could therefore be argued that the individual is more likely to be opened to professional treatment if the treatment is seen as making sense.

Losses and gains.

The journey with mental illness was described as involving a number of losses. Some were understood to act as illness/episode triggers; some were believed to interfere with coping while others seemed to impact on future possibilities. A number of losses were attributed to the illness itself, including loss of self, loss of the ability to function in a day-to-day living, loss of child custody or loss of relationships. Following an acute episode, the person would reflect on what he/she has lost and assess those losses in terms of their potential to be claimed back. Some losses could be reclaimed once the person was stabilised, some were grieved and let go. The range of responses to the loss was vast, from suppression and denial, to acknowledgment, grief, acceptance and adjustment.

The negative impact of mental illness on a person's life has been widely documented, with past participants reporting hopelessness and fear (McCann & Clark, 2004), estrangement and alienation (Deland et al., 2011), fear of one's inability to achieve his/her wishes (Jönsson et al., 2008), collapsed understanding of self (Ridge & Ziebland, 2006) and experiencing life as a reduced existence (Zolnieriek (2011). Some studies specifically cited loss as a consequence of mental illness, including loss of a sense of identity (Andresen et al., 2003) or loss of agency and intuitive social knowledge (Deland et al., 2011). One researcher identified responding to loss as playing a crucial role in recovery. According to Henderson (2010), recovery is a three-phase process of overcoming loss that involves acknowledgment of the experience, adaptation to one's losses and finally adjustment. The person needs to first acknowledge what has been lost, accept that he/she no longer possesses the same capabilities he/she once had and then make necessary changes so that he/she can regain as much as possible of what has been lost while adjusting to those losses that can't be regained.

Henderson's (2010) model places loss at the centre of recovery efforts while at the same time it highlights the processes involved in overcoming its effects. In a similar way, the present study indicates that it is not so much the number of losses or their relative severity that helps determine the person's potential for being well but rather the

person's response to the loss. This is in line with resilience literature which indicates that individuals can develop mechanisms that allow them to adapt to and thrive even in difficult circumstances (Davydov, Stewart, Ritchie, & Chaudiew, 2010; Edward, Welch, & Chater, 2009). In the present study, a number of participants had recalled quite profound experiences that could be debilitating yet that did not necessarily dominate the person's narrative. Adaptation was not about suppressing the loss or trying to pretend it did not affect the person but rather about acknowledging it as something that helped direct the person's life yet not allowing it take over. Those individuals who became fixated on what they had lost, whether in the past or in terms of future plans prevented themselves from seeing other opportunities for potential gains. As Torgalsbøen (2001) suggested, individuals need to be given an opportunity to grieve and let go of earlier dreams so that they can pursue other potential sources of gratification.

Just as they acknowledged past losses, participants talked about gains. They discussed what they had achieved/been achieving in spite of the challenges of living with mental illness; they also talked about those skills and abilities that were temporarily lost yet that they were able to claim back. They also talked about their future goals. Some goals were goals they had always aspired to, some were goals that were amended to fit present circumstances while others were new goals. The person's future was seen with hope yet within the parameters of personal limitations. Especially those individuals who had experienced stability and wellness in the past, in spite of setbacks, were able to see stability and wellness in the future. They were able to use their own experience to feel hopeful. Those individuals who had had ongoing difficulties or who had experienced frequent episodes may have needed to look to others for support and messages of hope.

Hope and optimism have been identified as key components/strategies of recovery (e.g., Onken et al., 2007; Resnick et al., 2005; Ridgway, 2001; Smith, 2000). Andresen and colleagues (2003) suggested that hope can come from within or can be triggered by other people. It was further suggested that for hope to be effective it needs to be translated into a commitment to get well and recover (Davidson et al., 2004). This is certainly supported by the present study. Hope was rarely explicitly mentioned yet hope for the future was indirectly indicated in all narratives. It seemed that at the time of acute illness finding hope within self was more difficult than when the person was

functioning well; it was usually at such times that hope was triggered by other people. It should be pointed out that even where messages of hope were not clearly stated, the individual was attuned to what others were indicating. Telling a hospitalised individual at the height of being ill that things will not improve was highly damaging.

In addition to feeling hopeful about future, the person needed to do things towards a hopeful future. The majority of participants in the present study seemed to be doing well. When talking about future they rarely mentioned hope as related to their illness; rather illness took the back seat as something that is under control and the focus was on the rest of their living. In that way talking about future plans with an individual with mental illness was not much different from what talking to a 'normal' person would be. Those individuals who seemed to be doing perhaps less well were more likely to mention hope of improved coping and functioning, or hope of treatment being effective, yet even then a hope/plan for better mental health was just one of many hopes/plans for the future.

Vision of a future where the person was not dominated by his/her illness was an important part of the narrative but not the sole determinant of where the person was heading. Rather, participants seemed to indicate a back-and-forth movement between the past, the present and the future. Past was important because reflecting on past experiences, achievements and setbacks helped the person make sense of what was happening now. Future planning was equally important because it gave the person something to strive for. However, wellness seemed to be most closely linked with being grounded in the present. Feeling contentment with what the person had, as opposed to didn't have, was linked to the concepts of balance and control. It was not about being cured but rather about being stable, with symptoms under control. The person who was well was also able to strike the right balance between withdrawal/passivity and social/occupational over-commitment as well as balance what they have lost with what they have gained.

Gadamerian hermeneutics emphasise the back-and-forth movement between the horizon of the past and the horizon of the present, as well as between the parts and the whole (Lebech, 2006; Smith, 1993). Learning about past losses and potential gains therefore represented a back-and-forth movement between the person's background

knowledge and experience, and his/her interpretation of current events which then formed the base for future undertakings. It was not so much about what it was the person lost and could or could not reclaim but rather the person's interpretation of and response to those losses and future goals. A personal loss had the potential of taking over the person's narrative and negatively impact on his/her ability to get well and stay well. However, just as the horizon of the past does not determine the present, the loss did not necessarily determine the person's functioning. Just as the individuals approached their illness as something that they were trying to make sense of and place as only one part of the whole, the loss could be interpreted and reinterpreted in such a way that it was not necessarily made less painful but perhaps less influential: only one aspect that could be managed within the wider context of the person's life.

Conclusion.

The present study showed that living with mental illness is a gradual learning journey through which a person continues to collect information and use that information to make sense of what is happening. Learning about self, learning about mental illness and its role in the person's life, learning about the person's role in his/her care and finally learning about external resources, whether in the form of the formal mental health system or a peer support network, all influence the person's adaptation to what is at times quite distressing experience. Whereas professional helpers can provide an explanation and treatment of mental illness, they do not necessarily determine how the person explains the illness to him-/herself or what the person finds effective to control symptoms of the illness. In addition, the focus of formal interventions was not necessarily the sole focus of the person's management efforts; more often than not the person also had to develop coping strategies to deal with the consequences of mental illness and its treatment as well as other contextual factors, including trauma and loss. Finally, it was important to acknowledge that mental illness, with all its limitations and negative consequences, did not prevent the person from planning, pursuing and achieving goals.

Chapter 6

The lived experience of mental illness

Part II: Social and relational factors

Overview

This chapter is a continuation of Chapters 4 and 5, presenting data gathered via unstructured interviews with 25 participants who talked about their experience of living with mental illness. While Chapters 4 and 5 focused on person-centred factors, Chapter 6 discusses social and relational factors. Specifically, in its first theme it examines the role of professional help, including that of medication, hospitals and mental health professionals. It also explores those aspects of care that participants found most and least helpful. The second theme involves the role of other people with a focus on relationships with significant others and peers, the impact of mental illness on other people as well as issues related to disclosure.

Findings

Theme 1: Professional help.

All participants had some experience of professional help although the degree of service utilisation varied greatly from a few psychotherapy sessions to multiple hospital admissions, both voluntary and involuntary, with at times quite extended stays. Majority of the participants were treated within the public health system; a few experienced both a public and private type of care. Just as the usage differed from participant to participant, their perception of how helpful the service was in their treatment varied greatly. Overall, however, professional help was valued as an important, but not the only, part of their illness management.

Medication.

If you're truly going to say that mental illness is as valid as any other form of ill health then [...] why not accept medication? I don't follow, yeah... I know I have slightly elevated blood pressure if I don't take tablets for it so I'm not gonna stop taking them (Bill).

I don't like it [medication], never have done but I'll probably take it for the rest of my life. And like my pastor has always said, we all have to take medication. I mean I don't know whether you take vitamins because you might take vitamins and I've worked in a health food shop where you're not just selling fruits and nuts and stuff but there is vitamins and there's powder to bring up muscles and you know, and I've worked in the pharmacy where you have not just the medication but you've got the vitamins as well so people in other words probably take something (Molly).

Medication was mentioned by all participants and all but one had taken some psychotropic medication in the past. (The one participant who had not taken any medication however admitted to “self-medicating” with marijuana.) The general understanding was that sometimes it took a long time to find the right medication(s) at the right dosage that would work for the person. However, this understanding only developed with time, and the periods of trialling new medication where the persons could experience quite severe adverse effects were recalled as being difficult and distressing. The process was better handled by those participants who had a trusting relationship with their practitioners and who were explained what “finding the right medication for you” may entail. Where this communication was missing, the person may have been left feeling like an object that things were done to, rather than with, with no regard to what the person was experiencing.

I guess initially I think it was the change in medications that frustrated me too because I started with one drug, Aropax, which did nothing for me because the GP in my mind can be really useless. This particular GP I don't think has got that specialised knowledge. And then I went on Prozac and then I'd been on all these different ones but I guess, yeah, it's just that sort of faffing around. I'm not blaming anyone, I'm not blaming the doctors or anything but it's just, obviously the consumer being me, I'm the one having to go through the symptoms and the dry mouth and this and that and the weight gain and this sort of thing and I think that some are more understanding than others I suppose but luckily I've had mostly understanding professionals (Rachel).

The idea itself of having to take medication was something the person had to learn to accept. There were a number of misconceptions and fears that may have prevented the individual from accepting medication in the first place and from not taking it as prescribed or stopping it altogether once the person was on it, even though

only a few participants recalled having been put on community order and depot injections because of past non-compliance. There were also genuine reasons for resistance to medication, primarily because of side effects. Heavy medication that dramatically altered mood or “zonked people out”, medication that led to extreme weight gain or sexual dysfunction, or that caused tremors and other side effects were cited as causing genuine concerns, and some participants expressed anger at having been subjected to something so distressing.

Well, they're too quick to decide that they're gonna give you this medication and if you don't like it, [...], you know. It shouldn't be like that, it's like, you know... I was given medication that made me shake so violently that I could barely bloody walk. And clearly I should not have been on that medication, clearly, you know, so they shouldn't have... they should have like just given me something mild, you know... I don't think it was managed very well at all, quite poorly actually, quite poorly because they doped me up to the eyeballs and that didn't help. I mean, you know... and then that gave me the shakes and they gave me pills to stop the shakes and they gave me this to stop that... (Isaac).

I sort of more like the psychologist method of talking things through because a lot of psychiatrists propose more drugs and from what I've been through with the allergic reactions to a lot of medications I'm kind of scared of that or put off going down that path, anything that I don't know what it is it is going to do to me... ...It was kind of scary though, some of the side effects. Like once I was sitting outside and my legs started jumping about and stuff. It was very scary (Vanessa).

Once the right patient–medication fit was found medication was seen as an important, sometimes crucial, part of treatment even though the understanding was that the pill doesn't cure the illness. Some participants talked about being well in the past which led them to believe that they no longer needed medication. Once they stopped they generally relapsed which they saw as a lesson that medication is something that will always be part of their lives. Only a few participants successfully came off medication without any negative consequences. The idea of staying on medication for the rest of their lives was not appealing but was accepted. A few participants talked about not having to take medication as the ideal outcome but were also aware, often from past experience, that this outcome was perhaps not possible for them to achieve.

Hospitalisation.

The vast majority of participants had been admitted to hospital at least once. For some participants, hospitalisations were traumatic, especially if they were admitted involuntarily. This was usually the case with psychotic episodes which in themselves could be scary and distressing, and coupled with being taken somewhere against their will could have lasting consequences. Hospital admission was in a few cases the first contact with the mental health system the person had and the first time the person realised that he/she had mental illness.

He [GP] suggested, he said, have you got a private cover, I will put you in the local hospital in a private ward for a week or two, and you're just gonna have a good rest. And I thought well, maybe I do need a rest, um, and I did rest. I don't think I really ventured out of bed for a few days but eventually I read the chart at the bottom and that was the first time I saw the word depressed (Bill).

This means that while the primary role of psychiatric hospitals, certainly within the public system, was to manage acute episodes and stabilise the person, hospital admissions could in fact represent a life-changing moment when the person realised he/she was no longer “normal”. Unfortunately, an ongoing dialogue through which a practitioner could help individuals find meaning in their experience was largely missing.

I think one of the other things as well as is they talk to you when you first come in but they don't talk to you later down, later downstream when you've got a chance to recollect and realise what was going on... ... One of the things they didn't do is they didn't get me to talk, um... I didn't talk to them about my idea of what mania was all about and, um, so, there was very little talking (David).

Hospitals were not always judged in a negative way and for majority of participants simply presented one form of care.

...when I went to [hospital] I didn't even know what that was about because I'd never been there before so I was scared there the first four weeks because I didn't know what they were gonna do to me, you see. But after that I ended up back there the second time and I realised what the place was for, was to help people and things like that (Heather).

It could be said that even for those participants who were at one point treated as involuntary patients the issue was not whether or not their illness required hospitalisation but how well the admission was handled. Where hospitalisations were seen as useful, participants talked about seeing them as the starting point of treatment; as an opportunity to slow down, take time out from their stressful lives and refocus on their health; as a place where they could rest and be taken care of while they got back on their feet; or simply a place they could turn to when they could no longer cope on their own.

Some participants experienced both public and private hospital treatment and were able to compare the two, with neither one of those seen as superior. The private system was valued for its easier access, privacy and better quality of facilities but was also seen as expensive and possibly leading to dependency without necessarily providing better medical and psychological care. In both cases, hospitals were rarely seen as therapeutic environments or places of healing but rather as holding (safe) places.

I don't think the psychiatric department believes in psychotherapy because... They tend to medicate you, get you in, like after your breakdown they get you in, they medicate you and then they send you on your way, no explanation of what happened or why it happened... (David).

Professionals.

The participants recalled having had some experience with a variety of professionals, including general practitioners, psychiatrists, psychologists, counsellors, nurses, occupational therapists and social workers. They were not always clear about professional distinctions and about who was responsible for what. Most confusion seemed to be about the role of psychologists and counsellors, as well as psychologists and psychiatrists, and while a large number of them recalled having received counselling (mostly related to sexual abuse or substance abuse), only a few had worked with a (clinical) psychologist. In spite of this confusion, participants seemed to have compartmentalised aspects of their illness and its appropriate management so that if they wanted to talk about medication they would see a psychiatrist (or a General Practitioner) while if they wanted to address excessive drinking they would be asking for alcohol counselling. While this mirrored the way the mental health system itself was

compartmentalised, it presented problems that could have implications for treatment.

Firstly, having numerous professionals attending to various problems meant that the persons had to tell their story repeatedly and had to make themselves vulnerable while establishing new relationships. Some participants solved this by only disclosing those things that they saw as relevant to the problem in question and while it may have been effective for some it could also lead to situations where certain practitioners were not aware of factors that could influence their treatment.

Secondly, clear division of problems was not possible and seeing a large number of specialists was equally difficult, yet crossing the invisible line between different compartments was not always possible. Several participants talked about the difficulties caused by the time-limited nature of consultations with medical practitioners. If the primary mode of treatment was medication then the participant would be expected to see a psychiatrist or a general practitioner and would be asked to talk about medication-related issues. If the participant wanted to discuss problems outside these parameters it wasn't always possible, not necessarily because the practitioners would not be interested but because the consultations allowed for only a brief discussion. Most participants were accepting of this and understood it as an external constraint created by the system but it was them who were left with the decision of whether to take the problem elsewhere, whether to seek help outside the professional care (significant others, peer support) or whether to keep the problems to themselves.

Thirdly, compartmentalised care is highly dependent on how well the individual players communicate with each other. Participants mentioned examples where they were assigned a different psychiatrist every few months who seemed to have very little knowledge of the patient, or where they were discharged from hospital without receiving any information about follow-up care. Finally, compartmentalised care is only effective when the individual has a clear understanding of who is responsible for what so that they have realistic expectations of the relevant form of help. In order to develop this understanding there needs to be a discussion of this area which sadly seemed to be missing in many cases so that the individuals were left to work this out by themselves. As Gwen pointed out, such lack of clarification could foster false hope:

I think it's important for patients in a hospital whether it is mental or physical health,

that the person that's coming to see them explains exactly who they are and what their role is, you know, otherwise they might think that the person they just talked to is gonna solve their problem that person doesn't deal with because they've talked about it. Well, that's not fair, it's really not fair when people are so vulnerable, you know, giving false hope...

Perhaps the only clear association the participants had was that between a psychiatrist and medication. In fact, apart from hospitalisations, the most stories of professional care were with regards to treatment received from psychiatrists. Psychiatrists and their role in treatment tended to be judged in a fairly positive light, even though numerous examples of bad practice were cited. Psychiatrists were mostly understood as being the persons prescribing medication and the ones responsible for the patient and therefore holding certain power.

I couldn't say to him, I think this is a possibility, right, because he already had his view and he was the man at the desk and I was the one on the couch. He was getting paid, I was paying, he was dispensing, I was taking, you know, and that was the only way he could see it, right. And I try not to treat people in life that way, and I certainly don't like being treated that way (Andrew).

The issue of power was mostly relevant when it came to diagnosis and choice of medication but was most acutely felt in the cases of involuntary treatment and community treatment orders.

I found out he was very cruel to his patients. They all were. I was distressed by being threatened to be drugged like that and I was hostile towards him because I thought he was mistreating his patients. They were all mistreating their patients. And they still do. And they're basically like the mafia, they attack people that can't be punished in other ways. Like basically they have a hostile pile of mentalities, hostile mentalities or hostile behaviours or anti-social behaviour and bad behaviour so the medical professions attack them with their [...] various witchcrafts and wishing them bad will (Oliver).

When people ask me, you know, they talk to me about the way they've had their treatment or the way they've been mistreated, you know, I usually say, is there nothing you'd like to do about that if you could? If they say yes, it's like, well, there's consumer groups, you know, there's this, there's that, and for the majority of people it's like, oh,

it's just too hard, isn't it, if you start making waves, I mean, if your doctor's not gonna like you if you start making complaints and things, you know, because they still feel very vulnerable. There's still the opportunity for people with mental illness to be locked away somewhere and you know, they're still afraid, lots of people are still very afraid of it, you know, the consequences (Gwen).

The fact that the professional had the power to make decisions that had consequences for the person's life led some individuals to become very cautious in their disclosure. Some came to tell only what they thought the practitioner wanted to hear, while others were very selective in their description of their experience. Liam spoke of distrust he felt towards professionals:

Most mentally ill people often they're holding stuff in from the past and they just don't go and blurt it out to everyone, that's just stupid, stupid to tell that because you know it's often... I think people become unwell, you know, because they've had problems they can't deal with and they're often problems which they're not gonna go and tell anyone, you know, like you're not gonna go and tell any psychologist or any person because I've experienced going and telling things to psychologists in the past and the psychologist doesn't even help but then that individual has information about my life and about my past which often they're not to be trusted with...

Others indicated awareness of how seemingly innocuous traits and behaviours could be misinterpreted as symptoms, and carefully self-monitored. For instance, Bill and Rachel recalled:

I haven't lost my sense of humour and I think it's very important to have one because if you're gonna be crazy for a while, you're gonna be surrounded by crazy people so you need to have a sense of humour, you really do, yeah. And a lot of professionals you deal with don't have a sense of humour. So if you dare to exhibit one sometimes you're seen as acting out or behaving bizarrely (Bill).

I've also been asked about the, when I had delusions and how, because it's often like a religious aspect and mine was that as well. And then I got asked the question, are you religious. Well, I am, as fate would have it but you know what I mean, it was sort of, they're trying to break it all down and it's not easy. I think they're trying to see everything in the light of bipolar, say but I think I'm a vivacious person anyway (Rachel).

Overall, there was some agreement on what was helpful and what was not.

What helps.

Diagnosis and medication.

Diagnosis was usually seen as helpful. It was often seen as the starting point of treatment. In giving the problem a name it made it real and legitimate; if it has a name it is a real illness and real illnesses can be treated. Diagnosis and its explanation also helped explain often bizarre, frightening and confusing experiences.

Diagnosis to me is important, yeah, it is important. Because it gives an idea and it gives you an idea of what to work with as well, so, it doesn't stigmatise me at all, I mean I think it's unfortunate they talk about... schizophrenics get a bad name because you get this paranoid schizophrenic attack somebody and instead of calling him a deranged person they call him a label, which is common with other people who are quite decent, law-abiding, healthy, not healthy but, maybe sick people but they're not violent and I think it's a shame and media is to blame for that, yeah... But otherwise knowing what to work on, I think, is important, you know, knowing, having some idea of the illness... (David).

Once medication was tailored to the individual, the person usually started to see an improvement and came to accept it as crucial to illness management. For some participants, the quest to find the right medication was a slow process of trial and error.

Good working relationship.

Some participants talked about their preference for working with a particular type of professional but overall the specialisation and the type of treatment was less important than the relationship the person had with that particular professional. Mutual trust and respect were often cited as crucial to developing good alliance, together with the ability to listen. Participants were quite attuned to how well they were listened to; just because the practitioner appeared to be listening didn't mean that the individual felt he/she was truly heard and understood. Gwen talked about her dislike of what she perceived as scripted communication while Isaac wanted professionals to be gentle and willing to try and understand the person's experience.

I would expect them to look me in the face and use my name when they speak to me and I would expect them to listen and I mean really listen. Not do their old hmm, yeah, hmm, yes, and how do you feel about that?... there's a lot of health professionals and I find it more so in the mental health field, it does sound as though every consultation is scripted. And I find that problematic because it doesn't come across as genuine. It doesn't come across as though this is me you're talking about, you know, you could have said that to the person before me and to the person after me but we're different (Gwen).

Mostly gentleness, mostly gentleness and um... someone that's prepared to listen, really... Like I see one guy now, the new guy that I've got, I've only seen him once, but he doesn't shut up. He just doesn't shut up at all and it's like, hang on a minute, what are you trying to understand from this? You know what I mean? You're doing all the talking, just pumping me full of ideas and I'm like, what do you, what do you know about me anyway?... Ability to listen is one thing and, um, ability to understand, you know, because the things are complex, you know. I remember one guy, Dr [name], a long time ago when I was first sick, he was a private guy but he was very good. And he was the first guy that I liked, all the others, I despised them because of what I'd sort of been through, you know. And he used to always say, he'd ask me things and I would answer him and then he'd be hang on a minute, he would say, let me understand. That's what he used to say, let me understand and it was sort of, um, an honest thing, you know, a really honest thing sort of... because I used to, I was trying to, I was trying to tell him but he wasn't understanding it because I wasn't articulating as well as I possibly could have (Isaac).

Good professional practice also left room for collaboration so that the person was involved in all steps of treatment planning and implementation. Medication which seemed to be the primary mode of treatment for the majority of participants was more likely to be accepted if it was truly discussed with the participant. This included explanation of the professionals' reasons for choosing that particular medication, discussion of its possible side effects and willingness to review the choice if the individual raised concerns about it. Similarly, if an individual seemed particularly distressed by side effects those side effects needed to be taken seriously rather than dismissed as unfortunate but unavoidable.

I mean there is a fine line between OK, here's the pill, go and do with it what you want and it's a shared responsibility and I think, that's the thing. It's definitely up to the medical professional to explain how you take something, also to explain what to expect as in side effects or whatever, and which then you need to come back and talk about specifically. Don't expect everybody to read that very fine print and hope they're gonna understand it because a lot of people, if they come across a lot of big words that they don't understand, they won't read any further anyway. It's like, this is obviously not for me to read, I don't understand that, so it needs to be talked about properly and make sure the person understands (Gwen).

A number of participants criticised care that was too clinical. Some mentioned specifically the medical model as being too focused on the psychopathology to the exclusion of everything else that was equally important. Participants wanted to be seen as unique individuals, not as diagnoses or clinical cases. On the other hand, professionals who were able to see past the illness, who knew personal aspects of their patients' lives and who were able to show their own humanity were seen as good practitioners. Such relationship had no, or much less pronounced, power difference; the patient and the practitioners were seen as equal partners, both with their own expertise and both with the same proclivity to make mistakes.

Finally, as mentioned in earlier sections, participants self-monitored but also looked to others for feedback. This included practitioners who were used as one source of information about the individual's functioning. Sometimes this was in the form of oral confirmation of something the individual learned from his/her self-monitoring; at other times the individual deduced the feedback from the practitioner's behaviour. If the practitioner reduced medication dosage or if he scheduled less frequent sessions, this was seen as a sign that the person was doing well. Sometimes the practitioner raised concerns about the person's coping but those concerns were discussed and a solution was worked out together with the individual.

Fostering hope.

...it's been more, yep, we're gonna focus on whatever level of wellness I can achieve, we're not gonna focus endlessly on what's wrong with me and what I need to take, what situations I need to avoid and we're going to more positively embrace... we're

gonna focus on what I can do and not endlessly despair about what I can't do. And there's a lot of things I used to do that I don't do or can't do and I don't mourn them greatly. I'm quite happy finding the right things I can do, yeah.

The above quote from Bill exemplifies that hope can be maintained even following the acknowledgment of limitations placed by the illness. Even though there were things the person was perhaps no longer able (or temporarily unable) to do it didn't mean that there was nothing else for the person to strive for. Examples of professionals failing to promote hope were perhaps just as frequent of examples of supportive professionals.

I've been in states where the doctors told me I'm not gonna recover and my body's shaking and I'm on five different medications and I can barely string a sentence together and you know my eyes are always glassed over, I'm just a total wreck, smoking a hundred cigarettes a day or whatever, just chain-smoking all day and just not having fun at all (Liam).

I've had, you know, been questioned by psychiatrists over the years, you know, oh, so this work you do at [place of employment], do they pay you for that? Of course they pay me! Oh, and what is it you do? ... This is the consultant psychiatrist, you know, what is wrong with the world? Don't they believe in what they are treating? You know, that's my argument to that. They can't do, otherwise why would they question the ability of their patients? (Gwen)

The communication of hope was both verbal and non-verbal. It could be argued that it is more difficult to maintain hope at the height of an acute episode, than when the person is stable, which is where professional input is perhaps more needed. Simple comments, such as "you're doing OK", were reassuring. Showing interest in the individual's life, in his/her interests and plans, communicates that there is and will be life outside mental illness. Sometimes hope was specific, for instance hoping that new medication will work but often hope was more general, simply hoping that the person will be OK and able to attend to their life. Professionals also indicated hope when they didn't simply accept treatment that was only satisfactory but instead kept searching for options that would allow for more meaningful life. As Liam's aforementioned quote showed, if the illness is treated but the individual remains unwell and in addition is

experiencing severe side effects than the treatment is not successful. Retaining that line of treatment says to the patient that this is as good as it gets. Failing to look for better solutions could be interpreted as the practitioner giving up on his/her patient. As Alice noted:

I do hope so [things will work out] and I believe that I've got a doctor who's prepared to, um, have the same attitude and won't just give up on me easily.

Having treatment options.

The participants were treated with the help of medication, psychotherapy and counselling. Although medication was cited as the primary mode of treatment, and was generally accepted as such, there was resistance to promoting it as the only treatment. Even where participants were accepting of medication, having the option of saying whether or not the person wanted to trial a new medication, versus staying on the old one, was seen as having treatment options. Some participants talked about having to search themselves for alternative forms of treatments and expressing their disappointment about not being informed earlier or sometimes at all. Being provided with choices was one way practitioners could promote responsibility at the same time showing the individuals that they had control over their treatment.

One of the biggest things is willing to look up different treatment methods versus just saying, well, here you go, I'm just gonna put you on this medication, who sort of, I suppose wants to match you with something where it's not just a case of treating you with medication, um... gives you some options to actually be proactive to do something and that's probably one of the things with going to see a clinical psychologist now is that, you know, in itself going to see her about my reactions but then she gives me stuff to go on and do and you know, to apply, not necessarily on a hugely grand scale... (Janet).

What does not help.

Difficult access.

When it came to access, there was a marked difference between the public and private mental health systems. Since majority of the participants could not afford private health cover, they had to utilise the public system, which they believed was

insufficiently funded. This means that voluntary admissions occurred only under extreme circumstances. While this was understood to promote reliance on the individual's own resources, some participants talked about being subjected to extreme stress and feeling like there was no help when it was most needed.

Once hospitalised, the individual was put on medication regime and while there were activities to keep patients busy other treatments were limited. Access to psychiatrists and psychologists was limited.

I was supposed to see someone to talk to and you had to put your name on the list, never, never saw anybody in the four weeks, never saw... so you're waiting there because you think you're gonna get called and they just didn't turn up, didn't, oh, she should be coming soon, so you just didn't end up talking (Heather).

...just someone you can trust and to... just sort of say, am I doing the right thing? Not wanting specific answers but understanding why I wanted to do certain things, so that's the sort of thing I'd expect. I mean it would be nice to have some psychiatrist but to me it's just too clinical... When I was in [hospital] at one time, I mean I was in there for months on and off, I couldn't see a psychiatrist once... there wasn't anyone there that I could talk to, I did get very friendly with an older psychiatric nurse and she was really good and I poured my heart out (Bridget).

Access to specialists was difficult outside hospitals as well. Even where the individuals managed to secure a session/consultation these were seen as too infrequent or too brief to be able to address the individual's problems within their whole context. This was seen as a shortcoming where an opportunity to start the healing process was lost.

Poor continuity of care.

Poor continuity of care referred to those aspects of treatment ranging from repeated changes of psychiatrists, lack of information about available resources, and poor communication between practitioners, to no follow-up care upon discharge from hospital. Several participants also mentioned that while they found psychotherapy useful, the limited number of sessions under the current mental health plan meant that ongoing psychological support was difficult to access.

I don't think it's right that when a clinic closes down, they don't, they say to you, you go and see them for the appointment but then you don't realise that they are closing down until they say, OK, we don't need to see you anymore and they don't send you a letter to say, we have finished our agreement but since then we will be closing down, if you need any help, this is where you go. You're left like that (Heather).

It would work so much better if they did do that [psychotherapy] and like if it was an ongoing care... Like when I came out of [hospital], I'm not sure what the second time, I thought they had done a good job by me. I stayed in contact and came back to talk to them but like one of the guys was on the phone, um, for my whole interview, off and on, you know, like the phone would ring, he would answer the call and put it down, um, and that was just so off-putting that I didn't go back again (David).

No guidance to address adjustment to hospitalization.

For some participants, the first time they realised something was wrong was when they were taken to a psychiatric hospital. They may have felt that something was not quite right prior but they had no understanding that the something was mental illness. They may have had poor understanding of mental illness in general and only a vague idea of the role of psychiatric hospitals. For a number of them, the process involved being taken away, medicated and kept in a hospital without anyone explaining what happened, where they were and why, what the disorder they were diagnosed with meant, what the treatment was, its expected outcome as well as possible drawbacks. That the process was missing or incomplete also meant that the individuals were denied an opportunity to provide their own understanding. While it is possible that the communication was there but the individual either could not remember it or he/she was too unwell to fully process what was said at the time, it does not negate the fact that they were left to work things out for themselves.

Paternalistic system of care.

Just as participants talked about what they thought of as “good practitioners”, they disclosed examples of poor practice. Being authoritarian and dismissive, unwilling to admit mistakes, not listening to patients’ concerns, treating individuals as cases or not taking into account patients’ own knowledge and personal beliefs were seen as barriers to good working relationship. These could all be summarised as paternalistic type of

care where the practitioner is seen as the person who has the expertise and holds power whereas the patient is the subject that things are done to.

Just the way they treat you, the way they treat you. It's like, you know, it's like they're stamping the product, you know what I mean? The product's going past on a conveyer belt and they're stamping it, the product and if you bob your head up they'll just stamp you a bit harder, you know what I mean? They're just not really caring, they're too busy, they're just doing what they want to do (Isaac).

