Experiencing Psychosis

Personal and Professional Perspectives
Contents

List of tables and figures xi
List of contributors xii
Preface xvi
Acknowledgements xix

1 Introduction 1
Jim Gekkie, Patte Randal, John Read and Debra Lampsire

2 The importance of personal narratives in recovery from psychosis 5
David Roe and Paul H. Lysaker

PART I
Recovery 15

3 Recovery from ‘psychosis’ 17
Jacqui Dillon

4 Hurrying slowly: Initial steps towards recovering from psychosis 23
Larry Davidson

PART II
Cultural perspectives 33

5 A cultural and personal perspective of psychosis 35
Egan Bidois
Contents

6 Exploring culture, subjectivity and psychosis
INGO LAMBRECHT AND MELISSA TAITIMU

PART III
Spirituality

7 Subjective experience of spirituality and psychosis
PATTE RANDAL

8 Spirituality and psychosis
DAVID LUKOFF

PART IV
Existential/sense of self issues

9 When you have lost yourself, there’s really not very much left
ARNHILD LAUVENG

10 The uncertainty of being: Existential aspects of the experience of psychosis
JIM GEEKIE

PART V
At risk mental state

11 At risk of developing psychosis: A personal account
RORY BYRNE

12 At risk of developing psychosis: The research perspective
KATE HARDY

PART VI
Trauma

13 My body remembers; I refused: Childhood trauma, dissociation and psychosis
WILMA BOEVINK AND DIRK CORSTENS

http://www.routledgementalhealth.com/experiencing-psychosis-9780415580342
14 The subjective experience of the link between bad things happening and psychosis: Research findings
JOHN READ

PART VII
Hearing voices

15 The sounds of a wounded world
DEBRA LAMPSHIRE

16 Myriad voices, myriad meanings: Review of the research into the subjective experience of hearing voices
VANESSA BEAVAN

PART VIII
Delusional beliefs

17 Deluded loner
JOHN WRAPHIRE

18 Subjective experiences of delusions and paranoia
MICHELLE L. C. CAMPBELL AND ANTHONY P. MORRISON

PART IX
Negative symptoms

19 Negative symptoms: More, not less
ELEANOR LONGDEN

20 The subjective experience of negative symptoms: Characteristics of emotional withdrawal
JAMES A. LE LIEVRE, ROBERT D SCHWEITZER AND ALAN BARNARD

PART X
Family perspectives

21 I called you my brother
JAY NEUGEBOREN
Chapter 2

The importance of personal narratives in recovery from psychosis

David Roe and Paul H. Lysaker

What we attend to is a matter of choice, a choice which is influenced by the context in which this choice is made. What we choose to attend to amongst the endless possibilities presented to us at any given moment is also a by-product of what we were taught, trained, encouraged and reinforced to view as valuable. A child may sit with his parents at a circus and be fascinated by a child his age sitting in the next row. His parents may actively encourage him to pay attention to the stage where the exciting show for which they bought expensive tickets is taking place.

At any given moment, a combination of internal and external forces, with various degrees of harmony or tension, influence what we end up choosing to attend to. For example, as clinical psychology interns at a community mental health clinic, we would, with great reverence, bring the raw data of the ‘Bender’ and ‘Draw A Person’ tests to supervision sessions with the chief psychologist who we simultaneously admired and feared. Our emerging clinical skills were primarily attuned to cues signifying what we should be attending to as well as its ‘correct’ interpretation. The size, proportion, intensity and location of the shapes and lines, so we learned, had profound meanings which we were taught to attend to and interpret in specific ways to complete a ‘successful’ assessment. At least successful enough so that the chief psychologist would approve our taking the licensing exam.

