Treatment and recovery in first-episode psychosis: A qualitative analysis of client experiences

by

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Contributions of Authors

As the first author of both studies, I (Deborah Windell) made a significant and critical contribution to the theoretical rationale, interview development, data collection, analysis and presentation of the material.

Dr. Malla provided ongoing consultation and substantial assistance in the organization of results and manuscript preparation.

Dr. Norman made a substantial contribution to the framework for both studies and provided ongoing consultation for analytic procedures and interpretation of findings.

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ABSTRACT

Background: There is currently very little research on recovery from the perspective of individuals with recent-onset of psychotic disorders. Forming a better understanding of the subjective meaning of recovery and recovery experiences during this early phase of recovery can inform effective and meaningful service design and practices.

Method: Thirty individuals recovering from psychosis and receiving specialized early-intervention treatment were interviewed regarding the meaning and experience of recovery from psychosis during the early phase (2-5 years) of the illness course.

Results: Recovery was described as a multidimensional experience that included aspects of "illness recovery," "psychological recovery," and "social recovery." Seven common early recovery experiences were identified. Individual variations in the magnitude of described disruption of self and social functioning, duration of the illness-acceptance process and the process treatment negotiation greatly influenced the experience of recovery.

Conclusion: Differences in illness acceptance and social recovery trajectories have important implications for understanding individual responses to the experience of psychosis, its diagnosis and treatment. These differences emphasize the importance of assisting individuals with the construction of meaning and the reengagement in social roles following the initial illness experience.

RÉSUMÉ

Contexte: Il y a actuellement peu de recherche sur la rétablissement du point de vue d'individus après un premier épisode de psychose. La formation d'une meilleure compréhension de sens subjectif des expériences de rétablissement pendant cette première phase de rétablissement peut informer le design efficace et expressif des services et des pratiques.

Méthode: Trente individus se rétablissement de la psychose et recevant un traitement de première intervention spécialisé ont été interviewés à propos du sens et de l'expérience de rétablissement de la psychose pendant la première phase (2-5 ans) du cours de maladie.

Résultats: La rétablissement a été décrite comme une expérience multidimensionnelle qui a inclus des aspects de "la rétablissement de maladie," "la rétablissement psychologique," et "la rétablissement sociale." Identifiées ont été sept premières expériences de rétablissement communes. Les variations individuelles dans l'étendue de perturbation décrite de soi et de fonctionnement social, la durée du processus d'acceptation de maladie et de la négociation du processus de traitement ont beaucoup influencé l'expérience de rétablissement.

Conclusions : Les différences dans les trajectoires d'acceptation de maladie et de rétablissement sociale ont des implications importantes pour comprendre les réponses individuelles à l'expérience de psychose, sa diagnose et traitement. Ces différences accentuent l'importance d'assister les individus avec la construction de sens et avec le réengagement dans les rôles sociaux après l'expérience de maladie initiale.

CHAPTER 1 –BACKGROUND AND PROJECT DESCRIPTION

Thesis Structure

The present thesis consists of the following:

1) an introductory chapter reviewing current theories of recovery and relevant research on the topic, as well as describing the conceptual and procedural connections between manuscripts;

2) an explanation of the conceptual framework of qualitative approaches to recovery;

3) a manuscript entitled "The Personal Meaning of Recovery among Individuals Treated for a First-Episode of Psychosis" reporting the findings of a study investigating the *meaning* of recovery by exploring the recovery notions and definitions of individuals who have been recently diagnosed with a psychotic disorder;

4) a manuscript entitled "The Experiences of Early Recovery among Individuals Treated for a First-Episode of Psychosis" reporting the findings of a study investigating the experience of recovery early in the course of the illness by exploring early recovery experiences among individuals who receive early intervention care following their first-episode of psychosis, and;

5) an overall conclusion synthesizing the findings of both studies and outlining important service design and delivery implications.

Introduction

The phenomenon of recovery from serious mental illness, especially recovery from schizophrenia, is increasingly considered a topic of great interest in both clinical practice and research. The current state of affairs appears to emerge as a collective agreement of a more hopeful view of illness course and recovery, the result of a culmination of four distinct forces: promising reports from longitudinal studies of outcome, encouraging reports of improved outcome with early intervention, advances in treatment efficacy and the emergence of the recovery movement.

Longitudinal studies of outcome

Contrary to the Kraepelinian legacy, a series of rigorous international longitudinal studies have reported a broad heterogeneity in outcome for mental psychotic disorders (for a review see Calabrese & Corrigan, 2005), with at least a quarter and up to two-thirds of people with serious mental illness achieving substantial recovery from the disorder in terms of amelioration of symptoms and other deficits and personal, social and vocational functioning within what is considered a normal range (e.g. Ciompi, 1980; Davidson & McGlashan, 1997; Harding, Zubin & Strauss, 1987; McGlashan, 1988). These findings have important implications for research, clinical practice and public policy, as well as for theoretical models of the disorder.

Advances in treatment efficacy

A growing body of empirically-based research shows that recovery from schizophrenia is greatly enhanced by evidence-based treatments (Falloon et al, 2004). Subsequent to the advent of antipsychotic medications and more recently better tolerated, and in some cases more effective (e.g. Clozapine), second generation antipsychotics, the effectiveness of psychosocial interventions (assertive community treatment, family psychoeducation, supported employment and social skills training) in combination with drug treatment is now well established (Liberman et al, 2005). This has resulted in increased optimism regarding the malleability of course and outcome provided by these new treatments.

Specialized early intervention (SEI)

Over more than a decade there has been growing enthusiasm for the possibility of improving outcome in schizophrenia-spectrum disorders through provision of specialized interventions early in the course of illness (Malla et al, 1999; McGorry et al, 1996). The primary reason for such interest regarding the potential benefits of early intervention is based on the notion of a “critical period” during the first 2-5 years following onset of psychosis, when it appears that outcome trajectories are established (Harrison et al, 2001) and interventions are likely to have a maximal effect on outcome (Birchwood et al, 1998). The beneficial effects of SEI for clinical and functional outcomes, above that achieved with traditional services, has been confirmed by controlled research trials (Petersen et al, 2005; Craig et al, 2004) and a recent meta-analysis (Harvey et al, 2007). However, the long term sustainability of these benefits remains inconclusive. These encouraging findings have no doubt been translated into enthusiasm for proliferation of early intervention programs internationally.

The Recovery Movement

The “new vision” of recovery that emerged from the Mental Health Consumer/Survivor Movement in the 1970’s in the US, UK and elsewhere advocates for the rights of self-determination and community inclusion for individuals with mental illness. This notion of recovery put forth by consumer advocates and their supporters proposes a more optimistic and personally empowering model that emphasizes the ability to enjoy a safe, dignified and gratifying life in the community despite ongoing experience and effects of mental illness (Davidson & Roe, 2007).

Models of Recovery

Currently, these forces have culminated in a shift toward hopeful expectations and commitment to the goal of recovery among mental health advocates, clinicians and policy makers. Pessimistic expectations that assume eventual subsuming of the person by the illness appear to be replaced by the general consensus that people can and do recover, and hence the importance of developing effective and meaningful treatment interventions. However, while these notions of recovery are not mutually exclusive, they reflect conceptually different optimistic notions of mental illness: one is that it is something that can go away over time, and the second is that it is something that many people can successfully manage while living a meaningful and fulfilling life (Davidson & Roe, 2007). Therefore, it appears that researchers, clinicians and service users may have different ways of defining the term recovery, with the application of this “increasingly ubiquitous yet elusive” concept to practice being inevitably inconsistent (Davidson, O'Connell, Tondora, Staeheli, & Evans, 2005). Each of these two approaches to the concept of recovery and their concomitant tools of inquiry and assumptions are reviewed below.

1. Clinician/Research-based models of recovery

The definition of recovery in the scientific literature is generally from the perspective of the disease and involves the elimination or reduction of symptoms and return to premorbid levels of function. This common concept of recovery is conceptualized and measured as an "outcome" - an end-point of functioning achieved and maintained for a specified period of time. The definitions currently in practise comprise a variety of dimensions, ranging from relatively restricted disease-focused definitions, to more elaborate multidimensional operationalizations (for a review see Liberman & Kopelowicz, 2005), but is most often determined by presence or absence of psychotic symptoms.

In that regard, the Remission in Schizophrenia Working Group recently developed an operational definition for symptom remission in schizophrenia that incorporates both symptom severity and duration components (Andreasen et al, 2005). They proposed a definition of remission that represents a distinct threshold for symptom severity that corresponds to diagnostic criteria for the disorder where absent, borderline and mild symptoms do not influence the individual's behaviour and are below the threshold that would justify a DSM-IV diagnosis of schizophrenia. They propose that a consensus definition of remission or recovery would ultimately include cognitive and functional outcomes, and that the inclusion of metrics of functioning alongside this symptom remission definition in investigations would be useful in order to expand knowledge of the relationship of remission to recovery of functioning. To date, research examining Andreasen's (2005) consensus remission criteria and indicators of wellness outcomes has demonstrated an association between remission and measures of functioning, but the criteria has not been linked to improvement in subjective reports of well-being (e.g. quality-of-life measures) (Van Os et al, 2006; Wunderink et al, 2007).

The outcome measures most frequently used in clinical studies of schizophrenia have often included functioning improvement in a variety of domains in addition to levels of symptoms (typically positive symptoms, although sometimes the presence of depression, anxiety and/or negative symptoms as well), and resource utilization (e.g. Harding et al, 1987). However, variations in specific criteria employed between studies have made it difficult to make comparisons between outcome reports (Liberman et al, 2002). There has been increasing interest in developing a standard, operational definition of recovery that reflects both the course and consequences of the illness and that can be utilized for empirical investigation. While role functioning is increasingly included as a measure of outcome, the field at present lacks well-validated measures of functioning and productive activity (Bellack, 2006), necessitating consensus among clinicians, researchers and service users to operationalize functional levels consistent with a definition of recovery (Liberman & Kopelowicz, 2005). A standardized multidimensional definition of recovery that has received research attention is proposed by Liberman and colleagues (2002). They suggest a definition of recovery that is a "multi-modal, socially normative inventory of personal assets and freedom from psychotic symptoms" and as such includes assessment outcomes in symptomatology, vocational functioning, independent living and social relationships.