I found that he was, you know, if I talked to him about anything that was slightly alternative, he just turned off, and he was the wrong person to deal with me, you know, or I was the wrong patient for him, we were not suited, you know, he was too structured. I'm not a structured person... .. I remember one day, I mean, I've done stuff with medicine people in America and I showed this guy something I'd been taught there at a ceremony, and he just laughed, derisively laughed at me, you know. And that was probably the turning point for me. I thought, 'this man has a closed mind, what am I doing talking to him, I'm letting this man mess around with me, and he's got a closed mind' (Andrew).

Theme 2: The role of others.

The role of other people was one of the strongest themes that was identified quite clearly in every single narrative. Other people did not include just family and professionals but friends, co-workers, fellow illness sufferers, inpatients as well as members of the general public. All those people could have an impact on the illness development, its course and its treatment. It should be noted that since professional relationship have already been addressed within the theme "Professional help" they will not be further discussed.

Relationships with significant others.

Family members and close friends were the persons most often mentioned as having an impact on the participants' experience of mental illness. Supportive parties who were willing to learn about the illness, who were able to detect changes in moods or behaviours indicative of possible warning signs, who were standing by the person in times of crisis and who treated him/her as a complex individual with hopes and dreams

were credited for their positive influence.

Well, fortunately, my husband is very laid back and um, he doesn't take things personally if I say things to him that are mean and nasty because when I'm depressed and that and can be a horrible person and he's just kept the boat steady the whole time so the kids have been on a steady, steady keel the whole time and that's just thanks to him by defending them from me...(Alice).

However, participants also described having experienced unhealthy relationships that made coping very difficult or which were in some instances credited for causing the illness in the first place. For instance, Vanessa recalled a complex set of circumstances with family members at its centre as the reason she became ill. A loss of her mother to illness at an early age, followed by years of neglect, physical abuse and finally sexual abuse by her father, all within the context of isolation and ostracism on the part of the extended family culminated in her experiencing severe psychological difficulties, including depressed moods, obsessive-compulsive tendencies and hearing voices. Unfortunately, the cycle of abuse continued once she was discharged from hospital into the care of a foster family. It was not until she felt safe with another foster family that her symptoms improved.

...it might have been in 2002 when I started getting less voices because I felt more safe and... after all, the voices were a reaction from me feeling like I was in danger and I sort of needed to protect myself.

All participants who had had some experience with toxic relationships in the past talked about having to re-evaluate those relationships at some stage to determine how they impacted on them and whether or not there were any benefits to retaining them as they were. Some individuals decided to sever ties with the respective parties, whereas others decided to keep the relationships but only within tight boundaries.

I sort of broke the chain really, I sort of had to have a look around and say, OK, are things going to improve if I'm with that person in the next year? If it's not, it's time to go, I've got to break away, you know. Will things improve? How long have I put up with this for? How many more times do I have to put up with this for? And I decided that I couldn't see a future anymore with any of them and I said it's time to go, like to myself, I made it where I cut them off me, not telling them but not mixing anymore (Heather).

Even where relationships were seen as healthy, all interactions needed to be on the person's terms. Simply being with people was not in itself helpful. Some individuals talked about feeling suffocated when with others for too long; others mentioned not feeling comfortable with people visiting them and all interactions had to take place outside their homes. Too many people, people encroaching on privacy or one's natural tendency to be self-reliant could all play a role in the perceived helpfulness of interpersonal interactions. In general, the individuals had to learn what they needed from other people and then decide whether that particular relationship fulfilled that need.

Impact of mental illness on others.

Participants were able to describe how other people impacted on their illness and their ability to cope with it but not all of them had an awareness of how the illness impacted on others. Mental illness is generally seen as an internal, private experience and it can be so intense that it overwhelms the person experiencing it. However, not everyone had a full understanding how overwhelming it can be to others who are indirectly affected by it. Alice spoke of her surprise when she found out how her illness impacted on her daughter; it wasn't until the daughter wrote about the experience as part of a school project that she learned about it.

I was just quite shocked that it had affected her so much . You don't realise how much you affect the people around you because you're so caught up in just yourself and your blackness that you can't, can't see and feel what the people around you are seeing and feeling, yeah . And um, you can't sympathise with them even though you expect them to sympathise with you (Alice).

Others were more attuned to the impact on others but even with this knowledge were not always able to prevent break-ups. In fact, relationship losses were among the most common losses that could be attributed to mental illness.

My old mates, they weren't really friends, you know, and I had to make a new lot of friends and where I live they are friends because they're all in the same boat, you know, with mental illness. The people I used to hang around, I thought they were great, you know, but when I got sick they didn't want to know me, they weren't there (Frank).

I don't get a lot of family support which is really hard. My mum and dad ring me every night but that's all they do, they give me a call on the phone but that's not enough. I'd like them to spend a bit of time with me, they don't come to my house or anything, no. My mum meets me once a week but that's it, for coffee, but that's it. I just don't think there's enough family support and maybe that's because of my mental illness (Paula).

Whether because of its nature and severity that became too overwhelming for either or both parties, or because of the inability or unwillingness to understand what the other party was experiencing, one's mental illness had a far-reaching impact that went beyond the person diagnosed with it.

Other people with mental illness.

Every single participant had had contact with other people with mental illness, whether they met through life, in hospitals, in psychosocial centres, via supported accommodation or through support groups. These interactions were generally rated as positive. Support groups and psychosocial centres were seen as places where one did not fear judgment; there was no pressure to justify one's behaviour. People felt supported and accepted the way they were; others knew what the person was going through because they were all in the same boat.

A number of participants mentioned that all their friends were people with mental illness. It could be argued that having a group of people with the one common feature being mental illness could run the risk of mental illness becoming the centre of the persons' identity.

I actually think and my parents I think are much more, my family are much more like this, they say it's better just to mix with normal people which I think it's true to a degree. And whilst there's no such thing as a normal person anyway and doubtless the people you'll come across probably have mental illness as well because it's one in four people I think, yeah, it's more healthy to just speak with everyone and anyone because at the end of the day, we've all got things happening and I don't want to just be summed into one category (Rachel).

While some tried to solve this dilemma by making deliberate attempts to socialize with "normal" people, others used the shared experience as a source of support

but with the primary focus being not on the illness but on shared humanity and all the other aspects of their lives, from companionship, to shared sense of humour or shared hobbies and interests. Just like they sometimes accused professionals of not seeing them as complex human beings but as diagnoses, they tried to treat each other as someone whose illness was only one part of who they were.

However, even within the supportive community of people with mental illness there could be distinctions between “us” versus “them”. This was at times seen in the early stages of the illness experience when the person was coming to terms with being classified as mentally ill. Whether the person compared him-/herself to some preconception of mental illness or whether it was in the course of first hospitalisation where they met other sufferers, accepting self as mentally ill sometimes meant facing one’s own stigma towards other people with mental illness.

Other people with mental illness however also served as a base for comparison later on. Severely ill individuals or those who did not seem to be actively involved in their care sometimes served as reminders that things could be worse or as a warning of what could happen if the participant gave up or failed to take responsibility for his/her illness management.

Some people that I see here and elsewhere maybe celebrate being ill too much. I don’t think it should take over your life and you walk around saying I am depressed or I am whatever, I think you’re still you but I think you do need to embrace that you’ve got a few wires that don’t work too well and you’ve got to monitor it (Bill).

I’ve often seen schizophrenics because they labelled me schizoaffective, I’ve seen these people sitting there smoking and dribbling and shaking or pale and not making any sense or believing people are watching them or believing that they’re god or Jesus and stuff. The interesting thing with me is that I’ve always managed to pull myself from that situation and back into a better situation so I haven’t totally lost it because I think most of these people are just choosing not to recover, they’re just in too much psychological pain so therefore they’re just simply not going to bother to think about recovery at all. They’re just, they dwell on all the bad things or the traumatic things so you know they get sick from just eating bad diet or smoking cigarettes all day or drinking alcohol or taking speed as soon as they get a chance when they get out of the

hospital, they're never gonna recover (Liam).

Sometimes, however, seeing people who struggled with their illness prompted the participant to use their story as an example to help others.

Once you've been here [in hospital] a while and you get to know, yeah, well, my place in the set-up is to be an example to so-and-so, that's probably one of the reasons why I'm here. Why I'm here is to get better but I'm further up in the path than they are and I need to be an example to them and you can make yourself that example. And for the person who is looking up to you, if it's you, it's a big thing because they can see, gee, she was there taking that step and there is hope for me (Alice).

Disclosure.

There was some variability in terms of how comfortable participants felt about disclosing their illness to others. Although a few mentioned that they did not keep their illness secret, a large proportion of those individuals also admitted that they primarily socialised with other people with mental illness and therefore there was some shared understanding of psychiatric difficulties. For the majority of participants, however, disclosure was selective so that they carefully thought about to whom to disclose, when, how and under what circumstances. This caution was born out of past experiences, fears of being judged or misunderstood or simply because of a belief that other people do not need to know.

Why should I tell them? Most of the people I know have got a mental illness anyway. There's a couple that haven't, they know I've got it but they still treat me normal but if I'm going to shops or if they say to me where do you work I say I'm not working, I don't have to say I'm on the disability because they should, because I used to notice before that if I told them I just never saw them again. Because, I don't know, she's crazy, is she? This is just a stigma (Heather).

There was an underlying need to be seen as complex human beings who just happened to have mental illness. The individuals wanted to be accepted for who they were, not for what the illness represented to others; they wanted to be accepted for their qualities and contributions; wanted their work judged on its own merits, not because it was good for someone with mental illness.

I don't really worry about having to disclose but I must say I wish I could in the sense that, you know, if I had breast cancer although it would be hard I would still be able to tell people or if I had diabetes or if I had this and that. Yeah, no, I don't really worry as such but I guess I have at the back of my mind I wish I could. I've only told one colleague, only one colleague out of about, potentially about 30 staff members knows, that's not a big percent... .. And whether or not the people in my workplace or even certain friends, there may be different reasons for them not being very, um, you know, positive but at the end of the day I don't want to risk certain things so I know I have to be careful in terms of my job and that's a sad reality... you still, if you disclose a mental illness you're at risk, not so much of losing your job, but you're definitely at risk of people treating you differently and perhaps things not quite going your way and things like that (Rachel).

A number of participants mentioned stigma they had been subjected to in the past, whether by friends and family members, co-workers or strangers, and described a number of misconceptions other people had about mental illness. It appeared that there was either an unwillingness to try and understand the challenges people with mental illness faced or an almost automatic tendency to lower expectations of what the individual was capable of achieving. Either approach was discriminating. Interestingly, one participant pointed out that even where there was willingness to learn about the illness and take it into account, it could lead to unnaturally heightened sensitivity to any sign of possible distress.

I feel like there are some people, especially my manager at times, who are overly sensitive to the fact that I've got depression, it's kind of like, OK, are you coping, oh no, I'm not sure you are, instead of being reassured when I say no, I'm doing just fine that, you know, that comes at face value (Janet).

Discussion

As Chapters 4 and 5 indicated, the experience of mental illness is highly subjective and involves a number of internal processes, including the persons' understanding of what the problem is; their ability to manage the illness and cope with both illness-related and contextual issues; and their response to what they have lost or gained. However, the current chapter suggests that external domains are equally

important.

The use of the word external should be qualified. Whereas some clinical research could equate external factors with those that are fully outside the person, the present research indicates that those external factors are in fact well within the realm of the lived experience with the person at the core. In other words, where some approaches treat professional help in terms of what a particular clinician or intervention does to an illness this study points out that the clinician and the intervention in fact operate via their impact on and interaction with the individual. Similarly, factors such as peer or social support are not unidirectional processes but rather processes that function as mutual relationships.

The interconnectedness between person-centred and social factors is also seen in Gadamer's (1975) work, which suggests that although experience is subjective, this subjectivity is contextually embedded. According to Gadamer (1975), each person is dependent on the tradition and context; the relationship between individual subjectivity and universality (the person's historical, cultural and social context) is therefore mutual. This historically transmitted general understanding forms the basis for concrete understanding (Lebech, 2006). Gadamer (1975) believed that before individuals come to understand themselves through self-reflection and self-examination, they understand themselves via family and society. However, neither the individual subjectivity nor the universality take a precedence; rather, both are important in order for the individual to expand his/her horizon of meaning and broaden his/her knowledge of the phenomenon.

The role of contextual factors and background knowledge (partly formed by understanding stemming from culture, tradition and other players) is crucial; however, the nature of social interactions is important too. Gadamer (1975) believed that both experience and knowledge were inherently dialectical, with the dialectic of question and answer having a priority in both. Gadamer wrote about productive negativity of experience which refers to experiencing a limit to our generalisations and assumptions, experiencing some "not" (e.g., not as I assumed or thought). Experiencing such limits eventually results in better understanding of one's background knowledge, the matter at hand as well as oneself. However, in order to do so, the person needs to engage in a conversation as it is in conversation that a person is exposed to the other and therefore

experiences the limits of his/her assumptions (Gadamer, 2006b). Gadamerian conversation treats the two persons conversing as two parties engaged in a common search for understanding; the aim is mutual listening, rather than objectification (Gonzales, 2006).

As this chapter demonstrates, appreciation of contextual factors or the exploration of the other person's assumptions and interpretations were often lacking in professional interactions and, to a lesser degree, in non-professional exchanges. Such interactions were rarely characterised by mutual listening. Professional settings especially were often presented as places where clinical knowledge and expertise were assumed to take precedence over the patient's expertise. Yet as the participants indicated, it was when interactions were reciprocal with both parties engaged in shared meaning-making that the individual was most likely to benefit. In addition, as Chapter 8 will demonstrate, the willingness to experience the "not" could be transformative for the professional as well.

Professional help.

The role of professional help is undisputed. Both clinical and consumer-oriented research points out the crucial role of professional interventions in the management of mental illness. However, whereas clinical research would see this role as primary, the consumer research, and the present study, indicate that professional help is only one tool in the overall toolkit of strategies. The two aspects of professional care mentioned by every single participant, diagnosis and medication, were seen mostly as useful. Diagnosis helped explain what had been confusing and frightening symptoms and helped legitimise the participants' experience. For most participants it was also the starting point of treatment.

While a few participants questioned some of the diagnostic decisions made by their clinician, and some mentioned the double-edged-sword nature of diagnosis (providing explanation while also marking the person as no longer normal), once the diagnosis was made and some explanation provided it seemed to be no longer relevant. The actual label was less important than the nature of the problem the person was facing and therefore the type of management strategies the person needed to utilise. This is in line with Hayne's (2003) findings on the experience of being diagnosed where some

participants felt that diagnosis made them different and made them question who they were, while others reported that the diagnosis made the illness evident and through providing access to treatment made healing possible. Hayne concluded that diagnosis could be helpful where it provides means for communicating informative knowledge and where it leaves the person with the potential of future improvement.

In terms of diagnosis leaving individuals better informed, it was not clear from the participants' narratives just how much information they received regarding their diagnosis. Some mentioned doing their own research, others mentioned being told about brain chemicals that were not functioning as they should. In many cases what the participants took away was that they for instance suffered from a mental illness called bipolar disorder which is why they struggled with mood swings which is why they needed to be treated with a specific medication. The diagnosis was more often credited for helping to explain strange, confusing and distressing behaviours, thoughts and feelings. In some cases, it led the person towards forgiveness for some acts they have committed ("it wasn't me, it was the illness"). Yet it was also pointed out that laying the blame on the illness could run the risk of taking control away from the persons and leaving them powerless. It seemed that the diagnosis carried a complex set of connotations that were not necessarily limited to clinical aetiology and criteria but could include anything from forgiveness to personal responsibility, power and control.

The issue of control was evident right across all themes, including medication. The relationship between the person and medication was complex. On one hand, the participants seemed reluctant to accept the idea of having to be medicated for what were essentially psychological problems plus the idea of having to take medication possibly for the rest of their lives. On the other hand, there was an overwhelming acknowledgment of the positive impact of medication. There was a consensus that the right medication could make a significant difference in the person's functioning yet the quest to find the right medication was often long and distressing. Just as previous research (e.g., Jenkins et al., 2005; McCann & Clark, 2004; Piat, Sabetti, & Bloom, 2009; Tooth et al., 2003) found, the right medication was understood to be one that was effective in managing the symptoms and establishing some stability/equilibrium while not burdening the person with severe side effects. While it was impossible to predict how exactly a person would respond to a particular medication and therefore impossible

to completely prevent side effects, how well the process was handled relied strongly on the clinician–patient relationship and on the role the patient was allowed to play.

Smith (2000) talked about the need for continued communication with the clinician throughout the search. Happell, Manias and Roper (2004) reported on patients' dissatisfaction with the general lack of information about medication provided to them and with dismissive attitudes. They believed that each individual should have an opportunity to have a say in decisions regarding medication. Similarly, Deegan and Drake (2006) emphasised the importance of shared decision making in the whole treatment, including medication. The clinician–patient interactions should be viewed as those of two experts who share their information and who make all treatment choices collaboratively. As some authors pointed out, evidence-based treatments, including pharmacotherapy, are more likely to lead to recovery if they are delivered in the context of collaborative partnership that allows for shared decision-making (Davidson et al., 2009a, Mueser et al, 2002; Solomon & Stanhope, 2004; Torrey et al., 2005).

These principles were reflected in the present study. Comments, such as “it is happening to *my* body” were echoed right across the narratives, with the addition that the person should be able to help make decisions regarding medication. Where the decision was made for him/her without proper discussion, which should include explanation of possible side effects, the person was left feeling like an object with no control over what was being done to him/her. Given that many participants needed time to get used to the idea of having to take medication in the first place, and given how distressing the trial-and-error search approach could be under the best circumstances, it is perhaps not surprising that the issue of medication was so emotionally charged. Participants expressed anger at things such as being kept on medication that produced severe weight gain, sexual dysfunction or uncontrollable body movements or having their medication changed despite the old one working well. The common complaint was not only about the medication as such but also about no one listening to what they were saying.

Listening on one hand and providing sufficient information on the other were one part of the exchange. How that exchange was conducted was another. While some individuals were adept at clinical terminology and were able to read complex medical

information, for others the same approach could be off-putting. Overall, there was a strong need to be seen as individuals, in terms of knowing the person's life circumstances, preferences and social contexts. However, it also applied to tailoring information to the person. A person who did not have questions about a pamphlet describing their medication could truly have no questions, or he/she could be too embarrassed to admit that he/she could not understand it or read it in the first place. On the other hand not providing that information because of the perception the person would not understand anyway would be patronising. The key issue was knowing the patient well which could not be achieved without genuine interest in the person, honest attempts to get to know him/her and willingness to listen.

Listening and trying to understand were two primary skills cited by all participants. While it seems like an obvious assumption to expect practitioners to have those skills, the narratives clearly indicate that they were often missing. Whether they represented a true lack of skills or whether they were a result of structural constraints (e.g., too many patients for too few clinicians who had to limit the time spent in consultations) or other issues (e.g., clinician burnout), the participants demonstrated a great sensitivity to whether or not their clinician appeared to want to listen and whether he/she actually heard what they said. Superficial listening, disregarding the individual's opinion, dismissive attitudes or outright ridicule of the person's viewpoints prevented a solid therapeutic relationship from developing. Where the persons felt that the clinician did not trust and respect them as individuals as well as experts in their own illness, the persons were likely to respond with distrust and disrespect.

The issue of mutual distrust was not simply an issue that stood outside treatment. Even if medication was working to control some of the symptoms, the type of relationship within which the treatment occurred was very important. Researchers have consistently found that clinical guidelines, knowledge of mental illness and formal interventions were not enough to support recovery, and that it was the relationship with the treating health professional that played a crucial role in what impact the treatment had (Borg & Kristiansen, 2004; Topor et al., 2006). Paternalism, indifference, dehumanisation, judgmental attitudes, invalidation, caring for the patient but not the person, and viewing professional knowledge as the only expertise were seen as barriers to treatment and ultimately recovery (Barham & Hayward, 1998; Mancini et al., 2005;

Oades, Law, & Marshall, 2011; Tooth et al., 2003). On the other hand attitudes that were characterised by empathy, warmth, compassion and support, that emphasised shared humanity and that treated the person as an individual who had things to offer, who was capable of setting and working towards goals and who was able to make his/her own decisions were highly valued (Davidson et al., 2005a; Green et al., 2008; Mancini, 2007).

What the present study demonstrated was how attuned the participants were to signs of poor relatedness. Just as they were aware of being observed and assessed, they engaged in their own assessment of the professional. Topor and Denhov (2012) noted that individuals expect undisturbed and focused time from their professionals; the present study similarly showed that things like coming unprepared to sessions (e.g., not knowing any personal information about the person), answering phone calls while in session or not looking at the person while talking to him/her were observed and stored away in memory, and then used to assess for what they communicated about the clinician's attitude. Where exchanges were seen as paternalistic and inauthentic they could stem the flow of information with important information potentially not exchanged. Poor listeners were less likely to hear the patient's story and in fact being told the story in the first place. As Topor and Di Girolamo (2010) found, individuals adapt what they say depending on who they talk to, how they perceive the other person and on their past experience with that person; even in crisis situations the individuals make rational choices about whether or not to share their story. And yet as the present study demonstrated, being able to tell their story was a strong need the participants had, one that they were entitled to having met.

Telling a story and having that story heard and understood could in itself be therapeutic. Previous studies found that one-on-one therapy with a perceptive and respectful listener was highly valued (Cohen, 2005); such therapy could help the person gain insight into their thoughts and feelings (Ridge & Ziebland, 2006). As the present study indicated, the type of professional who engaged in the therapy and the type of therapy itself was not important. The specific intervention was almost never mentioned and it did not seem to matter whether it was delivered by a counsellor, psychologist, psychiatrist or a GP (even though medical professionals within the public realm were less likely to do so because of the time-limited nature imposed on them by the system).

The healing power of narrative seemed to work for several reasons. Firstly, the fact that the person's story was given attention communicated to the person that the story was important which by implication meant that the person him-/herself was important and worthy. Secondly, helping the persons verbalise what they experienced, thought or felt helped them put those experiences, thoughts and feelings into a more coherent whole that made sense and that was perhaps less frightening. It could be argued that at times of acute crisis the person's ability to be coherent and articulate is compromised. However, as the participants' stories indicate even in those times they are trying to make sense of what is happening. They might need more guidance or perhaps more time but they should be allowed to tell their story for the healing to begin.

Thirdly, a life narrative works with the concepts of the past, the present and the future. Talking about the past and how it led to the present leaves the person with the view of the future. A person who is well is more likely to look back and see past setbacks as opportunities of learning and past achievements as significant personal accomplishments that give him/her a sense of hope for the future. A clinician who knows his/her patient well will be able to support this realistic yet hopeful storytelling. However, a person who is unwell or only just getting past a period of ill health might need more or perhaps different assistance. As participants in Ridge and Ziebland's (2006) study remarked it is very difficult to remain positive while depressed which is when professionals should provide hope. Having to cope with debilitating symptoms, perhaps being hospitalised and dealing with the consequences of medication trials, and then hearing that the person will not get better is devastating and can lead to the person living out a self-fulfilling prophecy. On the other hand, communicating expectations of future improvement, always looking past the illness at the person and essentially helping the person tell a story that does not end with the present episode but that shows a potential of fulfilling future could make a difference in the person's overall coping.

The present studies showed that communicating hope is not limited to saying "you will recover". (In fact, as later chapters indicate, such a simple statement could be counterproductive.) Communication of hope covers a whole range of possibilities, from subtle signs to involved discussions. Individuals could take comfort from the fact that their practitioner schedules less frequent appointments when he/she feels that the individual is doing well. They appreciate that their clinician will not give up when

things are seemingly not improving and will keep searching for other treatment options. However, as the stories indicated, there was a thin line between seeing less frequent appointments as communicating hope and viewing them as signs of abandonment. What helps differentiate the two is good working relationship and opened communication.

While the benefits of talking therapies were clear to many participants, access to those therapies appeared to be limited. In terms of inpatient treatment, participants talked about not having anyone to talk to about their problems outside those issues related to medication. Outpatient therapy was limited to a certain number of sessions per year covered by general public insurance; private insurance and pay-per-session set-ups were outside the financial means of many. Where a talking therapy was mentioned, it was often in the context of counselling to address a specific problem, such as drug use, sexual abuse or domestic violence. In addition, many participants were unaware that such options were even there.

The issue of treatment options was one mentioned by many participants, and supports findings from previous studies (Jensen & Wadkins, 2007; Mancini et al., 2005; Topor et al., 2006). Just as professional help was only one of many management and coping strategies, medication was only one of many forms of professional help. Some participants were led to believe, deliberately or by omission, that medication was the only treatment available or suitable for them. Unfortunately, this prevented them from benefiting from even those limited options that existed. Some participants talked about almost accidentally stumbling across information about a treatment that they found very useful. Some of those useful tips were only received once the person had established a network of peers; unfortunately establishing such network took time. In addition, once the information was accessed the person had to contend with various eligibility criteria that may have denied them access. With all these delays and systemic failures the participants were denied the opportunity to access and use what they needed and when they needed it.

As the present research shows, the journey with mental illness requires that the person learns how to navigate their way through the mental health system, a system they had in most cases never been exposed to before⁴. Unfortunately, the participants

⁴ A number of participants talked about family members who had mental illness and recalled memories, such as hospital visits. However, true knowledge of the system only came with direct experience.

presented the system as a system that was clinical and impersonal, one that left them feeling objectified and powerless (like a product being stamped, as one participant put it). The system also appeared to be flawed in a number of structural ways, from compartmentalised care to poor intra-/interagency communication and poor continuity of care. Yet a system consists of individual players and it would seem that it often took one or two dedicated, caring professionals for the individual to start viewing the system in a more positive light.

One aspect of the mental health system that received mixed reactions was hospitalisation. Hospitals were described as potentially useful tools in treatment in that they represented a safe holding place where the individuals could rest and get back on their feet. Yet they were also associated with oppression and feelings of distress and powerlessness, especially if the person was admitted involuntarily. A number of studies demonstrated the negative experience of psychiatric hospitals, with individuals talking about their sense of being trapped and imprisoned (Perry, Taylor, & Shaw, 2007) and of having little control over their treatment and care (Zolnierek, 2011). It could be argued that first hospitalisations were particularly distressing. Perry and colleagues (2007) who explored the experience of first episode psychosis (and first hospitalisation) found that their participants struggled to explain their understanding of psychosis; this confusion was seemingly not helped by the lack of information they received prior to and while being hospitalised.

The failure to provide information was evident in the present study which indicated that the system largely lacked a process that would help the person's adjustment to being hospitalised, particularly when it was the person's first admission. It left the individuals to work things out by themselves which could have added to the confusion and distress, and which could only be viewed as a missed opportunity. At times it took several admissions before the person learned of the potential role of hospitals and their own place within the hospital. It could be argued that such missed opportunities could delay the commencement of the healing process.

Being admitted to a hospital was not simply a matter of accessing one form of treatment. Participants in Lally's (1989) study indicated a number of negative views of psychiatric hospitals and psychiatric patients they held prior to their first hospitalisation. The fact that they suddenly found themselves in that very same category meant that they

were faced with a conflict between their old beliefs and prejudices and their new views of self. Laithwaite and Gumley (2007) found that hospitalised individuals were trying to learn about themselves and to make sense of what happened in order to figure out what it was that led to them being hospitalised; the learning process was helped by trusting relationships with staff and family members. As the present study indicated, first hospitalisation could be a major life event.

When a person is hospitalised for the first time, he/she is faced with an overwhelming amount of new experiences that could be bewildering and frightening. The individual struggles with distressing symptoms, is taken to a whole new environment (at times against his/her will) that appears to have its own rules, and commences treatment that can be highly unpleasant. He/she also has to deal with the fact that he/she is now classified as having a mental illness which in itself can bring forth beliefs and presuppositions the person struggles to accommodate. The person is then faced with a new language of clinical terminology that can be difficult to understand. Finally, the individual is in a daily contact with other individuals who might seem to be extremely unwell and seemingly very different from, and unlike, the individual. This must raise a whole lot of questions: where am I, why am I here, what is happening, why is it happening, what is going to happen next? If those questions are not answered (or not even heard in the first place) the whole therapeutic environment is compromised.

The interviewed individuals did not deny that there were times when they were very unwell, and they usually assented that at such times hospitals could play a role. Yet they also indicated that even in those times of ill health they were trying to make sense of what was happening. They needed to hear information about the professional explanation of their problems but they also wanted others to hear how they explained the situation. Clinical diagnosis, professional interventions, or medication titles were all things that they learned over time. But their own thoughts on their illness were forming as they went through the experience and many beliefs were already there.

The role of others.

The role of other people has been widely documented in literature, and social domains are cited as playing a crucial role in recovery (e.g., Bradshaw et al., 2007;

Corrigan & Phelan, 2004; Ridgway, 2001; Schön et al., 2009; Topor et al., 2006). The actual symptoms of mental illness can lead to feelings of estrangement and compromised intuitive social knowledge (Deland et al., 2011) just as stigma associated with mental illness can help produce loneliness and isolation (Topor et al., 2006). However, the need for social engagement (Kooij, 2009), the need to belong and be accepted by others (Mezzina et al., 2006; Perry et al., 2007) and the desire for normalcy (Zolnierrek, 2011) remain and continue to play a role. Just as trusting relationships marked by reciprocity and mutual respect helped determine the impact of professional interventions, positive, respectful relationships helped determine how supportive social support really was in informal settings.

Both clinical and consumer recovery research recognizes the role of social interactions, and operational definitions, such as the one by Liberman and colleagues (2002, 2005), consider social activities as one criterion of recovery. Whereas the authors cited meeting with a peer at least once a week as one example, the present study and other research findings indicate that it is not the quantity of contact but rather its quality that plays a role (Pernice-Duca, 2010). The study participants clearly demonstrated that it was healthier and more adaptive to put limits on social interactions than to continue with relationships that were toxic to the person's wellbeing. Being with others per se was not necessarily helpful, even when those others could be described as supportive; it did not take into considerations contextual aspects, including personality factors such as introversion or the person's need to be self-reliant, or social and developmental history, such as longstanding patterns of being abused and dominated by others.

Henderson (2010) suggested that social support and reciprocal relationships act as external mechanisms of recovery in that positive interactions facilitate progress while negative ones impede it. Similarly, Davidson and Strauss (1992) pointed to past research on schizophrenia and expressed emotion to suggest that significant others can influence an individual's recovery in either positive or negative way. Family and friends could help create sense of belonging and could provide guidance and direction, practical help and advocacy (Davidson et al., 2005a; Topor et al., 2006). Fellow consumers could act as role models who provide support and hope based on shared understanding (Mancini, 2007).

The present study builds on these findings to further demonstrate the complexity of decisions involved in social exchanges. The participants talked about having to evaluate existing relationships in terms of how helpful they were; this ability to evaluate did not necessarily come naturally but had to be learned, often after a long period of unhealthy patterns of interaction. Disrespectful, rejecting or abusive relationships made adaptation, coping and illness management much more difficult; at times those same relationships were seen as the primary cause of the illness itself. And even once the person identified those relationships that were unhealthy, he/she was faced with the decision of whether to tolerate them further, continue with the relationships but within tight boundaries or whether to terminate the relationships altogether.

When describing supportive relationships, the word reciprocal is often mentioned. It refers to being able and willing to receive as well as offer support, and there were certainly examples of both, with many participants talking about doing things for and with peers or volunteering. However, what the study highlighted was the importance of being aware of the impact of mental illness on others, especially within the realm of relationships with significant others who after the process of de-institutionalisation are responsible for a large part of mental health care (Champlin, 2009). While most participants were able to talk about others' lack of knowledge and understanding of their illness and its impact on them, not all of them were able to appreciate the impact their illness had on others. It would seem that for relationships to be truly reciprocal, both parties needed to be aware of how the illness affected the other person.

Navigating existing relationships was fraught with potential problems but starting new relationships was equally difficult because the person was faced with the dilemma of whether or not, when and under what circumstances he/she should disclose his/her mental illness. Participants talked about having experienced stigma in all potential social situations, including with family, friends, professionals, as well as employers, co-workers and members of the general public. Sometimes this resulted in what could be called inverse discrimination where the other person was trying to be supportive and sensitive to any signs of the individual's perceived ability to function and unwittingly ended up undermining him/her. Overall, disclosure was highly selective

and often occurred after a period of time when the person felt secure that he/she will not be rejected.