But what does a child sitting in a circus or a bunch of frightened clinical psychology interns have to do with the importance of narratives in recovery from psychosis? It is because, like the child or interns, when talking with a person who has experienced psychosis, as a listener one has to choose what to attend to when trying to understand and provide help. As Miller Mair (1989: 1) put it: ‘We have not been encouraged to suppose that we are choosing to tell tales in particular ways, for particular ends, and for the approval of particular audiences.’ In a recent first-person account of psychosis, Kean (2009: 1) writes: ‘I was totally separated from myself, not knowing what action I was taking, let alone considering how to “communicate’ . . . I was unaware of myself, and my psychiatrist was unaware of me.’ In this chapter we will posit that a purpose for attending to the experience of persons with mental illness is to assist their ‘personal recovery’ (Slade 2009).
we are listening to people who have experienced psychosis in order to help them find the lives they are searching for, it would seem essential to carefully understand how they have made meaning of the story of their lives and their experience of psychosis. This process of developing ‘enabling narratives’ can occur without clinical assistance, and sometimes even despite clinical assistance, when those may undermine the narrators’ roles as authors of their own experience. Debra Lampshire’s account in this book is one such example.

But what do we know about the personal narratives of persons who have experienced psychosis? As we will see in the chapters which follow, many who have experienced psychosis are capable of constructing, and sharing, as they do in this book, their own unique narratives of their experiences and their varied ways of understanding, relating to and dealing with them. This chapter will focus on how we might listen to and understand the unique stories of unique persons who have experienced psychosis. It is divided into four sections. In the first we will explore what can be learned from first-person narrative accounts of mental illness. In the second and third we will explore qualitative and quantitative analyses of personal narratives. Finally, we will comment briefly on the theoretical and clinical implications of this work.

Researching personal narratives among people who have experienced psychosis

First-person accounts of mental illness

Modern descriptive psychiatry has tended to focus on what can be readily observed and measured. As such, much of our tradition involves persons in the position of expert drawing conclusions about the meanings of the experiences of others. Strauss (1989) was among the first to draw attention to how focusing narrowly on the effort to meet a particular conception of science has generated an unscientific tendency to ignore large amounts of important data simply because they are difficult to measure reliably using standard methodological tools. According to Strauss, essential information is lost in the process of systematically characterizing individuals' experiences on the basis of questionnaires or structured interviews. Frank and Frank (1993) point out, for example, that descriptive psychiatry’s ‘atheoretical’ stance actually posits a theory in itself: that the meaning people attach to their experiences, their beliefs about and attitudes towards their experience of psychosis, and their social and historical context are all unimportant. Morstyn (1994) argues that many concepts lose their essential meaning in the process of operationalizing them so they can be reliably coded and subjected to statistical analysis. Chadwick (2006) accuses biomedical approaches in schizophrenia research of trapping clinicians in conceptual schemes which prevent them from listening to the experiences of their patients, leading to the alienation of healer and sufferer. Lysaker and Lysaker (2008) note that without a valuation of the life and experience of persons with any condition we hazard
undermining the study of that disorder as a meaningful element of the human condition, amputating the person from the disorder.

One response to this criticism is an effort to understand psychosis from the ‘inside’ and explore the way it is experienced. Here we are referring to narrative characterizations of mental illness by persons who have experienced psychosis. Starting with pioneers such as Judi Chamberlin, Pat Deegan and Daniel Fisher, a growing number of people who had experienced mental illness and its aftermath began an international conversation about what it means to experience mental illness. A rapidly growing number of poignant first-person accounts began to be published in journals, books, and internet links, providing a much more rich, complex and personal perspective on having experienced psychosis, along with its social consequences. These first-person accounts helped the lay public as well as the professional community to realize that in order to understand the symptoms of mental illness it is not enough to just describe them. Instead, it is crucial to consider the personal context in which they take place, and the way they are experienced, perceived, interpreted and dealt with. It also became apparent that people who have ‘been there’ and ‘lived through it’ often acquire unique and valuable insights. For example, Chadwick (2006) draws from his experience as a psychologist, as a researcher and as someone who has experienced psychosis himself the importance of developing an attitude in which the person is the agent of his or her own beliefs and develops the ability to retain a critical reflective stance toward his or her own experiences. A powerful illustration of the profound challenge mental illness poses for one’s sense of self is found in Kean’s first-person account, which we will refer to again later.