A serious limitation of the various criteria described thus far is that they do not address the subjective appraisal of functioning or life satisfaction. The impact of the illness experience is often profound, extending beyond symptoms to include a loss of self-esteem, isolation, and the deleterious consequences of social stigma. These experiences are excluded from a disease process definition of recovery (Bellack, 2006). In recent years, improving service users' quality of life has been considered an increasingly important objective of treatment in schizophrenia, since improvements in these areas would be a significant step forward in promoting recovery (Leucht & Lasser, 2006). While the "recovery" concept extends beyond quality of life, it encompasses many of the same concepts as current multifaceted views of recovery (Bellack, 2006).

At a recent consensus conference of schizophrenia researchers, Nasrallah and colleagues (2005) proposed that clinical effectiveness will ultimately be reflected in the successful achievement of *subjectively predefined* social, educational, vocational, and interpersonal goals. Further, this broad category can best be measured by examining several interrelated outcome domains yielding a broader clinical perspective on the progress of treatment. The consensus among researchers was that effective clinical treatment is characterized by four outcome domains: symptoms of disease, treatment burden (side effects), disease burden (impact of the disease on the patient and members of his or her social circle), and health and wellness (long-term increase in healthy behaviours and restoration of wellness). An important and unique feature of the outcome criteria that they propose is that selected outcome domains reflect *multiple perspectives*. However, this definition lacks adequate instruction regarding procedures for integrating the perspectives of various informants (Bellack, 2006), and to date it has not been adopted by researchers.

In a review of the concepts of remission and recovery in schizophrenia, Leucht and Lasser (2006) conclude that recovery, which "encompasses both symptom remission and more functional aspects of persons' well-being, such as cognition, social functioning and quality of life" remains to be satisfactorily defined (p.161). In the absence of a single set of criteria for defining recovery it is difficult to assess the effects of current treatments on "recovery" per se. While such functional aspects of recovery, such as improvements in cognition and social functioning, are increasingly used as proxy measures of recovery, these measures require further research.

2. *Consumer-based models of recovery*

The phenomenon of recovery addressed in the consumer and rehabilitation literatures is fundamentally different from that studied by clinical research. Proponents of the former assert that recovery may be something quite different from the disease-oriented clinical concept (Anthony, 1993; Deegan, 1988; 1996). The processes that reflect the recapturing of a positive self and rewarding life, not the processes involved in achieving remission of symptoms and reparation of other deficits, may be equally or more important. The emphasis is instead on the importance of gaining and maintaining hope, experiencing supportive relationships, developing valued roles and responsibilities and developing a positive sense of self (Davidson, Sells, Sangster, & O'Connell, 2005).

This process-oriented paradigm of recovery is critical of the use of end-state (outcome) recovery research because of its lack of sensitivity and attention to the psychological and interpersonal changes that constitute the recovery process. As such, the consumer definition of recovery is limited in applicability to understanding the processes that lead to symptom remission and remediation of deficits, as they exclude objective measures of functioning or symptom evaluations from their definition (Davidson, O'Connell, Tondora, Staeheli, & Evans, 2005). This recovery concept also represents a model of care as well as conceptualization of possible outcomes (Anthony, 1993; Jacobson & Greenley, 2001). The consumer movement has become a collective political force advocating change in the psychiatric system towards "recovery-oriented services" that reflect the values of autonomy, integrity and self-determination inherent in the recovery model. Ultimately, the consumer concept of recovery does not reflect a clinical or scientific reality as much as it does a social and political one (Davidson et al, 2008).

The Subjective Experience of Recovery

Researching the subjective experience of recovery

The emergence of the "person behind the disorder" through the recovery movement, along with recognition of the significantly enhanced possibilities for recovery emerging from the longitudinal studies reporting higher-than-expected rates of recovery, have stimulated research that appreciates and investigates the role of the person in attempting to manage the disorder. This research has generally favoured the use of qualitative methodologies for identifying and illuminating those subjective factors and the role they play in recovery. To date, the subjective experience of recovery from schizophrenia has been examined from the perspective of grounded theory (e.g. Hirschfeld et al, 2005; Mancini, 2007; Noiseaux & Ricard, 2007), hermeneutics (e.g. Corin, 1990; 1998), ethnography (e.g. Jenkins et al, 2005, Jenkins & Carpenter-Song, 2005), narrative analysis (e.g. Thornhill et al, 2004), and phenomenology (e.g. Davidson, 2003; Koivisto et al, 2003). Common to all of these approaches is the pursuit of understanding the subjective experience of recovery within the "life-context" that it occurs.

These studies have been undertaken through reviews of the literature of first-person accounts (e.g. Turner-Crowsen & Wallcraft, 2002), focus group analysis (Ng et al, 2008), integration of multiple sources and perspectives (e.g. Noiseaux & Ricard), but most often through analysis of interviews with individuals who have experienced the illness (e.g. Davidson, 2003, Spaniol et al, 2002). Some researchers have sought to elucidate and describe the recovery process, its major dimensions, and factors that appear to be associated with the process, while others have developed theories of recovery, or proposed phase or stage models of recovery. These different approaches all seek to understand, through qualitative description and analysis, the lived experience of recovery specifically from the perspective of the individual experiencing it.

Numerous qualitative analyses of subjective experiences of recovery describe the core of recovery as encompassing transformation processes from an identity centered on stigmatized notions of illness and disability toward an empowered, positive identity marked by meaning and well-being (e.g. Mancini, 2007; Mancini et al, 2005; Pettie & Triolo, 1999). The crucial importance of a sense of agency and personal control in the subjective experience of recovery has been emphasized by numerous researchers (e.g. Jenkins & Carpenter-Song, 2005; Marin et al, 2005). There is a growing body of research exploring the critical personal and sociocultural forces involved in creating and maintaining chronicity (e.g. Corin & Lauzon, 1994; Davidson & Strauss, 1992; Estroff, 1989; Estroff et al, 1997; Larsen, 2005; Williams and Collins, 2002). Experiences that enhance hope, provide ways to make sense of experiences, provide opportunities for success and pleasure, enhance a sense of agency, and that provide support, mutuality and a sense of belonging are identified as "enabling" recovery (Davidson, 2003). Generally, it appears that the individual plays an unmistakably active role in coping, adapting, and promoting his/her recovery (Corin & Lauzon, 1992, 1994; Kotake Smith, 2000; Mancini, 2007; Marin et al, 2005; Roe et al, 2004) amid a complex interplay of subjective, psychological, environmental and social contexts (Ochocka et al, 2005).

Various stage models of recovery have been developed through consultation with service-users (Baxter & Diehl, 1998; Noiseux & Ricard, 2007; Ralph, 2005; Spaniol et al, 2002; Young & Ensing, 1999). These models emphasize the importance of self-determination in the recovery process (Baxter & Diehl, 1998; Ralph, 2005; Spaniol et al, 2002; Young & Ensing, 1999), and frequently make note of the nonlinear nature of the processes within the framework (e.g. Noiseux and Ricard, 2007; Ralph, 2005). These models can be helpful in identifying important common dimensions in the recovery process and for understanding the dynamics and person-environment interactions that promote or hinder recovery.

Measuring the subjective experience of recovery

The development of empirical measures of the recovery process as experienced by individuals with the disorder would enable evaluation of recovery-oriented psychopharmacological and psychosocial treatments for their ability to move people further along in recovery by using these factors as indicators of progress. They could also be valuable clinically for determining the treatment approach best suited to an individual at a given time. To the degree that clinicians are successful in helping clients to develop hope and gain personal responsibility and skills to manage their health care, they may be facilitating recovery even in clients with persistent symptoms and disability (Noordsy et al, 2002). Unfortunately, there is currently a considerable paucity in methods and measures for empirically examining these subjective processes. Some of these nascent instruments propose to measure component processes, while others propose to measure recovery phases, but the aim of all of them is to develop a definition that can ultimately serve research and clinical care. These instruments have all been developed by initially elucidating the subjective recovery components through analysis of personal experiences, and subsequently operationalizing these components. These components have been variously evaluated as a "collection of attitudes" (Resnick et al, 2005), a "network of constructs" (Corrigan et al, 1999; 2004), or as "aspects of the recovery process" (Jerrell et al, 2006). While the various factors included in these recovery definitions differ between these instruments, they share components assessing hope, empowerment, and personal confidence. An alternative instrument, the Stages of Recovery Instrument (STORI), recently developed by Andresen and colleagues (2003, 2005), not only assesses components of the recovery process, but also measures these processes within each of five overarching stages of recovery.

While the potential clinical and research utility of these types of recovery measures is considerable, attempts to develop measures of the subjective components of recovery require much more research to test the value of measurement of these various dimensions for evaluating the recovery process (Bellack, 2006). However, *any* measure of the consumer model of recovery is challenged (if not inherently conceptually and methodologically outmatched) to meaningfully measure the aspects of the "dynamic, complex, transactional, and highly individualized process of recovery" (Loveland et al, 2005).

Summary of Recovery Research

To date, research definitions of recovery currently use threshold criteria to measure symptom improvement, and increasingly include other domains of functioning and subjective experience in operational definitions of recovery. In contrast, research on the consumer model of recovery has focused exclusively on the "recovering" experience, arguing that this concept of recovery is not amenable to outcome measurement. As such, this model does not include objective measures of functioning or symptom evaluations in its recovery definitions. Those researchers that have attempted to develop "recovery process" instruments argue that progress in recovery processes can be measured directly in instruments whose components were derived from emergent analysis of the subjective experience of recovery.

It appears that the phenomenon of recovery addressed in the consumer/rehabilitation literature is fundamentally different from that studied by clinical research. It has been suggested that both of these forms of recovery can co-exist in any one person, and while not mutually exclusive, represent two different (and at times contradictory) aspects of recovery (Davidson & Roe, 2007). While there is tension between these paradigms, it is evident that these approaches both provide important insight into the phenomenon of recovery, and each should ideally be considered valid in its own right, and as complementary approaches in enhancing understanding of this complex and somewhat elusive phenomenon (Ng et al, 2008).