Some of the concerns related to disclosure were no longer relevant when the person was with peers. Whereas in interactions with non-consumers mental illness was one thing that marked the person as different (not “normal”), with fellow consumers it was a thing that they had in common and that led to shared understanding. With mental illness not being a point of difference it could be more easily pushed to the background so that the individuals could focus on all the other parts that constituted their identity. While it would make sense to seek others who understand their experience and are less likely to discriminate, a number of participants talked about the push-pull dynamic of community integration. On one hand they wanted to be accepted for who they were which was something they tended to find in consumer settings, on the other hand they expressed their need to socialize with “normal” people.

Ekeland and Bergem (2006) who interviewed 15 individuals to find out how they negotiated their identity learned that those individuals who accepted an identity based on mental illness had easier access to services and experienced fewer conflicts. While it was easier for them to establish identity, their integration was as part of a marginalised group. Those who did not accept their patient/illness identity wanted to be accepted as they were but reported feelings of loneliness and stigmatisation, and ended up feeling marginalised as individuals. These findings were supported by the present study which indicated that a number of participants managed relationships both within and outside consumer settings but that both arenas presented their challenges.

General community settings and interactions with non-consumers were more likely to satisfy the need for normality yet those interactions also raised the issue of disclosure with the risk of stigma and discrimination, or simply just “otherness”. Peer group and consumer settings were more likely to satisfy the need to be understood and accepted the way the person was yet the membership in those groups was dependent on being classified as mentally ill, therefore different, so as Ekeland and Bergem (2006) pointed out, integration occurred as part of a marginalised group. It appeared that at some stage an individual has to make a choice about who they want to associate with and to weigh up the costs and benefits of peer versus non-consumer interactions. It

would seem that for most participants a combination of both worked, as long as they had some control over those interactions.

The feelings of otherness did not relate only to interactions with non-consumers. The participants also talked about feeling different from some of their peers. The first realisation usually occurred during their first hospitalisation when they met other individuals who were in an acute state of ill health, so seemingly different from them yet classed as mentally ill, just as they were. As Lally's (1989) research showed, being hospitalised for the first time means the individual might be faced with a conflict between his/her prejudices toward psychiatric patients and the realisation that he/she is one of those patients. However, comparisons could occur at any other stage of the mental illness journey, with participants noticing those individuals who seemed to be doing less well which they attributed to a whole range of issues, from poor insight to greater severity to unwillingness to work on their recovery.

Conclusion.

McCann and Clark (2004) found that mental illness sometimes damages relationships while at others can elicit support from others, and concluded that the illness acts as a mediator of social relationships. Sells and colleagues (2004) believe that social factors play a key role in recovery but that it is critical that the person negotiates how, where and when he/she is with others. The present study supports these findings while at the same time extending them to show the complex interplay between the specific social factors as well as between those factors and the person-centred factors, as discussed in chapters 4 and 5. Effective professional help requires a trusting, respectful relationship that cannot be fully developed unless the individual's expertise is acknowledged; such expertise only develops as a result of the person's own learning about self and the illness. Good social support is reciprocal but reciprocal support depends on awareness of the illness and its impact. These findings clearly indicate that it is largely the contextual (non-clinical) factors and their interactions as well as the person's ability to understand and have some control over those factors that determine how well the person adapts to mental illness.

Given the characteristics of healthy social interactions, such as openness, respect, reciprocity and acknowledgment of the other person's viewpoint, it could be

argued that effective interactions are hermeneutic in nature. Supportive persons, both professional and non-professional, listen carefully to the individual's story, with special attention to the context and subjective interpretation. Hermeneutic interactions are akin to opened, non-directive conversations, with the emphasis on situatedness and contextuality and with the aim of mutual understanding of the respective meanings (Smith, 1993). It is such interactions that have the potential to mitigate power imbalance that often exists when communicating with individuals with mental illness, that can help the person tell his/her story as a coherent narrative, and that can therefore help promote and foster recovery.

Chapter 7

Reflecting on recovery

Overview

Seventeen of the 20 participants of the main study reported in Chapters 4, 5 and 6 completed a second interview which focused on recovery. The interviews started with a discussion of the RAS-R (Corrigan et al., 1999) which had been completed at the end of interview 1. Each participant was presented with their respective survey and was then told what their results suggested. Raw scores were not discussed; rather, the individuals received a brief description of the five domains of the survey and were asked about their thoughts on the domains. Where there were items that were scored low (“1” or “2”), those items were brought into the discussion. The individuals were also asked about their experience of completing the survey. Finally, discussion turned to the concept of recovery. The participants were asked whether they had come across the concept, what their thoughts on it were, how they would define it and what their personal recovery was/would be like.

Similarly to the first interviews, the interviews were largely guided by the participants. This means that not all of the content of the second interviews necessarily focused on recovery. Participants talked mostly about their lived experience, often adding or clarifying information that was gathered in the previous interviews. Therefore all data from interview 2 that were not directly related to recovery were included in the Stage I analysis reported in earlier chapters. This chapter reports on findings as related to the concept of recovery only.

Findings

Theme 1: Recovery Assessment Scale.

The Recovery Assessment Scale (RAS-R), in its revised form, is a 24-item scale designed to measure personal recovery. It assesses five domains: personal confidence and hope, willingness to ask for help, goal and success orientation, reliance on others, and not dominated by symptoms (Corrigan et al., 1999; Corrigan et al., 2004). *Personal confidence and hope* assesses the individuals’ hope for the future, their ability to handle stress and their views of personal goals as achievable. *Willingness to ask for help*

contains questions about the person's help seeking and willingness to ask others for assistance with problems and challenges. *Goal and success orientation* assesses desire to succeed and perceived ability to meet self-determined goals, while *reliance on others* focuses on the importance of others in goal attainment and recovery. *Not dominated by symptoms* includes items that refer to mental illness as not the main focus of the persons' life.

The scale yields a single score of recovery, ranging from the lowest possible of 24 to the highest possible score of 120 where the higher the score the higher the person's recovery. In the present study, the lowest achieved score was 53. The person with the highest recovery achieved the score of 112 (see Table 1). While such range could indicate a high variability in responses, the majority of the participants who completed the scale (15 out of 18) scored between 80 and 100 which would point to a rather homogenous sample. Overall, the mean total score was 99.39 ($SD = 13.17$).

Table 1. Participant RAS-R scores

	Gender	Self-reported primary diagnosis	Personal confidence and hope	Willingness to ask for help	Goal and success orientation	Reliance on others	Not dominated by symptoms	Total score
1	Female	Bipolar disorder	31	12	21	18	6	88
2	Male	Depression	28	12	20	11	12	83
3	Male	Depression	34	12	21	16	10	93
4	Male	Bipolar disorder	39	13	20	16	12	100
5	Male	Bipolar disorder	29	11	22	17	11	90
6	Female	Bipolar disorder	37	13	22	14	13	99
7	Female	Schizoaffective	26	13	19	16	7	81
8	Male	Bipolar disorder	38	12	22	14	11	97
9	Female	Depression	32	11	20	16	10	89
10	Male	Depression	33	11	18	15	12	89
11	Male	Schizoaffective	42	15	24	14	15	110
12	Female	Bipolar disorder	36	13	23	17	8	97
13	Male	Schizophrenia	35	12	23	18	12	100
14	Female	Schizoaffective	16	9	13	10	5	53
15	Female	Bipolar disorder	35	12	21	18	13	99
16	Male	Bipolar disorder	31	9	21	12	7	80
17	Female	Depression	30	13	19	15	8	85
18	Female	Schizophrenia	39	15	23	20	15	112

Recovery scores.

No statistical analysis was carried out since that was not the purpose of using the survey and since the sample size was so small. However, there seemed to be a pattern

where some items were scored low across most participants while some were scored high. The items that received the lowest scores were: “Fear doesn’t stop me from living the way I want to” (domain of personal confidence and hope), “My symptoms seem to be a problem for shorter periods of time each time they occur” (not dominated by symptoms) and “I can handle stress” (personal confidence and hope). The items that received the highest scores were: “I have goals in life that I want to reach” (goal and success orientation) and “I have a desire to succeed” (goal and success orientation).

The aforementioned items indicate that although the individuals were trying to move on with their lives and had some direction and something to strive for, their illness and their ability to handle stress and fear/anxiety could act as barriers. This theme was certainly evident in their narratives in which they suggested that although hopes and plans for the future were important, these were seen as only tentative because they could not predict whether or not, and to what degree, their illness would interfere.

Although it was hoped that the survey could help determine possible patterns in responses that would differentiate those individuals who scored at the higher end of the scale from those scoring at the lower end, that wasn’t the case. With the exception of one participant, the survey results indicated a relatively homogenous group of individuals who all scored in the higher middle to higher end of the scale.

Reactions to RAS-R.

Almost all participants (18 out of 20) were willing to complete the survey and expressed interest in feedback on their results.

I’d like some feedback on what I’ve put down there. I’ve done that out of my own, I’m not saying heart but I’ve done that to help myself and also to help the study (Colin).

With respect to the actual survey, it was generally rated as easy to complete, with comprehensive wording and questions that were not too difficult to answer. However, participants generally did comment on questions they found ambiguous or irrelevant; some provided comments on the questions and their own answers as they were completing the survey.

Look, I’ve said I strongly agree about the desire to succeed, yes, and I’ve put not sure that I have a purpose in life because I think one’s purpose shifts of course (Bill).

It is perhaps because the survey was presented to them after an in-depth interview that had managed to establish a relationship by treating the two parties as equal partners in a conversation that the participants were quite vocal about the survey. For instance, Keith did not initially rate item no. 15 ('Coping with my mental illness is no longer the main focus of my life') and instead wrote next to it: "*Never has been focus*". Similarly, Gwen rated item no. 11 ('I have an idea of who I want to become') as 1 (strongly disagree) although all the other items were scored 3 or higher; she also wrote next to the item "*I am me*". When asked about the item she said the following:

I don't want to become anybody else and if you read that exactly... Because I paused when I thought, can I read that meaning as, you know, a bit ambiguous, and then I thought no, I'll take it as it is written. Who do I want to become? I don't want to become anybody else, I want to always be me.

In general, two issues were pointed out. Firstly, some participants indicated a degree of self-awareness where they were careful about answering how things were as opposed to how they would like things to be. As Frank commented, "*I want to be truthful, you know, how I feel?*" Similarly, Bill said:

I found some questions very easy to answer and some questions... not difficult to answer but difficult to... as in putting down the reality as opposed to an optimistic view of it, I think. It's like, usually when someone says, good day, Zdenka, how are you and you say fine but afterwards you say, I had a miscarriage last week and I've got influenza and both my parents are dead, but I'm fine, it's like, yeah...(Bill).

The second issue related to the episodic nature of mental illness. It was noted that responses to the items were dependent on the psychological state the person was in and how much their illness interfered at the time of completing the survey.

I think a lot of it has to do with what particular illness it is and what stage of illness or wellness you're at... So I might say, you know, in a questionnaire, that yes, everything is fine and I'm feeling good and yes, I have goals, but I might have been on a high when I'm answering those questions. It's like getting a false positive, if you like, you know what I mean, because its reactions are very much governed by the particular mood I'm in on the day which doesn't really map recovery because, you know, through a stage of mental ill health, you will still have, in my case especially, have highs and deep lows... ..

[and] if you've got a similar group of bipolar people you will find that if you keep asking those same questionnaires every week, they will be all over the place so how do you measure that? (Gwen)

Theme 2: Conceptualising recovery.

Talking about recovery.

The participants' response to the word recovery was varied but none of them seemed to identify recovery as central to their narratives. Where the word was mentioned spontaneously as they told their story it was without further clarifying its meaning. The word 'recover' seemed to be used as a way of talking about feeling better and getting on with life. It was only when the participants were asked to define recovery and to share their thoughts upon hearing the word that there was a more detailed discussion of the topic.

Most participants indicated that they either had not come across the concept or that they had not given it much thought in the past. At one end of the spectrum of responses recovery was seen as something outside the person's experience, a concept the person could not relate to, regardless of how well he/she was doing. At the other end of the spectrum were participants who saw recovery as an important, but not dominant, part of their story. For instance, Rachel talked about recovery as regaining balance (equilibrium) that was lost during her illness. For her, recovery occurred in three stages: (1) recovering from the acute stage; (2) reconnecting with friends and starting treatment; and (3) maintenance.

A number of participants were also able to discuss recovery as part of a broader context, which indicated their awareness of the shift that has occurred within the public discourse of mental illness, both within consumer and formal mental health settings. For instance, Bill pointed out that he only started to hear the word in relation to mental illness in the previous two or three years. Keith voiced his doubts about the interest in the concept, speculating whether it was just "a passing phase". Gwen thought that recovery was a fashionable word that gets talked about without necessarily reaching the people it should be reaching. She also pointed out the danger of focusing on recovery without clear discussion of what the word refers to:

I think that it's something that, you know, it gets talked about a lot but nobody ever really explains to people what does recovery really mean, you know, everybody has this goal of recovery. We're not gonna talk about your mental illness we're gonna talk about your recovery. That can be very off-putting I think, you know, having that much emphasis on it because if a person is in a bad space that doesn't look very achievable... ... I also think that for people who are not in a good place, the idea of recovery often suggests that all of that help and assistance won't be there anymore because you've recovered. That's scary. So perhaps it prevents people from trying to recover from something. And it's very scary when you know how much you've needed all of these people there to help you through these things to feel that they might be withdrawn.

Contrary to narratives of mental illness which flowed naturally, the task of defining recovery seemed to be more difficult so that when the participants were asked to provide a definition they often answered with words that were almost followed by a question mark. It seemed as if they were faced with a foreign word, a concept that did not apply to them or a concept they simply hadn't thought of. In its simplest form, recovery was about getting better. Other descriptions mentioned the words 'to return to' (some previous state of being or functioning), 'balance (also maintenance or equilibrium)', 'normality', 'healing' as well as 'caring' (for self and others).

...it's a big caring experience because if you're caring for yourself and you're nourishing, it's a big nourishing thing which happens to yourself and then nourishing and caring for others (Molly).

Although there were concepts that seemed to be common across participants, it would be difficult to categorise the definitions because of significant overlap as well as because of similar ideas carrying different meanings. For instance, Gwen talked about returning to where one was before an event (of ill health) which she equated with returning to a maintenance phase. Alice described recovery as the ability to function like a normal person, which she believed would mean going back to who she used to be before the illness. Both participants talked about going back to something but one mentioned a state of relative well-being with the illness present but under control whereas the other one talked about a state that was free of illness altogether (i.e. normal).

Some descriptions incorporated clinical criteria. Most commonly, those included components of psychopathology (improvement in symptoms) and medication (no longer taking it).

Recovery I think it means trying to get better, you want us to get better and better and better, you know, that way I won't get depressed, I won't get paranoia, you want that to go away, everyone wants that to... I want that to go away eventually. And it won't happen overnight, I know, it's a lot of things... (Frank).

...just sort of live every day as it comes and just to live in hope. I do want to get to that stage of recovery and not be diagnosed with bipolar and actually be quite constant in my moods and have that calm nature about me and that's how I want to be (Tina).

If I came off my medication, then of course I would be on my way to recovery. But I don't see myself getting off my medication any time soon (Alice).

Some participants defined recovery as no longer requiring medication and other treatment, or no longer having a diagnosis. Such definitions approach recovery as almost synonymous with cure. Yet many of those same individuals often expressed doubts about whether mental illness could be cured. In other words they would see themselves as recovered if they were cured of their illness but because they did not believe that they could be cured they did not think that they could be fully recovered. In general, the participants talked about themselves as being in recovery as opposed to being recovered.

I can't think of any mental illness quite honestly that I've ever seen that is cured. It's not cured like influenza. I think the best you can do is to get people on track back to feeling well (Bill).

...you realise if you create something which is bad or you've been tormented, I had post-traumatic stress or whatever, you know you can't cure overnight, you can't cure overnight, that's just the reality. It's harsh, it would be good if you could just cure how you're psyche's working but it's not like a cut, you know, or like a burn, it's not just gonna heal up and be a little scar, your brain just functions differently to that (Liam).

Some participants said that their understanding of recovery has changed with time and with their growing knowledge of their illness. For instance, Janet remarked:

I suppose more so now than maybe it would have been previously is the sense of having a balance as far as recovery goes versus things being finished, being off treatment...

The design of the present study, which involved interviewing participants repeatedly over a period of time, provided an additional opportunity to see whether the recovery narrative was stable. While some participants confirmed their earlier understanding when re-interviewed, others indicated that the concept is fluid and highly dependent on what was happening at the particular time, as illustrated in the following example.

When Alice was interviewed for the first time, the topic of recovery was very briefly raised at the end of the interview. As she later admitted, that particular day she was feeling tired and had some difficulty concentrating towards the end of the interview. Her feeling unwell was perhaps one of the reasons why she found recovery a foreign concept that she just could not picture. In that same interview she also said that her illness was her life. By the time of the second interview she was feeling considerably better and was able to engage with the topic so that she saw recovery as getting back on her feet, taking on new responsibilities and challenges and being able to cope with day-to-day living. When she was interviewed the third time she was hospitalised but stable and functioning well. Her overall understanding of her illness seemed to have changed and she broadened her concept of recovery to include dealing with the actual illness as well as healing from the consequences of childhood abuse:

I still see it as something that's relevant because I know that you can be healed from the depression that's led by sexual abuse as a child and that and I think that there is a place of healing for me I've just got to find it and I'm almost there... ... the whole thing to me is something that I need to work on and along the way I've got my depression and my bipolar to deal with so I've got to take those into my leftovers from work and that sort of thing and spend the time that I am trying to get rid of that feeling of depression and that from the sexual abuse, get rid of the, scrape my heart clean and get rid of those things that still jab me.

The aforementioned discussion indicates that how people talk about recovery is just as important as what they believe recovery refers to. Using the word with the

assumption that both parties have the same understanding of its meaning could lead to misunderstanding but could also be potentially damaging. Similarly, believing that once a discussion of the concept had occurred, the topic was exhausted once and for all would be misleading. Just as the individual's understanding of illness and its role in his/her life was continuously evolving, the understanding of recovery may evolve as well. If recovery is to become part of the person's story it needs to be approached not as something static, something that retains the same characteristics as it was once believed to have, but rather as something that could change as the person's various internal and external factors change.

Finally, just asking for a definition could create an artificial discussion of something the person does not relate to. The participants demonstrated that such debates might produce criteria (symptom- and medication-free or cured) that the individuals themselves see as unrealistic. What seemed to be more productive in the process of talking about recovery was to specifically instruct participants to think about their personal recovery or what they believed their own recovery would look like.

Defining personal recovery.

Asking about personal recovery created a more engaged discussion than when the participants were simply asked for a definition of the concept. Yet even then the participants rarely viewed their experience of mental illness as a story of recovery, even though their own assessment of their perceived wellbeing (and their RAS-R results) would indicate otherwise. They were far more likely to talk about staying well and getting on with their lives than about recovering/being in recovery although it could be argued that those two ideas were if not synonymous then certainly closely linked.

Just as the task of defining recovery indicated, stories of personal recovery were just as varied as the illness narratives, clearly showing that recovery was something that was subjective and that involved steps that were unique to each person. It was also a journey that took time and hard work. Some participants expressed their belief that recovery only occurred with improved understanding and better coping/management skills, which in turn were the results of maturity. It was helpful to have others assisting but the work of recovery had to be done by the individual.

For everybody it's gonna be different and so my recovery, as I said, might be just being able to do six months of [college], um, where somebody else's recovery might be to get out of bed in the morning, so it really depends on the individual (Alice).

Although personal conceptualisations varied, there were two streams that summarised those descriptions: (a) returning to baseline following a crisis, and (b) living as best as one can given personal limitations and unique circumstances. The first definition refers to short-term, episodic recovery from an acute period of ill health. It was usually associated with attempts to reclaim temporary losses and with short-term, specific goals. The second definition refers to long-term, global recovery that occurred as a result of consolidated knowledge. It took into account what the person learned about himself, the illness and the relationship between the two from lessons accumulated during periods of both illness and wellness.

Returning to baseline following crisis.

When people talk about recovery, I would look at it from the point of someone who has been so sick, so debilitated by whatever their mental ill health is that they either need constant care by a carer, or they have to be hospitalised or they have to have increased and more frequent visits to the psychiatrist and medication's increased, that's what I class as being a period of ill health and I would class recovery as a return to where you were before that event, that's what I would class as recovery... So you can go through a stage of mental ill health like you can go through a stage of ill health in other areas. And I think when you get back to your maintenance phase that's your recovery. So you've recovered from an event but it doesn't mean to say that it won't happen again (Gwen).

Participants talked about mental illness as consisting of periods of ill health with times in between when things were better. Returning to baseline is therefore about going back to better times which they described as either normality, balance (also maintenance or equilibrium) or who the person once was. Overall, returning to baseline referred to two different concepts: one was return to a level the person was functioning at prior to the onset of illness. The second concept referred to returning to a level of functioning prior to an acute episode. Those two were not mutually exclusive. Individuals could talk about losing some skills and abilities during the time of acute

illness and then recovering those skills once they became well again while at the same time talking about recovery more broadly, in the sense of getting back to what was once normal for them. Return to pre-episodic functioning was about short-term recovery that required clear and specific goals. It involved learning about what had occurred during the particular episode, whether anything was lost during the episode and if that was the case, whether it could be reclaimed. Return to pre-morbid (normal) functioning was about long-term recovery. It required a succession of steps and continuous work on getting better in spite of possible setbacks. It involved learning about self, about the illness and the role it played in the person's life. Return to normality thus involved consolidating the lessons that were learned through each episode (in a sense pulling all the individual episodic mini-recoveries together) as well as lessons that were learned through periods of wellness.

Recovery, um, the ability to function like a normal person, and how do you define normal, but just to function at the level that you were functioning at before. For me, that's going back to 10-year-old, I don't want to function like a 10-year-old but when I was in my early 30s, I was manager of an office for exploration and drilling and I was very high up and I was motivated and I was coming up with new things on the computer for us to use and integrating it with the accounting package and just, I was really on top of my game. And to be back there again, that's where I would measure myself as being recovered (Alice).

Return to normality makes sense instinctively but is fraught with difficulties. With her quote, Alice illustrates how near impossible it is to define pre-illness normality. A number of individuals experienced problems from a very young age and they may not even remember what their baseline of normality was. For them returning to a pre-illness baseline would mean regressing to a level they were functioning at as children/ teenagers/ young adults minus the maturity and life lessons they had gained along the way.

Apart from the question of whether return to such functioning^A was desirable, the issue remains whether it would be possible. With the onset of illness, and with each subsequent episode, some tasks and responsibilities may be put on hold but the persons do not stop living. They collect experiences that change them as people and that keep them moving on in their lives. Just as it would be impossible to separate current

functioning from life experience, it would be impossible to aim for functioning that occurred under a very different set of circumstances.

The word 'return' means going back to something, in this case to past functioning. Holding past functioning as some ideal outcome is in itself problematic. Firstly, it may never be possible to hold down a full time job, volunteering and studying part time while raising a family as Gwen once did because the circumstances have changed and because the person's ability to do so has changed. Dwelling on what once was and therefore should be again could turn into an unrealistic expectation that sets the person up for failure. Secondly, focusing on past normality could prevent the persons from shifting their baseline or creating a new one.

Shifting the baseline.

Even those participants who were usually able to function quite well and who had developed effective illness management strategies may have had longstanding issues that impacted on their functioning. For those individuals, it may have been useful to reflect on pre-morbid functioning to see how 'normal' it really was. The onset of mental illness may have been challenging and distressing but it also had the benefit of allowing them to step back from their life as it was and to examine it to see whether it was healthy and whether it promoted effective functioning.

So becoming ill was permission for me to acknowledge stuff and get better instead of just permission to just go and celebrate, yey, I'm a schizophrenic, yey, I'm bipolar. I'm pretty impatient with that view, if you've got any control over it at all, yeah... (Bill).

As a result, rethinking the old normality could lead to a shift in functioning that could include anything from an ability to say no or determination to take responsibility for coping to no longer viewing work as central to one's identity. For instance, Frank who had struggled with friendships since he was a child learned to use alcohol to cope with interpersonal interactions. Making friends and having fun while drinking heavily was accepted as a normal way of being with others. It was through his recovery journey that he realised how unhealthy it was. Gwen who was subjected to childhood abuse only to be dismissed once she disclosed it to her parents learned that she did not deserve to be treated with respect and that it did not matter what happened to her ("it's only me"). She ended up repeating a pattern of dysfunctional relationships right through

her adulthood, being controlled, manipulated and abused by others. For her, recovery consisted of two parts: returning to baseline following episodes of bipolar disorder and gradually shifting that baseline to include self-worth, ability to set boundaries in relationships as well as the ability to address her fear of being alone.

Living as best as one can.

Living as best as one can given the person's particular circumstances referred primarily to long-term recovery. Some participants talked about going back to the person they used to be or functioning at a level they did prior to becoming ill. As discussed earlier, although return to such pre-morbid functioning would be very difficult, for some individuals it represented an ideal outcome. Even if such outcome could not be achieved, the individual wished to get as close to it as possible.

I think recovery for me is being as well as I can possibly be, um, being as close to who or what I ever thought I was, as close to that as I can be. There are things I once dealt with easily and happily, um, now that I know it's a smaller list than it was before but yeah, I think it's just... for me recovery is being as well as I can be so that involves understanding what's wrong, monitoring it and doing something about it. Not waiting for someone else to tell me, Bill, you're out of control. I think I've reached a stage where I know, I know when I'm unwell and I know when I need to see someone (Bill).

Not everyone had a clear understanding of what pre-morbid wellness looked like as they never experienced healthy adult functioning that was not affected by mental illness or by adverse life events. Some individuals reported having had mental health problems since at least adolescence while others talked about having had to struggle with negative life circumstances. Mental illness is usually seen as an internal factor, i.e. as forming part of who the person is and how well he/she functions yet the participants also pointed out its social aspects, such as stigma and discrimination. Issues such as childhood neglect and abuse, on the other hand, are believed to be external, that is, imposed on the person by others. Yet such issues, especially if prolonged, severe and/or occurring at a young age, have an impact on how the person views him-/herself and the world (the person's internal experience), and as a result help determine the person's sense of self and his/her level of functioning. Both internal and external factors thus create limitations that cannot always be overcome. Being able to acknowledge those

limitations and making them part of one's life without letting them take over required determination to do some long-term work.

I'm not really recovering, you know what I mean, I'm sort of, I've sort of recovered as good as I'm going to, I reckon, and it's just a matter of putting up with it and going forward as much as you can with what you've got, you know (Isaac).

Whether the persons were aiming at some re-created level of past functioning, whether they were shifting their baseline of normality or whether they were newly learning about what wellness felt like in their particular case, the focus was on day-to-day living, on having a balance and on realistic assessment of what the person was able to achieve.

Just really what I'm doing, recovery as in helping myself because people can run around, like you're trying to help or someone might talk to me and try to help me but when it comes down to it I've got to help myself. And you know what, I really am, I really am doing that. But then I've got to make sure I haven't got too much happening, so I've got to balance it and that's with the bipolar too, you've got to have a balance. Like not too high, not too low and in life you've got to have balances, not too many activities and a bit of peace and tranquillity within the body, not too much stress, a bit of peace, that's what I'm learning at the moment too... (Molly).

Starting points of recovery.

The participants did not generally talk about stages of recovery although some of them indicated that the early stage tended to be drug-assisted. If the medication was right for the illness *and* for the person, it could lead to a significant improvement in symptoms. With the symptom interference diminished, the person was able to start developing other coping strategies which then enabled him/her to turn attention to all the other aspects of his/her life. Chances of recovery therefore increased with increased stability which was partially achieved via medication. Although medication played an important role in both acute and maintenance stages, it could be argued that it was during the acute periods of ill health (particularly when it was the first episode) that medication played a major role in illness management and consequently recovery⁵.

⁵ It should be noted, however, that the participants did not specify whether the drug-assisted recovery of acute stages occurred because that is what worked best or because that is how it was practiced.

I mean, not much happens when you're in the locked ward. You're basically there until you recover a bit, enough to get out. Once you're out then you start doing OT and stuff and you start thinking there is a way out of here, you know (Isaac).

Most participants could not identify at what point their recovery started. Those who did, mentioned such varied factors as stable accommodation or no longer seeing oneself as a victim. For instance, Bill who had struggled with (among others) severe depression with suicidal ideation said:

*I think the starting point to recovery for me was ceasing to feel I wanted to be dead...
...when I decided I was content to be alive.*

Stability was clearly important, whether in terms of symptoms and/or the person's circumstances, including living conditions and relationships.

My counsellor, she helped me get this place that I'm in now because like I said, I used to live in so many places, about 36 moves I did from the time I was fourteen so I was very tired by then. So she got me a place and that was the beginning of everything. A stable place so I could start concentrating on all other areas of my life, you know. Because without a stable place you're all over the place, Zdenka. You can't think straight, you can't, you just don't know, you know, from week to week (Heather).

Components of recovery.

There seemed to be an agreement that recovery was something the person was doing or working on as opposed to something that was done for them or that happened to them. It was closely linked to the idea of *personal responsibility* and agency, as discussed in previous chapters. Another important part of recovery was the *ability to manage the illness* so as to minimise its interference with the person's functioning. The more the illness interfered the fewer resources the person had left for other areas of his/her life so that even the simplest tasks of daily living seemed to be at times incredibly difficult. However, the relationship between mental illness and circumstances was reciprocal so that the more adverse life circumstances interfered with the person's ability to function the more likely he/she was to experience worsening of symptoms.

Acute episodes tended to be managed within hospitals, and inpatient treatment was primarily centred on medication whereas outpatient treatment provided more varied options.

For instance, lack of secure accommodation and fear of becoming homeless were quite real for a number of participants, currently or in the past, and they greatly contributed to their illness.

I was in [hospital] once and I had no sort of flat or house or anything to go to, and that was a bit of a worry, you know, that contributed to my illness, you know. Well, I mean the logistics of life are a huge problem to just about everybody (Isaac).

Coping with life challenges and coping with mental illness were two separate yet interrelated areas that vied for the same pool of resources. If one area took over it left fewer resources for the other area and therefore left the person vulnerable to relapse and/or to overall worsening of his/her functioning. A number of the coping strategies identified as important for keeping one's symptoms in check were in fact general strategies that could be applied across problems. Knowing how to maintain healthy balance, being aware of personal limitations, the ability to set boundaries in relationships as well as physical self-care, having fun or meditation were not illness-specific; rather they were general strategies that were applied to a variety of life challenges and that ensured that the persons knew what it took to get better, regardless of the challenge in front of them.

Getting better was perhaps the primary aim directly linked with mental illness. In order to get better the person needed to believe that it was possible. *Hope*, optimism and faith in recovery played a role, whether originating from within the person or from others around them.

Now that I know things have changed and medication has changed, I'd say listen to the doctor and do what the doctor says, you know. And then when you're offered community treatment order then you can consider other options, you can think about a naturopath or whatever you want, you know? But I think the first thing is, don't rebel because that doesn't help. That just drives you further round the bend if you rebel against things. But then again don't be, um, don't allow people to placate you either, just be slightly assertive and have faith in your own recovery so that you know you're gonna recover and you can go forward. And you can work and you can enjoy life and you can do things and make, um, make positive input into the community (Isaac).

I would certainly welcome the opportunity to tell people who are not in the pits of despair but are somewhere on their journey, I would welcome the opportunity to tell them... it's wrong for me to tell them that they can make it but perhaps to tell them that it is possible to make it. And not to hold myself up as some shining example but just to explain that you eventually come to terms with everything in you, make accommodations in your attitude, your lifestyle, your behaviour, so that you can get on with a life (Bill).

Both participants communicated the belief that recovery was possible. Both participants also talked about recovery as about making adjustments to better incorporate illness into their lives so that they could move on. As *Study I* (Chapters 4 and 5) showed, the impact of mental illness on the individuals' lives tended to fluctuate so that there were times when it acted as an overwhelming force while at other times it only stayed in the background. Similarly, the focus of recovery work tended to fluctuate from illness to life management, just as the proportion of coping resources dedicated to dealing with the illness fluctuated. The aim was to treat mental illness as only one of many life challenges.