What lies behind the symptoms is a tormented self, a highly personal experience unchangeable and irreplaceable by any physical treatment . . . Despite the ‘usual’ voices, alien thoughts and paranoia, what scared me the most was a sense that I had lost myself, a constant feeling that my self no longer belonged to me. This has nothing to do with the suspicious thoughts or voices; it is purely a distorted state of being. The clinical symptoms come and go, but this nothingness of the self is permanently there . . . what scared me the most was a sense that I had lost myself, a constant feeling that my self no longer belonged to me. . . . What he [the mental health professional] chose to see was nothing but the symptoms alone. I feel that my real self has left me, seeping through the fog toward a separate reality, which engulfs and dissolves this self . . . the real ‘me’ is not here any more. I am disconnected, disintegrated, diminished . . . Schizophrenia is ultimately a disorder of the self, a disturbance of one’s subjective self-experience and the external or objective reality.

(Kean 2009: 1)

Qualitative studies of personal narratives

In addition to influential first-person accounts there have been growing efforts to systematically study personal narratives. Adopting a narrative perspective helps
us to understand how people create narrative identities, develop the capacity to make sense of and organize past experiences, seek to understand themselves as unique individuals and develop a sense of continuity across their lifespan (Raffard et al. 2010). Narrative research has helped us to better understand the recovery process of one’s sense of self after experiencing psychosis. Focusing on narratives broadens the horizons concerning the range of factors that influence a person’s understanding of, and response to, the onset of psychosis. Working from such a position, Estroff et al. (1991) referred to illness-identity work as the process through which a person learns about and incorporates psychiatric explanations once he or she comes into contact with mental healthcare or composes counter-claims about illness and self in reaction to a biomedical explanation. In their view, this process generates two main types of talk about self and illness: normalizing talk, which disputes the assignation of illness and reauthorizes either the condition as commonly occurring or the person as not sick, and illness identity statements, which include self-representations that incorporate illness. Roe and Ben-Yishai (1999) identified five distinct categories that speak to different relationships that emerge in this process. In the first category, participants separated their ‘healthy’ self from their ‘ill’ self. This separation occurred at the narrative level, in the story the participants told, which revealed various stages of perception of self in relation to their illness, shifting from a ‘split’ between the two to a fuller and more integrative story which included various aspects of self and illness over time in which the self was protagonist. This sort of stand is in line with a shift along the theoretical construct from invalidation to validation (Geekie & Read 2009), during which one’s authority over the interpretation moves from being undermined to being validated.

In addition to the contribution of narratives to developing a better understanding of important changes in the experience of self and self in relation to illness, other studies have provided useful insights into the process of recovery and helped to identify distinct stages. Ridgway (2001) published first-person accounts of recovery and identified broad common themes including moving from despair to hope, from withdrawal to engagement, from passive adjustment to active coping, and reclaiming a positive sense of self, meaning and purpose. In another study, Jacobson (2001) analyzed published narratives of recovery using a dimensional analysis and identified component processes which corresponded to four central dimensions: recognizing the problem, transforming the self, reconciling the system and reaching out to others. Based on a select sample of the recovery literature, Andresen et al. (2003) proposed a five-stage model which included a shift from a moratorium characterized by denial towards rebuilding a positive identity and experiencing growth.

Finally, qualitative research has emphasized the potentially powerful healing value of narratives. Stories are a way of curing the wounds that illnesses often create, helping to make sense, redraw maps and find new destinations (Gold 2007; Roe & Davidson 2005). Narratives provide an important tool to search for and create a personally meaningful way of making sense of psychosis and

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The importance of personal narratives (Larsen 2004), to find meaning (Wagner & King 2005), and to communicate and earn the respect and validation of others (Geekie & Read 2009).

Stories provide narrators with the opportunity to renegotiate the meaning, sequence and connection between past and present life events and accept themselves and their personal histories. Narratives also provide a fundamental tool to help communicate with others as stories are comforting and help bond people together (Gold 2007).

**Quantitative studies of personal narrative**

In contrast to work which has sought to discern the common themes and qualities of personal narratives of persons who have experienced psychosis, more recent literature has sought to quantify in some manner the degree to which personal narratives cohere or fail to cohere in an adaptive manner. This literature has sought to determine to what extent the relative absence vs. presence of certain aspects of a personal narrative can be objectively observed and to what extent their presence is predictive of various outcomes. What are the ways in which personal narratives differ from one another and how are such differences related to wellness?