Limitations of Current Research

1) The meaning of recovery among early-intervention service-users

There is currently limited consensus within and between stakeholder groups regarding criteria that should be used to define the multidimensional nature of recovery, and little consensus regarding standardized operational measures that are most appropriate to use (Bellack, 2006). To date, empirical work on recovery-as-outcome has adopted definitions imposed by researchers and few have sought to inform their definition with the lived experience of service-users, despite repeated calls for collaboration in developing a consensus definition of recovery that makes sense to all stakeholders.

To date, the limited amount of research on the subjective meaning of recovery has been undertaken only with individuals with chronic mental illnesses. There have been no explorations of subjective recovery definitions and notions among individuals early in illness course and/or individuals who have experienced a more favourable course, despite evidence that ideas about the illness are different for individuals early in recovery compared to later in the course (Larsen, 2004). It is also plausible that individuals who have received early and comprehensive treatment intervention following a first-episode of psychosis may have experienced a more positive illness course (Harvey et al, 2007), and may therefore identify different criteria for a subjective definition of recovery from those who have experienced a more chronic course. Unfortunately, despite the abundance of reported rates of symptomatic and functional outcome in individuals treated in early intervention programs for psychotic disorders, there are currently no estimates of how many individuals identify themselves as "recovered," and little understanding of the subjective notions of recovery held by these individuals.

Therefore, it is important to pursue the viability of developing a shared, consensual definition of recovery that honours as much as possible various perceptions of valued and desired treatment outcomes. An open dialogue between stakeholders regarding the perceived value of particular outcomes is essential to developing and evaluating interventions that are meaningful as well as effective in achieving outcomes and enhancing processes of recovery valued by service-users as well as service providers and researchers. Investigating recovery definitions among service-users may allow for the identification of critical components of recovery that traditionally have not been included in recovery outcome definitions dominated by professional perspectives and/or to confirm (or contradict) outcome definitions identified by clinicians and researchers as subjectively meaningful. It is important to understand and identify the components of recovery identified by individuals with recent-onset psychotic disorders so that this understanding can be integrated into early intervention design and practices, including the potential to enhance understanding of early treatment adherence and service engagement responses.

2) Representativeness of recovery experiences

The vast majority of qualitative investigations into the subjective experiences of recovery have been undertaken with individuals many years after onset of the illness, and who typically are continuing to participate in mental health services (e.g. Davidson, 2003; Jenkins et al, 2005; Ng et al, 2008), and thus may only be representative of recovery experiences of individuals with a relatively chronic illness course. Individuals who have recently experienced a first episode of psychosis represent a more inclusive group regarding potential outcome trajectories, encompassing the breadth of outcome more closely representative of recovery experiences among all individuals who are diagnosed with a psychotic disorder (Menezes et al, 2006). Therefore, examining recovery experiences in this group of individuals represent a unique opportunity to examine early processes and influences that may promote early positive outcome.

While this critical period of early recovery has been the topic of an abundance of quantitative research on outcome following a first-episode of psychosis, in-depth investigations of the phenomenon from the perspective of the individual remain largely absent. Although there is increasing interest and recognition of the importance of exploring the experiences of individuals during this critical period (Judge et al, 2008; Hirschfeld et al, 2005; MacDonald et al, 2005; Werbart & Levander, 2005; Woodside et al, 2006), including the experience of specialized first-episode treatment (Larsen, 2007a, 2007b; O'Toole et al, 2004), there is currently a dearth of research from the perspective of individuals with recent-onset of psychotic disorders investigating early subjective recovery experiences.

Exploring the important subjective processes early in recovery following a first-episode of psychosis can enhance our understanding of the ways that individuals experience the initial episode of a psychotic illness and its treatment, and the ways that these experiences of illness evolve over the early course of the illness. Such investigations may offer new insights into the factors that promote (or hinder) recovery from psychotic illnesses. An improved awareness of important recovery processes as experienced by the individual enables the identification of potential opportunities and methods for encouraging and enhancing positive outcome, thereby informing the development and refinement of effective early intervention services.

Conceptual Bridge of Manuscript Content

The aim of this research is to identify the *meaning* of recovery among individuals who have been recently diagnosed with a psychotic disorder in order to aid in building consensus of divergent recovery ideas and priorities among service-users, clinicians and researchers. The present study also seeks to examine the subjective *experience* of early recovery for individuals who receive specialized early intervention (SEI) care following their first-episode of psychosis. This analysis seeks to shed light on similarities and variations between individuals in terms of the evolution of recovery experiences over the 3-5 year period following the onset episode.

The subjective *meaning* of recovery and the subjective *experience* of recovery are related but conceptually distinct areas of inquiry. As such, they have been investigated separately while acknowledging the dynamic relationship between them (for example, some individuals may define recovery as a process or collection of processes). In-depth examination of each phenomenon may provide important insight for understanding individual responses to experiences of early psychosis and treatment. The former may illuminate the important personal notions of recovery that influence perceptions of illness and treatment, while also providing useful information by which to develop and implement evaluation of treatment initiatives. The latter may illuminate the important processes of recovery that are subjectively important and potentially malleable, thereby enhancing opportunities to promote positive outcome. Knowledge of the perspectives of individuals who have received early and intensive phase-specific treatment following a first-episode of psychosis is currently lacking in both areas. Both studies were derived from the same interview text with separate analyses of the interview transcripts undertaken within the framework of the specific research question (recovery definitions versus recovery experiences).

CHAPTER 2 –CONCEPTUAL FRAMEWORK

Methods of Inquiry

While multiple methods have been used to investigate the phenomenon of recovery from psychosis, no single method or combination of methods are inherently superior to others, the selection of a method being determined by multiple factors, such as the researcher's epistemological standpoint, chosen theoretical framework and the specific goals of the study.

Quantitative measures of recovery consist of various objective indicators that reflect a positivist perspective within which components of human behaviour can be measured through hypothetico-deductive methodology (Guba & Lincoln, 1989). These measures of recovery are advantageous because of their relative ease of administration and information gathered that is universally understood (Loveland et al, 2005).

Alternatively, the constructivist perspective of human behaviour, which asserts multiple, socially constructed realities, is increasingly accepted as a valuable epistemological perspective. These qualitative-phenomenological methods consist of a variety of techniques designed to capture subjective experiences with the goal of discovering the meaning of a phenomenon within a particular context (Schwandt, 1994). These methods offer the benefit of capturing the unfolding, individualized and comprehensive nature of the process of recovery by examining it as a dynamic, multidimensional and interrelated phenomenon (Loveland et al, 2005). This paradigm views change in terms of nonlinear, reciprocal transactions that are nested within context, allowing evaluation of transactions between person and environment in the recovery process.

Interpretivism

Interpretivism is a conceptual framework that combines ideas stemming from the German intellectual tradition of hermeneutics, the phenomenology of Alfred Schutz, and criticism of scientism and positivism in the social sciences influenced by the writings of philosophers critical of logical empiricism (Schwandt, 1994). Interpretivists generally emphasize the uniqueness of human inquiry, with the goal of understanding the complex nature of experience from the point of view of the experiencing individual. The paradox of how to develop an objective interpretive science of subjective human experience causes a conceptual challenge of synthesizing phenomenological subjectivity and scientific objectivity (Schwandt, 1994). Contemporary theoretical descendants of these interpretivist founders have addressed this paradox in several ways.

Interpretative Phenomenological Analysis

The Interpretative Phenomenological Analysis (IPA) method is an increasingly popular approach to conducting qualitative research in psychology, offering a theoretical underpinning, a set of methodological procedures and a body of studies (Chapman & Smith, 2002). The major theoretical origins of IPA include phenomenology (Giorgi, 1995), hermeneutics (Palmer, 1969), idiography (Smith et al, 1995) and symbolic interactionism (Blumer, 1969). Since the emphasis of IPA is on "sense-making" by both participant and researcher, cognition is a central concern (Smith & Eatough, 2007), sharing with the social cognition paradigm an interest in the relationships between verbal report, cognition and physical state (Smith & Osborn, 2003). In this way, IPA differs significantly from discourse analysis, which is skeptical of mapping verbal reports to underlying cognitions (Smith & Eatough, 2007). While IPA shares a concern with mental processes with the social cognition paradigm, it diverges significantly in preferred methodology for examining these processes (Smith & Osborn, 2003).

The aim of IPA is to explore lived experience, seeking to illuminate the individual's personal perception or account rather than the formulation of objective statements about the object or event itself (Smith et al, 1999). Although IPA is concerned with understanding what the particular respondent thinks or believes about the topic under discussion, it recognizes that these cognitions are not transparently available, and that analytic processes are required. As this methodology is interpretative, access to the experience of another depends on, and is also complicated by, the researcher's own conceptions (Smith, 1999). This means that the balance of 'emic' and 'etic' positions is critical in IPA. In the former (phenomenological, insider) position, the researcher prioritizes the participants' world view as central to the account, while in the latter (interpretative, outsider) position, the researcher attempts to make sense of the participants' experiences in a way that answers a particular research question (Reid et al, 2005). This is attempted through a subjective and reflective process of interpretation (Smith et al, 1999). The analyst engages in an inductive process whereby the original ideas are continually compared and contrasted to the textual evidence. This process of coding, organising, integrating and interpreting of data is detailed and labour intensive (Reid et al, 2005).

The outcome of all these analytic and evaluative processes in IPA is a set of themes, often organised into some form of structure. These themes typically provide the topic and focus for the analytic commentary in IPA reports. This interpretative commentary frequently makes use of verbatim examples for illustration and support. Reid and colleagues (2005) state that a successful analysis using IPA is: 1) interpretative/subjective - results are not presented as facts; 2) transparent - interpretations are grounded in examples from the data, and; 3) plausible - to participants, analysts and general audiences.

Smith and colleagues (1999) describe two approaches to IPA: (a) The basic method, an ideographic case-study approach, suitable for small samples of up to ten respondents resulting in a single case study or an exploration of themes shared between cases, and (b) a method recommended for larger sample sizes that includes additional procedures for exploring patterns and relationships within and between conceptual groups. These procedures can be particularly useful when a theoretical explanation or model is the goal of the research.