Facilitators of recovery.

Recovery could be facilitated by a whole range of factors, both internal and external to the person. Some individuals talked about what they saw as *innate characteristics* or personality traits that helped them on their journey, including the ability to articulate thoughts and feelings, personal determination or the ability to bounce back. Others talked about having *someone* or something *to be well for*, whether it was a loved one, a pet or the person him-/herself.

Well, the big thing in my case has been having five children and loving them very much, um, so it was always important for me to be as well as I could for them (Bill).

[Pets] are my family, they've been my lifeline all this time... I know that when I've been at the lowest of the low I wouldn't trust anyone to look after them, at least not the way I do so I have to be there to do that (Gwen).

Another factor was the *willingness to learn* and the willingness to *do work*. Whether the learning occurred through reflection, talking to other people or research, it

was an ongoing process without a fixed outcome. Knowledge was not gained once and for all but rather it kept evolving.

I'm still learning, I'm still learning about things, about myself, I'm still trying to figure myself out, you know what I mean? I just feel that I'm trying to heal my life. I'm trying to heal myself and it takes a long time. It's probably a life thing (Heather).

Some people credited self-help groups and peer organisations for improved understanding whereas others found other people's testimonies less helpful and relied primarily on subjective retrospection. Overall, it would seem that *peer settings* helped mostly because of the support they provided not because the individual was inspired by other people's success. Peer settings provided acceptance and sense of belonging, and helped combat feelings of otherness and abnormality. Interestingly, stories of recovery were sometimes seen as beneficial when one was the storyteller but not when the story was told by someone else. For instance, Alice believed she could use her example to help others while at the same time acknowledging that the others may not necessarily be opened to listening.

It's very hard to say oh, there's me going to be like her because she's, it's very hard to say that and have it from your heart, you know, because you have to be in that place yourself when you're ready to be helped and that's the problem with depression, you're not always in a position where you feel like you can be guided.

What Alice's quote indicates is the question of *timing*. It was simply not enough to know what the person needed; it was necessary to determine what he/she needed at a particular time. As discussed in previous chapters, mental illness was associated with a number of losses which often had to be worked through (or grieved, let go, compensated for or reclaimed). It was therefore important that the person and/or others determined to support him/her worked out what sort of assistance was needed at what time. For instance, Heather who was forced to leave home at a very early age and has had to look after herself and others ever since was offered cooking classes while hospitalised. While possibly beneficial for other patients it was the wrong sort of intervention for her at the time.

I think I told you when I was in the hospital the first time, they wanted me to do courses there, cooking courses. I didn't want to do it so I didn't go. They were looking for me at

[hospital]. That was the first time I went there and I was crying, and the lady, I didn't even hear her coming, and she came from behind and she said to me, why aren't you doing the cooking course and I said, I don't want to do it because I'd cooked all my life, Zdenka, I needed someone to cook for me, you know, for a change, I was tired, you know. It was all still in here [points to her head] and the last thing I wanted to do was to go and learn how to bloody cook, you know. And I remember there was a punching bag there and I used to do this [makes punching motions], it was good. And I just wanted them to leave me alone so I could figure things out, you know.

Similarly, trying to encourage an individual to actively participate in treatment, when that person is consumed with worry about his/her financial situation or is temporarily unable to carry out even the most basic of tasks of living is equally likely to be ineffective.

When people are mentally unwell they often have a lot of other stuff that becomes chaotic in their lives, it's no point providing the right medication, it has to be holistic, otherwise it's going round and round in circles, so if their housing is inadequate no pill is going to make it any better. It needs to be followed through, it needs to be, you know, the right services, that person needs to be guided through those services as well, you know, that's the time when, we'll worry about making you empowered later but right now we'll hold your hand and lead you. And that's doing the appropriate thing at that point in time. I can remember being referred to a social worker for one particular thing and she was suggesting all these services and I just sat there and said 'but you will have to call them for me, I can't do it right now' and fortunately she was 'of course!'(Gwen).

Gwen talked about the importance of timing but also highlighted the need for *holistic care*. Participants were aware that there was more to mental health than interventions targeting the actual symptoms. As the coping strategies identified in previous chapters indicate, caring for physical health and for one's spiritual needs was equally important. However, those coping strategies were less likely to be effective if basic needs (e.g., need for security or need for shelter) were not met.

Finally, an important facilitator was *good clinical care* which was characterized by a trusting, respectful and reciprocal relationship with a professional who was a good listener and who showed a genuine interest in the person's story as well as the

determination to collaboratively work out the best way to tackle the client's (patient's) challenges. The person also needed to be willing to ride the rollercoaster of fluctuations that are such part of mental illness and to be able to offer the type of assistance that was needed by a particular individual at a particular time. Such approach to treatment required flexibility which allowed the clinician to take charge when the client needed more direct guidance but also to let go when the client was functioning better and therefore capable of taking responsibility. Rigid, paternalistic, one-size-fits-all type of treatment could therefore act like a significant barrier.

Well, I know what it[recovery oriented care] means for some people. Basically it means I have to do what you say and I've got to get better, putting it very simply. And let's face it if you don't have enough knowledge about how things work that's how people can look at things that they don't understand. Because a lot of people do think, I have to get better. Because this is what you do for me. They don't really fully understand how much participation they can claim. Although they're told that, you know, you have a voice in the mental health system, blah, blah, blah, and you have advocates and all the rest of it but they don't know how to use it. You know, they don't understand how responsible the individual is supposed to be in that whole plan. But then again why should they feel they have any responsibility when people are still talking down to them (Gwen).

Discussion

The study explored the concept of recovery from the affected individuals' perspective, as embedded in their lived experience of mental illness. Although findings on the concept of recovery and on the lived experience are reported in separate chapters the two concepts overlap and form parts of one narrative. The process of recovery was facilitated by the way the individuals conceptualised their illness, by their coping and management strategies, and by their responses to what they had lost or gained, with other people playing a significant role. The study did not provide a unanimous definition of recovery, although achievement of such definition was never the purpose of the study. It however illuminated how important the process of talking about recovery was and how such discussions could help determine the person's sense of wellbeing.

Just like the interviews exploring the topic of lived experience, discussions of recovery took the form of opened conversations. Gadamer believed that two parties of a conversation understand each other via common search for understanding but that it is not them who direct the dialogue but rather the things that are said (Gonzales, 2006). He also believed that hermeneutic understanding only occurs when the two parties bring their respective assumptions into play (Gadamer, 2006a). Although the researcher's knowledge of the topic of recovery was based on previous research and exploration, this background knowledge was not superior to that of the participant.

Many of the participants had not come across the concept of recovery as applied to mental illness before the interview; however, they nonetheless entered the conversation with their own assumptions that influenced how they responded to the concept. Gadamer (2006a) wrote that the person who understands cannot make claims for superior position; rather her/she should allow his/her assumptions to be put to the test in the process of understanding. Talking things out in a conversation therefore allows both parties to move beyond the circle of their own assumptions and prejudices and reach greater insight (Gadamer, 2006b). The word 'recovery' is value-laden and has been used in multiple, often contradictory, ways. The Gadamerian principles as applied to the present research allowed for the various assumptions and prejudices associated with recovery and related concepts to be brought into a conversation with the aim of shared understanding.

Recovery Assessment Scale.

The participants were introduced to the topic of recovery with their completion of the Recovery Assessment Scale (Corrigan et al., 1999). Routine outcome measurement is considered a standard component of clinical care but has been criticised for its reliance on assessment of clinical outcomes, primarily those related to symptoms and levels of functioning, and there have been calls to include recovery measures as well (Dickens, 2009; Lakeman, 2004). An Australian review of recovery measures identified 33 instruments assessing either individual recovery or recovery orientation of services but only 8 instruments were judged to have a potential for routine use in mental health services (Burges et al., 2011). The rest of the instruments were excluded for a range of issues, such as being too long, not having been subject to scientific scrutiny or

not having sound psychometric properties.

Apart from concerns about the instruments themselves and what they assess, there is also no consensus on how the measures should be used. Burges and colleagues (2011) pointed out that decisions about usage should include questions of whether recovery measures should be added to or used instead of existing measures as well as questions of whether the focus should be on stages of recovery or overall recovery. The present study cannot address issues related to systemic, standardised data collection, even though the participants agreed that the scale was easy to understand and easy to use which seems to confirm its potential for widespread use. However, the study did indicate new ways of using the scale in clinical practice.

Scales such as the RAS-R (Corrigan et al., 1999) may be well suited to tracking development and possible improvement over time, from commencement of treatment and in regular intervals while in treatment to its cessation. But the scale itself could be used as an actual therapeutic tool. Andresen and colleagues (2010) suggested that recovery subscale scores could be subject to discussion and contribute to the development of the therapeutic relationship. The present study confirms that collecting data about the individual's functioning can be useful for the person's coping if and when those data are explored afterwards. The total recovery score was less meaningful than discussion of its domains and patterns of responses for each individual participant. For instance, a participant who scored consistently high across domains but answered one or two items with a low score was asked questions about those items which helped clarify such responses and put them in context.

The five domains of the RAS-R (Corrigan et al., 1999) were presented as only some factors believed to be important for recovery; their discussion acted as an opening to a discussion on recovery in general. The discussion of domains however rarely uncovered issues that had not already been explored in previous conversations. The scale was introduced only once a basic relationship had been established, and following an in-depth exploration of the person's story. The data generated by the scale were not unique and generally did not uncover new information. What was important about inclusion of the scale in the project was the fact that the participants were able to discuss their view of the measure and receive feedback.

The vast majority of the participants indicated that they were willing to complete the survey and that they had completed surveys in the past, either as patients/clients or as participants. Yet in the past they rarely, if ever, received any feedback. Research indicates that receiving feedback can in itself be beneficial to the person's wellbeing. For instance, Fossey, Epstein, Findlay, Plant and Harvey (2002) spoke to 18 individuals who were provided with feedback of results following their participation in a project about community functioning of people with mental illness. Results indicated that verbal feedback that focused on strengths could help foster hope and empowerment and could help improve the person's self-esteem. On the other hand, because some participants tended to view surveys as pass/fail tests, not giving them feedback could result in reinforcement of negative self-evaluations.

Participants of the present study expressed appreciation for being able to discuss what the survey was designed to measure and what their results indicated. (One participant asked for a copy of the scale for future reflection). This helped to present the survey as a tool that was not used by the researcher for her own purposes but as one that was also beneficial to the individual completing it. Translated into clinical practice the survey could highlight strengths and potential areas of improvement but could also become part of a therapeutic dialogue. Although designed with strong consumer input the survey on its own could be regarded as just another clinical instrument. On the other hand, with feedback and critical reflection the scale could help promote involvement and participation in treatment.

Conceptualising recovery.

The participants initially found it difficult to relate to the concept of recovery. Descriptions of recovery sounded as definitions of something that was outside their experience of mental illness. Even those individuals who could be regarded as high functioning saw recovery as an important but not dominant part of their narrative. Their stories were not stories of recovery but stories of adaptation, gradual improvement and getting on with life. Yet it is these very same processes that previous literature has identified as key features of recovery (e.g., Henderson, 2010; Ochocka et al., 2005). In other words, although the individuals talked about the concept as not necessarily relevant to them, they talked about an experience that could be described as being in

recovery. It was only with careful guidance that the individuals were able to engage with the topic and possibly shift their preconceived ideas of recovery, such as that recovery meant being symptom or medication free.

What resulted from reflections on the concept was the view of recovery as a gradual process of improvements and setbacks, marked by a learning process about self, about the illness and about the role the illness played in a person's life. This is in line with consumer literature which describes recovery as a process, or a journey, that comes from within the individual and that occurs incrementally over time and that involves successes and setbacks (Bellack, 2006; Brennaman & Lobo, 2011; Leamy et al., 2011; Ochocka et al., 2005). Because of its close relationship to learning, recovery was fluid and its conceptualisation could change with time, depending on new knowledge and on present circumstances, in essence representing a hermeneutic process.

Recovery literature has been typically treated as belonging into one of two separate categories: clinical (outcome) or consumer (process) studies (e.g., Bellack, 2006; Silverstein & Bellack, 2008). Both approaches have their advocates and their critics. The clinical model of recovery could be accused of trying to objectify and simplify something that is inherently subjective and complex. It has also been criticised for overly focusing on psychopathology and the limitations it places on the individual which helps create a pessimistic outlook with expectations of little improvement (Brennaman & Lobo, 2011). The consumer model, on the other hand, has taken into account the subjectivity of the individual's experience but has been at times dismissed as being unclear and nonspecific (Bellack, 2006; Liberman et al., 2002). It focuses on personal strengths and growth, and it is primarily future and goal oriented, however, there have been fears that it can set unrealistic expectations. In addition, aiming at goals without acknowledging the person's limitations and without taking into account the episodic nature of mental illness could be just as damaging as focusing on the illness alone.

The present study shows that recovery is not an either-or choice but rather that both approaches are useful. The participants talked about the importance of having their illness under control and about reduced symptomatology as a crucial part of being well. They also credited medication for helping them attain stable functioning; stabilisation

(or maintenance) was in turn seen as one of their goals. In addition, they often spoke in terms of outcomes as linked to recovery, like when Alice mentioned completing six months of college as a mark of being on the road to recovery. While being completely symptom or medication free was mentioned (but with the acknowledgement that it was an ideal but possibly unrealistic aim), no one equated recovery with a specific outcome. Yet clinical discourse and clinical concepts were clearly important.

At the same time, the participants talked about working on getting well, which included using their own personal resources to cope with illness and other life challenges, having something to strive for and generally believing that things will be OK. However, they were also aware that even with careful planning goal achievement could be prevented by another episode of their illness. Their orientation remained primarily in the present and it was closely associated with realistic appraisal of personal limitations. A narrow focus on goals could in fact be a pessimistic endeavour as it could suggest that the challenges the person was facing were ignored or not taken seriously.

It would be wrong to present the two models as in complete disagreement with each other; current clinical conceptualisations do take into account social and occupational functioning (e.g., Liberman et al., 2002, 2005) just as consumer definitions acknowledge the effects of mental illness (e.g., Anthony, 1993). What seems to differentiate the two models is the primary focus (the illness versus the individual). Both are important but both could be blamed for failure to recover. In the first case it could be claimed that it is the illness that prevents the person from getting better while in the second case the fault could lie with the person who is not working hard enough. On the other hand, success can equally be seen within the parameters set out by the models, that is, the person is doing well because the illness has been treated versus the person is doing well because of personal determination to get well.

In reality, as the participants' stories suggest, recovery generally involves elements of both. The severity of the illness, the frequency of its episodes and its interference with functioning played an important role in how well the person was doing. However, the subjective wellbeing was equally influenced by personal efforts, in terms of determined attempts to try and understand and in terms of coping and illness management strategies. The key process of such recovery works was the negotiation

between the illness and the person in such a way that left room for personal responsibility, which would leave the person feeling like there was always something he/she could do while at the same time knowing that there were others he/she could turn to for support.

The difference in primary focus was not the only distinguishing factor; there is also a difference in the way the two approaches view factors of recovery. For instance, both models acknowledge the importance of activities, whether in the form of work, study, volunteering, recreation or socializing (e.g., Andresen et al., 2003; Bradshaw et al., 2007; Liberman & Kopelowicz, 2005; Mancini, 2007). However, one approach treats those activities as criteria of recovery (i.e. signs that the person has recovered) while the other treats those as mechanisms of recovery (i.e. ways of facilitating recovery); in other words, one approach sees them as a destination whereas the other tells us how to get there.

Aspects of both recovery models could be seen right across the narratives but the combination of those elements was unique to each individual. Recovery was seen as a process, which would be in line with the consumer definition, but outcome conceptualisations were not irrelevant either. Overall, two basic concepts can be found in the narratives: return to baseline following a crisis or a period of ill health, and living as best as one can given personal limitations and unique circumstances. Returning to baseline has some similarities with the clinical term of 'return to pre-morbid levels of functioning'. Especially those individuals whose onset occurred in adulthood tended to talk about returning to pre-morbid levels; they had managed to establish their identity and they had experienced normal adult functioning which then served as their baseline of normality, one to which they wished to return. Although they were aware that recreating the very same level of functioning was not possible and that some adjustments were necessary, they aimed at getting as close to who they were prior to becoming ill as possible.

The adjusted baseline of normality was also used as a point of reference in between episodes of illness. Return to pre-episodic baseline involved reclaiming temporary losses when possible and getting back to maintenance. Maintenance was the adjusted normality, one that was established following the person's experience with

mental illness. Therefore, return to pre-morbid functioning could be seen as return to normality whereas return to pre-episodic functioning could be seen as return to maintenance (new, post-onset normality).

Return to pre-morbid functioning remains a somewhat controversial concept, one that is ambiguous and difficult to achieve, and as Liberman and Kopelowicz (2005) pointed out, one that could lead to levels of functioning below normal range. The participant narratives seem to confirm this notion and there was a sense that the baseline they were returning to was something that was created and recreated with their experience. Whether based on some levels of past functioning or whether a result of new learning about wellness, shifting the baseline seemed to be an important part of the recovery journey. Shifting the baseline referred to adjustments of functioning due to the challenges associated with mental illness. However, shifting the baseline also referred to broader changes in the person's life.

The onset of mental illness was generally highly distressing but it also allowed some individuals to step back to rethink their priorities and reflect on how healthy their pre-illness baseline was. Some participants learned that their normality was previously influenced by patterns of responses that had developed as a result of adverse circumstances or life events, often relating to relationships with other people. Shifting their baseline was therefore not directly related to mental illness but involved changes in views of self and others which were more adaptive and which as a result promoted more effective coping.

The experience of mental illness did not lead to people living parallel lives: one dedicated to daily living and one dedicated to coping with mental illness. The fact that the individuals had to deal with the challenges of living and the challenges created by the illness meant that they had to use one pool of resources to deal with multiple issues. At times of crisis when the illness tended to take over it left fewer resources to cope with other demands, and vice versa. Therefore, a large part of recovery was about managing illness fluctuations and interference as well as about managing other stressors (or 'the logistics of life'). The aim was to get them to a point where they presented only a minor disadvantage, one that could be overcome or managed. Once such stage was reached and maintained the person could focus on living as best as he/she could in the

context of personal limitations and circumstances. It would therefore seem that the two core processes outlined in this chapter, return to baseline and living as best as one can, were two complementary processes that represented fluctuations in focus: the first one was occupied primarily with getting the illness under control while the other one referred to maintaining illness stability that then allowed the person to get on with life.

If mental illness presented a major challenge to affected individuals then mental health would seem to be the desired state one would be striving to achieve. Yet the narratives did not seem to indicate that the ups and downs associated with mental illness represented fluctuations between periods of health and ill health. When consumer literature refers to late stages of recovery, it uses terms such as striving to attain a sense of well-being and higher levels of functioning (Young & Ensing, 1999), living a full and meaningful life and achieving personal growth (Andresen et al., 2003), living beyond the disability (Spaniol et al., 2002), or regaining balance and peace of mind (Henderson, 2010). Adame and Knudson (2008) suggested that rather than viewing recovery as a dichotomy of either health or illness the focus should be on simply living.

The present study suggests that doing well was about stability. The words used by the participants were not personal growth or wellness but balance or maintenance. The term maintenance seems to have some similarities with terms such as symptomatic stabilisation or remission which are usually associated with the clinical views of recovery and which are therefore believed to inadequately capture the experience of recovery (Davidson et al., 2005b; Liberman & Kopelowicz, 2005). The present study certainly supports this link, with maintenance being linked with mental illness, meaning that the symptoms are not significantly interfering with the person's life, but maintenance was still seen as a desired state that did not necessarily equate with severely restricted living.

Many of the participants seemed to be reluctant to talk about themselves as recovered or recovering even though they seemed to be, by both clinical and consumer criteria. More than half had not been hospitalised for a number of years, engaged in activities that were seen as productive by both personal and societal standards (work, study or volunteering) and socialised with a number of consumers and non-consumers on a fairly regular basis. They tended to talk about trying to lead a normal life but the

concept of normality seemed to be elusive and if one wanted to go one step further, would in fact suggest that the question ‘what is normal’ is incredibly difficult to answer.

Although the consumer and clinical models seem to disagree on what emphasis should be given to symptomatology they in fact both suggest that without some degree of illness control recovery would be difficult. But then the question remains: once the illness is made more manageable what happens next? Without proper discussion of what normality really means linking words such as growth, wellbeing and meaningful life to recovery (and therefore mental illness) could create the perception that it is the illness that prevents the person from being happy and living a good life. In other words the individual might believe that once the illness no longer causes significant impairment all the problems will go away; striving for maintenance then might seem like not good enough. It has been pointed out that some individuals with severe mental illness may hold romanticized views of what life of the non-mentally ill is like and may therefore struggle with the notion that such life has its own difficulties and can be quite mundane (Buck et al., 2013; Davidson, Ridgway, Kidd, Topor, & Borg, 2008). It would therefore seem that discussions of recovery and its underlying assumptions and biases should also include exploration of what the person believes “normal life” means to him or her.

Conclusion.

This study presents support for the suggestion that the clinical and consumer models of recovery are not two conflicting concepts but rather two different perspectives of the same phenomenon. Both approaches talk about improvement or betterment but they differ in their primary focus, with the former emphasising symptoms and other clinical factors, and the latter concentrating on person-centred and other non-clinical factors. In addition, one approach is concerned with the final outcome while the other attempts to understand how the person got there. Both approaches, with their respective components uniquely combined by each individual, seemed to be relevant.

The two approaches have previously been divided on the issue of whether, how and with what recovery should be assessed. The Recovery Assessment Scale (Corrigan et al., 1999) used in the present study measures concepts that are derived from consumer

views of recovery yet the fact that the scale reduces individuals' experience to quantifiable constructs ironically moves it closer to clinical approaches. It would therefore seem that although it is important to decide what is assessed it is equally important to determine what happens with the data afterwards. On an individual level, to be truly useful for the individual the assessment should be brought into a discussion between the assessor and the person assessed, and should not be a one-way conversation where the assessor explains the results but rather a two-way exploration of the underlying constructs that should be presented in a way that points out relative strengths and areas for improvement. Such discussions could help establish therapeutic alliance and promote active participation in treatment.

The present study highlighted the risks associated with talking about recovery without first discussing what the word means to the respective parties and without clarifying potential misconceptions. The participant narratives indicate that recovery involves two processes that can co-occur: one is return to baseline following a crisis and the other is living as best as one can given personal limitations and circumstances. Participants also discussed components of recovery (such as personal responsibility and hope) and facilitators of recovery (such as willingness to learn, holistic care and the importance of timing), both of which further our understanding of recovery. However, the most significant contribution of this study is the actual demonstration of the fact that the word recovery has multiple, often contradictory meanings that seem to be difficult to reconcile. Participants did not always see recovery as relevant not because they did not believe they could get better and live the life they wanted but because their idea of recovery did not seem to correspond with their actual experience of it. Recovery as a concept will remain relevant and useful as long as its subjective meanings are not just assumed but fully explored with each individual.

As mentioned in the chapter, recovery was closely linked with the person's ongoing learning and therefore represented a concept that could change with new experiences and circumstances and with improved understanding. The principles of this essentially hermeneutic process could also be used to reconcile the two primary approaches to recovery. If the clinical (outcome) approach represents one horizon of meaning and the consumer (process) approach represent another horizon, then rather than looking at them in terms of either/or dichotomy they could be mutually explored

with the individual with the aim of shared understanding and with the awareness that the concept was fluid. While it may not help answer the question of how best to conceptualise recovery in a way that would be universally accepted and that would help provide operational criteria as the basis for further research, the hermeneutic approach could be a useful tool in clinical, interpersonal settings.

Chapter 8

The experiential aspect of research

Overview

Ten of the 20 participants of the main study agreed to a third interview. Although attempts were made to schedule each third discussion 6 months after the first respective interview, this was not always possible due to a number of circumstances, such as holiday travel, scheduling problems and illness. One participant experienced a relapse that required repeated hospitalisations and eventually invited the researcher to conduct the interview in the hospital, approximately 10 months after the initial interview.

The primary aim of the third interview was to present a summary of the researcher's analysis of the participants' stories and to give the participants an opportunity to provide feedback on this analysis. From the Gadamerian approach, which is based on the principle of active participation of both the researcher and the participant, the process of providing and receiving feedback helped close the hermeneutic circle; repeated interviewing was also used to achieve greater interview authenticity (Yanos & Hopper, 2008) and to establish trustworthiness (rigour) (Koch, 2006). The second aim of the interview was to further explore some of the topics that may have come up during transcription and analysis and to allow the participants provide an update on their lived experience and, potentially, new meanings.

The interviews started with the participants updating the researcher on what they had experienced in the preceding 6 to 10 months. The researcher then provided her summary of the participant's story as she understood it. The summary was organised into thematic groupings consistent with the study findings (e.g., coping strategies, the role of others) and was presented in a conversational manner which allowed the participant to reflect on what the researcher said and to clarify potential misrepresentations. The participants were also encouraged to add anything they thought was relevant to their story that had not been discussed previously. Finally, at the end of each interview the participants were asked to reflect on their experience of being a research participant.

Due to the nature of topics covered in the third round of discussions, the data were added to previous findings and analysed within the respective thematic contexts. For instance, if an individual provided new information about professional help the information would have been added to and analysed with other data related to the same theme and subsequently reported as part of Chapter 6 (*Social and relational factors*). However, after all the data from Stage III had been categorised and analysed accordingly, the researcher was left with a great amount of information that could not be added to previous thematic categories but that was nonetheless very rich in what it added to the study. The information related not so much to what was said about the experience of living with mental illness but to the context within which the discussions took place and to the research process itself. Specifically, the information could be understood as falling into one of two broad categories: (a) being a research participant, and (b) relating to the researcher.

Once the remaining data were analysed and the two aforementioned categories classified, the researcher returned to the material collected during the first two stages to identify further comments related to the research process. In addition, the researcher looked through her journal data for information that helped clarify the actual interview data. Subsequent analysis confirmed the two main themes, as mentioned above, each containing two subthemes.

Finally, given the interactive nature of research guided by Gadamerian principles, the researcher also felt it was important to reflect on her own experience. Throughout the research, she read and re-read notes, comments, descriptions and reflections in her journal to see how her own horizon of meaning was developing. This helped her not only during the analysis of participant data but also during the actual data collection. Because her pre-understanding helped determine her responses to participants and therefore played a role in the interviews it was important to be aware of this background knowledge and to treat it as something that was dynamic, that is, as something that could be shifted and enlarged and therefore something that ultimately led to increased knowledge (Lebech, 2006).

The present chapter therefore describes the experiential components of research, from both the participants' and the researcher's perspective. Specifically, it discusses

the reasons the participants gave for participation, their experience of the research process and the type of interactions they had with the researcher, as well as the researcher's reflections on her experience of conducting a study within a Gadamerian framework and on her personal and professional growth.

Findings

Theme 1: Being a research participant.

Reasons for participation.

I'm keen to help because people are gonna be going through these problems in the future as well (Isaac).

I feel it's part of my healing. To someone like yourself to understand people like us and all the millions of other people like us, because unless we tell people how we feel it's not going to... people are not going to listen and understand and everything else. So although it really, yeah, I'm glad I came (Bridget).

Several participants said that they believed that research was important or that they simply liked the idea of research in general; some of them had even participated in research in the past, generally in the form of surveys. They also believed that they had something to say, something that could be used to help others in a similar situation and help the researcher. Some participants mentioned their hope that the research could eventually help change the way the mental health system currently operates. One participant talked to her peers about the research and encouraged them to contact the researcher. She even posted a brief testimonial next to a flyer advertising the research in one of the psychosocial centres.

I've tried to recruit so many people to call you, I said, you know, 'you could find it really interesting. You might learn something about yourself, I certainly did, it's not gonna be anything horrible, you know' [laughs], I've been really trying to sell it, you know, 'you could help in the way the mental health system could work so if you've got any real gripes about it you've got a chance to tell somebody'... (Gwen).

While some participants were quite spontaneous about their decision to participate and they told their story with great openness, in most cases the decision

seemed to be made after a careful consideration. None of the participants found their life with mental illness to be an easy journey and so to contact or approach a complete stranger with the idea of telling her about a very personal and often painful experience took a great amount of trust and courage. Some of the symptoms or difficulties related to mental illness, such as anxiety, problems with concentration or with social interactions, would have made their involvement difficult yet they persevered which would indicate that the individuals saw some benefit in participating.

Like to come here today, I actually had extra medication because I knew I was going out. I mean, I've known where this place is for years and years, but I had to put my GPS on, I had to print out maps. I mean I got here, I just thought, I'm gonna be sick, you know. Everything just builds up (Bridget).

The whole process was driven not only by the initial decision to participate but also by an ongoing commitment to be part of the research process. Especially those participants who were recruited via psychosocial centres often used the opportunity to talk to the researcher during her visits in between the interviews as well as after their participation was officially finished. While many of the conversations involved general chat that was unrelated to the topic under investigation, the participants also provided personal updates on issues such as commencement of therapy, change of medication or relational problems that impacted on their coping.

In addition, a number of participants used additional tools to help tell their story. Some used email correspondence when they thought of something they wanted to add or clarify. Others shared physical examples of things they believed formed part of their story. For instance, Keith showed the researcher a note he wrote as a child about leaving home which he believed demonstrated a certain style of responding that made him different from other children and that may have indicated early signs of mental illness. Alice let the researcher read a note she wrote in preparation for an appointment with her psychiatrist. Following her treatment with ECT, Alice struggled with memory problems and therefore started to write notes so that she did not forget what she was going to discuss with her psychiatrist. Sharing the note with the researcher illustrated her use of coping strategies. Heather offered to bring the researcher a copy of a book she found helpful in understanding herself and in coping with fear. These examples indicate that although the study consisted of up to three interviews per individual the actual

participation was a much more involved process. The participants thought about their experience prior to being interviewed and in between the interviews and they wanted to ensure that their stories were truly heard.

The experience of participation.

When asked to reflect on what it was like being interviewed about their life with mental illness, the participants described the process as a positive experience, some of them saying that it was fun or that they enjoyed it. This in spite of the fact that several participants became quite distressed during their interviews. It was clear that some of the topics discussed brought back memories of events that were highly distressing at the time and that had lasting consequences.

Well, I mean, I found myself shaking a bit because of the adrenaline. And it's the fight or flight response and I don't want to fight you and I don't want to run away so I don't know what the story is. It's... I don't know. I suppose it's the rational mind experiencing... I mean like talking about being molested or stressed, whatever, in here [points to his head] it's not an issue but obviously in the gut it is (Keith).

No, no, it was fine, it was only when I said it at the end when I was just talking a bit about [first psychotic episode], it was, yeah, at one point... but no, that was fine. I know when I start to get a bit emotional I just have to kind of like just work through it but it's alright. It's not like I'm about to get really upset but I just, you know, it makes you think, ooh, yes, still a little bit there, so, yeah... (Rachel)

Bits of it were a little bit difficult but it's just my life and what I've been through so there's not much I can do to change what's happened in the past. I think you can only change the future, you can't change the past (Vanessa).

Although the researcher took great care to make sure that the participants were as comfortable with the process as possible it was perhaps unavoidable that some of the discussions were rather confronting. There was no pressure on the participants to disclose adverse life events; the participants were able to guide the interviews and to disclose only as much as they wished. The researcher also ensured that none of the participants walked away from the interview in distress (mental health resources were also made available). On the other hand several of the participants remarked that being

able to talk about difficult issues, ones they had perhaps thought about for some time, brought a sense of relief.

Relief was not the only positive response to being interviewed. The participants discussed having learned something new about themselves and being able to look at things from a different perspective. For some individuals, memories were fragmented. By telling their story, they were presented with an opportunity to put those fragments into a narrative that made sense. In general, being able to verbalise some of their thoughts and being asked questions about aspects of their experience they had not previously considered seemed to be beneficial. The person felt better, stronger, with improved understanding.

It's nice because it helps you clear your mind as well at the same time as you're sharing with the person, it helps you clear your mind as well, or help me clear my mind and it just makes me a little bit stronger (Alice).

I feel relieved. Like, I've said things that I've never really said before (Isaac).