In one of the first attempts to quantitatively study personal narratives, Lysaker et al. (2006a; 2006b), developed the Scale to Assess Narrative Development (STAND). The STAND was constructed on the basis of narrative theory which stresses that a sense of self can vary from a state of more to less coherence according to how it is constituted with a past and present as embodied within the stories one tells oneself and others. The STAND contains four Likert scales which can be applied to rate speech samples in which persons give a narrative account of their lives. The four subscales assess the extent to which individuals portray themselves within their own life stories as having:

i. Illness Conception, or realistic life challenges
ii. Agency, or a sense of being as an active agent in their own lives
iii. Alienation, or meaningful bonds with others, and
iv. Social Worth, or value in their community.

In the first empirical study of the STAND (Lysaker et al. 2006a), narratives of 34 participants with a diagnosis of schizophrenia spectrum disorders were analyzed. An acceptable degree of inter-rater reliability was established and higher scores on the STAND were found to be associated with greater levels of self-esteem and greater overall readiness for change. Specifically, greater levels of readiness for change were linked with greater Illness Conception and greater self-esteem was linked to higher levels of Social Worth and Agency. In the second study (Lysaker et al. 2006b), with a sample of 65 persons with a schizophrenia spectrum disorder diagnosis, higher STAND scores were linked to higher levels of hope and social function, and lower levels of positive and disorganization.
symptoms. In subsequent studies lower STAND scores were found to be linked to higher levels of self-stigma (Lysaker et al. 2008). Finally, higher STAND ratings have been found to be correlated with greater levels of quality and quantity of social relatedness independent of the effects of related constructs such as hope and self-esteem (Lysaker et al. 2010a).

From a different angle, Saavedra alone (2009) and with colleagues (2009) has analyzed the narratives of adults with a diagnosis of schizophrenia. It is reported that it is possible to distinguish narratives in terms of the extent to which persons define themselves as a patient, the degree of agency they perceived in their lives and the extent to which highly implausible accounts of life experiences obscure underlying meaning. These different dimensions were linked with differing degrees of health and well-being.

Investigating where personal narratives may break down in terms of narrative content, Gruber and Kring (2008) have explored the degree to which the emotional quality of a life event affects how it is narrated. In comparison with persons who do not experience any mental illness, they note that persons with a diagnosis of schizophrenia tend to tell less coherent narratives in terms of temporality and appropriateness of content when strong emotions are at play. Raffard et al. (2010) confirmed that persons with a diagnosis of schizophrenia tend to have greater difficulties constructing coherent narrative accounts of their lives. They noted that greater duration of illness predicted greater difficulties in narratizing life events and that higher levels of negative symptoms predicted fewer connections between persons and the events of their lives and fewer meaningful details about those events. These findings may possibly reflect having been more exposed to the dominant medical paradigm within mental health care, a framework which tends to promote the notion that there isn’t any meaning in the person’s experience, and that it is not related to life events and context.

Implications for theory and practice

**Personal narratives as a crucial domain of recovery**

One implication from the material presented above is that personal narrative, or the meaning persons make of their lives in a storied manner, may stand as a unique dimension of recovery. As suggested above and elsewhere (Lysaker et al. 2010b; White & Epston 1990), the story one tells about one’s life, including the experiences of illness, may be related to symptom severity and the achievement of milestones, but it is not reducible to those events. To have or not have symptoms and to have or not have a job are not the same as to have or not have a rich story of one’s life. Similarly, to have hope for the future or a view of oneself as capable or likable would also seem to be related to the kind of story one tells of one’s life. A personal narrative, its richness and adaptiveness, cannot be reduced to a matter of possessing a certain degree of hope or self-esteem. Certainly, there could be very rich narratives in which hope is slim and there is an articulate
expression of marginalization. It is also possible that a disconnected narrative could serve a protective function as well.

As an illustration, we suggest that in Kean’s (2009) narrative described above, we can find an individual who speaks with a coherent authenticity. This authenticity, importantly, is not just a matter of hope, symptom remission or empowerment. She is actively making meaning of her own life, in her own voice. The meanings she makes possess consensual validity but she is not reading from a script or endorsing beliefs that might be found in a recovery questionnaire. Accordingly her life is her own, no matter how painful, and as such she is capable of making her own sense of her dilemma and deciding what to do. Her narrative – because it is her own – allows her to possess some ownership over her life, to function as an agent in the world, no matter how painful that world is at the moment.