IPA is not a prescriptive approach, but instead provides a set of flexible guidelines that can be adapted for specific research purposes (Smith & Eatrough, 2007). It provides a basic process of moving from descriptive to interpretative, but does not seek objectivity through a detailed, formal procedure (Smith et al, 1999). There is no attempt to test a predetermined hypothesis of the researcher; rather, the aim is to flexibly explore a topic in great detail (Smith & Osborn, 2003). The majority of published studies using IPA are within the field of health psychology, where IPA's engagement with subjective meaning usefully prioritizes an in-depth understanding of the individual's experience of health and illness. However, IPA has been successfully applied to an extensive range of psychological inquiry (Brocki & Wearden, 2006). Relevant to the present studies, IPA has been used in research with participants with psychotic disorders (e.g. Knight et al, 2003; O'Toole et al, 2004; Rhodes & Jakes, 2000), and very recently applied to the study of recovery from psychosis in particular (e.g. Billings et al, in preparation; Pitt et al, 2007). Increasing confidence in IPA is reflected in the accelerated rise in published studies across a wide range of psychological inquiry (Reid et al, 2005).

Analytic Procedure

The data in the present study were analysed using IPA procedures outlined by Smith and colleagues (1999) specifically for large sample sizes. The topics of interest are the subjective experience of recovering and the meaning of recovery among individuals early in the course of a psychotic illness who had received treatment in a specialized early-intervention program. Because we were asking two distinct research questions of the data (meaning of recovery and experiences), descriptions of experienced processes of recovery were distinguished from subjective meanings of "being recovered" throughout the analysis, and the two topics were analysed separately. Separate master lists for each transcript were made; one set of lists included themes related to descriptions of the meaning of recovery, and the other set of lists included themes relating to subjective processes of recovering. However, there were occurrences where the same text was included in both analyses, as some aspects of recovery were described as processes.

CHAPTER 3 – MANUSCRIPT 1
"The Personal Meaning of Recovery among Individuals Treated for a First-Episode of Psychosis"

The Personal Meaning of Recovery among Individuals Treated for a First-Episode of Psychosis

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Abstract

Background: Despite the abundance of reports of symptomatic and functional outcome in individuals treated in early specialized intervention programs (SEIP) for psychotic disorders, there are currently no reports of self-evaluated recovery and little understanding of the subjective nature of recovery in early phase of psychotic disorders. An enhanced understanding of subjective notions of recovery is important for the development and evaluation of interventions that are not only effective but also meaningful to both service-users as well as providers.

Objective: This study examined subjective definitions and rates of recovery among individuals recently treated in a SEIP.

Method: Semi-structured interviews were carried out with thirty individuals in the first few years following treatment of a first-episode of psychosis. Interpretative Phenomenological Analysis was used to examine variations in the personal meanings of recovery. A typology of recovery definitions based on phenomenological descriptions was constructed. In addition, subjectively appraised recovery and objectively measured recovery were compared for congruence.

Results: From the subjective point of view, recovery is a multidimensional experience and for most individuals a personalized and achievable goal. Individuals described recovery as a state comprising improvement in one or more domains of "symptom recovery," "social recovery," and "psychological recovery." Congruence between subjective and objective definitions of recovery revealed agreement in some domains (e.g. symptom improvement), while highlighting recovery domains of subjective importance in addition to those typically used in outcome research (e.g. recovery of the self).

Conclusions: Service-users can identify subjective recovery criteria that provide an important contribution to the development of a consensus outcome measures that are meaningful to service-users as well as clinicians and researchers. Understanding subjective notions of recovery can help to guide service design and practices that are oriented to the recovery goals of service-users.

The Personal Meaning of Recovery among Individuals Treated for a First-Episode of Psychosis

Recovery from schizophrenia has now been widely discussed within the mental health field for nearly two decades, fuelled by a more hopeful view of illness course and recovery. Definitions of recovery include those that are philosophical, those based on grounded theory from lived experience, and those involving operational definitions that have shaped practices and research studies. These definitions, which view recovery alternatively as a process or outcome, are often at odds with one another, and both are currently lacking consensual criteria specificity and standardized measurement (Bellack, 2006; Liberman & Kopelowicz, 2005). Therefore, at this stage it is clear that people with schizophrenia do experience recovery, but without reliable and valid measurements, scientific understanding of recovery is limited. If "recovery" is to fulfill its promise of transforming services to enhance meaningful and positive outcomes it is critical that the issues of conceptual confusion and empirical measurement be resolved.

The definitions of recovery found in the scientific literature are generally from a disease perspective and involve the elimination or reduction of symptoms and a return to premorbid levels of function. This definition would be conceptualized and measured as an "outcome" - an end-point of functioning achieved and maintained for a specified period of time. Within this common concept of recovery, the definitions currently in practice range from relatively restricted disease-focused definitions, to more elaborate multidimensional definitions (for a review see Liberman et al, 2002), but is most often determined by presence or absence of psychotic symptoms. The outcome measures most frequently used in clinical studies of schizophrenia include levels of symptoms (typically positive symptoms, although some also measure the presence of depression, anxiety and/or negative symptoms), social disability and resource utilization (for a review see Liberman et al, 2005). There has been increasing interest in developing a standard, operational definition of recovery that reflects both the course and consequences of the illness and can be applied to empirical investigation.

Recently, the Remission in Schizophrenia Working Group sought to develop a set of operational criteria for symptom remission in schizophrenia that can be applied to clinical practice and research across a range of treatment settings and that incorporates both symptom severity and duration components (Andreasen et al, 2005). They proposed a definition of remission of symptoms that requires complete or relative absence of symptoms on the grounds that remission determination should be made on "both clinical and heuristic grounds" and related to the clinical goal of "remission-recovery" in schizophrenia. This definition proposes a period of symptom remission of at least six months in duration, reflecting the fact that for the majority of individuals, the course of illness alternates between acute psychotic episodes and stable phases of full or partial remission. While this definition may offer a reliable measure of symptom-based recovery, it is acknowledged to be an incomplete measure of "recovery."

A multidimensional definition of recovery that has received research attention is proposed by Liberman and colleagues (2002). They suggest a definition of recovery that is a "multi-modal, socially normative inventory of personal assets and freedom from psychotic symptoms" (p.258), and as such it combines assessment outcomes in symptomatology, vocational functioning, independent living and social relationships. They justify this combination of outcomes as: i) representing areas for diagnosis of schizophrenia; ii) consistent with the WHO International Classification of Impairment, Disability and Handicap; iii) often cited by consumers as personal goals, and iv) reflecting "social and economic importance."

To date, empirical investigations have typically used these types of researcher-imposed recovery-as-outcome definitions, and few have sought to inform their definition with the lived experience of service-users, despite repeated calls for collaboration in developing a consensus definition of recovery that makes sense to all stakeholders. This goal requires eliciting a range of viewpoints on definition criteria for recovery from service users, caregivers, clinicians and researchers (Andreasen et al, 2005; Liberman et al, 2002). Unfortunately the diverse perspectives of professionals, family members and consumers have not been systematically integrated in the investigation of recovery (Bellack, 2006).

This reluctance may be in part due to the perception that scientific and consumer concepts of recovery are irreconcilable (Davidson & Roe, 2007). Current studies of outcome tend to emphasize return to normal function, whereas consumer advocates often use "recovery" to describe a process of managing one's mental illness, moving beyond the psychological effects, and pursuing a personally meaningful and fulfilling life in the community (Anthony, 1993). This latter meaning emphasizes the importance of hope, supportive relationships, personal responsibility, empowerment, social inclusion, meaning and the pursuit of individual goals, but not necessarily the absence of symptoms (Davidson, Sells, Sangster, & O'Connell, 2005). Therefore, the notion of recovery put forth by the Recovery Movement and reflected in much of the qualitative research to date is that recovery is experienced as a process, not an outcome. There are various recovery instruments that have been developed, for the most part, from analyses of subjective descriptions of recovery. Some of these instruments assess components of the recovery process as experienced (Corrigan et al, 1999; 2004; Jerrell et al, 2006; Resnick et al, 2005), while others assess recovery as a series of stages or phases (Andresen et al, 2003; 2006). All of these instruments are in the early stages of empirical validation. As such, qualitative research on recovery has examined descriptions of the subjective recovery experience as a collection of processes, while empirical research has focused on developing and applying operationalized outcome definitions of "recovery," almost exclusively without collaboration with service users.

It is uncertain whether or not consensus regarding outcome definition criteria is possible among service providers, researchers and service-users, given the emphasis on recovery as a process, rather than an outcome, by service-users. While acknowledging that recovery may very well be a lifelong process, it is important to determine whether it is nevertheless possible for service users to identify subjectively important components of the experience of "being recovered," or if this schism of meaning between stakeholders renders a service-user-derived (or collaborated) outcome measure of recovery an impossible and/or reductive undertaking. Therefore, it is important to investigate the viability of developing a shared, consensual definition of recovery that honours as much as possible various perceptions of valued and desired treatment outcomes.

Preliminary evidence suggests that there are both shared notions and distinct differences in the meaning of "being recovered" between health professionals and service users (Liberman et al, 2002; Tsang & Chen, 2007). There is some evidence that subjective definitions of recovery tend to be "harsher and harder to meet than those of professionals" (Ng et al, 2008). To date, the limited amount of research on this topic has been undertaken with individuals with chronic mental illnesses (e.g. Ng et al, 2008). There is currently no research examining subjective recovery *definitions* among individuals early in illness course despite evidence that ideas about the illness are different for individuals early in recovery compared to later in illness course (Larsen, 2004). Although a preliminary instrument was developed to assess perceptions of illness, treatment, appraisal of self-recovery and appraisal of relapse risk among individuals with recent-onset psychosis (Chen et al., 2005), this instrument focuses specifically on the formation of illness attitudes, rather than recovery attitudes.

It is important to understand ideas of recovery specific to this unique group of service-users so that positive treatment outcomes in areas of subjective importance can be identified. Integrating such knowledge into early intervention service design and practices could be especially useful for enhancing our understanding of the varied responses to treatment and service engagement. This information would also be helpful in the identification of critical components of recovery that traditionally have not been included in recovery outcome definitions dominated by professional perspectives.