I suppose in some ways just our discussion and you know, some of the questions that you asked, made me think about opportunities of possibly changing my approach to how I would manage things and you know, very much I suppose the awareness that it's not something that's just an overnight fix but that it may remain in my life in some aspect but maybe I'll be able to manage it differently (Janet).

I think it made me think about a few things and also I suppose having sort of verbalised some stuff probably made a few things clearer to me because I think after we spoke I'd thought of a few things I wanted to add and I think I added them (Keith).

Theme 2: Relating to the researcher.

The nature of the research process meant that the participants developed some sort of a relationship with the researcher. Multiple interviews over a period of time, an opportunity to speak to the researcher during repeated visits to the psychosocial centres, phone conversations and email exchanges all contributed to very active and involved participation for both the participants and the researcher. The participants thus had an opportunity to get to know the researcher not only as a representative of the mental health field but also as a fellow human being.

Relating to a person (Let's play a game of pool).

Although a certain curiosity about the researcher as a person was demonstrated by those participants who were not recruited via psychosocial centres, it was primarily the centres that allowed the participants and the researcher to bond via shared humanity. The researcher made a total of 33 visits over a period of 13 months. Although not every visit involved an interview the visits were nonetheless important and relevant to the research. Apart from the opportunity they provided for recruitment, observation and informal conversations, the visits also promoted the development of relationships. Sharing a cup of tea, playing a game of pool or discussing current affairs may seem like trivial pursuits yet it was these activities that helped the centre members see the researcher as a fellow human being. Several individuals decided to participate only once they got used to the researcher's presence over a period of time involving numerous visits. It is this process that helped portray the researcher as someone who was not threatening; the informal exchanges may have thus contributed to the minimisation of the power imbalance that might have otherwise existed.

The representation of the researcher not as a researcher but as another human being had its challenges. Some participants were regular attendees of the centres and therefore spoke to the researcher repeatedly. They seemed to feel comfortable in her presence and consequently started asking her personal questions which presented the researcher with an ethical dilemma. Personal disclosure is closely linked with trust and intimacy; trust and intimacy in turn contribute to the development of close relationships, both personal and professional. While giving a bit of herself may have played a role in the participants getting closer to the researcher, and therefore more willing to tell their story, it made the researcher question the boundary between professional and personal relationships. She ensured that there was no socialisation outside the centres or the interview settings and she only ever disclosed what she felt comfortable disclosing. She also ensured that the attention always turned back to the other individual or to neutral topics. However, the relationship boundaries remained fluid and at times quite challenging to maintain.

The dilemma primarily concerned relationships from the researcher's point of view; however, some participants showed an interesting awareness of it. For instance,

Keith once asked the researcher about her nationality which she consequently disclosed. Later on (during the second interview) he apologised for his question.

I mean that sort of thing, like to me it just seems, why would anybody worry about asking that sort of question and then I think, oh no, you know, I've asked a personal question.

When the researcher remarked that she, as a researcher, was asking a lot of personal questions, Keith said:

Yeah but that's your job. And that's your privilege and it's really hard for you to be in your position.

The fact that the researcher was often seen as just a person was demonstrated in a number of ways, from offering her a cup of tea to asking about her wellbeing when she appeared to look tired. Heather who had suffered severe abuse as a child once spent a bit of time describing what the abuse entailed. Details of it were quite horrific and at the end of the interview she asked the researcher if she was OK. The researcher's journal shows the following reflection:

At the end of the interview she asked me if I was alright after hearing about the abuse and I said I was. She said, 'well, now you will have to go and talk to someone' and I assured her that if I have to debrief I have a support network. I was quite touched that she even cared about that. She felt better about getting things off her chest but at the same time she wanted to make sure that it didn't affect me.

This exchange supports earlier findings (reported in Chapter 6) on the role of others which indicate that supportive relationships are generally reciprocal in nature. The participants regarded the researcher as someone who was interested in them and who could potentially help, and they wanted to show that they could give something back, whether by demonstrating their own interest or by telling their story and therefore helping the research.

Relating to a mental health professional.

The researcher made sure that her actual role (a doctoral student conducting research) was clear to all parties, including staff and non-participant members of the

psychosocial centres. This role seemed to be understood and the researcher was often asked about how her project was progressing. Yet to many individuals she seemed to hold a much broader position, as a representative of the mental health field. Some participants showed her the medication they were taking, while others asked questions about psychological treatment or about the difference between a psychologist and a psychiatrist. A number of participants asked for clarification of clinical jargon or mental health concepts, or to help them clarify something they had been trying to understand.

I used to get paranoia and I didn't know what paranoia means. And I still don't know what it means exactly. Could you explain that a bit more? (Frank)

I think the childhood has a lot to do with it, do you think so? Even at my age? (Heather)

While the researcher promoted herself as only a researcher, the participants seemed to see her as a carrier of multiple roles with unclear boundaries. To them she was a person with knowledge of mental illness, a researcher and a counsellor/therapist, sometimes all three roles at once. Given her professional background, the researcher found it interesting that at any of the times of being interviewed only three of the total sample of 25 participants were seeing a psychologist. One participant reported having been referred to a psychologist after her last interview; for her it was the first time she was going to see a psychologist in spite of having spent 25 years in the mental health system. Another participant mentioned in his third interview that he thought that some of his issues could perhaps benefit from seeing a psychologist and consequently made an appointment. For most participants, the researcher was the only psychologist they had interacted with for a long time, if not ever.

Although the researcher reiterated several times the limitations of what she could do as a researcher, the participants seemed to struggle with the separation between research and therapy. For instance, one person sought the researcher to tell her that another individual was interested in counselling and whether the researcher was available. Another participant, Frank, asked for further contact during his first interview.

And if I have any queries, like if I don't get to see my psychiatrist and you're learning, can I contact you or that's not possible?

The researcher then reminded him that the talk was only a research interview and although the researcher could help answer some general questions related to mental health she could not provide counselling. Nonetheless during the second interview Frank asked for the researcher's business card and wanted to make another appointment. He seemed to see little difference between what he knew as counselling, and the research interview: both involved two individuals forming a relationship, and talking about personal matters to an understanding party.

The blurring of the boundary between research interviews and therapy sessions can be viewed as understandable in view of the common factors of both, primarily confidentiality and the use of dialogue. The researcher was seen as someone who could provide a safe, confidential environment. A number of participants disclosed some very painful and distressing experiences that they struggled talking about with other people.

I don't know where to start [learning about self], see, now I'm crying because it's sort of like a relief to talk about it because I don't seem to have anyone to talk about it. And then when you talk about it, like to [name], he says don't be stupid. It's like, that's not the sort of answer I want to get (Heather).

Talking to the researcher allowed the participants to release some of their pent-up emotions and at least temporarily feel better. It was not clear whether their reluctance to discuss personal issues with others was because of their isolation, their wish not to burden others with their problems or fear of being misunderstood. It seemed that even those individuals with a strong support network sometimes needed an independent third party that they felt they could trust with intimate information.

In addition, the researcher was not pressed by time constraints; some interviews lasted up to two hours. Contrary to the very brief consultations most of the participants experienced within formal care settings, the interviews did not focus on the most pressing issues but rather explored the participant's agenda within its full context. It is possible that it was this opportunity to tell their story the way they understood it and to tell it to someone who was genuine in her attempts to hear what was said and to truly understand it that helped create what could be described as a therapeutic setting.

Theme 3: Being a researcher.

Researcher's background.

The researcher started her studies as a mature-aged student following her decision to pursue her interest in psychology. She was also an immigrant who had assimilated with the Australian culture but who nonetheless had some experience with 'not quite belonging'. She had conducted qualitative research in the past and had prior experience with conversational interviewing: she had completed a project on the experience of being referred from general practitioners to psychologists, and an exploratory study on the lived experience of mental illness. Her interest in recovery started during her post-graduate studies; this interest was not prompted by her formal studies where the topic of recovery received only a minimal attention but rather by her contact with consumer organisations. She had used one such organisation to recruit participants for the pilot study which then led her to learn about other work done within consumer settings and finally to explore the topic in professional literature.

Being an active participant in research.

The researcher's work was informed by Gadamerian principles that treat dialogues (interviews) as opened, non-directive conversations between two parties, each carrying his/her understanding and pre-suppositions. Both parties are actively engaged in the process and both act as co-creators of meaning. Such approach could not be successfully followed without a degree of creativity and flexibility, and without viewing each participant as a unique individual. It was this aspect of the interview process that sometimes stood in contrast to the researcher's pre-judgment as related to conducting interviews.

There were times at the beginning of the data collection when the researcher lost focus on the reciprocal nature of Gadamerian interviewing as she worried about the technical aspects of it. Doubts about whether she asked the right question (open-ended versus closed), whether her questions were leading or double-barrelled, or whether in fact there were too many questions sometimes prevented her from truly engaging with the participant.

The interview was a bit slow in the sense that [participant] rarely elaborated on her answers and I felt that she needed quite a bit of guidance to help her tell her story. I asked a lot of questions, more than I would have liked. I also know that as much as I tried to pose open-ended ones, I ended up asking a whole range of closed questions (journal entry).

However, as the research progressed and she became more comfortable with the active role, this conflict was less of an issue. The researcher became more experienced and managed to build strong professional relationships with most of her participants which in turn helped provide relaxed, yet still professional, environment. Moreover, she started to reflect more on the philosophical underpinnings of the process and less on its methodological aspect.

Gadamer viewed experience not through its results but as an ongoing process, a dialectic of question and answer (Gonzales, 2006). Similarly, the researcher no longer viewed data collection as a series of steps that each started with a technically ‘good’ question and finished with an appropriate answer but rather as a back-and-forth movement between the two parties that required reflection in view of their own pre-understanding. Finally, the researcher focused less on ‘doing’ research and more on ‘being with’ the other person.

Being with others and fostering emotional closeness may have been useful research tools but also presented an ethical dilemma, as seen in an earlier discussion of the difficulties related to maintaining boundaries. The researcher had to find ways of reconciling what she understood as ethical conduct and flexibility.

...this growing closeness highlighted one fact which was becoming a bit of a dilemma for me. I came to the centre as a researcher yet because I was spending so much time there not interviewing, I started developing something similar to a friendship with a number of the members. But that was unethical, right? The code clearly stipulates that I cannot have dual relationships; I cannot be a researcher and a friend at the same time. Just as I cannot be a researcher and a therapist. Yet where is the line? I felt that the fact that I made myself available and gave a bit of myself to the members allowed me access to participants, allowed me to gain their trust and established better working relationship (journal entry).

Issues related to self-disclosure and multiple roles seemed particularly challenging, especially in the consumer settings. The researcher was strongly aware of the need for boundaries while at the same time struggling with the notion that the line between various roles and the line delineating self-disclosure as acceptable versus self-disclosure as a boundary violation was not always clear. For instance, the researcher's accented English prompted questions about her nationality. Similarly, the last stage of data collection occurred with the researcher in a late, and very visible, stage of pregnancy. While very personal, discussion of both issues was inevitable and did not seem to disrupt the researcher's relationship with the participants. In fact, sometimes personal information acted as a useful platform for exploration of a range of factors, such as one participant's own immigration journey as a potential trigger of his mental illness.

In addition, the participants proved to be careful observers of others. Just as they were quite sensitive to cues about whether their clinician was listening in doctor–patient settings, they similarly indicated their awareness of the researcher's engagement. For instance, one second interview was progressing at a slow pace with the participant providing only very brief answers with little elaboration. The researcher became preoccupied with her own thoughts about what she should do to get more detailed responses, which was noted by the participant:

Participant: Have I worn you out now?

Interviewer: No, I'm just going through some of the things that often pop up in interviews to see whether I've missed any topic with you but right now I can't really think of anything... some people have lots of comments about the survey I gave you, some people are OK with it, same with the recovery...

Participant: Yeah... Well, like I said, I don't see myself recovering further to this, you know...

Overall, each instance of self-disclosure was carefully considered in terms of its function and potential impact on the participant. Nonetheless, the researcher found that the balance between keeping professional boundaries while retaining authenticity and personal connection had to be constantly monitored.

Being a mental health professional.

As discussed earlier in the chapter, participants sometimes addressed the researcher with questions about clinical aspects of their experience. These questions, together with the actual stories they told, often forced her to confront her own beliefs and knowledge of what she understood to be mental illness and its treatment. The diagnostic process and the role of psychiatric labels, the role of psychotropic medication, the role of professional help and the nature of recovery were amongst the topics most often discussed by the participants and most often reflected on by the researcher. While she managed to reconcile the two sources of expertise, clinical and experiential, more or less successfully on many of those topics, the question of wellbeing remained quite elusive.

She interviewed individuals who seemed to be functioning quite well yet suffered a relapse during the data collection process. Others exhibited symptoms of illness but managed to keep all the other aspects of their lives in relatively healthy balance.

Here was a man diagnosed with one of the most severe disorders and who by all professional understanding needed treatment. He was on a community order, getting regular injections. By clinical definitions he was receiving evidence-based treatment yet it was obvious that the medication did little to his delusions (even though I am aware that I didn't see him un-medicated and therefore have nothing to compare his state to). I couldn't help but think 'is this the best we can do in cases like [his]?' Yet apart from that he was functioning quite well and he didn't see any reason for change... ...When I probed a bit more around his delusions it appeared that [participant] had a very busy mental life, with lots of different ideas buzzing around his head. One of the reasons he didn't like some of his medications in the past was because it took away that cognitive busyness and as a result robbed his life of something he quite valued. I felt that the idea of being more "normal" didn't appeal to him because of certain dullness it offered (journal entry).

The researcher noticed that the participants could not always define or describe a state of subjective wellness. While it could be argued that this was due to the chronic nature or severity of their illness, the researcher started to become aware that

wellness/wellbeing was difficult to discuss in large part because it was difficult to conceptualise in the first place. ‘How do we know a person is doing well’; ‘what and who determines wellness’; and ‘is wellness synonymous with recovery’ were some of the questions the researcher struggled with, both as research questions and as human dilemmas. She came to appreciate it as something that was fluid and something that had to be constantly negotiated.

Overall, the researcher was repeatedly reminded that mental illness forms only a part of who a person is. If she were asked to provide a brief description that characterised all the hours she got to spend with “the mentally ill” she would probably say how “normal” she found such interactions and that what she shared with the participants was greater than what differentiated her from them. The experience also forced the researcher to come to accept the limits of professional expertise and to accept the notion that often there are no definite answers. She felt that her clinical knowledge was enriched by adding the extra dimension of non-clinical factors. As such those interactions and reflections became an important part of her learning journey, both as a person and as a mental health professional.

Discussion

The three studies of the current project were informed by Gadamerian principles that suggest that a phenomenon is not simply experienced but rather interpreted by each individual in view of his/her general presuppositions and personal understanding (Polkinghorne, 2000). When the phenomenon is explored in a conversation between two parties, both draw on their experience and background knowledge which is brought into the process. The conversation functions as a back-and-forth exchange that involves active participation and that promotes reflection and improved understanding.

Given the interactive and reflective nature of the research interviews it was important to attend to the factors involved in the experiential process of research as well as the interview content. The findings suggest that participation was not reduced to providing responses to questions but instead involved a complex set of factors, including the participants’ reasons for and commitment to participation, their subjective experience and their relationship with the researcher. Similarly, the researcher’s role went beyond the function of an impartial party that poses questions and records

answers. Rather she became a participant herself which led her on a learning journey that incorporated the actual findings of the studies as well as lessons on a personal and professional level.

The subjective experience of participation is rarely explored beyond the acknowledgment of the potential risks that vulnerable populations, including individuals with mental illness, might experience. Yanos, Stanley and Greene (2009) suggest that although vulnerability in research, whether capacity based or power based, needs to be taken into account, interview-based studies asking about participants' symptoms, day-to-day activities or thoughts and opinions generally present only minimal risk to the individual. In fact, making decisions for individuals in order to protect them from harm may represent paternalistic approaches that violate their autonomy (Lakeman, McAndrew, MacGabhann, & Warne, 2013). As existing research indicates participation occurs for a number of reasons, including altruism, and is generally viewed as a positive experience (Sikweyiya & Jewkes, 2013; Taylor et al., 2010). This is true for psychiatric research (Jorm, Kelly, & Morgan, 2007) as well as trauma research, even with participants in the acute aftermath and those symptomatic for PTSD (Griffin, Resick, Waldrop, & Mechanic, 2003). Even where individuals become distressed during their participation, the distress tends to be transitory and does not necessarily lead to negative evaluations (Jorm et al, 2007).

The participants of the present study described a wide range of motivating factors, mostly related to altruistic attitudes. Helping the research that was believed to be important, helping the researcher, but primarily helping others in a similar situation were all cited as their reasons for participation. Many of them seemed to be committed to the research; they used additional tools to supplement the interview data and they used further opportunities to communicate with the researcher. Overall, they described their experience as good, fun and enjoyable; an experience that had some positive, often unexpected, emotional consequences.

The fears about potential harm are well founded and should not be taken lightly. Haverkamp (2005) suggested that qualitative researchers should develop an ethic of "trustworthiness" as they acknowledge their responsibility to promote the best interests of their participants. As the present study showed, distress while reflecting on painful

events was not common but it did occur. Yet it did not seem to have any lasting effects and it did not necessarily lead to negative reactions towards the research experience. In fact, sometimes it acted as a release mechanism that brought with it a sense of relief. Although helping participants feel better or stronger, or helping them make things clearer in their minds, were not the stated aims of the research they clearly indicated that research interviews can have therapeutic benefits.

Research participation as a therapeutic activity has received only limited attention in the literature even though catharsis and increased awareness of problems (Taylor et al., 2010) as well as empowerment, healing and sense of purpose (Jorm et al., 2007) have been noted. Lakeman and colleagues (2013) suggest that being able to tell one's story and share his/her feelings, being heard and consolidating one's memories helps the individual make sense of his/her experience which in itself can be therapeutic. This was evident in the present study that showed how powerful narratives could be.

Although most participants would have had an opportunity to tell their story before, either in formal treatment or consumer settings, or with their significant others, it seemed that a full exploration was not always possible. Formal treatment settings tended to be time limited and focused on clinical aspects of the experience, whereas consumer settings promoted primarily non-clinical focus. Understanding significant others had been acknowledged for their support yet many individuals seemed reluctant to discuss certain issues with them. In contrast, the research interview provided a safe, unhurried, confidential environment in which the participants could tell their story within its full context.

It is not possible to clearly identify those factors responsible for the therapeutic benefits but it would seem that shared humanity played a role. Although participation occurred within the parameters of a professional research relationship there were a number of opportunities that allowed the researcher and the participant to get to know each other not only as two parties engaged in research but as individuals with shared values, experiences or interests. It was this commonality that allowed for close connection with the other person and that promoted self-disclosure. In addition, it could be speculated that, somewhat ironically, it was *not* having expectations of therapeutic benefits that allowed for therapeutic processes to come through. Whereas in therapist-

client settings both parties work towards improvement with some anticipation of better outcomes no such expectations were attached to the research process, which made the actual therapeutic experience so unexpected and therefore perhaps more noticeable.

The other factor that potentially played a role was the overlap between therapy and a research interview. Holmes (2013) suggested that both a therapist and a researcher use similar tools, including forming rapport or encouraging the individual to tell a story. Others similarly pointed out that elements such as ensuring confidentiality (Haverkamp, 2005) or providing a safe, containing environment in which the person can share his/her feelings and make sense of his/her experience (Lakeman et al., 2013) are inherent to both therapy and qualitative research interviews. The present study suggests that working towards shared understanding, as opposed to some suggested outcome, in a safe and confidential environment that promoted active engagement for both parties may have played a role in the research experience acting as both a research conversation and a therapeutic dialogue.

Although shared humanity and shared characteristics of therapy and qualitative research had some benefits they also posed a number of ethical dilemmas, primarily with respect to researcher self-disclosure and multiple roles. Although professional self-disclosure has received great interest in literature, it remains a controversial issue (Gibson, 2012). In addition, discussions tend to centre on therapist self-disclosure with researcher self-disclosure receiving only limited attention. Earlier suggestions that therapist self-disclosure should always be avoided have shifted towards considerations of self-disclosure as a potentially useful therapeutic tool, provided that the therapist self-discloses for appropriate reasons, retains focus on the client and monitors the client's response (Bridges, 2001; Hill & Knox, 2001).

It could be argued that the aforementioned guidelines for therapist self-disclosure could be modified for research situations. Certainly in the present study the researcher was very carefully monitoring her self-disclosure and the effect it had on the participants. Although she tried to limit self-disclosing statements as much as possible she found that avoiding them altogether was not possible. As Gibson (2012) pointed out, consciously or not, therapists are self-disclosing all the time, both verbally and non-verbally; the same principles seem to apply to research situations. While the participants

showed curiosity about the researcher as a person and sometimes asked personal questions, they also revealed their observational skills. Although interpersonal skills may be compromised in some individuals in the acute periods of their illness, their general ability to attend to verbal and non-verbal cues and messages is not necessarily absent, as seen in the participants' statements that ranged from questions about the researcher's accent (nationality) to comments about her appearance (tired) or body language ("worn out" by an interview).

In addition to questions of self-disclosure, the researcher was also faced with the risk of potential boundary crossings related to multiple roles. Although she became quite close with some of the participants, she was mindful of differentiating between being a friendly researcher (a compassionate professional) and being a researcher as well as a friend (dual roles). She also had to carefully monitor her own responses to ensure that they remained within research boundaries, particularly at times of participant distress.

Although psychologists are equipped with unique skills that allow them to enter qualitative research projects as relational ventures, it also means that participants may hold certain expectations about the psychologist's skills and knowledge and may not always differentiate between researcher and therapist roles (Haverkamp, 2005). They may assume that the aim of every clinical research project is therapeutic (Yanos & Ziedonis, 2006). Knox and Burkard (2009) point out the importance of handling a participant's emotional distress in a supportive way without resorting to therapeutic responses. Yanos and Ziedonis (2006) propose for clinician-researchers to use education and self-awareness to help them develop "good judgment" that will help them resolve ethical conflicts.

In the present study, the researcher found that how she defined her role was not necessarily how that role was viewed by others. The participants tended to regard her in a much broader sense as simply a psychologist, that is a person with clinical knowledge and skills that could be used in multiple ways. A person with such expertise could answer clinical questions and clarify confusing concepts; act as a non-judgmental listener who was bound by the rules of confidentiality; and provide a holding environment in which emotional distress could be safely contained. While the

researcher's role and intentions were defined at the beginning of the research process, she had to restate and clarify the limits of what she could do with/for the participant right through the whole process. She understood role confusion as a potential risk that needed to be monitored and that was her responsibility to manage.

The researcher's participatory role may have caused ethical dilemmas but it also allowed for closer connection with the participants which in turn promoted their disclosure. Professional relationships have been acknowledged for the role they play in treatment and recovery. It has been suggested that while formal knowledge and skills are important, it is factors such as creativity, showing an interest in the patient/client as a person, friendship, mutual trust and discovering fellow humanity that help determine how helpful the relationship is to the individual (Borg & Kristiansen, 2004; Green et al., 2008; Schon et al., 2009; Topor et al., 2006). Although there are some parallels between clinician–client interactions and the research setting, researcher–participant relationships as such are rarely explored in the literature. The present study was not designed to address this topic yet there are some tentative indications that the relationship the researcher had with the participant played a role in how the interviews proceeded and the way the participant stories were explored. Although being able to give a bit of herself at times made the researcher feel vulnerable, and although flexibility and personal involvement were in many ways more difficult to monitor and manage than strict boundaries (researcher as an objective observer) would have been, those very same factors might have been the reasons for why both the researcher and the participant were able to gain something from their respective participation.

It has been noted that psychotherapy can be transformative for both parties and that effective therapists are those therapists who constantly compare new information with their existing knowledge, who seek feedback from their clients and who based on that feedback adjust their approach (Kottler & Hunter, 2010; Miller, Hubble, & Duncan, 2008; Sparks, Duncan, & Miller, 2008). While it would be presumptuous to call herself an effective interviewer, the researcher found that approaching each participant as an individual, adjusting her interviewing style and being flexible was important. She also found that “being with” the other person was more important than posing technically good questions. Finally, she allowed the participant stories to challenge her own preconceptions and improve her understanding. Apart from the intended outcome of the

research enterprise (findings addressing the research question) the researcher-as-participant experience proved to be transformative.

Although the present chapter treats the process of interviewing as separate from the interview content, the process findings are in fact informative with respect to what they add to previous findings. The participants reflected on their lived experience not as detached observers describing a series of events that had occurred in the past and that had come to some sort of a conclusion but as active agents who talked about an ongoing process. Their participation therefore became part of their journey and part of their learning about illness and wellness as well as about themselves. Secondly, their research experience could also be understood as fitting in with illness management and coping strategies. The decision to take part and to commit to the study required personal responsibility. Contributing to research was seen as being fun and being productive, and it also provided them with an opportunity to socialise with another person. The relationships they formed with the researcher gave them an opportunity to engage in respectful, reciprocal interactions. In addition, verbalising their thoughts and feelings, and creating a cohesive narrative helped them find meaning in their experience.

Finally, the fact that the participants were able to describe a complex set of events and circumstances and articulate their understanding of some quite difficult concepts; that they made research participation part of their lives; and that they were able to relate to another person could in itself be seen as an indication that recovery is possible. The participants were individuals with severe mental illness who are often believed to have limited insight and a compromised ability to engage in the social world and be productive members of the society. Although the stories show that mental illness tends to be episodic and that periods of ill health can have devastating consequences, it would seem that with appropriate timing and appropriate guidance the individuals can create coherent narratives of their past, present and future.

Conclusion

This chapter reported on those research factors that were not directly linked to the topics under investigation (lived experience of mental illness and recovery) but that were nonetheless crucial parts of the exploration. It seems that what the stories told was just as important as how they were told and under what circumstances. The research

process did not start with the participants signing their consent forms but with the initial motivations underlying their decision to take part. Altruism, curiosity and the belief in being productive may have played a role, together with ongoing commitment and willingness to trust the researcher and explore their experience.

The research design required that both parties acted as participants who were able to relate to each other holistically. Just as the researcher was able to look beyond a diagnosis to see the person behind the stipulated roles (a participant and a person with mental illness), the participants had a glimpse at who the researcher was as a fellow human being. Although such close relationships created a number of ethical dilemmas they were also instrumental components of the research process. Thus being a participant and being a researcher became the mechanisms of the research, parts of its context as well as its own subject of inquiry.

Chapter 9

Paula's story

Introduction

Chapters 9 and 10 are dedicated to the stories of two participants. It is believed that the two narratives help illustrate some of the research findings, with respect to both the content and the process. In addition, they serve as two examples of a participant horizon of meaning. Whereas Chapter 8 provided information about the researcher's journey towards improved understanding, the current chapter and the one that follows describe that journey from the participant perspective.

The present chapter describes the story of one participant who could perhaps be described as “being stuck”. The reason her story is included is because Paula exemplifies a large number of individuals with mental illness who have not progressed on their journey towards greater stability and wellbeing. Paula's RAS-R (Corrigan et al., 1999) scores were the lowest of the whole sample, providing further support for the suggestion that her recovery journey had barely begun. The researcher felt that it was important to honour the story of someone who might have otherwise been overlooked in research. Traditional clinical (outcome) research might have treated her as an “outlier” that doesn't fit and therefore needs to be managed, or might have simply classified her as non-recovered. Consumer, process-oriented research might not have considered her for participation in the first place; she would not see herself as recovered/in recovery and therefore would not meet the selection criteria. And yet the information she provided was important, highlighting the challenges of someone who struggled to find meaning in her experience.

The researcher met Paula at a psychosocial centre where the two were introduced by one of the staff members. She had been recently discharged from a psychiatric hospital after another, in her view unsuccessful and traumatic, hospitalisation. Her decision to participate might have been influenced by her need to tell someone about her mistreatment yet she also seemed to appreciate the opportunity to tell her whole story. Although Paula had agreed to meet for further interviews she failed to attend the pre-arranged second interview and any attempts to contact her were unsuccessful. The information gathered from her is therefore limited to what has been

learned from one interview and her RAS-R (Corrigan et al., 1999) scores. Nevertheless, that information is deemed important as it provides a glimpse into the experience of someone who is yet to move past the initial stage of recovery.

Narrative outline

The illness journey.

Paula's story was marked by a circular preoccupation with her body image. Whereas other participants talked about fluctuations and a back-and-forth movement the overall trend was of learning and shifts in understanding. Paula's story, however, was one marked by breakdowns and (often involuntary) hospitalisations that seemed to produce little change in her view of what the problem was and how it could be managed.

Paula traced the beginning of her difficulties back to her childhood: her preoccupation with being "skinny and pretty" was evident very early on with the first serious attempts to radically slim down dating back to when she was about 14 years old. Her physical and psychological health deteriorated to the point where her family feared for her life. She was removed from school (never to return) so that she could be under family observation at all times but only started eating once two anorexia sufferers, whose story Paula read in an article the day before, spoke to her in her dream.

... and they came to me in my dream and they begged me to eat, the one that had died, the two of them came to me and I'm sure they saved my life because they came to me, and sometimes I resent them for it because I have to live with so much pain.

Although Paula had experienced periods of relative stability (once for an extended period while she worked with animals), those did not last long as she struggled with yet another episode of ill health. Her attempts to cope were ineffective and largely self-destructive; each episode was remembered primarily in terms of body weight fluctuations. When asked to reflect on her journey overall, she saw no improvement which she seemed to attribute solely to the mental health professionals. She talked about herself not as a person with mental illness but as the illness itself; her illness became her identity.

And when an anorexic has to talk to someone about putting on weight, they don't want to know about it. If anyone mentions the words 'you need to put on weight' they just don't want to know you.

Conceptualisation of mental illness.

Paula did not specify what she believed the cause of her illness was but she did indicate attempts to try and understand what was happening to her. She did not dispute that she had mental health problems, which she believed stemmed from childhood and adolescent experiences, but she disagreed with her diagnosis which was not helped by the fact that there was no consensus on what the diagnosis was in the first place.

Well, they diagnosed me with bipolar, schizoaffective disorder and something else, um, first they thought it was a personality disorder, then they thought it was bipolar and then they thought it was schizoaffective disorder. I don't think it's either of them, yeah. Then they started thinking yeah, maybe she does have problems with anorexia, so they're starting to get it right but it's taken them, like, years and they're still not giving me the right counselling...

Just like many other participants, Paula found it easier to talk about what it felt like when she was unwell than to describe signs of feeling well. She talked about being ill as having negative thoughts about her body, feeling flat and depressed, being disorganised and finally shutting down when she was heading for another breakdown. She also described intense feelings of self-hatred and a need for control. Being well was seen in comparison to her ill health: feeling happier and more motivated.

Illness management and coping.

I don't think there's much you can do about that except for exercise and being around positive people really helps too. I think the people that you are around really makes the difference, being around positive people, you know...

Paula seemed to have a limited range of coping strategies. She believed that the primary responsibility should lie with the professionals yet at the same time she expressed frustration with the clinical assessment of her problems and therefore the failure to provide appropriate treatment.

I think they should get some strategies in place for how to deal with my emotions, how to stop feeling depressed, how to feel happy, um, normal ways that other people conduct their lives so I can learn a normal, a normal healthy...

She talked about working with animals and being with positive people as helpful; and she frequently mentioned exercise as a coping strategy. Yet while undeniably effective for many individuals, Paula's use of exercise seemed to feed into the vicious cycle of extreme weight-loss and obsessive thoughts related to her body image.

Losses and gains.

There have been numerous losses caused either by the illness, by the dysfunctional strategies she was using to cope with it or by treatment. Her life and normal development were severely disrupted very early on in life; she never had a chance to complete her education or go through the process of individuation and identity development. From hair loss as a side effect of medication, losing custody of her children and losing financial independence to experiencing brain damage as the cumulative result of extreme weight-loss and substance abuse, her losses were complex and profound. However, in spite of these losses and in spite of the "stuckness" she experienced, she retained some hope for the future with tentative plans to go back to school or perhaps find a job working with animals. She had stopped drinking and she hoped that she would find the right treatment.

I'm learning more now how to keep myself safe. Since I stopped drinking...

Professional help.

Paula's account of professional help was one of constant disappointment, frustration and resentment. She believed that her assessment of the problem was disregarded and that she was misdiagnosed. She resented having experienced involuntary admissions and treatment, and she regarded the treatment she had received as inadequate at best, harmful at worst.