It may be essential for future studies of recovery to take into account the stories of people seeking to move towards recovery. It may be that to fail to take these into account would mean missing an important way in which a person has achieved or is still struggling to achieve a degree of health. Longitudinal studies of narrative and other objective and subjective aspects of recovery may furthermore allow for the discovery of answers to a range of important questions. For instance, how often do changes in narrative precede or follow changes in other facets of recovery such as the development of hope, success in work or symptom remission? What sorts of experiences are linked to the development of a rich personal narrative for persons who previously had lost the thread of their life story? As persons recover, how important is it that the trauma of psychotic experience itself is processed and understood?

The systematic consideration of personal narratives, both in a qualitative and a quantitative sense, would seem to promise some answers to these questions and also helps us to keep alive an awareness of the individual person who not only experiences a range of challenges but also actively makes meaning of them.

**Personal narratives as a means to facilitate recovery**

If we accept personal narratives as a unique element of recovery, it seems natural that they be considered in discussions of both existing and evolving treatments, rehabilitation and system change.

One place to think about this issue in terms of current treatments (e.g. Acceptance and Commitment Therapy and supported employment) is to begin with the consideration that during those treatments there are often lengthy conversations between persons with mental illness and their clinicians or rehabilitation specialists. While those conversations may often be problem-focused, these conversations may also involve how persons understand their life. Many conversations in interventions such as these likely include discussions in which clients clarify what in the course of their life has gone wrong, what has not gone wrong, and what they hope for, grieve and plan to do about it. These sorts of conversations may also help to identify the narratives clinicians use in making sense of
12 The importance of personal narratives

psychosis and help them to focus on enabling narratives rather than imposing information.

If narratives grow through the telling and retelling of one’s story then there should be room within these interventions for persons to be afforded a place to decide how they choose to understand their current challenges in light of what they believe has transpired over the course of their life. Assisting with this may require treaters and rehabilitation specialists to speak with clients in a consultative, non-hierarchical way, one that does not authoritatively usurp a person’s right to make their own sense of their needs and hopes. It may, though, be essential at times to also invite clients to pursue opportunities to decide what they believe. In this way, it may be useful to conceptualize services and interventions as processes that are more than treatments for problems. Interventions could be seen as offering consultation regarding the different ways the recovering person is telling their story of the experiences of living with a mental illness and its aftermath. Indeed, it is possible that this is a non-specific factor already at work within the practice of many of these interventions. Such possibilities are consistent with developments in recovery-oriented psychotherapy as discussed elsewhere (Lysaker et al. 2010a).

With respect to the development of new services, the work reviewed above also seems to point to the possibility of interventions which might focus specifically on personal narrative in the context of other issues. One illustration is a structured group intervention we have recently developed with the goal to decrease self-stigma among people who have experienced psychosis (Yanos et al. in press). The intervention, which we entitled Narrative Enhancement/Cognitive Therapy (NECT) features a guide for the practitioner aimed to help explain the rationale, tone and technique, as well as handouts that can be used to guide group discussions. In addition, the manual includes worksheets that can be used to help group members to learn and practice skills for coping with internalized stigma by identifying cognitive distortions or dysfunctional attitudes related to having a mental illness. Finally, and most directly related to the topic of this chapter, the intervention focuses on offering participants the opportunity to tell their own unique stories and provide constructive feedback to the stories of other participants.

Overall, the work reviewed above seems to us to point to a wide range of possibilities for professionals to develop new ways to directly seek to facilitate the process of constructing and telling stories. In formal and informal consultation, in individual, group, family and community settings, we see the promise of helping persons who have experienced psychosis to find their own consensually valid ways of framing the past, seeing themselves as not just defined by illness, feeling a sense of control over illness and that life gives meaning to particular events in the present, as well as communicating with others. Perhaps most important is that by refining and developing new interventions we can support persons becoming the authors of their own life story and an active agent, a self, authoring a new story. The following chapters provide a rich and diverse source to help move along this important path.
References


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