The primary aim of this research is to identify the meaning of "being recovered" among individuals who have been recently diagnosed with a psychotic disorder in order to aid in building consensus of divergent recovery ideas and priorities (among service-users, clinicians and researchers) by which to guide service design and practices. This investigation into subjective notions of "being recovered" (e.g. cure versus process) combines quantitative "objective" analysis of recovery outcomes with subjective perspectives of the meaning of "being recovered." In so doing, we seek to address two primary research questions: 1) what is the congruence of objective research-defined recovery and self-report rates of recovery, and 2) what is the meaning of "being recovered" among individuals who are early in recovery following their first psychotic episode.

Method

This investigation of the lived experience and subjective meaning of "being recovered" among individuals previously treated in a two-year specialized early-intervention program for psychotic disorders used various quantitative objective measures of outcome, as well as a qualitative design and Interpretative Phenomenology Analysis (IPA) method for analysis of participant narratives.

Participants

Participants received intensive specialized care for two years following their first episode of psychosis, followed by a less intensive but specialized care at the time of interview. Participants were recruited from a sample enrolled in a long-term outcome study at the Prevention and Early Intervention Program for Psychoses (PEPP) in London, Canada. The nature of this early intervention program and standard assessment protocol has been characterized elsewhere (Malla et al, 2003; www.pepp.ca). At the time of interview, individuals were 3-5 years post program entry, with just over half (56.7%) interviewed three years after treatment initiation, and approximately a quarter (26.7%) interviewed five years after treatment initiation. The study from which participants were recruited involves annual comprehensive assessment of outcome in the domains of symptomatology, functioning (social, vocational and cognitive), and quality of life over the five years following program entry and treatment initiation. All consecutive participants presenting for their annual study follow-up assessment were invited to participate in a one-time qualitative interview to explore subjective ideas of recovery. Of those approached, 30 (90%) individuals agreed and completed the interview. The inclusionary criteria for the source study were: treatment for two or more years in the early-intervention program, diagnosis of a psychotic disorder, 16 years of age or older, competence to provide informed consent, and no evidence of mental retardation. Participants provided informed consent as approved by the University of Western Ontario Ethics Board for Health Services Research.

All participants were interviewed at the time of program entry using the Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I: First et al, 1995) to determine diagnosis. Clinical and demographic information are presented in Table 1. Participants ranged in age from 19 to 42 years (M = 25.9 years, SD = 5.3). Just over three-quarters (76.7%) of participants were male and 90% were single.

Measures

Qualitative interview. A semi-structured interview guide was designed to elicit in-depth accounts of the subjective meaning of psychosis and recovery. The specific topics included current self-assessment of recovery, as well as identification and description of critical components and general ideas about the subjective meaning of "being recovered." Other related topics included in the interview (e.g. experienced processes of recovery) were analysed separately and the results reported elsewhere. The semi-structured interviewed was developed according to the guidelines outlined by Smith and Osborn (2003). Diagnostic and clinical terms (e.g. "schizophrenia" or "psychosis") were not used in the interview unless mentioned by the participants, and instead the terms used by the participant were adopted by the interviewer. At the end of the qualitative interview participants were asked to rate current psychotic symptoms on a scale of 0-10 (0 = absent) by a description of symptoms, rather than the term "psychosis" (e.g. "hearing or seeing things that are not there").

Interviews were conducted by the first author at the time and place of convenience to the participant. The length of interviews ranged from one to three hours. Interviews were audio-taped and transcribed verbatim.

Quantitative recovery assessments. In addition to the qualitative interview, assessment of "recovery" according to various research criteria was undertaken through quantitative measures. These assessments of participants' recovery were evaluated according to the following definitions: 1) remission of positive symptoms at the time of the interview, 2) remission of both positive and negative symptoms at the time of the interview, 3) remission according to consensus criteria outlined by the Schizophrenia Working Group (Andreasen et al, 2005) that consists of positive and negative symptom remission for at least six months prior to interview, and 4) "recovery" according to the definition proposed by Liberman and colleagues (2002), a multidimensional definition that encompasses remission of positive and negative symptoms, at least half-time competitive employment or school participation, independent living (no day-to-day supervision for daily activities and schedule from family or other caregivers) and social functioning in peer relationships for a period of two consecutive years.

Symptom remission for all definitions were determined by ratings of positive and negative symptoms using the Scale for the Assessment of Positive Symptoms (SAPS) (Andreasen, 1984a) and the Scale for the Assessment of Negative Symptoms (SANS) (Andreasen, 1984b). Rating thresholds employed were proposed by The Schizophrenia Working Group, and correspond to diagnostic criteria for the disorder, namely psychoticism (hallucinations and delusions), disorganization and negative symptoms. Therefore, this definition of remission of low-mild symptom intensity level corresponds to ratings of two or less on each global rating for the SAPS and SANS. Assessment of symptom remission duration (for both Andreasen's and Liberman's criteria) was determined using SAPS and SANS ratings for symptom remission at the time of interview, along with weekly positive and negative symptom ratings for the specific duration (six months and two years respectively). In order to assess the criteria for the three additional dimensions of Liberman's recovery definition (vocational and social functioning), ratings on the Life Chart Schedule, an instrument developed in collaboration with the WHO to elicit longitudinal outcome data, were reviewed (WHO, 1992). The specific Life Chart Schedule ratings were those designed to elicit social conditions (employment, study, living arrangements), and were supplemented by annual ratings for the previous two years for the Daily Life Activities domain and Social Relations/Support domain of the Wisconsin Quality of Life Scale - Provider (WQL-P) and Client Versions (WQL-C) (Becker et al, 1993). These ratings of Liberman's functional and social functioning were completed by two independent raters (for the eight participants that met Liberman's criteria for two years of full symptom remission) with 100% agreement. The assessment of "recovery" was irrespective of premorbid states for all measures.

Analysis

The data were analysed using Interpretative Phenomenological Analysis (IPA) procedures outlined by Smith and collaborators (1999). The IPA researcher's goal is to develop an in-depth understanding of the individual's account of the processes by which they make sense of their experiences rather than the formulation of objective statements. This exploration of the meanings used by informants as it relates to a particular topic is attempted through a subjective and reflective process of interpretation of the individual's account by the researcher (Smith et al, 1999). IPA is not a prescriptive approach, but instead provides a set of flexible guidelines that can be adapted for specific research purposes (Smith & Eatrough, 2007). While IPA typically retains an idiographic focus, with ten participants at the higher end of most recommendations for sample size, Smith and colleagues (1999) state that there is no right or wrong IPA sample size, and that larger samples are useful for focus groups or comparison groups, where the exploration of one phenomenon from multiple perspectives can help the IPA analyst to develop a more detailed and multifaceted account of that phenomenon. We chose to include a large sample size (by IPA standards) of 30 participants due to the known variation in recovery experiences and a desire to explore patterns of similarity and difference in meaning-making within the group. Smith and colleagues (1999) outline a specific framework and guidelines for conducting IPA with a larger sample size (generally greater than 15 participants). These guidelines were followed in the analysis.

The transcripts were examined sequentially, each carefully and repeatedly read before transforming initial ideas into themes that attempted to capture the essential meaning of the text. These themes were subsequently evaluated and combined into general higher-order themes for each transcript before bringing them together to identify general broad categories between cases. This involved searching for patterns and connections between ideas, as well as contradictions and tensions, while attempting to make thematic linkages between diverse themes. Once general categories were identified, associated text was examined to elucidate shared aspects of the participant's experience in relation to the general theme, initially coding these aspects provisionally, and then grouping them into meaningful categories. Throughout the analysis, constant reflection and re-examination of the verbatim transcripts was utilised to confirm that constructed themes were meaningfully and closely connected to the source material.

While the goal of IPA is an enhanced understanding of the content and complexity of meanings rather than measuring their frequency, the benefit of large IPA sample sizes is the opportunity for exploring patterns and relationships, and it is therefore useful for facilitating the analysis of patterns of similarity and differences within and between conceptual groups. Because we are interested in potential variations in the experience of "being recovered," we examined the distribution of categories within and between individuals. Pertinent examples of applications of IPA procedures to construct meaning-based typologies among subjective accounts were consulted for guidance (e.g. Rhodes & Jakes, 2000).

In addition to the qualitative analysis of subjective ideas of recovery and the meaning of "being recovered," the distribution of self-reported recovery rates was also calculated. The distribution of recovery according to each outcome-research definition was also calculated for each of four research outcome definitions: 1) positive symptoms remission at time of interview, 2) positive and negative symptom remission at the time of interview, 3) remission as outlined by Andreasen and colleagues (2005), and 4) remission as outlined by Liberman and colleagues (2002). The congruence between self-reported recovery and objectively defined recovery was calculated for percentage of agreement both within and between cases for each outcome definition. Finally, self-reported recovery was compared to self-assessed psychotic symptoms.

Results

Rates of recovery and non-recovery

In addressing our first research question of the congruence between objective and subjective rates of recovery, we compared rates of recovery (defined according to various objective research criteria) to self-reported rates of recovery. All individuals were asked in the course of the semi-structured interview whether they had, in their estimation, recovered from psychosis. Of the 30 individuals interviewed, approximately half (57%) stated that they had recovered according to their personal definition of recovery. Many of the individuals who stated they had not yet recovered noted that they had nonetheless made considerable gains toward recovery.

These recovery rates are in considerable contrast to the recovery rates according to positive symptom remission at the same time point, where 24 (80%) participants were in remission from positive symptoms, and only 6 (20%) participants were not. This suggests that there is more to the subjective meaning of "being recovered" than just the experience of positive symptoms. Interestingly, people who felt they had not recovered showed poor congruence to non-recovery positive-symptom remission (only) ratings (46.2% agreement), with seven people (23.3%) reporting themselves as not recovered who were in remission of positive symptoms. See Figures 3 and 4 for subjective/objective recovery agreement and subjective/objective non-recovery agreement distributions.

This congruence increases significantly when negative symptoms are included in the research outcome definition. In fact, the best congruence between self-reported recovery and "objective" recovery is with remission criteria of both positive and negative symptoms at the time of interview (no specific duration required). The rates according to this comparison are 57% for self-reported recovery and 50% for positive+negative symptom remission, and 43 % self-reported non-recovery and 50% non-remission. Even more illuminating, the congruence of those reported as recovered with those individuals in remission (positive+negative at interview) was 82.4%, and congruence of those reported as not recovered and not in remission was 92.3%.