I said, look, this isn't the place for me, anorexic doesn't want to be locked up, she wants to get out and enjoy her life, she's been through enough pain and suffering, she doesn't want to be locked up in a mental institution, it's the worst thing for her and all they do is feed you, they don't give you much else to do...

In spite of regarding her previous experience with psychological help as unsuccessful, she believed that the most appropriate help should include counselling/psychotherapy. She indicated some awareness of her dysfunctional thought patterns and therefore the type of help she was likely to benefit from.

I think I need one on one intensive counselling because I need to work through some childhood stuff, I need to work through some adolescent stuff and some, you know, some of that depression. I need to find out what, why I think I'm fat, why do I need to, like they're talking about how it's like control, how I feel like I've got control, yeah, over something...

Overall, Paula did not see her treatment as partnership but rather as a “me versus them” dichotomy. She had to deal with professionals who did not seem to understand her needs, who did not listen to her and who prescribed medication with severe side effects; with an institutional set-up that stripped her off privacy; and with a system that had the power to “lock her up”, remove her children from her custody and take away her right to independent management of finances. While understandably very distressing, she was as yet to identify the things she had control over and she could do, as opposed to things that were denied to her. Similarly, there seemed to be little recognition of the potential role she could play in her own treatment. Professional help was seen as an oppressive force rather than a tool she could use to help her cope and get better.

I just said, they wanted me to stay longer and I just said, look, it's too depressing in here, I just don't want to stay here, I want to come out, there's crazy people everywhere I look, there's no privacy, I just said it's just terrible conditions in here, the environment isn't very good for me and then I said, can I get a transfer to [hospital]... and they said, if you go then you just take yourself with you wherever you go and I'm like, yeah, that's all true but [hospital] just isn't a very nice place.

The role of others.

Right from the onset of her problems while still a teenager Paula had enjoyed a strong family support until about five years ago when her parents put her on the public trustee to manage her finances.

I don't get a lot of family support which is really hard. My mum and dad ring me every night but that's all they do, they give me a call on the phone but that's not enough... .. I'd like them to spend a bit of time with me, they don't come to my house or anything, no. My mum meets me once a week but that's it, for coffee, but that's it. I just don't think there's enough family support and maybe that's because of my mental illness.

Paula was clearly hurt by the loss of support which was that much more pronounced because her overall social network appeared rather limited. Contrary to many of her peers, Paula attended the psychosocial centre only sporadically as in the past she had felt taken advantage of. She also found interactions with other individuals with mental illness as not always very helpful because they were “crazy”. The ‘me versus them’ dichotomy that was evident with respect to professional help was also evident in her assessment of other individuals with mental illness whom she regarded as different from herself. In addition, it would seem that although she was aware of the impact other people’s illness had on her she had only a limited appreciation for how her illness affected others (such as her family).

I find it hard being around other mentally ill people... .. because sometimes they've got issues and you've got issues, yeah...

Recovery.

Paula completed the RAS-R (Corrigan et al., 1999) without questions or without offering any written or verbal comments. She scored consistently low across all five domains, indicating little hope for the future and for successful achievement of goals, as well as poor perceived help and support from other people, with mental illness remaining a strong focus in her life. Looking at individual items that were scored either very low or very high, it shows a person who does not like herself, who seems to see little purpose in her life, who lives in fear and believes to have a limited ability to handle stress and challenging situations. It also shows a person who has little hope for the future and doesn't believe in her own ability to meet her personal goals. She also seems to believe that there are not many people who would like her for who she is, who would believe in her and who would always be there for her. Her illness continues to interfere with her life to a significant degree. On the other hand she has a desire to succeed and she has goals that she wishes to reach.

Because Paula did not complete the second and third interviews, there was no opportunity to explore the concept of recovery with her. From the limited information that was provided spontaneously in the interview it seemed that she regarded recovery at least as painful as the illness itself, with recovery, although not defined, possibly seen as involving striving for normality. Given the severity of her illness that started early in her life it could be speculated that her view of normality was based on preconceptions of what she believed “normal ways that other people conduct their lives” were, rather than some baseline built on past experience.

Process.

Paula’s recall of past events was strongly affected by her preoccupation with her body image, with each episode of ill health defined in terms of how much she weighed when admitted to a hospital and how much she weighed when she was discharged, and how she felt about such body transformations. At one stage while talking about her current situation she said: “....so I feel fat now, yeah... to look at, do I look fat?” at which point she stood up so that the researcher could have a closer look. Her need for other people’s positive assessment of her was in direct contrast to her self-assessment, something she was aware of and tried to understand.

The researcher’s journal data indicate that the interview with Paula reminded her of a parent-child interaction. The researcher could only speculate on why she had such emotional response but it is possible that it was partly because of the early onset of Paula’s illness, which interfered with her development and prevented her from developing healthy maturity, and partly because of power imbalance. In a way, Paula’s story stood out for the researcher not so much because of illness severity but because of the marked power imbalance. The researcher-participant difference that tends to occur in research settings seemed to be magnified by the perceived difference in maturity. Yet the researcher did not feel disconnected from the participant and wanted to hear more of her story.

Summary

Analysis of Paula’s narrative indicates someone who has experienced ongoing distress and psychological pain yet who saw little possibility of improvement. Her journey was characterised by frequent episodes interspersed with periods of relative

symptomatic stability. Whatever lessons she may have learned through each episode were not consolidated in a manner that would promote shifts towards global improvement. Her illness has been interfering to such a degree and for such a long time that it seemed to take over a significant part of her identity.

Paula identified a limited range of coping strategies. She had experienced severe losses that negatively affected her yet did not seem to consider whether or not some of those losses could be compensated for or reclaimed. She felt misunderstood as a person and she felt that her illness was misunderstood too. She talked about what she believed others should do but didn't, yet showed little awareness of her potential role in her care. Similarly, treatment was believed to be the responsibility of professionals who were at the same time criticised for their perceived inadequacy. Relationships were treated as uni-dimensional with little indication of reciprocity. Paula felt that she was alone in her fight with mental illness, with themes of alienation and otherness ('me versus them').

Paula could be categorised as severely and chronically ill, non-compliant and treatment resistant. Yet such designations would only represent one, very narrow, perspective that ignores Paula's horizon of meaning and contextual information. Paula's story did not lack hope. She did contemplate what she could do in her future, she continued to search for treatments that might be beneficial for her and she did her best to function within the strict conditions placed on her (e.g., tightly controlled access to finances; limited access to her children). She had some social support and she was learning how to keep herself safe in terms of previously risky behaviours. Many of her "difficult behaviours" made sense while placed in her life context, such as her non-compliance with medication (because of side effects) or her resistance to hospitalisation (because of past adverse experiences).

Regardless of what Paula's diagnosis was (anorexia according to Paula versus mood and/or psychotic disorder according to clinicians) it did not seem to provide useful information that would ultimately guide treatment. In addition, the treatment that was provided seemed to be limited to medication for symptom management and nutritional plan for weight gain without addressing Paula's psychological difficulties. Gadamer believed that we cannot move towards improved understanding unless we question the limits and adequacy of our existing assumptions and prejudices (Gonzales,

2006; Polkinghorne, 2000). Therefore we cannot gain knowledge unless we ask questions; it is through the interactive process of questions and answers that we may experience greater appreciation of a phenomenon (Polkinghorne, 2000).

There are indications that Paula continued to ask questions but her questioning seemed circular without a significant shift in her understanding. The clinical explanations presented to her did not make sense to her and were therefore discarded, and whatever answers she came up with were not sufficient to challenge her pre-understanding and therefore failed to promote the interpretative process. It seemed that the interactions she had within the mental health system consisted of two parties each focusing on its own respective horizon of meaning without any attempts to reconcile the two viewpoints and reach shared understanding. Unfortunately, Paula's engagement with the research was limited to the one interview. Having been able to establish a closer relationship, explore Paula's experience in more depth and examine the pattern of interactions between herself and Paula might have left the researcher with greater appreciation of what happens to those participants who have as yet been unable to move towards wellness.

Chapter 10

Heather's story

Introduction

This chapter tells the story of Heather, a 54-year-old woman whom the researcher established a close relationship with. Unlike Paula (whose story is discussed in Chapter 9), Heather was an engaged participant who not only completed the three research interviews but often spoke with the researcher during her frequent visits to the psychosocial centre Heather attended, and who on one occasion asked for a confidential chat about some relationship difficulties she was experiencing at the time. Also unlike Paula, Heather was actively engaged in her own treatment taking responsibility for getting and staying well. However, those two stories were not intended as the opposite sides of a continuum (non-recovered/recovered). Heather would not consider herself as recovered as she continued to struggle with symptoms of her illness and with the consequences of past traumas, and as she experienced ongoing difficulties in social interactions.

One of the reasons the researcher decided to include Heather's story was to show to readers how the themes discussed in previous chapters interacted on an individual level. Although the findings of the three research phases are discussed separately they all form parts of the whole so that for instance discussions of one person's recovery journey could not occur without consideration of the way the person conceptualised his/her mental illness or without acknowledgment of the person's losses and gains, or the person's relationships with others. The second reason was the place Heather's story played in the researcher's own journey. The researcher first met Heather at the beginning of the data collection phase and continued to informally meet with her until the data collection was completed. Heather's openness, willingness to answer questions but also ask questions of her own, and her generosity not only provided rich data but also helped demonstrate the potential benefits of the hermeneutic principles (such as "being with" the other person; conversational style of interviewing; acknowledgment of contextual factors; focus on shared understanding rather than obtaining "the truth"). The interviews with Heather thus not only helped advance the understanding of the phenomenon in question but they became part of the personal

learning for both the researcher and the participant.

Heather first approached the researcher after she had seen her interact with other members of the centre and after she had been told by others about the research project. The researcher explained in more detail what the research participation entailed after which an appointment was made for the first interview. Heather was very articulate and opened about her experience. She needed only little prompting to tell her story and disclosed a great deal of at times very painful events. The details of her story were collaboratively pieced together to form a detailed and complex narrative that was marked by distress and severe difficulties but that was nonetheless filled with hope. She accepted mental illness as part of her life, one that was strongly influenced by longstanding relationship difficulties. She saw the emergence of her illness as directly linked to trauma. Her illness journey was a journey of healing.

Narrative outline

The illness journey.

Heather started her story with the events that immediately precipitated her first episode but also included previous life circumstances that she believed played an important role in the development of the illness. She was subjected to complex and prolonged abuse by her mother who eventually told her to leave home at the age of 14. In addition to being abused she also witnessed one of her siblings being severely mistreated. The family context amplified the nature of the abuse; out of four siblings two were abused and two were not. Heather was discouraged from making friends and the only other potential source of support, the extended family, chose to stay away. The abuse seemed random, only occurred when the father was not present and was firmly denied when its signs (e.g., bruises) were called to question. Such unfairness, unpredictability and denial magnified the actual abuse and failed to provide sense of physical and interpersonal safety, and nurture Heather's developing sense of self.

The cycle of abuse continued right into adulthood. Heather maintained her relationship with her mother and continued to be exposed to abuse; only this time one of her non-abused siblings took part as well. Heather was also married to a man who mistreated her. She had limited social support and no awareness of available services but she managed to stay employed and functioning relatively well. Then her father

passed away. Heather was now in her 30s and with the only positive influence gone, her ability to cope started to decline. The grief, coupled with subsequent loss of employment and marital break-up finally led to a breakdown and first hospitalisation.

[W]hen my dad died that was it, that was when I got sick and you know, all this sort of stuff and I didn't realise all this stuff, you know, which is what I was saying, it takes years and years to recover, I suppose and to find your own way again. Because when my dad died I had no one, did not know where to turn to, you know, nobody... like my dad's sister and auntie didn't want to know us because they didn't like my mum. What's it to do with me? What's it to do with me, you know? They didn't want my dad to marry my mum. I can't help it... ... at the time I was married then, and everything got too much, you know, my dad had died, I lost my job, I had a lot of money, when I say a lot of money, I lent 20,000 dollars to my brother once and I never got it back. So that was another thing as well.

By now Heather was starting to become aware that things were not OK but she had no knowledge of mental illness and the mental health system.

I was so angry and upset. I couldn't fight back. I had no one to talk to because I didn't know that I had a mental illness, I didn't know that there were people out there that you could talk to. I was all alone.

The first attempts to get help were prompted by other people but were unsuccessful. She attended one session with a psychiatrist upon a suggestion by her employer who noticed signs that something was not quite right. She was assessed but there was no follow-up. Next she was committed to a psychiatric hospital by her mother; Heather found the experience extremely frightening and escaped from the hospital. It took two further admissions until she learned that she was suffering from a mental illness that had a certain name and that could be treated.

So I ended up in [hospital] because everything got too much because I couldn't cope, I couldn't eat, I couldn't cook, I didn't even know how to make a cup of coffee. I still remember being in the kitchen, I looked out the window and I thought, how the hell do I make a cup of coffee. I just didn't know anymore. What I do remember is, it was like being a baby and I'd forgotten how to live, if you know what I mean. I had to start from scratch.

She started taking medication and spent almost two years in counselling to help her work through the consequences of past trauma. She was also provided with disability pension and secure housing. With some of the pressure of daily living removed, she was able to start focusing on herself and on getting better. Her healing journey began but some of her relationship difficulties remained and she suffered further trauma when her house was broken into and she was severely injured.

So it all came together and then after when you think that you've done your healing there then you feel like you want to meet someone and then you meet someone and it's alright for a little while and then it's like, nah, they don't have the same idea as me or, you know, that sort of stuff or to do with the family, their family, they might have had problems and I didn't want to be involved with the family that had problems because I'd seen it myself, so then it was back to being alone again and then I got robbed, that's right. Then I got robbed and I got a brick thrown in my face, yeah, I nearly died. So just as I was starting to get well, two [men] broke into my place.

Heather was left traumatised and her mental health started to deteriorate again. She had to receive further counselling and had to have her medication increased to help her stabilise. However, as distressing as the experience was she thought the fact that she survived meant that she had a second chance in life and she got back to her healing process.

It's awful to think, even now it sort of grips me with fear to think that that's what happened but I was getting a second chance and then, so then it was that counselling and I became very nervous and for six months I was becoming very, obsessive compulsive disorder, checking the doors every five minutes, I couldn't sleep at night, I had to take medication, it was scary.

At the time of her research participation Heather saw herself as being in a good place. She knew her illness, understood its warning signs and employed a number of coping and management strategies to stay well, one of which was more effective management of relationships. Given the role dysfunctional relationships played in her life and in her illness, Heather started evaluating all social interactions in terms of the impact they had on her. She kept those relationships that were healthy and supportive, and terminated those that were toxic. She was able to break the cycle of abuse; she also

stopped seeing herself as a victim. She had a better awareness of who she was, what she wanted from others and she felt more confident in her abilities to do what she wanted in life, not what others told her to.

Conceptualisation of mental illness.

People used to say you're mad, you're crazy, you know, you're this, you're that. For a while I did believe it. But I knew I wasn't that mad, you know what I mean? It's just an illness.

Heather knew that she was not feeling well but had no awareness of mental illness. She was called crazy by people in her life so initially found it difficult to understand her experience. Eventually she learned the name of her illness and had a chance to reflect on what she had been through. She came to believe that her illness was the result of trauma, with the long history of abuse and interpersonal difficulties playing a role, and her father's death acting as a trigger.

I didn't realise that by talking about it I had all this burden, I was always sick, Zdenka, always, always sick. Always sick from, you know, sick, toxic sick from all that crap. And then once, it took me years to get over it, you know, it takes years to get over things and then when my dad died, you know, it was like a string had been cut. And it was all sort of, all the stuff was coming out of your head. You know how, it's funny how things happen to you and you think oh, how come it didn't come out now? And it's not until something bad happens that's when it all comes out.

Heather accepted that she had an illness that impacted on her life, and possibly would stay in her life indefinitely, but she also believed that it was something that could be managed. She talked about getting impulsive urges or what she called "too much energy" that needed to be released in a safe way, such as going swimming. She also became overwhelmed if there was an interpersonal conflict and found it difficult to cope. She could lose concentration and would be "all over the place". She could also become overwhelmed with too much stimulation (too many people, loud music, etc.) and in the past experienced paranoid and delusional thinking.

I remember I was working in [department store] and there used to be a TV screen on the wall and they used to play music all the time. And sometimes when there was no

one around and it was just me doing my job, the music used to get into my head and it started to make me do funny things. It was the type of music they had on and you couldn't tell them to take it off. I started to listen to the words and the words started to get ingrained in my brain and I started to, started thinking that it was like a story being told and I was sort of like doing what it was telling...

Heather was keen to hear her diagnosis and didn't have a problem accepting it even though it was changed a few times and even though she was not completely sure of its meaning.

At one minute it was schizophrenia and then, I was taking, you know, it took them a while, a few years because the medication wasn't working for me... Then they told me I had bipolar disorder and schizoaffective, I'm not even sure what schizoaffective is. Bipolar disorder is the mood swings but schizoaffective, I'm not even sure what that is.

Knowing the diagnosis was not important because of the actual label but because of what it signified: she was not crazy but instead suffered from mental illness that was legitimate and that was being treated. She was able to talk about her clinical symptoms (including mood swings, paranoia and anxiety) and accompanying symptoms that included such varied experiences as impulsive urges, outbursts, inability to concentrate or inability to carry out daily tasks.

I remember once, a few years back I wanted to jump on the train track, I know, it's silly, isn't it but anyway. Every time I went to the train station, I kept looking down, at the city one, I kept looking down and "I need to jump down, I need to jump down, I need to jump down" and then one day I thought I've got to get it out of my system, so I made sure there was no train coming because I could see by the sign at the top seven minutes or whatever, and I sort of pretended to drop something down there, so I actually jumped down and then pretended to look for it and then I jumped back up. So I got it out of my system but I haven't done it since. But it's terrible when that sort of thing happens that you've got to do it, you know...

Heather knew what it felt like when she was ill but she could also identify signs of being well. Contrary to some participants who saw wellness as absence of symptoms Heather could describe wellness as a state when she could think clearly and concentrate, when she felt happy inside and was smiling more. She spoke about not having to deal

with fear and tension, and about looking after herself and liking herself. She emphasised the word ‘contentment’ and talked about wellness as a spiritual feeling.

Illness management and coping.

Heather saw staying well as her responsibility and was able to identify a wide range of coping and illness management strategies (such as reflexology or self-help books) that helped her deal with both the symptoms of her illness and other life stressors. She was aware of warning signs and knew how to prevent things from escalating, yet she was also willing to look for help if she felt that her coping strategies were no longer sufficient. However, she also pointed out that even when a person had coping strategies and was generally aware of available help once in distress those strategies did not necessarily come into mind.

Well, sometimes when things happen you forget that there is someone that you can ask for help, you know what I mean? You forget that there is those numbers, the Careline or the [psychiatric emergency service], you know what I mean? Your mind becomes blocked when I need it.

When Heather talked about coping she did not only describe the specific strategies but also identified in what way the strategy helped. For instance, Heather said that she was going swimming because she enjoyed that particular type of exercise but also because it helped her release pent-up energy. She enjoyed arts and craft because it calmed her down and because being creative allowed her to express herself.

Heather also talked about the importance of security. She had been working continuously from the age of 14 until the onset of her illness; living without secure housing and living with the pressure of having to provide for herself, especially once she became unemployed, contributed to the emergence of her illness.

I was scared. I became so vulnerable because I didn't know there was such a thing as the dole because I hadn't heard of the dole. I didn't know what I was going to do. I felt like an Italian lady that's probably been around for 50 years and her husband left her and what was she gonna do, you know, so that's how I felt.

Heather felt that her healing could not truly start until she lived in a stable place which allowed her to concentrate on getting better.

I've always been kicked out of places when I was younger. I moved about 36 times, probably more but I did work out one day... I actually got a map in a mapbook and I actually counted the suburbs I went into and I remember it was over 30, you know, from place to place to place to place, and I got very, very tired moving because it's very draining, very emotional, especially when you're working

I started thinking a bit clearer, she [counsellor] helped me get a place because she asked me if I was happy where I was and I said no. I said I'm sick and tired of moving all the time, it was a private rental, so I said I'm sick and tired of moving all the time so we started to talk about that and I told her I wanted my own place. It took me a few years after I got my own place to feel secure that I was never gonna get kicked out again, do you know what I mean?

Given Heather's history of dysfunctional relationships one of the most important variables in her coping was her ability to manage relationships. She enjoyed socialising but too much interaction was overwhelming. Conflict could prevent her from thinking clearly and could make her illness worse.

I needed to get away but I didn't know where to go, I didn't know who to turn to, I didn't know who to ring because I had no one to ring. I didn't think about ringing up, you know, a care line because I just didn't think. And so anyway, last week, not last week, the week before I think it was, beginning of February, I went to [town]. Because I'm on the pension, you get a pass to go away so I deliberately went away for four days so I could think clearly and spend some time on my own. And I know that I like being on my own, you know. I can think clearly, I can do things properly, I don't have the tension there.

She described herself as a loner and said that pulling back (getting away and spending time on her own) was important. She also had to learn how to put boundaries on relationships, how to say no and how to choose who to spend time with, how long and under what circumstances. She tried to monitor interactions and "nip conflicts in the bud" before they escalated.

I know when I've had enough, yeah, and then I can say good, off you go when years ago, you know, if someone would come around, you're pretty scared to tell them to go, and three hours later it's like, oh god, you know what I mean? And you just can't cope. So that's how it's always worked for me since.

Losses and gains.

Stress less. That's my plan anyway, to live a long time.

Heather's experience demonstrated how difficult it was to tease apart those losses that were caused by her illness from those that were caused by circumstances but nonetheless contributed to or impacted on the illness. Her childhood abuse did not allow her to learn about secure attachment and healthy, reciprocal relationship which then impacted on her adult relationships. Although her mother was physically present through most of her life Heather talked about not having had a mother. She learned to live with a sense of abandonment, the memory of stolen childhood and a sense of fear.

My counsellor used to see me, if the phone rang because if I, if my sister rang and if I didn't answer it after two phone calls, she would abuse me and I would start vomiting. I would start vomiting because I was scared of her because she was like my mum. It's always been on fear, my life has always been based on fear that's why, even now I still have fear.

Heather was forced to quit school at the age of 14 which is something she continued to have regrets about.

[I feel] sad, cheated, cheated because if I knew it was gonna be like this I, I don't know, what could I have done, at fourteen you're very vulnerable, aren't you. You've got no choice, you've got to get a job at fourteen, you've got to survive, do all the crappy jobs that you can get, McDonalds, Hungry Jacks, even though you hated it, you didn't think about going to school at night time to learn something because you wanted to go out and play.

She could not pursue her occupation dreams due to limited education. At the same time she believed that her illness in combination with external factors precluded her from studying or holding down a job full-time in the future.

Yeah, if I'm not well, I go downhill, I can't cope, I can't cope with [college,] you know, with all the yelling and screaming, I can't cope, I can't concentrate because I've had it all my life. I would do things and I would chuck it in after a couple of times, do things, try and learn something, I couldn't concentrate, you know? I reckon I would have been good at something, like they do a test on you and from what I've done they reckon I

could have been a bank teller, I could have been a musician, all good jobs, a florist...

The illness on its own, at its most severe stage, interfered with her life to such a degree that she was unable to attend to even the most basic tasks of daily living. Yet as she mentioned she had not been so unwell in a number of years. Because the illness had been stabilised she was able to start reclaiming some of those losses as well as creating new opportunities. She had a new ability to manage relationships, she did voluntary work and she was able to pursue her creative interests. She attended college part-time (but with interruptions) and she had plans for future travel. She considered relocating to another place, far from the reminders of what had happened to her.

I sort want to make a new life because I just feel that I've been here for, I was born here and there's a lot of past here and no matter which area I go... I remember certain things and I sort of don't, I sort of get reminded, of course you can't help getting reminded but I feel like I want to go somewhere else and get away from all that now, you know what I mean?

In spite of her future plans she remained focused on the present. She said that she did not know what future might hold and she still had to “sort a few things out”. The process of healing and learning about self was ongoing and required hard work. Her one constant aim was to look after herself and live a long life.

I'd like to think that I live a long time, that would be my revenge, you know what I mean? That would be like my revenge. Who knows but I'd like to think that one day I might outlive all the family, like my mother especially and then at least I can say, well, I might have been treated like [s...] and had this and this and this done to, child abuse and all this sort of stuff but look like I've looked after myself...

Heather's story demonstrated that both past experiences and future plans were important but mostly within their orientation toward the present. She thought about her past and tried to make sense of it, mostly with regards to how it impacted on what was happening to her now. Similarly, plans and goals gave her some direction but only when they were grounded to present circumstances that she had some degree of control over.

Professional help.

Heather's early attempts to seek help were initiated by others, with almost no

input from her. Those experiences did very little toward her understanding of what was happening and in fact created further distress. Heather's first hospitalisation was so frightening and so difficult to understand that she tried to escape and in fact succeeded on her second attempt.

By the time I'd got out the door, I just walked on to the lawn and someone said, hey, come back. And I thought, oh, they got me, you know. So they took me back upstairs and they moved me to another room where they could actually see me, so I was in front of the station, they call it, you know the station? And I thought I'm never gonna get out of here. Nobody was even coming up talking to me and asking me what was wrong, and I didn't even know what I was there for. And I thought, this is, what's going on, I'm going crazy, you know. And then I thought, I'm gonna have to run away again. And I made sure this time I did a good job.

...so that was my first experience... They must have thought 'she's crazy, that girl' but I didn't even know, I knew I wasn't well but that was because there was a lot of crap going on, you know, with my mother, horrible. So when I heard her [mother] say, get rid of her, I thought automatically they were going to kill me. So that's what I thought the lady was doing with the needle. So when I ended up in [another hospital] the first time, I was scared because I thought they were gonna rid of me here. Scary, isn't it? Just those words, get rid of her.

It took repeated admissions and her own observations before she learned that she had mental illness and she learned to accept psychiatric hospitals as playing a role in its treatment. While she appreciated hospitals as secure places where she was physically looked after she was also able to identify numerous flaws in their operation. There was no process in place that would help her understand what the place was for and how it could help her, and there was no one who would be willing to help her find meaning in her experience.

Yeah, the first time [at hospital] was scary, I didn't know what was happening, the second time I sort of got the gist of it, the third time was better because I knew then I needed someone to cook for me, so it was good that there was a meal always ready for me, you know, because I got to a stage where I was really tired, I didn't want to cook anymore, I was becoming weak. And I didn't know that, you know, I didn't know what [hospital] was, I didn't know what sort of a place it was, I didn't know it was for people

who were unwell. But I used to keep to myself when I was in [hospital]. I used to do the walk around the actual hospital, you know if they had walks in the morning I would do that and a couple of times they had a counsellor there that they said if I needed someone to talk to I had to put my name on the list, well I did, you wait and no one turned up, so that was very frustrating, very frustrating.

What could be described as the behaviour of a paranoid patient, one who was noncompliant with the treatment protocol actually made sense in light of how she viewed her experience. She was committed to an unfamiliar place without an explanation of its function. She ran away because she was injected against her will, again without any explanation. She spat out her medication because she did not know what it was supposed to treat. She refused to do cooking classes because she had been cooking most of her life and instead wanted someone to help her make sense of what had been happening.

Heather herself admitted that it is likely that the medication she was first prescribed and expected to take was in fact explained to her but she was “all over the place” to be able to concentrate and take in what was said. Unfortunately, with only very limited opportunities to speak to staff, what could have been further chances to provide explanation as part of ongoing communication did not occur. Similarly, a form of treatment provided on the hospital grounds that Heather found very useful but did not discover until late admissions may have been discussed with her yet without her full awareness. Not ensuring that the individual was taking information in meant lost opportunities; the person could not make an informed choice if she/was unaware of those treatment options that were actually available.

In that time that I was in [hospital] I never saw a sign that said there was a creative expression building at the back there. And it wasn't until I'd been in the hospital three times that I went wondering one day and saw these people there doing their crafty thing or whatever and I thought, what's this here and I'd gone inside and I thought that is exactly what I needed to do when I was in there the first time. I needed to do some creative expression which is drawing, the teacher will pick a topic and she will say draw something about your childhood or whatever it was, you know. And when I found out about that straight away I put my name down and I was there for four years, once a week for four years. And I tell you what, that was the best thing ever, it was exactly

what I was looking for. I didn't know what it was called when I was unwell, I didn't know what it was that I was looking for but that was exactly what I found and I used to look forward to going there.

The problem of communication was not just limited to inpatient treatment or to doctor–patient interactions. Heather also gave examples of systemic or inter-agency problems that impacted on things such as mishandled discharge from hospital or poorly executed referral from one service to another.

When they told me I could go, um, I left and caught the train but then I became depressed because I had to go to the city and I got panic attacks because I was amongst all these people because I'd been in the hospital, there's not many people, for four weeks, you know, and there's not many. And all of a sudden, boom, you're like in a big crowd. I got panic attacks and I thought once again that people were looking at me 'oh, there's that nutcase' and I had to run away. I remember running back to the station and going home, shutting the doors, I felt safe. But I heard after that that somebody should have taken me home in a car, not left me out in the bloody, catching the train but honestly I became scared, I was paranoid, I was scared, you know, it's like being thrown to the wolves.

In terms of treatment overall, medication was accepted as playing a part even though she had suffered severe side effects until the right one was found. She had worked with psychiatrists, GPs and a counsellor. She credited medications for helping her stabilise and hospitals for temporarily taking care of her when she was too unwell to do so herself but she mostly benefited from intensive counselling.

I had a counsellor... I had her for four years. Every week, for three years I had her. I think I started off once a week or twice a week but it was full on, yeah, and I told her all the stuff that I'd never told anyone and I used to cry. I used to cry but I got a lot of it out, I didn't realise what was there. It's hard to believe in four years you can still have something to say each week but I think it was for an hour each week. So she was the only one that I was ever able to confide in stuff and that's when she said to me that, um, you're gonna have to go on the disability pension because I couldn't go back to work because it was too upsetting for me, you know, because I'd been abused as well...

She found counselling/therapy useful as it helped in a number of ways. Because of fractured relationships and limited social network, she often felt there was no one to talk to. Having someone to talk to, someone who showed interest in her story gave her more confidence. If she was struggling, “churning all in”, talking helped ease her anxiety. Psychotherapy also helped her work things out so that things started to make sense and problems seemed more manageable. Heather also indicated that the way ‘talk’ is used depends on what stage of illness the person is at. At acute times the therapist may need to be the one doing most of the talking, reassuring and explaining. Once the person is stable the therapist should be primarily a good listener.

I saw somebody in there, a psychiatrist, she was asking me, you know, the problems, what the problem was. Sometimes you can't talk about it, you need them to talk to you first.

The role of others.

The role of others in Heather’s life was perhaps amongst the most significant determinants of her functioning. She believed that the long history of being abused and mistreated led to the development of her illness in the first place. It also impacted on how she viewed herself with respect to other people and how she handled conflict. In addition, negative interpersonal interactions could lead to her becoming unwell and/or could significantly interfere with her ability to manage the illness.

...so with the schizoaffective that I have when somebody upsets me, I'm all over the place, I can throw things, you know, I don't mean to but it's because they push me, you see.

The onset of mental illness forced Heather to re-examine her relationships and to re-evaluate them in terms of the impact they had on her. She learned to terminate relationships that were toxic and to put strict boundaries on those that had the potential to make her unwell. The emergence of her illness therefore had the unexpected benefit of teaching her new interpersonal skills, from assertive communication or the ability to say no to being able to manage interactions so that she had some control over where, when, how long and under what circumstances the interactions took place.

I used to, you know, do things for them and then I thought, well, I'm not really getting the gratitude, you know, maybe I was being too nice but then I didn't know how to say

no, I was scared to say no, you know, if somebody said oh, do you want to come around or, you know, whatever, you go, yeah OK, and then you think, oh, you know, you didn't want to say no because you didn't want to let them down. But now I say no, you know, depending on what the situation is, I ask questions, ask questions, you know, and then I make my mind up.

When I have coffee with some friends that I have, um, we just spend like an hour or an hour and half because I'm not one that likes to have a friend that hangs around all day. I suffocate. I can't handle it. So for me it's enough to meet someone at one o'clock, talk about whatever it is, you know, and then an hour and half later we just go our own way.