However, this congruence drops considerably when the duration criterion of six months is added. Despite the superficial appearance of agreement in rates of recovery, of those individuals who assessed themselves as recovered, only 64.7% meet Andreasen's criteria of positive and negative symptom remission for a period of six months (or more). Not surprisingly, as stricter definitions of objective recovery are applied to the sample, the rates of objective recovery greatly decrease. For example, while 80% of the sample meet recovery criteria of positive symptoms only, this is reduced to 16.7% when Liberman's multidimensional and longer-term recovery criteria are applied.

Congruence of self-report recovery to self-reported symptoms

In order to explore the relationship of subjective experience of recovery to the *subjective* experience of psychotic symptoms, individuals were asked to rate their own psychotic symptoms between 0 and 10 (with 0 representing a complete absence of psychotic experiences). However, the self-report symptom rating responses ranged only from zero to five (see Table 2 for distribution with self-reported recovery). A little under half of the participants (43%) rated their symptoms as either a "zero" or "one." Examination of congruence of symptom report with self-reported recovery status revealed reasonable agreement between these subjective symptom ratings and self-assessment of recovery (84.6%). This means, however, that two participants who rated their experience of symptoms as zero also indicated that they had not recovered. There was also considerable agreement between those individuals who rated their symptoms as three or above to their self-assessments as "not recovered" (85.7%). Interestingly, there was some variation for those individuals who rated themselves a "two" (suggesting a mild rating) for symptom severity – these four individuals were equally divided in their respective subjective assessments of recovered or not recovered.

Qualitative definitions of recovery

Analysis of themes regarding the meaning of recovery revealed four general categories of recovery definitions. These categories are (in order of prevalence): 1) illness recovery, 2) psychological recovery, 3) social recovery, and 4) recovery is not possible. See Figure 5 for distribution of themes.

Illness recovery. The "illness recovery" category incorporates various aspects of symptomatic alleviation. For many individuals, descriptions of "illness recovery" included affective, cognitive and negative symptoms in addition to positive symptoms of psychosis. Approximately three quarters (77%) of the sample identified one or more affective, cognitive, positive psychotic and/or negative psychotic symptom domains in the recovery definitions. Sixty-percent of informants offered a definition of illness recovery exclusive to positive psychotic symptoms.

For some individuals, illness recovery was described not as an *elimination* of psychotic symptoms, but as subjective control over the extent and influence of the symptoms. Therefore there exists variation between individuals in the threshold of symptoms that are experienced subjectively as recovery. This is likely related to subjective distress rather than simply presence or absence of symptoms. This individual variation may account for the discrepancy in subjective symptom ratings and self-evaluation of "recovery" attainment. However, it should be noted that the subset of individuals (10%) who made this explicit distinction was comparatively small in this sample.

Psychological recovery. The category of "psychological recovery" encompasses experiences corresponding to the psychosis-related losses of a coherent sense of self and a sense of control. Approximately two thirds (66.7%) of participants included one or more sub-themes of psychological recovery in their recovery definitions. The component subthemes of "psychological recovery" were: "knowing something is wrong," "understanding the illness," "being able to do something about it," "accepting the illness," "back to being myself/feeling better about myself" and, "putting it into perspective."

"Knowing something was wrong" was described as a subjective awareness of change in one's self-experience. "Understanding the illness" was described as a sense of having a coherent and plausible framework, or explanation, for the experience of psychosis that was congruent with the illness experience and beliefs. This was directly linked with "acceptance of illness," the experience of having reconciled one's perspective on the meaning of the experience (e.g. short-term or chronic). Being able to do something about it," reflected the experience of knowledge regarding potential (personalized) avenues for agency and control of the experience (often described as a developed "self-awareness"), and the experience of being able to enact these strategies. This component of recovery often involved specific lifestyle changes in the best interest of one's recovery. "Back to being myself/feeling better about myself" was experienced as a restored sense of self that encompassed multiple meaningful dimensions. This restoring experience related to the loss of self experienced as a result of the illness and the loss of self experienced as a part of the social and personal consequences of the illness experience. Finally, "putting it in perspective" was described an experience of one's self and life where the illness was not a dominant part of their day-to-day experience. This subtheme sometimes included a positive and accepting perspective on life. The component themes of "psychological recovery" reflect various recovery *processes*, but were appraised and experienced as indicative of "being recovered" once important tensions were resolved.

Social recovery. Sixty percent of participants included a "social recovery" subtheme in their recovery definition. The "social recovery" category incorporates the themes of "being able to talk to people/knowing how to talk to people," "working/going to school," "having friends," and "having a partner/spouse." At its essence, the meaning of social recovery was a positive social identity and normative social inclusion by many people:

> *I'll know if recovery's occurred for myself when I do get a job and I keep the job. And I do make new friends and, and get into a relationship. So once those things start happening and I'm able to keep those things in my life, then I'll know recovery has happened.*

Over half (53%) of individuals identified meaningful engagement in a valued role as a component of recovery definitions. Three quarters (40% of all study participants) of those individuals indicated specifically that employment would be an essential component of recovery. The weight given to goal of role resumption in recovery varied between individuals. For some individuals, the specific role did not have to be congruent with the prior-to-illness role in order to be experienced as adequate for their "being recovered" role functioning criteria, while others emphasized the importance of developmentally normative functioning.

Forty-percent of participants specifically identified social participation in their recovery definitions. Specifically, recovery was experienced as participation in peer relationships for many individuals. Romantic relationships were also frequently described as an indicator of being recovered. While relationships with family were often described as playing a crucial *role* in recovery, these relationships were only rarely described as a specific *component* of the experience of "being recovered."

A subset of individuals indicated that "social recovery" was (or would be) experienced as establishing independent adult living. The individuals who described the important of independence in recovery definitions emphasized that "being recovered" involved competence and maturity as a young adult. Restored social confidence was also a critical component in the meaning of recovery for many individuals. This was described as an ability to confidently approach and engage in relationships.

Recovery is not possible. For most participants, one could have the experience of "being recovered" while acknowledging the continued presence of illness and/or vulnerability to relapse risk. In contrast, some individuals experienced "being recovered" as something that could only occur if one no longer had an illness (or had not had one in the first place). Two individuals indicated that recovery from psychosis was impossible, because the illness was inevitably a chronic condition:

> *I can't say I'm recovered, because I'm still ongoing, you know. I'd like to have a recovery. I never thought about that, I never talked that term with the doctor before, so I don't know. Maybe I am recovered, with the voices being gone, but they said I'd have to be on medication for the rest of my life. It doesn't go away.*

> *I'm not recovered. That would make me not mentally ill anymore.*

These were the two individuals previously identified as offering a symptom rating of "zero" while also providing a self-assessment of "not recovered." This meaning of "recovery" as synonymous with "cure" was infrequent, but illustrates the considerable conceptual variation in subjective notions of recovery.

Recovery Definition Accounts

The components of recovery identified by individuals were highly varied, ranging from straightforward absence of symptoms to complex definitions involving multiple domains. Five permutations of recovery domain inclusion or exclusion were present in the sample. The distribution of these recovery definition accounts is illustrated in figure

6. These variations in "recovery types" included: 1) "I+P+S" - combined themes from all three recovery domains, 2) "I+P" - combined "illness" and "psychological recovery" domains, 3) "I+S" - combined "illness" and "social recovery" domains, 4) "P+S" - combined "psychological" and "social recovery" domains, and 5) "I" - exclusive "illness recovery" domain inclusion. The least common recovery account was the exclusive "illness recovery" typology (10%). More than three quarters of participants (76.7%) proposed a composite definition of recovery comprised of two or more recovery domains. The most common recovery typology (26.7% of the sample) was a tri-composite (illness, psychological and social recovery).

Medication in recovery appraisal

Treatment participation (e.g. attending clinic appointments) was a commonly identified criterion for "being recovered" for many individuals. Specifically, medication behaviour was described as a critical part of "being recovered" by more than a third (37%) of participants. However, there was direct opposition between these individuals regarding the specific role of medication in recovery definitions. One-fifth of study participants indicated that taking medication was an integral component of recovery, whereas just under one fifth (17%) indicated that *not* taking medication was a prerequisite for recovery.

Failure to recover

Those individuals (43% of the sample) who described themselves as "not recovered" typically indicated that this was due to non-achievement of desired social roles, or to not yet experiencing remission of symptoms. Some of these individuals described having a "previous recovery" when they had a period of symptom alleviation or elimination and/or had returned to valued to roles prior to a relapse. Optimism for a "return" to "being recovered" was emphasized by these individuals, and the necessary steps described. These participants appeared to be confident (or at least stated) that they would once again recover:

> *I haven't fully recovered right now, but I see me recovering ... because I have friends who are older than me with mental illness and they have fully recovered. I have one*

> *friend in particular who told me that when he was my age he had a really hard time and didn't think he'd ever recover, but he did slowly recover, and now he's fully recovered. So I know it can happen.*

In contrast, many of the individuals who stated they had never recovered expressed disappointment, frustration and even despair about this fact. They often described their experience with psychosis as a prolonged, difficult battle with a powerful and destructive force over which they had limited control. In response to my question "would you say you have recovered?" one woman responded:

> *I don't know. It could be unreachable for the rest of my life. I don't know. According to people, I'll be able to get out of it, but is there such a thing as 100% recovery in psychosis?*

And finally, some individuals who identified themselves as not recovered stated that recovery was not a possibility for those with mental illness (as described above). While these individuals often observed that one could perhaps hope and strive for improvement, negative perceptions about illness and social stigma barriers to regaining a sense of control and well-being were a common focus of recovery descriptions.

Discussion

Our findings confirm that individuals can make self-assessments of the extent of their recovery, and that they hold specific meanings that they apply to their appraisal of "being recovered." Despite the highly individualized nature of the recovery concept and experience, the findings suggest that subjective recovery definitions generally share some or all of themes of self reconstruction, social and vocational functioning and symptom alleviation. Distinct differences in the meaning of recovery illustrate the broad continuum of recovery notions even within a relatively homogeneous group. Comparisons of subjective and objective rates and components of recovery revealed important points of convergence and divergence.