In terms of disclosure, most of the people Heather socialised with were consumers themselves and were therefore aware of her mental illness. With respect to other people, Heather tried to “act just like normal” and chose not to disclose. She talked about stigma: about being treated differently once people found out and about misconceptions people had about mental illness. She was therefore very careful about whom she told about her illness.

...people get funny when you've got an illness, depending on what it is... ... They think everybody's got schizophrenia, everybody who's got mental illness is crazy, you know, it's not like that at all, it's just that if some people have become unwell because of circumstances in their life...

Recovery.

I'm still learning, I'm still learning about things, about myself, I'm still trying to figure myself out, you know what I mean?

Heather was willing to complete the RAS-R (Corrigan et al., 1999); she was making comments as she was completing the survey which helped explain her answers. Her total recovery score was within the range of scores achieved by the vast majority of the other participants. She scored high on the domains of *willingness to ask for help*, *goal and success orientation* and *reliance on others*. The other two domains received a mixed response, with items related to symptomatology, handling of stress and fear as well as items related to confidence in who she was receiving the lowest scores. This was in line with her narrative which indicated that there were times when her illness interfered with her ability to function. She described her life as filled with fear and she

found it difficult to cope with stress, especially when it was interpersonal. Finally, she talked about having lost herself in the past and about feeling mixed up, “confused inside here in the soul”.

I looked back yesterday and I thought, you know, all of my life I felt as if I was always putting other people first. I’m putting myself first and then when they come into my life I put them first and they still... I don’t know maybe they don’t understand me, maybe I don’t understand me, maybe I’m a mixed up person.

Heather did not seem to view recovery as a significant part of her story, even though it seemed that this was because of the word itself not so much the concept it represents.

Interviewer: Has anyone ever talked to you about recovery?

Heather: Um, recovery, recovery, they probably have but I have forgotten it. Um...

Interviewer: Different people have different ideas about recovery, what would you say recovery would be for you?

Heather: Recovery, um, trying to get better? And what to do... um, and how to pick it, how to pick when you’re not well, is that what you mean?

Interviewer: Well, as I said, different people have different views; that’s why I was wondering how you would see recovery in your case...

Heather: Oh, in my case, I would see it as that I want to be left alone. I like to be alone so I can think clearly, not a lot of hustle and bustle around...

When Heather talked about recovery she rarely used the word itself but instead talked about healing. She learned to manage her illness and her main focus shifted to primarily looking after herself. She believed that healing involved learning about who she was so that she could “sort myself out”. It was a lifelong endeavour that required work on her part but with help from others. She saw wellness as her responsibility.

I thought I don’t care if I spend a lifetime doing this but I’m gonna spend the rest of my life looking after myself and trying to live as long as possible.

Heather did not identify a clear starting point of recovery but it seemed that stability, in clinical terms as well as living circumstances (finances, accommodation) was important. Two other events seemed to play a role: when she terminated the most dysfunctional of her relationships and therefore broke the cycle of abuse; and when she stopped seeing herself as a victim.

I remember just one day I was walking past and I looked at myself in the mirror and then I walked back again and I went 'gees, you'd better do something about yourself', I looked really lost. I looked in the mirror and I said 'you'd better do something about yourself instead of looking like a victim'. I was playing the victim, I was a victim. It was 'poor me' kind of thing, you know... I've got nothing now, no job, no parents, nothing, on the pension. And I remember it was from that day on I decided, yes, I can afford whatever I want even if I have to put it on layby... And that's what I've done ever since. I said to myself, and I started reading books about confidence and all that sort of stuff, you know, just all sorts of different books, you know, the new age stuff. So I learned quite a bit through them...

However, her journey was full of setbacks and fluctuations in functioning. Her illness and her coping abilities were part of a large context and could not be treated as separate from personal circumstances. Factors such as memories and consequences of past trauma, interpersonal difficulties or her need for privacy may not have been clinically relevant but nonetheless had an impact on how well she was doing at any given time. Although she wanted to see some outcome that would indicate that she was finally healed she also understood that she may never reach such point. In spite of this she was able to remain hopeful about her future.

That's what I'm waiting for... that's what I think I'm waiting for, Zdenka, to say, to wake up one day and say, hang on a minute, I'm alright.

Still a lot of work to do, Zdenka, still a lot of work to do but, you know, I'm not gonna say, right, I'm gonna end it all. I'm not gonna give up hope although sometimes I do but there's always something that keeps me still going.

Process.

Heather attended the psychosocial centre on a semi-regular basis and always had

at least a brief chat when the researcher visited. She believed that research was important but had some doubts about practical applications of its findings and about whether it will ultimately make a difference to those most affected: the individuals with mental illness.

I thought like now that you're here, Zdenka, that we're discussing things, you would think that, there's probably people before doing it with other people, they would pass it on and yet they're still not learning, are they? They're still not learning what to do. Maybe they should have the mental illness to find out for themselves. It's one thing to learn but do they really grasp it? I think we would make better teachers.

Heather rated her experience of participation as positive. She felt it helped her to talk about her experience even when discussion of some topics was quite painful.

I feel good because I had someone to talk to; it sort of gives me the extra will to go, to keep going. I know it's hard. It's good that you rang me.

The relationship between Heather and the researcher seemed to be reciprocal, based on mutual respect and trust. Heather talked about finding the interactions helpful yet also communicated her hope that her story was helpful to the researcher. The researcher was able to provide her with some information about services that Heather expressed interest in. Heather in turn looked for ways to make her story more coherent so that for instance when she talked about a violent home invasion that left her traumatised and ultimately led to relapse, she offered to bring photos of the marks the assault left on her. Similarly, when she mentioned some books that she found very helpful at one stage of her recovery she offered to bring a copy to show the researcher. Overall, Heather described herself as a nurturing person who liked to do things for others which was evident in her interactions with others and in gestures such as bringing a home-made cake to the centre and sharing it with others.

Although Heather understood that the conversations she was having with the researcher were part of a research project she nonetheless treated them as almost a replacement for counselling. In her first interview she told the researcher that she had not seen a counsellor/psychologist in about two years even though she felt that she could benefit from talking to someone. She then approached the researcher during one of her visits between the second and third interviews saying that she wanted to talk to

her about some relationship difficulties she had been experiencing. The researcher emphasised that she could not provide counselling and that the only thing she could provide was listening to which Heather agreed⁶.

During that conversation Heather discussed topics that had been covered in the previous two interviews, adding more details and further explanations. However, she primarily focused on an intimate, long-term relationship that she had been struggling with and that started to negatively affect her functioning. By being able to verbalise her experience and put in words some of her thoughts she was able to start making sense of that experience. The researcher's role was to listen and to gently guide her through the meaning making process. Overall, Heather seemed to find her conversations with the researcher beneficial and expressed her hope for future interactions.

Maybe next time I'll see you we can have another chat and see how we go from there...

Summary

Heather's story helps illustrate how the themes identified in the three phases of the current project interact in a complex manner to form a coherent narrative. Her illness journey did not start with the first breakdown or the first hospitalisation; instead its roots could be traced to early childhood experiences and adverse circumstances, with dysfunctional relationships playing a crucial part. Trying to understand the impact of those experiences on her life was an ongoing process, one that played part in Heather's healing journey.

Heather told her story as a narrative starting with childhood trauma through a pattern of toxic relationships to the death of her father which triggered her illness, and finally to her present state of being stable. Yet even when relatively well, with the knowledge of self and the illness, with better understanding of the mental health system, with effective coping strategies and greater confidence, the illness tended to fluctuate depending on what was happening in her life at the time. Her story thus illustrated that the clinical treatment of illness, one that may leave out the non-clinical context, is less

⁶ The conversation was not audio-recorded but the researcher wrote notes afterwards where she believed the information could help provide more detail or clarify topics covered in the two preceding research interviews.

likely to succeed unless it takes into account the role of the person's particular past and present, and potential future, circumstances.

Heather was able to describe the signs of ill health and she was equally aware of what a state of relative wellness felt like. She did not see illness and wellness as a clear dichotomy of symptoms/no symptoms but rather as fluid concepts which overlapped. The diminished impact of symptoms played a role in being well but wellness was seen as more, as a sense of contentment, being able to look after herself and to like herself, and as a spiritual feeling.

Knowing her illness was important for management and coping strategies, which ranged from reflexology, creative outlets and exercise to knowing when to seek help. Given the key role relationships have played in her life the ability to set boundaries and to manage social interactions, together with the option of being alone, were very important. Withdrawal and isolation tend to be seen as either signs or consequences of mental illness yet in Heather's case they were used as coping strategies. This subjective use of a strategy highlights the point that focusing on the illness to the exclusion of everything else is not effective; it would be very difficult to judge a functionality of a coping strategy without knowing the subjective context.

The pattern of dysfunctional relationships was also closely linked to Heather's past losses. Although some losses were reclaimed or otherwise compensated for, many continued to affect how she viewed herself with respect to others and the world, and how she viewed her future opportunities. The theme also showed how difficult it was to separate those losses from Heather's illness; some represented consequences of the illness while others were believed to contribute to its onset and its fluctuations. Yet in spite of the acknowledgment of and reflections on her losses, Heather retained a strong focus on her present with hope for the future.

The role of others signified one of the strongest themes in Heather's narrative but it was not limited to the part played by some of her significant others and it was not defined solely in terms of dysfunction. Heather had supportive people in her life and she enjoyed interactions, although within tightly controlled boundaries. The social factors also included professional help.

Heather's early experiences of professional help, mostly hospitalisation, were

rather traumatic and clearly demonstrated that the person needed to learn to navigate the mental health system in order to use it effectively. In spite of the early, mostly unsuccessful, attempts Heather came to view hospitals as safe places that took care of her basic needs and helped stabilise her; however, they provided only limited opportunities for exploration of her own perspective and there seemed to be no guidance in terms of helping her adjust to the setting or to help her make sense of the experience. Out of all professional relationships and interventions, Heather appreciated art therapy and counselling the most as they both focused on the person, not the illness, and as they both promoted self-expression. They both therefore became part of the healing process.

Heather talked about healing and getting better, about wellness as feeling content, and she mentioned numerous factors (e.g., understanding of her illness, hope, personal responsibility, social support) that are frequently associated with recovery. She defined recovery as trying to get better and knowing signs of ill health; her personal recovery was about being left alone which seems to refer to her need for contained relationships. In spite of this she didn't seem to identify with recovery although that was not because she did not believe that she could lead the life she wanted, in spite of limitations and constraints related to her illness and circumstances. Neither could it be claimed that the word itself was foreign to her; she spontaneously stated that it takes a long time to recover. Yet the discussion of the concept did not progress as smoothly as the exploration of her story, which would suggest that the word itself is value laden. It carries multiple meanings and although it seems to be instinctively used as a reference to getting better, the person does not seem to think about its actual meaning unless specifically instructed to. Her story thus suggested that if recovery is to become part of the person's narrative its subjective meaning should not be assumed or imposed but carefully explored with the individual.

Heather showed great willingness to explore her story, no matter how painful some of her memories were. It is somewhat remarkable that given her interpersonal history and her need to carefully manage all interactions, she was able to relatively quickly develop a close and trusting relationship with the researcher. She seemed to be aware of the overlap between therapy (counselling) and research interview and it is perhaps because she found counselling beneficial in the past that she was able to open up about her experience. She decided to participate because she hoped her story would

help others (and helping others was part of her nature) but she was also able to gain something from her participation. It helped her clarify some aspects of her experience, it brought a sense of relief and it also strengthened her determination to look after herself. Her story is remarkable not because it represents a success story or because of what Heather has achieved, but because it demonstrated the importance of contextual information and because it showed that although achievement of some outcome is to be celebrated it is important that the person just keeps going.

Chapter 11

Discussion

This final chapter summarises the research findings and their respective contributions to the body of knowledge, highlighting the most significant aspects of the lived experience, recovery and research participation, as discussed by the participants. It also points out that recovery should be understood as two separate yet related processes of episodic and global improvement, and that greater attention should be paid to the way recovery is assessed and discussed with the individual. The chapter then provides a discussion of some of the challenges encountered by the researcher with respect to participant drop-out and recruitment, and the use of personal reflections as a source of data. Next, the chapter explores clinical implications, which have been organised into five sections: hermeneutics in research and therapy; the role of hospitals and the mental health system; mental illness and trauma; recovery assessment; and the role of clinical psychology in the treatment of severe mental illness. The chapter ends with suggestions for future research and a conclusion.

Summary and contributions

Research findings: mental illness and recovery.

The present research set out to broadly explore people's experience of mental illness and to examine the way a person might incorporate the concept of recovery into such life experience. The project found a wide range of person-centred and social/relational factors that helped determine how well an individual was coping and functioning at any given time, because of and in spite of the person's illness. While some of those factors are well known (e.g., personal responsibility), others have rarely been addressed (e.g., awareness of the impact of mental illness on others) and yet others were shown in a greater complexity (e.g., multilayered acceptance).

The research also helped demonstrate that it is not specific factors as such that play a role in the person's coping and functioning, but rather their subjective interpretation, the way they are embedded in the person's context and the way they interact with other factors. So for instance while social support is undeniably a significant determinant of functioning and recovery (e.g., Bradshaw et al., 2007;

Ridgway, 2001; Schön et al., 2009), for some it might be more important to not have dysfunctional relationships than to have supportive ones. Similarly, a medical explanation of mental illness has been linked with passive acceptance and compliance (Sayre, 2000; Speed, 2006) yet the findings indicate that it is not the explanatory model per se but rather the way the person uses it and whether or not its usage allows for some degree of control that help explain the person's attitudes and behaviours. In fact sometimes it is more meaningful for the person to be accepting of having no model at all.

The project also made a contribution to the discussion on the concept of recovery. Previous research has been typically divided into assessing recovery with predetermined criteria with little input from the affected person, or exploring recovery from the perspective of individuals who see recovery as key part of their narrative (Silverstein & Bellack, 2008). The present study helped demonstrate the process via which recovery is addressed by individuals who may not have come across the concept, as applied to their illness, or who may not identify with it. Phase I found that the illness journey was understood by the participants as an experience that started before the actual onset of illness and that continued, usually via treatment, towards stabilisation. Stabilisation (also balance or maintenance) was seen as a desirable state, not one that referred to restricted existence but one that in fact promoted healthy living. Stabilisation was not limited to symptomatic stabilisation but involved multiple aspects of functioning that included such varied factors as balanced lifestyle (e.g., diet, nutrition, sleep), stable accommodation or reciprocal, supportive relationships.

Stabilisation was also closely related to recovery. Phase II suggested that participants saw recovery as two separate yet complementary processes. One referred to episodic recovery that involved returning to baseline following an acute episode, while the other referred to long-term, global recovery, one that entailed living as best as one could in view of limitations caused by the illness and specific circumstances. Stabilisation could be the person's baseline, one he/she returned to after a period of ill health. However, not everyone who had improved following an acute episode could talk about stabilisation because even if symptoms had diminished other areas of functioning may not have improved. For that person a shift in baseline, towards global stability, was necessary.

Overall, it would seem that the difference between episodic and global recovery was a difference in primary focus. In episodic recovery, the primary focus was on symptoms and their direct consequences, such as inability to carry out some daily living tasks. In global recovery, the illness may still interfere but the persons have developed coping strategies that allow them to effectively manage their illness. With the pool of coping resources no longer consumed with the primary task of acute management they can turn their attention to other areas of their lives⁷.

The participants rarely talked about stages of recovery. Even though multiple models have been proposed in the past, there is no consensus on how many stages there are, what is involved in each stage or even when recovery starts. There is also very little discussion related to what happens when a person remains “stuck” in the initial stage, which is typically experienced as highly confusing and overwhelming (Andresen et al., 2003; Spaniol et al., 2000). And as some authors indicated, there may be an overlap between stages so that it might be difficult to distinguish between adjacent stages (Andresen et al., 2006; Davidson & Strauss, 1992). It may well be that stages of recovery can only be identified in retrospect. The present study adds further complexity by pointing out that recovery may in fact involve two different processes, each potentially with its own stages. The interconnectedness of those processes makes recovery work that much more difficult, especially when it comes to the very first acute episode of ill health.

At the acute stage of mental illness the person is faced with confusing or frightening experiences and may desperately wish to be cured and to return to where they were, with all their past competencies and abilities. Coming to terms with the idea of having mental illness (which may involve facing their own prejudices), trying to reclaim whatever might have been lost during the episode and searching for treatment that works may be part of short-term recovery work. However, the persons may also have to face the reality that some losses may be permanent, that illness management is an ongoing process that requires knowing the illness and self-monitoring, that mental illness has wider consequences, such as stigma, and that the illness might place

⁷ It should be noted that all participants saw their illness as being episodic. The two processes of recovery identified in the sample may not apply to that subsection of the clinical population whose problems are chronic, rather than episodic.

limitations on what they can do. They also have to accept the reality of possible future episodes without becoming immobilised by passive resignation. A person may thus experience a cycle of ‘deterioration in functioning – hospitalisation – symptomatic stabilisation’ repeatedly, without necessarily getting closer to improved wellbeing and long-term recovery. Although he or she might have been seen as having had episodic recoveries with a return to baseline, the baseline is such that it does not promote long-term progress. It would seem that for long-term progression towards improved functioning the person needed to be able to consolidate lessons learned from each episodic recovery and to reflect on wellness.

Wellness and normality.

The project raised questions about what it is the person with mental illness could be ideally aiming for. If recovery is not an outcome but rather a process, should the person be aiming at being in recovery? If so, and if there are stages of recovery, should the final stage be the desired state? And finally, what is the relationship between recovery and wellness; is wellness (or wellbeing) the desired state that is achieved via the process of recovery?

Models of recovery describe their final stages in varying terms. Thus a person who has recovered (or reached the final stage of recovery) is someone who has built healthy interdependence (Baxter & Diehl, 1998), who has regained a sense of balance (Henderson, 2010), who has developed a functional sense of self (Davidson & Strauss, 1992) and who has reconstructed a positive, multidimensional identity (Pettie & Triolo, 1999; Shea, 2010). The person is able to live beyond the disability and connect to others (Spaniol et al., 2000), while experiencing improved quality of life (Young & Ensing, 1999) and personal growth (Andresen et al., 2003).

Andresen and colleagues (2003) pointed out the similarities between their final stage of recovery (growth) and psychological wellbeing. Others have suggested that conceptualisations of recovery should include aspects of both functioning and wellbeing (Yanos & Moos, 2007), and that mental illness cannot be discussed without considerations of mental health, which consists of emotional, psychological and social well-being and which includes aspects such as life satisfaction, self-acceptance, autonomy or positive relations with others (Keyes, 2003).

Turning to the current project, being well and being normal were perhaps among the most valued aspirations, even though the narratives indicate uncertainty about what those two concepts refer to. Some participants found it easier to describe their illness than wellness, and struggled with the concept of normality. Other stories indicated that some individuals may have never experienced healthy adult functioning unaffected by illness prior to becoming ill. There seemed to be an underlying assumption that the illness presented a major obstacle that prevented the person from being like other, “normal” individuals. Yet as Green (2004) wrote, with or without mental illness, “well-being waxes and wanes as a normal part of living and interacting” (p. 295). She also warned that some conceptualisations of recovery could set up standards of functioning that can only be found in a subsection of the general population.

Whether or not the person has a baseline of normality he/she wishes to retain or to return to post-episode, it would seem that he/she should be encouraged to reflect on how he/she views wellbeing and normality. This reflection might include acknowledgment of wellbeing as a fluid state that fluctuates across time, rather than a fixed outcome that is achieved or that naturally occurs to those individuals who do not have mental illness. Similarly, there needs to be a discussion regarding the nonexistence of objective normality. Although there may be certain societal expectations and norms, normality is created and recreated by each individual; it takes into account subjective personal and contextual factors, and it changes as the person is faced with new experiences. The project indicates that those individuals who felt they were generally coping well were those individuals who were grounded in the present, but with the acknowledgment of past experiences and future goals, and who seemed content with what they had and what they could do. It could be argued that those very same individuals were therefore able to construct and accept their subjective normality. Normality would therefore refer to the baseline of functioning that was constructed and reconstructed by the individual as he/she gained knowledge via new experiences and interpretations; wellness in turn represented a step up from that baseline (subjective normality) towards enhanced functioning.

Talking recovery.

It has been suggested that recovery is not a value-neutral term and that perhaps a

different word or phrase, such as healing, getting on with life or living a good life, would be more appropriate (e.g., Adame & Knudson, 2008; Ralph, 2000; Tooth et al., 2003). The present studies certainly demonstrated that the word recovery was not universally accepted by all participants, even those whose stories could be generally described as stories of recovery. Some individuals talked about healing while others mentioned being in a good place, being as well as they can be or having a balance. For a number of participants the word recovery seemed to carry a very narrow meaning, usually indicating cure (e.g., complete absence of symptoms or no longer needing medication), which perhaps prevented them from being able to identify with it.

Given how loaded and confusing the word is, the question is what could be done to make the concept subjectively more accessible and relevant. One option would be to start using an alternative. Unfortunately, it would seem that any attempt to replace recovery with another word or phrase might be fraught with the same difficulties that recovery has encountered. For instance, if we were to choose “living a good life”, what does “a good life” represent and who determines whether a person is living it? We might be faced with the same problems of struggling to achieve a consensus on the new concept’s definition, its operational criteria and ways of assessing it.

Another option would be to stop using the word altogether. If recovery is done by the individual, facilitated by the clinician and supported by the community (Townsend & Glasser, 2003), in other words, if recovery-supporting practices, strategies and activities are in place, does it matter what the process is called? Some have certainly suggested that unless the term is clarified with the individuals and their families it may be preferable to not use it at all (Meehan et al., 2008). However, on a more systemic level, interest in recovery has generated an immense amount of valuable research, and the term itself has found its way into consumer pamphlets, policy documents and autobiographical books. To stop using the term would now be impossible. In addition, there seems to be a general understanding that mental health services need to be transformed towards being more person-oriented and collaborative while providing real treatment options and integrated services (Davidson et al., 2009a; Farkas et al., 2005; Oades et al., 2005; Piat & Sabetti, 2009). It would be very difficult to carry out such transformation without having a unifying theme that would, in simple terms, describe where the transformation was heading.

There are two remaining issues that relate to the language of recovery. One is the issue of “talking recovery” instead of “doing recovery”. This relates to those situations where a service uses the recovery language in its documentation without actually changing its practices (Smith & Bartholomew, 2006). The present project clearly shows that individuals are aware of what is or isn’t helpful, and what their expectations of a service or a practitioner are. Collaborative relationships with practitioners who are willing to listen and understand the individual’s perspective; interventions and attitudes that communicate hope; treatment options; and good intra- and interagency communication have all been identified by the participants as factors that work. Those same factors also characterise recovery-oriented services. The participants also indicated that they are becoming more aware that they have a voice in treatment. It could therefore be argued that the individuals will pay more attention to what is done than to how the service is labelled, and where there is a discrepancy between the terminology and the practice the persons might ignore the recovery language or they might become sceptical of the service. In any case the discrepancy is likely to be noted.

The last issue relates to “talking recovery” instead of “communicating about recovery”. Meehan and colleagues (2008) stressed the importance of being able to communicate about recovery without just using the term. It is perhaps inevitable that recovery language will find its way into mainstream clinical discourse (e.g., intervention titles or mission statements), and there will be an assumption that the word carries an official meaning. Yet if that meaning is not brought into a discussion the person may substitute it with his/her biases. As the project suggested, this may lead to views of recovery as something outside the persons’ experience because of very narrow definitions that recovery is believed to carry.

Communicating with the person about recovery does not mean only asking about the person’s definition or only providing that particular service or practitioner’s view of recovery, whether outcome or process. It means a back-and-forth exchange that aims at reconciling the two viewpoints and that should include a discussion of both short-term goals and long-term expectations. Such communication should be an ongoing process that takes into account the fact that the person’s view of recovery may change with time and with new experiences and further reflections. The discussion may

also take into account related concepts, such as normality and mental health/wellbeing. However, as Davidson and colleagues (2009b) noted it is not possible to predict what normal would look like for any given person; it can only be determined over time as the person engages in his/her chosen pursuits. This means that subjective normality should not be treated as a fixed outcome to be achieved but rather as an evolving concept that may need to be periodically revisited with the individual.

Research findings: mental illness and research participation.

The project further contributes towards our understanding of the experiential nature of research participation, from both participant and researcher points of view. Participation of psychiatric populations is rarely explored even though some motivating factors and therapeutic benefits have been noted (Sikweyiya & Jewkes, 2013; Taylor et al., 2010). There have been well justified fears that participation could be distressing and therefore harmful, yet both previous research (Jorm et al, 2007) and the current project indicate that such distress tends to be transitory.

The project suggests that the persons' participation does not necessarily start with the commencement of the interview but with the initial decision to take part. When the persons read or hear information about a research project and start considering participation, they might start thinking about the pros and cons of participation, may try to anticipate what such participation would involve and may think about their prospective contributions. The persons may even start rehearsing their story. They therefore enter the project with certain expectations and possibly some preparation, and with hope that telling their story might help someone else and that such benefit might outweigh any potential downsides.

The wish to help the research or others facing similar problems was identified quite strongly in the participant narratives, together with the evaluation of research participation as a positive experience, one that left the participants feeling better, stronger or relieved, with a clearer understanding of what they had gone through. That research participation can be therapeutic has been acknowledged in the past but generally the phenomenon remains largely unexplored (Jorm et al., 2007; Lakeman et al., 2013; Taylor et al., 2010).

Telling one's story can in itself be beneficial but it would seem that the

environment in which this story-telling occurs as well as the audience the story is told to play a role too. The researcher strove to provide a safe, opened, confidential environment in which both parties operated as active agents working towards shared understanding. Participation was not something that was imposed on the individual but rather an event or series of events the individuals chose to undertake. Taking responsibility for their role in the research process, being productive, engaging in social interactions and putting their experiences together in a coherent narrative therefore formed part of their learning about self, others, illness and wellness which is a process that characterised their lived experience.

Just as the participants were actively engaged in the process, the researcher's role required that she became a participant herself, someone who reflected on her own experience of participation and on what she personally learned from it. Her professional knowledge and skills were important but perhaps not sufficient for developing close relationships, characterised by shared humanity. She therefore had to learn how to retain professional boundaries, especially with respect to self-disclosure and multiple roles, while at the same time being open, flexible and personally involved. The whole research endeavour was therefore less about the technical aspects of doing research, even though they were certainly important, and more about being with the other person.

Limitations

One limitation of the project relates to sampling. The sample was small and largely selected from within one geographic area, and therefore may not represent the typical experiences of individuals with mental illness. However, qualitative projects are locally focused and richly conceptualised (Marecek, 2003), with an emphasis on the specifics of an experience rather than generalised laws and processes (Haverkamp, 2005). It has been suggested that readers should be provided with sufficient information about the research context to enable them to make a judgment about transferability of its findings to other contexts or settings (Koch, 2006; Whitehead, 2004). Contextual information, in the form of descriptions of interview settings and processes and examples of journal entries, was presented throughout the thesis.

The second limitation was the rate of drop out. Phase II was completed by 18 out of 20 participants which is a completion rate of 90%. However, Phase III was

completed by only 50% of the original sample. Only one participant specifically responded that he did not wish to complete the third interview; the rest of the sample were individuals whom the researcher was unable to reach or who found it difficult to accommodate the interview within their schedule. The first aim of the third interview was to provide feedback on the researcher's analysis of each participant's narrative; those interviews that had been completed generally recognised the analysis as a true representation of the narratives. The second aim was to provide an update on the preceding 6 months, while the third aim was to reflect on participation. While the missed interviews might have added further information, comments on participation were made even when not prompted (in interviews 1 and 2); overall, the existing data were judged to be sufficiently rich and varied to justify the decision to cease further attempts to contact the participants.

The third limitation relates to the source of recruitment. Although attempts had been made to employ a variety of recruitment methods, the final sample of 25 participants (5 participants of the pilot study and 20 participants of the main project) was not equally distributed across settings. Four individuals were recruited via a self-help group, 15 individuals came from two psychosocial centres while the rest (6 participants) volunteered after they saw internet postings. The fact that the majority of the sample came from consumer organisations might be seen as a limitation since they might represent a distinct subgroup. However, apart from the use of peer settings as a form of coping and a source of support there appeared to be no thematic differences that would differentiate between the narratives told by the two subgroups.

The final limitation concerns the use of personal reflections as a source of data. Researchers' active involvement has been recognised as important for qualitative inquiry since researchers help construct the researched world via their role as agents who collect and interpret the data (Finlay, 2002; Mantzoukas, 2004). In Gadamerian hermeneutics specifically, it is assumed that the researcher becomes part of the hermeneutic circle, the analytical movement between the whole and the part (or between expressions and their meanings) that aims at mutual understanding (Smith, 1993; Whitehead, 2004).

In spite of the recognition of the researcher's active role in the process, some

have warned against potential self-absorption and narcissism, and against preoccupation with one's own experience at the cost of participant data (Finlay, 2002; Holloway & Biley, 2011). In the current project, the researcher engaged in reflexive writing that helped her monitor the development of her horizon of meaning and its potential impact on the research process, and she ensured that the participant data retained primary focus. However, it has been proposed that since hermeneutic tradition requires the researcher's self-awareness of her influences some information about her should be included (Whitehead, 2004). Given that the experience of research participation appeared to be such a strong theme in the present study, and given the role the participant–researcher relationship played in the research process, the researcher believed that a strong case was made for the explicit inclusion of the reflexive data.

Clinical implications

Hermeneutics in research and therapy.

The project was strongly influenced by the philosophy of Hans-Georg Gadamer whose work examined the conditions of understanding with an emphasis on the dialogical nature of hermeneutics (Gadamer, 2006a). Gadamer believed that each person is embedded in culture, history and tradition that together help form the person's assumptions and prejudices (i.e. pre-understanding). While we cannot remove ourselves from our embeddedness we can use it to examine our pre-understanding and broaden our knowledge (Lebech, 2006).

Gadamer (1975) wrote about understanding as the fusion of horizons: the historically transmitted pre-understanding and our present range of vision. The past thus does not stay in the past but rather, as our pre-understanding, continues to exist within the present. However, although the horizon of the past is closely related to the horizon of the present, it does not determine the present because it is subject to interpretation and re-interpretation with each new situation (Lebech, 2006). The horizon of the present thus has a loose texture that does not bound the person; rather, through the process of understanding it moves to create a new pre-understanding for future undertakings.

Gadamer also proposed for experience not to be interpreted through its objectified results but as a process through which our pre-understanding is challenged (Gonzales, 2006). When we experience a phenomenon we already possess certain

assumptions, prejudices and generalisations that may or may not confine us. It is when we question the limits and adequacy of such assumptions that we are able to move beyond those confines towards understanding and towards 'knowing better' (Gonzales, 2006; Polkinghorne, 2000). Knowledge cannot be gained without questions; questions have priority in knowledge. However, the Gadamerian dialectic does not mean empty questioning in which answers are irrelevant but rather an opened and interactive process in which answers to initial questions provoke further questions; the aim is increased understanding and greater sensitivity to the situation whether one has a dialogue with oneself (self-understanding) or with someone else (understanding).

The project utilised Gadamerian principles not only to guide its methodology but also to inspire a whole new approach to 'being in research', so although some of the principles were used specifically as part of the design (e.g., the hermeneutic circle as an analytical tool) their biggest influence was as a philosophical approach to the conceptualisation of mental illness, to research, and by implications, to clinical practice. Smith (1993) pointed out that the philosophical version of hermeneutics, such as the one inspired by Gadamer, is not about accurate representation of objective meaning but rather a common search for a mutual understanding. Hermeneutic inquiry is therefore conversational: practical and moral, rather than technical (Gonzales, 2006; Smith, 1993). The researcher strongly believed in the principles yet it was only through her reflective writing that she became aware of how much she had been influenced by her formal training related to the technical, as opposed to relational, aspects of interviewing. She eventually experienced a shift from her initial focus on posing technically good questions to conversing and 'being with' the participants. The technical 'know-how' became less important than the conversation and the partnership.