The meaning of "being recovered"

It appears that subjective definitions of recovery vary greatly between individuals, are deeply contextual, and reflect the range social and cultural models of mental illness that are adopted or rejected by the individual. The variation in "possibilities for recovery" that was found among recovery meanings is in line with Estroff and colleagues' (1991) finding that temporality (whether the informant sees his or her condition as acute (recurrent, time-limited or chronic) is an important dimension of illness explanations. The directly opposing perspectives regarding the role of medication in recovery definitions suggest the influence of variations in contextual notions of mental illness adopted by individuals in their subjective models of recovery (recovery versus cure). The specific potential factors that may account for some of this variation (e.g. gender, severity of first episode) were not explicitly examined in the analysis.

Along with acknowledgment that many of the processes of recovery were ongoing, the vast majority of individuals appeared to easily conceive of recovery as an end-state, albeit one that could be repeatedly lost and regained. Our findings are in line with those studies that have explored service user recovery definition criteria that have found evidence of a divide between informants in personal meaning of "being recovered" as a process versus a multidimensional collection of outcomes (e.g. Corrigan et al, 2005; Thornhill et al, 2004). Similar to these studies, *some* participants defined recovery as an ongoing process, while others defined recovery as the cessation of psychotic symptoms as well as optimal functioning in multiple life domains (work, satisfying interpersonal relationships and independent living). The latter definitions are similar to "recovery" definitions offered by outcome researchers.

Congruence of subjective and objective ideas of recovery

There appears to be better congruence between objective and subjective definitions of recovery when negative symptoms are included in the definition. This congruence worsens when the required six-month duration of remission is applied. However, this non-congruence between recovery rates stems from those individuals who identify themselves as recovered. Among those individuals, only 64.7% met Andreasen`s criteria for remission, whereas the rate of agreement between non-recovery/not-in-remission remained the same when the duration of symptoms criteria was applied. This suggests that some individuals may not evaluate a temporal dimension in symptom reduction-elimination as necessary to subjectively experience "being recovered."

It is perhaps not surprising that so few individuals (16.7%) met recovery criteria according to Liberman's definition given its multidimensional complexity and demanding duration (two years). This may be because a sustained duration of two years is an unreasonable requirement for remission duration given that a large number (56.7%) of individuals in the present study were only three years into recovery following their first-episode. It has been observed that this initial period of recovery is primarily focused on symptomatic recovery, while social and functional recovery are increasingly regained following symptom stabilisation (Whitehorn et al, 2002). In addition, it may be unreasonable to expect that it is normative for adolescents or young adults to sustain education or vocational activity for a consecutive period of two years and/or to be independent to the degree described in Liberman's definition.

Domains of recovery

The subthemes of the "psychological recovery" domain are abundantly confirmed by research that has reported the critical importance of acceptance of illness (e.g. Cunningham et al, 2005; Kotake Smith, 2000; Munetz & Frese, 2001; Young & Ensing, 1999) and regaining a subjective sense of control over the illness (e.g. Cohen, 2005; Ochocka et al, 2005; Pitt et al, 2007) in the subjective experience of recovery. Some individuals in the present study experienced "being recovered" as recapturing their "old self," while others experienced it as an altered and new identity. Regardless, many participants described recovery as consisting of a self in line with a desired self, where the experience of the illness did not dominate one's identity. This finding corresponds to the abundant qualitative research on recovery that describes reconstruction of a positive and efficacious sense of self as an essential aspect of recovery from schizophrenia (e.g. Davidson, 2003; Davidson & Strauss, 1992; Estroff, 1989; Czuchta & Johnson, 1998; Jacobson, 2001; Jacobson & Greenley, 2001; Mancini, 2007; Noiseux & Ricard, 2007; Pettie & Triolo, 1999; Spaniol & Koehler, 1994). It is probable that the notion of "insight" would be related to the subjective perception of the importance of these aspects of recovery. Variation between individuals could be influenced by their interpretation of their experience (isolated episode versus chronic illness) and their perception of the personal and social consequences of their experience. However, nearly all individuals in the sample (93.3%) identified their experience as an illness, so the influence of individual differences in the meaning of the illness concept on the identification of psychological recovery in subjective definitions is likely to be context-dependent.

While it may come as little surprise that subjective definitions of recovery differ from research definitions, the variation between individuals regarding the weight of experienced symptoms in subjective assessments of recovery is noteworthy. These individual differences are illuminated when exploring subjective definitions of recovery. In contrast to the consumer literature on recovery that asserts that recovery from serious mental illness does not require remission of symptoms or other deficits (e.g. Deegan, 1988), we found that most (70%) of the individuals interviewed regarding their personal definitions of "being recovered" included symptom alleviation (in many cases elimination) as one essential component. Therefore, it appears that individuals may perceive themselves to be "recovering" while experiencing symptoms and other deficits, but "recovered" only once these experiences stopped. The importance of a sense of control over symptoms that was reported by some informants is also confirmed in the literature (Deegan, 1996; Fisher, 1994; Ridgeway, 2001) as subjectively important in recovery.

Meaningful engagement in valued roles and participation in normative relationships were common critical components in the meaning of recovery. Subjectively experienced "social recovery" required role functioning of a fully normative level (i.e. competitive full-time employment) for many individuals. These findings confirm the vital role of meaningful social connections and fulfilling roles within the recovery experience (Davidson et al, 2001; Mancini, 2007; Sells et al, 2006; Topor et al, 2006; Young & Ensing, 1999). Given the developmental stage of the majority of participants, it is not surprising that friendships and romantic relationships were the most frequently identified relationship components of "social recovery." This confirms previous finding of the critical importance of friendships in the early recovery experiences of young adults (MacDonald et al, 2005; Beanlands et al, 2006).

Medication

Interestingly, some (17%) participants reported that recovery could not occur if they still needed medication. This finding is consistent with current research on service-user recovery definitions carried out with both longer-term (Corrigan et al, 2007; Ng et al, 2008; Thornhill et al, 2004) and recent onset (Chen et al, 2005) illness populations. It appears that the issue of maintenance medication in recovery definitions may differ between service users and providers (Liberman, 2002), with some service-users identifying medication discontinuance as a necessary condition of "being recovered." It is important to understand this difference, as it may illuminate critical incompatible ideas of the meaning of recovery within the therapeutic setting. These conflicting ideas may hinder effective communication and mutual understanding between service providers and service users.

Implications for measuring recovery

The inclusion of criteria that reflect subjectively important recovery criteria in outcome measures enables the evaluation of treatment interventions as meaningful to service-users and impactful on their subjectively important outcomes. The findings of the present study speak directly to how "being recovered" is experienced and so they offer an important contribution in the development of outcome measures of recovery. The components of the "psychological recovery" domain are very much in line with the consumer model's concept of recovery as recapturing and developing a positive sense of self, meaning and purpose. This supports the inclusion of recovery measures that assess these important aspects of recovery in addition to traditional outcome measures of symptom remission and social functioning in recovery research. This could be accomplished using general "recovery" measures (e.g. Andresen et al, 2003, 2006; Corrigan et al, 1999; 2004) or by measuring the individual components such as empowerment, self-esteem, hope, or well-being (e.g. Noordsy et al, 2002). There remains an important need in developing and validating such measures in order to make this inclusion possible.

However, it is clear that for most individuals, "being recovered" was also experienced as symptom remission (both objectively defined and subjectively assessed). Similarly, both Corrigan and colleagues (1999) and Resnick and colleagues (2004) found that subjective measures of self-reported recovery were strongly and negatively associated with psychiatric symptoms. The large number of individuals (77%) who included remediation of symptoms as at least *part* of "being recovered" validates the assessment of symptom improvement traditionally associated with empirical research on recovery as a subjectively meaningful outcome. It seems the value of the role of symptom reduction in the subjective experience of "being recovered" should not be ignored, or assumed to be primarily an outcome concern of researchers. However, it may be clinically useful to develop and include measures of subjective distress caused by symptoms in outcome assessments, as this would assess the subjective experience of symptoms in addition to measuring their presence.

Finally, the remarkable emphasis of roles and relationships in recovery definitions supports the inclusion of social functioning measures, particularly in peer relationships, in research evaluations of outcome. This finding also confirms the importance of assessing the impact of early phase-specific and multimodal treatment on functional status and quality of life - something that is currently lacking, as research in early intervention has thus far focused on remission of symptoms (Killack et al, 2006; Malla & Payne, 2005). To date there have been no randomized control trials of the effects of different models of treatment on functional and quality of life outcomes (Malla & Payne, 2005).

How, then, should such diverse aspects of recovery be combined and measured? It would seem an enormous challenge to attempt to integrate them all into an amalgamated definition of recovery. Recently, Lieberman and colleagues (2008) suggest that due to heterogeneity in domains of recovery it would be more useful to dispense with global notions of recovery definitions, and instead define recovery in terms of improvements in specific domains. They propose that relevant domains (according to current research) include brain function, symptom control, cognitive function, functional capacity, quality of life and self-agency. The latter category reflects the issues described in the recovery literature, and are somewhat compatible with the components of the "psychological recovery" domain in the present study. This approach appears to be a practical and reasonable solution to the challenge of meaningfully integrating subjectively identified recovery criteria into a global definition of recovery, and permits inclusion of outcome domains specifically meaningful to service-users.

However, even if these psychological processes/outcomes are assessed using instruments designed to measure them or by operationalizing and measuring the component processes using standardized instruments (e.g. measures of hope, empowerment, etc.), there remains the problem of the considerable variation in subjective recovery definitions. It is a challenge to develop "meaningful" recovery measures that stay true to the experience of the individual, when this meaning varies so much between individuals. Noordsy and colleagues (2002) propose that this problem can be addressed by including secondary quantifying measures of personal relevance in order achieve a balance between the needs of objectivity and qualitative value and validity. Slade and Hayward (2007) recently suggested the incorporation of individual preferences into intervention evaluations, such as having participants choose their own primary outcome measure from a selection of standardized measures. Further consideration of this issue by stakeholders would be valuable.