The philosophical influence of Gadamer's hermeneutics permeated the whole research endeavour and helped demonstrate the potential usefulness of hermeneutics as applied to research and clinical practice. Firstly, it helped view the person's experience as embedded in culture, history and tradition. This means that the illness was not seen as a bundle of symptoms but as something that was interpreted by the individual in view of his/her assumptions and prejudices, which were in turn influenced by the person's past and by his/her culture. The contextual factors were at least as important as the person's psychopathology. This not only provided rich data but also showed how the individual

components interacted, which in turn promoted meaning-making processes. Lysaker and Roe (2013) warned that although evidence-based interventions are the cornerstone of mental health care, narrow focus on interventions could strip psychosocial suffering of the context, meaning and culture within which it is embedded. It is believed that framing client–practitioner interactions in philosophical constructs, such as those of Gadamer (1975), could help counteract some of the risks associated with such clinical emphasis.

The idea of a hermeneutic circle as a back-and-forth movement between the parts and the whole therefore implies that individual parts cannot be fully understood unless considered as part of the whole; the whole on the other hand is less likely to make sense unless all individual parts are taken into account. This means that taking mental illness out of the person's life context is likely to disrupt the person's ability to make sense of what is happening but it also prevents him/her from tapping into his/her pool of coping resources. If the persons' traumas, past losses and relational difficulties, but also their competency, resilience and ability to create their own explanations of mental illness are not taken into account the potential for healing and recovery is greatly compromised.

The participants pointed out the way the mental health system is compartmentalised. Even when the complexity of their situation is acknowledged the situation is broken up into different problems each addressed by a different professional. While it would be impossible for one individual or one profession to take care of all different needs (medication, psychotherapy, housing, financial support, etc.) the professional helpers should have greater appreciation for the role of the person's contextual factors and his/her need to find meaning. The helpers should also have greater appreciation for each other's expertise, both within the formal and consumer settings, and utilise such expertise as part of holistic care with the ultimate goal of helping the individual get better.

The second application of hermeneutics relates to the conceptualisation of knowledge as a dialogic inquiry. When we find that our background understanding does not sufficiently explain a particular situation we start a questioning process that challenges our assumptions and that may lead to a shift in our interpretation that

ultimately gives us greater appreciation of the topic (Polkinghorne, 2000). Improved understanding can only be achieved through examination of our pre-understanding.

In the research context the researcher acknowledged the influence of her background knowledge (formed by professional knowledge as well as personal biases, assumptions and past experiences) just as she was aware that each participant was influenced by his/her own background knowledge. Gadamer (2006a) wrote that a conversation cannot be carried out if one person positions him-/herself as superior in terms of knowing in advance the pre-understanding of the person he/she is conversing with. Therefore, the aim of the conversations the researcher had with the participants was not to superimpose her knowledge on the other person or to abandon her viewpoint in order to substitute it with the other person's. Rather the aim was a mutual understanding of the meanings with emphasis on situatedness and contextuality (Smith, 1993).

In clinical practice, individuals seek help (or are forced to accept help) when they are unwell and struggling with distressing and confusing symptoms. However, those symptoms are not representations of something that exists within yet outside the individual but rather small parts of a much broader life context. Each individual has his/her own past, unique context and subjective way of looking at things which are all brought into the professional relationship. Expecting the person to abandon those or to treat them as irrelevant can not only rob him/her of the opportunity to use them as potential assets and tools of coping but could in fact exacerbate the symptoms by interfering with the person's ability to make the illness experience part of his/her story.

The third application of hermeneutics to research and practice is the principle of inquiry as a practical but also an ethical and moral task that produces not an objective or universal knowledge but an increased understanding and greater appreciation of the situation or topic (Polkinghorne, 2000; Smith, 1993). The two parties are engaged in a conversation where both contribute to the questioning process and where both draw on their background knowledge. The researcher found some interactions confronting not because of the subject matter per se but because of the way it challenged her pre-understanding. Being able to accept the limits of her assumptions not only improved her understanding of the topic under investigation (mental illness and recovery) but also led

to personal transformation.

Reconceptualising a clinical interaction not as a quest for truth but as a dynamic process of interpretation and reinterpretation may be challenging for the professional because it requires that he/she accepts a certain degree of uncertainty. Yet such uncertainty is nothing compared to the confusion and a profound sense of loss that may be experienced by the individual seeking help. While biomedical (or biopsychosocial and other) explanations may hold the truth for the professional they may be completely meaningless and therefore unhelpful for the individual. Rather than forcing the client to substitute his/her views for those of the professional, both parties should draw on their own expertise and work towards mutual understanding; the process could turn out to be transformative not only for the client but for the professional as well. Effective therapists have been described as those who make the most of their clients' resources, who seek clients' feedback and adjust their approach accordingly and who constantly compare new information with the existing knowledge (Miller et al., 2008; Sparks et al., 2008). Clients can thus become teachers and therapeutic relationships become reciprocal (Kottler & Hunter, 2010).

The role of hospitals and the mental health system.

The vast majority of the participants had been hospitalised at least once, and although their views of hospital treatment varied greatly hospitals were rarely, if ever, associated with healing and therapeutic processes. At best, they were seen as safe, holding places that could temporarily take care of the persons' basic needs, stabilise them and help them get back on their feet. At worst, hospitals were seen as tools of oppression. Yet hospitals could play much greater role in helping the individuals make sense of their experience.

Solomon and Stanhope (2004) pointed out that it can take up to 20 years for research findings on effective treatment to find their way into routine clinical practice; most individuals with severe mental illness thus have no access to effective services (Torrey et al., 2005). This means that although from a clinical point of view hospitals provide evidence-based treatment that treatment is often limited to pharmacotherapy, with other forms of empirically supported approaches either unavailable or only offered to small groups of patients. Whether it is because of financial constraints, overburdened

staff or resistance to new interventions the type of treatment offered in hospitals is rather limited. In addition, with the shortage of beds in the Australian public system hospital admissions are reserved for the most acutely ill individuals who are discharged as soon as their symptoms are stabilised.

Short stays during acute periods of ill health may be viewed as not providing sufficient time for finding a long-term solution while long stays are reserved for those individuals who are seen as chronically and severely ill and who are therefore believed unlikely to improve. Yet in either case the hospital stays can be used as part of the person's story-telling efforts. They can serve as "time-out" periods when the person can step back from the stress of everyday living to reflect on what happened and therefore learn a lesson about factors such as triggers, coping strategies or their current relationships. It is important that they have someone who asks "what happened" and who will listen to their answer. Lysaker and Buck (2006) wrote about recovery-focused psychotherapy as a non-hierarchical dialogue in which practitioners help clients create their own narrative. Although psychotherapy is usually the domain of outpatient treatment there is no reason why such psychotherapeutic dialogue could not start while still in the hospital.

The need to make hospitalisations meaningful parts of the persons' narrative is even more pronounced when the person is admitted to a psychiatric hospital for the first time. As the participant stories indicated, first admission was in many cases the time when the person was first made aware that he/she was suffering from mental illness. Even if they were aware that something was not quite right many did not seek help until things escalated to the point where they were hospitalised. During one hospital stay the person may have thus learned that he/she had mental illness, that the illness had a certain name, that it required treatment and that the treatment may be ongoing. On top of experiencing distressing symptoms the persons thus had to face their own, often prejudiced, views of what mental illness is, had to learn about a system that had its own rules and that often gave them little degree of control, and had to come to terms with the idea that their lives may never be the same. Each new idea and experience would be a major challenge that required adjustment; that the person faced many of these concurrently, and often alone, could in itself be highly distressing.

As the project findings indicate, hospitals largely lacked a process that would help patients adjust to and make sense of the process of being admitted into a psychiatric hospital. Individuals were left to work things out for themselves which in some cases required repeated hospitalisations and therefore repeated, and at times perhaps avoidable, periods of acute distress. The reality of psychiatric hospitalisation (including prescriptive treatment and loss of privacy) was thus compounded by what the hospitalisation represented (being labelled as mentally ill). Not being able to somehow accommodate these new experiences and place them in the context of their lives prevented the individuals from taking the first steps towards healing and recovery.

Although the person's ability to comprehend what was going on may have been impaired, it would be wrong to simply assume that they are too ill to understand or, at subsequent admissions, they have done it before and therefore know what is going on. The often repeated complaint that they needed someone to talk to yet no one was available suggests how important it was for the individuals to work out how their illness fitted into their narrative.

Clinical explanations are certainly important. For instance, literature suggests that diagnosis can be seen as helpful where it communicates useful information and promotes healing (Hayne, 2003), and where it provides direction for treatment (Howard, 2006). Yet as Howard pointed out, diagnostic labels could be limiting in the long term. In the current project, diagnosis was credited for providing an explanation for some of the participants' bewildering and confusing experiences and for making those experiences legitimate. However, once the diagnosis was incorporated into the person's experience it seemed to lose its importance. So while diagnosis was important and needed to be discussed, especially in the early stages of treatment, treating it as an all-encompassing knowledge discouraged full exploration of the illness not only as a psychiatric entity but as a phenomenon experienced and interpreted by the affected individual.

Hospitals, many of which use custodial, prescriptive approaches focused on compliance (Smith & Bartholomew, 2006) are not places in which meaning making processes are promoted and yet paradoxically for many individuals it is not until they are officially diagnosed, often while hospitalised, that they start to look back and put

together seemingly unconnected parts of their living into a more coherent whole. The diagnosis therefore had the potential to take uncertainty, confusion and fear out of the equation and in a way anchor the experience. Yet whereas the mental health system puts diagnosis at the centre of its efforts – as something that explains what is happening to the person and that determines the treatment approach – the individuals treat it as only one small part of their story and as something they felt entitled to reject if it didn't make sense or if they could not incorporate it into their narratives. Having a partner, someone who has clinical knowledge and skills but who is equally willing to utilise the individual's expertise, to help them tell their story should thus become a key part of formal care.

Mental illness and trauma.

Well over half of the sample talked about trauma and its role in their illness experience. Whether as a cause, a trigger, a mediator or a consequence, trauma was believed to be strongly linked with the person's mental illness. While trauma used to be treated as of little relevance to illnesses such as schizophrenia or bipolar disorder, recent research indicates that both childhood and adult trauma may act as causal factors for severe mental illness, may exacerbate symptom severity and may play a role in a more severe prognosis (Read, van Os, Morrison, & Ross, 2005; Rubino, Ribolsi, Niolu, Magni, & Siracusano, 2012). The fact that individuals with severe mental illness are much more likely to be exposed to trauma than the general population (Grubaugh, Zinzow, Paul, Egede, & Frueh, 2011) makes the argument for more serious consideration of trauma that much more compelling.

Grubaugh and colleagues (2011) showed that trauma exposure is not limited to sexual and physical abuse in the community but also within inpatient settings; in addition, aspects of the treatment itself (e.g., involuntary hospitalisation or seclusion) can be highly traumatising. Yet in clinical settings trauma is often overlooked as secondary to clinical symptoms (Grubaugh et al., 2011) or the same symptoms are re-categorised, for instance from psychosis to PTSD, once trauma is identified (Read et al., 2005). Patients may struggle with disclosure of their abuse; if the practitioner does not ask they may not talk about it.

It is rather remarkable that the study participants quite openly talked about past

trauma with the researcher yet at times remarked not having talked about it with their treating practitioners. One can only speculate about the potential reasons: no time constraints on the research interview, compared to formal health care appointments; the association of psychology with psychotherapy; or the fact that they had worked through their trauma in the past and felt more comfortable with self-disclosure. There was also one aspect of the public mental health system - which was where the vast majority of the participants were treated – that might have played a role. The treatment usually involved brief sessions with a psychiatrist or a GP focusing on the management of medication. The individuals were acutely aware of the time-limited nature of the sessions and usually prioritised their problems to the most pressing ones. There was also an assumption that medical practitioners would only be interested in medical problems and psychopathology which is what the individuals ended up discussing.

It would not be accurate to present the issue of trauma as having been completely neglected. A number of participants did receive psychological treatment/counselling which they believed had helped and, of course, not everyone needs psychotherapy. Some participants used reflection and existing coping resources or they turned to alternative forms of help, such as peer support or spirituality. Yet there was also acknowledgment that no matter how much work one does to deal with trauma its consequences may never quite go away. In addition, trauma was often treated as separate from mental illness and even where the link was acknowledged the primary focus remained on one or the other, rarely both.

The complexity of trauma was illustrated very well in the participant narratives. Trauma exposure was cited as responsible for the onset of illness in the first place or for triggering its episodes. Trauma was also seen as influencing the severity of the illness and as interfering with the person's overall ability to cope. The type of traumatic event varied greatly, from childhood sexual, physical and emotional abuse, death of a loved one, a violent home invasion and assault, to having to flee one's country, and one person could have multiple trauma experiences. However, the symptoms of mental illness themselves were sometimes extremely distressing, just as were some experiences within the mental health setting (particularly first hospitalisations, involuntary admissions or involuntary ECT but also ineffective or unethical psychological treatment). While traumatic events that occurred in the community were rarely

addressed in treatment, trauma related to the illness and its treatment was even less likely to be discussed. It is understandable that a person might be reluctant to disclose adverse experiences of the mental health system to a representative of the very same system (such discussions seemed to be left for consumer settings) yet it is important that practitioners acknowledge the severity of those experiences and their consequences.

The participants were quite clear about the link they saw between their traumatic experiences and their illness. Ignoring this link or outright disputing it can severely disrupt the person's attempts to pull pieces of their lives together to form a cohesive narrative. It also creates self-doubts about the person's ability to create such narrative. In addition, insisting on symptoms as more significant than the trauma when the person feels otherwise means that a major cause of the person's distress is not taken into account which can severely compromise treatment effectiveness. Such interference with what is a natural process of meaning-making therefore robs the person of an opportunity to use his/her own capability as a resource of coping and may prevent him/her from actively engaging in treatment. On the other hand, supporting this process or providing guidance where this process is temporarily compromised is likely to have therapeutic benefits.

Recovery assessment.

As discussed in detail in the literature review, recovery assessment does not represent a unitary approach but rather a range of conflicting ideas about what should be assessed, how that 'something' should be operationalised and how it should be measured. Whether following a clinical or consumer conceptualisation, any recovery scale is a tool that produces some sort of a score, and a tool that can therefore be used in various ways. Outcome assessment showed that recovery is more common than once thought (Jobe & Harrow, 2005) while stage instruments could help determine the type of therapeutic activities to be used to help an individual at any given time (Andresen et al., 2003). Other scales may help track the person's progress across time, may help direct service provision or determine the degree to which a service promotes recovery (Siggins Miller, 2003).

Although there is no doubt of the current and potential usefulness of recovery measures, the actual therapeutic benefit to the individual is less clear. There have been

discussions about what should be assessed but perhaps attention should be also turned to how that assessment is used. Routine standardised measures have become inevitable components of service provision and it is suggested that typical clinical assessment should be supplemented by measures of recovery (Burges et al., 2011; Dickens, 2009; Lakeman, 2004). Having data on a person's psychopathology and levels of functioning as well as non-clinical factors such as willingness to ask for help (Recovery Assessment Scale), self-empowerment (Mental Health Recovery Measure) or hope and optimism (Recovery Orientation) would undoubtedly provide a more complete picture of where the person was at. Yet the person could derive much greater direct benefit if he/she were encouraged to utilise the scale as a learning tool.

Research indicates that assessments are often seen as pass/fail tests which, without feedback, may reinforce negative self-evaluations; however, such perceptions can be mitigated by a sensitive discussion that points out relevance to daily life, that is straightforward yet authentic and that focuses on strengths (Fossey et al., 2002). Others suggested that outcome assessment should be useful to the individuals in helping them make sense of and cope with their mental illness (Siggins Miller, 2003). Andresen and colleagues (2010) believe that recovery measures have a place in clinical work as they could provide areas for discussion and could help nurture the therapeutic relationship.

The participants of the current project showed interest in hearing feedback on the results of the Recovery Assessment Scale (Corrigan et al., 1999). They were encouraged to engage with the assessment process and many provided oral or written comments as they were completing the scale. The tool was used as part of the story-telling, not as a separate activity done for the researcher's benefit; the data were collected about them but also with them. The assessed domains as well as the patterns of responses further served as platforms for exploration. If making sense of one's illness plays an important role in coping and adaptation then participatory assessment with sensitive feedback could become part of such meaning-making processes.

The role of clinical psychology.

The project indicated that in spite of the growing number of practicing psychologists in Australia (Pachana, O'Donovan, & Helmes, 2006) exposure of individuals with severe mental illness to psychological treatment is still relatively rare.

Clinical psychologists have been trained to assess mental illness, and to develop, research and evaluate evidence-based programs, and have therefore been involved in the development of a number of effective psychological interventions for individuals with severe mental illness; yet only a small proportion of clinical psychologists is actually involved in the care of this clinical population (Mueser, Silverstein, & Farkas, 2013; Reddy, Spaulding, Jansen, Menditto, & Pickett, 2010; Roe, Yanos, & Lysaker, 2006). Whether because of financial constraints of the system, perceived lack of competency, or biased views (Roe et al., 2006; Servais & Saunders, 2007; Wahl & Aroesty-Cohen, 2010) this under-representation means that the unique and varied skills they possess – from their understanding of human development and behavioural change to functional assessment, case formulation and research skills – are not fully utilised (Cohen, Abraham, Burk, & Stein, 2012; LeVine, 2012).

There is a whole range of potential roles clinical psychologists could play in the care of those with severe mental illness, as researchers and evaluators, developers of new interventions, policy makers, clinical supervisors, trainers, mentors and many others (Cohen et al., 2012; Reddy et al., 2010). There are also potential opportunities for clinical psychologists to play part in the actual service delivery. Emphasis on the development of a strong therapeutic alliance and a collaborative, shared relationship; focusing on the whole individual instead of symptoms; holistic functional assessment; family interventions and, of course, delivery of evidence-based programs are only some of the contributions clinical psychology can make (Cohen et al., LeVine, 2012; Reddy et al., 2010; Roe et al., 2006; Pérez-Álvarez, García-Montes, Vallina-Fernández, Perona-Garcelán, & Cuevas-Yust, 2011).

The project provides further support for incorporating the skills of clinical psychologists into the care of people with severe mental illness. Counselling and psychotherapy were rare, especially in comparison to biomedical approaches, yet they were highly valued. Apart from specific problems that were addressed, such as treatment for substance abuse or counselling for childhood abuse, the participants were looking for a receptive, understanding audience for their stories. Lysaker and Buck (2006) suggested that the individuals should be assisted in developing stories of themselves and the illness, and that the therapist needs to pay attention to his/her role as audience for such narratives.

Although the participants were engaged in research interviews and not psychotherapy, they nonetheless reported a number of therapeutic benefits because they were able to release pent-up emotions, disclose in a confidential environment and explore their experience the way they understood it. It was not the researcher who set the agenda, decided which information was relevant or what a particular experience meant. The opportunity to construct a coherent story that made sense to the individual was at least as important as the final “product” (a narrative of living with mental illness).

Clinical psychologists could also play a much greater role in hospitals. Currently, their work seems to be largely limited to inpatient assessment. Although important, the project suggests that there is a much greater need for admitted patients to work through their experiences, and whenever possible this ‘working through’ should start while still hospitalised. At the moment any ‘talk’ usually takes the form of clinical explanations which tend to be offered as the only viable alternatives. In addition, the clinical explanations focus on viewing symptoms as manifestations of a mental disorder that needs to be diagnosed and treated. Yet the personal narratives clearly show that adjustment to psychiatric hospitalisations is a lot more complex. Being able to talk about confusing and distressing symptoms, the fear and uncertainty associated with (particularly first) hospitalisations, the persons’ own theories about why they became ill or their struggle to adjust to the idea of being classed as mentally ill are only a few examples of new concepts and experiences the person needs to somehow incorporate into his life. An onset of mental illness can be seen as a collision of the normal and the abnormal; clinical psychologists, with their knowledge of both types of functioning, could prove to be a great asset for treatment teams.

Future research

Research interview as a learning tool and a therapeutic activity.

Research exploring the reasons for participation and the experience of being involved in (psychiatric) research is scarce. This paucity is all the more surprising given the indications that although research participation can sometimes lead to distress it can overall be beneficial to the individual (Jorm et al., 2007; Lakeman et al., 2013; Taylor et al., 2010). The project provided further support for such indications showing that

research interviews do have the potential to bring therapeutic benefits to the participants. However, research supporting these claims is scarce and the actual processes involved in research participation as having therapeutic outcomes are still largely unknown. The project suggests that the interview environment and the participant-researcher relationships play a role but the actual mechanisms underlying both factors will need to be explored.

One proposed mechanism is the overlap between therapy and a research interview. Both involve confidentiality, rapport and safe, containing settings; and both require usage of tools such as encouraging the individuals to tell a story and share their feelings (Holmes, 2013; Haverkamp, 2005; Lakeman et al., 2013). Yet this overlap also creates a number of ethical dilemmas since therapy and research are two separate activities that need to be contained within their own boundaries. The questions of how to handle participant distress and how to promote therapeutic processes in qualitative interviews without “doing” therapy, how and when to self-disclose in research, and how to develop close relationships with participants without violating boundaries need to be addressed. Answering these questions will require examination of participant and researcher perspectives as well as careful examination of ethical principles specifically applied to qualitative interviewing.

Subjective incorporation of recovery.

The project showed that even though participants sometimes mentioned the word recovery and even though many of them could be described as being in recovery, the concept was not necessarily embraced by them. If recovery is to become the guiding principle of mental health care it needs to be discussed in a way that is meaningful for both sides of the debate: practitioners, researchers and administrators as well as clients and their families. Research suggests that individuals are not always comfortable with the word recovery and prefer an alternative, such as life vision (Marshall, 2008) or getting on with life (Tooth et al., 2003). Studies also indicate that even where staff are trained to provide recovery-oriented services this may not necessarily translate into practice. For instance, in Marshall’s (2008) study participants, who were consumers working with staff who had trained in the Collaborative Recovery Model, reported that staff failed to spend adequate time, if any, on discussions of the concept of recovery. It

is possible that this failure was in part because of inadequate training, the staff members' own confusion about the concept, or their doubts about recovery. In any case this area deserves further attentions, perhaps exploring professional attitudes towards recovery as well as whether and how those attitudes change once the concept is brought into a discussion.

Future research should also explore the process of incorporation of recovery into the person's life experience. Consumer perspective on recovery is largely based on first-person accounts in which people who had recovered or who were in recovery reflected on their journey; in some respects recovery acted as lenses through which the experience was retrospectively evaluated. What is less certain is how individuals incorporate recovery as crucial and meaningful part of their lives or how they move from seeing recovery as something foreign and something outside their experience towards viewing it as relevant to them. More attention also needs to be placed on examination of related concepts, such as wellness and normality in mental illness.

Concepts of severe mental illness and recovery in graduate training.

The researcher's interest in severe mental illness and recovery was inspired by some of her studies and her clinical training but the strongest influence were her own pursuits of the topic and some of the consumer work she had come across. She believed that the topic of recovery in severe mental illness deserved greater attention within the mental health system and that such efforts should start with formal training.

Clinical psychology training is on the rise both in Australia and overseas (Norcross, Karpiak, & Santoro, 2005; Pachana et al., 2006). However, research also shows a trend of gradual migration away from the public sector which is where one would encounter more severe client presentations (Byrne & Davenport, 2005; Stokes, Mathews, Grenyer, & Crea, 2010). Most clinical psychologists work in private practice (Mathews, Stokes, Crea, & Grenyer, 2010) and they generally work with those individuals who are at the mild to moderate, rather than severe, end of spectrum of mental illnesses (Servais & Saunders, 2007). One of the reasons for the under-representation of clinical psychologists in the care services for individuals with severe mental illness is lack of interest and perceived lack of competence which is partially related to the type of training provided (Mueser et al., 2013; Roe et al., 2006). There are

indications that clinical programs do not sufficiently prepare students for working with individuals with severe mental illness (Roe et al., 2006). In fact, clinical doctoral programs tend to have more coursework on pharmacological treatment than psychosocial treatment for severe mental illness and clinical programs in general tend to focus on formal assessment but not as part of integrated treatment teams (Reddy et al., 2010). These are some of the reasons for why students, and later practicing psychologists, choose not to work with this population even where relevant opportunities are available (Mueser et al., 2013).

There are indications that a number of mental health professionals, including psychologists, share negative public attitudes towards individuals with severe mental illness, viewing them as dangerous, unpredictable, incomprehensible and unlikely to recover (Servais & Saunders, 2007; Wahl & Aroesty-Cohen, 2010). Yet little is known about how those attitudes and beliefs develop and what role formal training can play in countering them. Research also needs to address student perspectives; existing research has so far focused on the views of directors of clinical training programs or practicing psychologists. Finally, more attention needs to be paid to how severe mental illness is discussed in training programs and how recovery is approached (if in fact it is addressed at all). If recovery from severe mental illness is to be embraced by mental health professionals the process should start with their training.

Conclusion

The aim of the project was to gain greater insight into people's experience of mental illness, the meanings they gave to their experience and the factors that influenced their journey. The second aim was to explore how they responded to the concept of recovery and how that concept fitted in with their experience. It is believed that the project, which was informed by the philosophical principles of Gadamerian hermeneutics, answered these questions and in the process made significant contributions to the body of knowledge.

Firstly, the project showed that people's experience of mental illness was in fact the experience of life as influenced by mental illness to a greater and lesser degree and mediated by a wide range of contextual factors. These factors included the persons' understanding of how their illness developed, and the lessons they had learned about

themselves and others as well as about illness and wellness. They also included multilayered acceptance, acknowledgment of trauma and its consequences, and acknowledgment of and response to various losses and gains. The experience was also influenced by the persons' management and coping strategies which usually, but not always, included professional interventions.

Professional help as a theme covered a range of individual, collective and systemic factors which included medication, diagnosis, hospitalisation, individual practitioners and the quality of working relationships. The participants demonstrated great awareness of those factors that were helpful (e.g., hope or treatment options) and those that were not (e.g., no process in place to help individuals adjust to hospitalisation). The experience was also strongly influenced by the role of other people, whether friends and family members, other individuals with mental illness or the lay public.

The complexity of the factors and their interactions pointed out that trying to treat mental illness in isolation was less likely to be productive than treating it in context, holistically. Viewing symptoms as the primary targets of interventions represented a narrow focus on something that was only a small part of what is called mental illness which in turn represented only one part of the person's life. While the symptoms of mental illness fluctuated and could at times overwhelm the person's ability to function they still formed only part of a whole. That part could not be fully understood without understanding the whole just as the whole could not be appreciated without understanding of the individual parts.

Secondly, the project highlighted the importance of talking about recovery as part of reciprocal communication. Recovery, whether episodic or global/life, may be perceived as irrelevant, foreign or unrealistic unless both sides (clients–practitioners, participants–researchers, etc.) engage in opened, reciprocal interactions in which both sides explore their respective views and biases with the aim of mutual understanding. Such recovery conversations should also include the topics of “normality” and “wellness/wellbeing”.

The project further pointed out that what is measured (whether outcome variables, psychological aspects or stages of recovery) is just as important as how the

respective measure is used. Routine assessment is helpful in a variety of scenarios, from scientific exploration of components of recovery, to evaluation of the effectiveness of interventions or informing policy directives on the nature and structure of a mental health program. However, encouraging individuals to ask questions or make comments as they complete the survey, and discussing with them the results and patterns of responses could help develop and nurture therapeutic relationship and could promote active engagement in treatment.

Thirdly, the project offered a rare opportunity to have a closer look at the experiential side of research, from both participant and researcher points of view. The findings suggest that although participants enter research for a range of mostly altruistic reasons they may in fact gain personal benefits from it. Being able to tell their story to an engaged, genuinely interested audience in a safe, unhurried, confidential environment had a number of positive outcomes, from enjoyment to relief to improved self-understanding. Although some participants did become distressed as they recalled painful events, the distress seemed temporary and did not necessarily result in negative evaluations of participation.

The project could not clearly identify the mechanisms responsible for such potentially therapeutic outcomes even though the relationship with the researcher seemed to play a role. The researcher acted as an active participant who drew on professional expertise but who was at the same time opened to the participants'. She was focused less on the technical aspects of research and more on the relational ("being with") ones. The search for mutual understanding, the link of shared humanity as well as flexibility and acceptance of a degree of vulnerability all seemed to play a role. Although the researcher-participant relationship raised a number of ethical dilemmas it was instrumental in developing trust which resulted in greater willingness to open up and tell one's story. This openness in turn led to improved understanding of the phenomenon under investigation as well as improved (self)understanding for both the participants and the researcher.

Finally, the research provides a rare demonstration of how a philosophical approach could be used to improve understanding of psychiatric conditions. Gadamerian hermeneutics in this case not only guided the chosen methodology but also

served as a new approach to understanding of mental illness. The principles of the fusion of the horizons of meaning, the dialogue and the hermeneutic circle were useful constructs when employed in data collection and analysis. However, the research also showed that applied hermeneutics could play a much larger role on an interpersonal level, including research and clinical settings.

According to Gadamer, understanding can be reached together only via a dialogue/conversation (Gonzales, 2006). Conversing is not simply about adding one opinion to another, carrying one's opinion through against someone else or speaking past the other person. It is, however, about building up a shared aspect (i.e. the topic of discussion) and building up an agreement in understanding, which eventually transforms the viewpoints of both parties (Gadamer, 2006b). Such conversation cannot be carried out if one of the conversational partners takes up a superior position, believing to know in advance the other partner's assumed truth. Adopting this stance means that the person did not allow him-/herself to truly enter into the conversation and put his/her own assumptions to the test. Gadamer (2006a) believed that the process of understanding (a topic, text or another person) should include the critique of oneself.

Gadamerian principles were highlighted throughout the thesis with the intention of illustrating their actual and potential use in psychological research and practice. The researcher is convinced that such application of hermeneutics could help psychologists approach mental illness as something that is contextually embedded and that is interpreted by each individual in view of his/her pre-understanding and present range of vision. Even those individuals who are highly distressed and confused by their experience already hold a number of assumptions and prejudices that they utilise to make sense of what is happening. Working with, rather than against, these assumptions as part of a conversation in which both parties put their respective assumptions to the test would lead to a shift in understanding, which could in turn affect the person's functioning.

As the researcher found out from personal experience, accepting her professional expertise as simply forming one part of one horizon of meaning required that she accepted a degree of vulnerability and uncertainty. However, allowing herself to experience the productive negativity (i.e., the "not as I thought") led to greater

appreciation of the lived experience of mental illness, a shift in her background knowledge and ultimately better understanding of herself.

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Appendix

Recovery Assessment Scale – Revised (RAS-R)

RAS-R

Name or ID Number _____ Date _____

PLEASE ANSWER THESE ITEMS ON AN AGREEMENT SCALE WHERE 1 IS “STRONGLY DISAGREE” AND 5 IS “STRONGLY AGREE.”

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
1. I have a desire to succeed.	1	2	3	4	5
2. I have my own plan for how to stay or become well.	1	2	3	4	5
3. I have goals in life that I want to reach.	1	2	3	4	5
4. I believe that I can meet my current personal goals.	1	2	3	4	5
5. I have a purpose in life.	1	2	3	4	5
6. Even when I don't care about myself, other people do.	1	2	3	4	5
7. Fear doesn't stop me from living the way I want to.	1	2	3	4	5
8. I can handle what happens in my life.	1	2	3	4	5
9. I like myself.	1	2	3	4	5
10. If people really knew me, they would like me.	1	2	3	4	5
11. I have an idea of who I want to become.	1	2	3	4	5
12. Something good will eventually happen.	1	2	3	4	5

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
13. I'm hopeful about my future.	1	2	3	4	5
14. I continue to have new interests.	1	2	3	4	5
15. Coping with my mental illness is no longer the main focus of my life.	1	2	3	4	5
16. My symptoms interfere less and less with my life.	1	2	3	4	5
17. My symptoms seem to be a problem for shorter periods of time each time they occur.	1	2	3	4	5
18. I know when to ask for help.	1	2	3	4	5
19. I am willing to ask for help.	1	2	3	4	5
20. I ask for help when I need it.	1	2	3	4	5
21. I can handle stress.	1	2	3	4	5
22. I have people I can count on.	1	2	3	4	5
23. Even when I don't believe in myself, other people do.	1	2	3	4	5
24. It is important to have a variety of friends.	1	2	3	4	5