Treatment implications

The findings of subjectively valued and meaningful outcomes have a variety of implications for service design and delivery. The emphasis among individuals on the critical importance of "social recovery" (role and relationship participation and improved social confidence and competence) reinforces the importance of designing and delivering treatment designed to promote positive functional and social outcome. The findings provide support for the importance of supported employment and supported education initiatives in early intervention treatment. The subjective emphasis on peer relationships confirms Davidson and colleagues' (2001) assertion that increasing opportunities for establishing and successfully engaging in friendships should be considered to be a primary focus of recovery-oriented care. It seems probable that simply intervening *early* will not have a beneficial impact on occupational outcome, and that the incorporation of specific targeted interventions early in the course of illness are likely to bring about greater success in vocational functioning improvement (Malla & Payne, 2005). Addressing these areas will be essential for ensuring full, meaningful and sustained recovery in individuals with a first-episode of psychosis (Killack & Yung, 2007).

The finding that comorbid psychiatric symptoms figured prominently in recovery definitions and were at least equally distressing to many individuals as psychotic symptoms suggests that incorporating interventions designed to address these difficulties would be relevant and beneficial for some individuals experiencing early psychosis.

The current finding of the notion of medication as contradicting the possibility for recovery among a subset of individuals supports researchers who have suggested that it is prudent to work with service users to influence their perceptions on this matter (Liberman et al, 2002). Ng and colleagues (2008) argue that doing so is important for improving treatment adherence and enhancing the individual's sense of success and control.

Limitations

Our research has several limitations. One important limitation is that the vast majority of participants were Caucasian, and therefore the findings cannot reflect variations in ideas of recovery that may be more common among other ethnic and social backgrounds. An additional limitation is that recovery definitions were elicited at a single time point, and therefore offers no information regarding the evolution of recovery definitions. This is an important limitation, as it has been noted that ideas of recovery change over time (Estroff et al, 1991). Another potential limitation is the application of IPA methods for such a large sample size. As IPA is an idiographic method, the analysis of large data set risks a relatively superficial interpretation compared to the spirit of idiographic inquiry, with potential loss of subtle nuances in meaning. However, in an attempt to minimize this risk, a deliberate attempt was made to carry out an equally attentive analysis for each case and several cycles of analysis were repeated. Finally, an inter-rater reliability assessment among multiple researchers of the application of coding themes to the text was not completed.

Future directions

It would be desirable to replicate the identified recovery dimensions. The present analysis proposes a framework for exploring variations in recovery definitions through delineating recovery typologies from described lived experiences of recovery. In so doing, these findings suggest potential avenues for further research in explaining these recovery account variations. More research is needed to understand the ways that concepts of recovery are shaped. The influence of sociocultural context, individual factors (e.g. gender) and illness course experiences on subjective ideas and meaning of recovery are important areas of future exploration.

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Table 1:

Demographic characteristics of participants

Characteristics	**n**	**Percentage**
Self-report recovery		
Yes	17	57
No	13	43
Gender		
Men	23	76.7
Women	7	23.3
Ethnicity		
Caucasian	27	90.1
Asian	1	3.3
Black	1	3.3
First Nations	1	3.3
Education		
Not graduated high school	9	30
Graduated high school	10	33.3
Attended some university or college	6	20
Graduated college	2	6.7
Graduated university	3	10
Marital Status		
Single	27	90
Married/Common-law	2	6.7
Divorced	1	3.3
Diagnosis		
Schizophrenia	16	53.4
Schizoaffective	8	26.7
Psychosis NOS	3	10
Substance-induced psychosis	2	6.7
Bipolar I with psychotic features	1	3.3
Employment and school at interview		
Full-time	7	23.3
Part-time	3	10
No	20	66.7
Disability pension at interview	12	40
Living circumstances at interview		
Alone	4	13.3
With family	20	66.7
With spouse	3	10
With friends	3	10
Atypical Antipsychotic Medication at interview		
Yes	27	90
No	3	10

Table 2:

Self-reported symptoms and percentage distributions of self-reported recovery

Symptom Rating (0-10)	Total Number	Number and percent self-report recovery	Number and percent self-report non-recovery
0-1	13	11 84.6%	2 15.4%
2	4	2 50%	2 50%
3	3	0 0%	3 100%
4	1	0 0%	1 100%
5	4	0 0%	4 100%
Unknown	5	2 40%	3 60%
TOTAL	30	16	14

Figure 1: Recovery rates by recovery definition

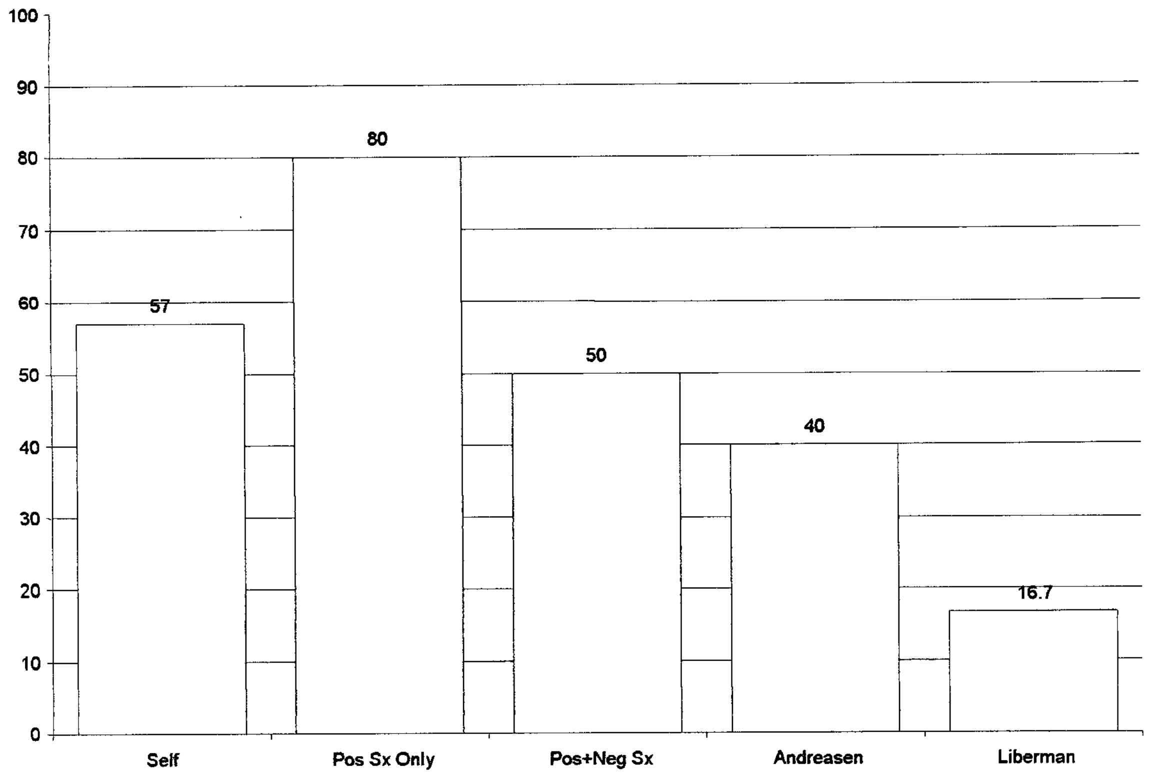


Figure 2: Non-recovery rates

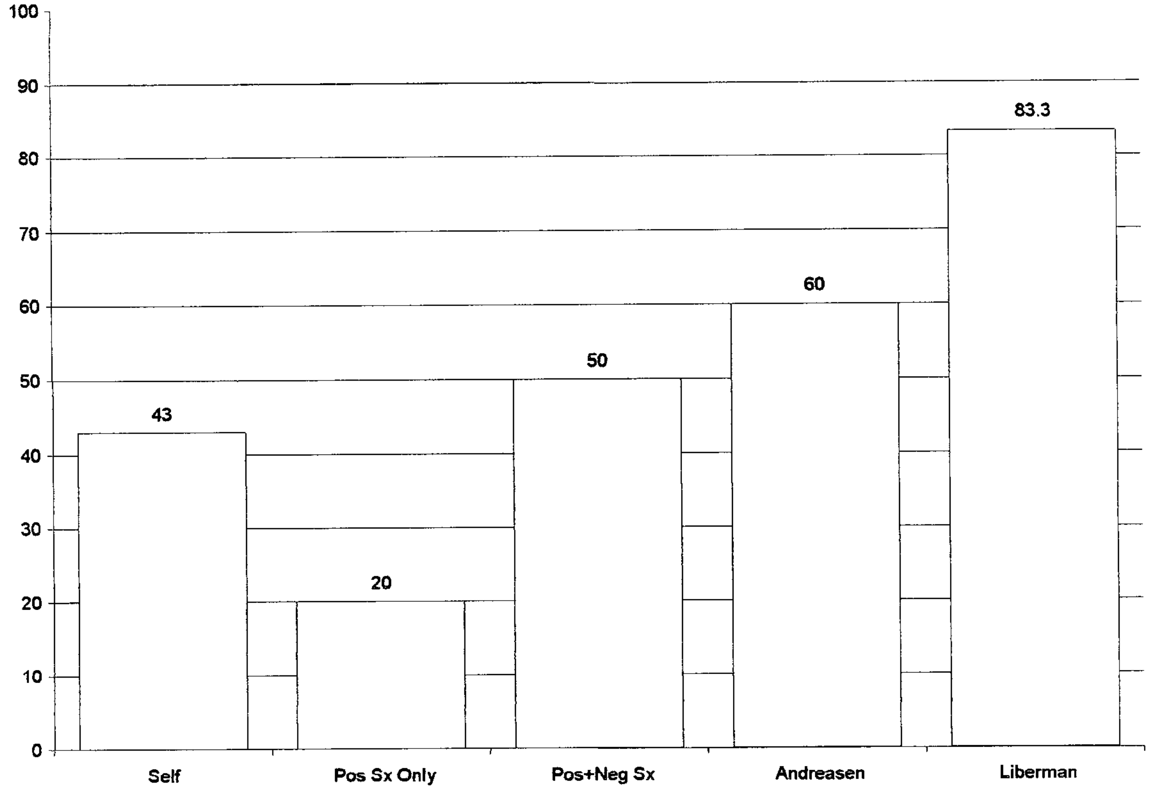


Figure 3: Objective + Subjective recovery congruence

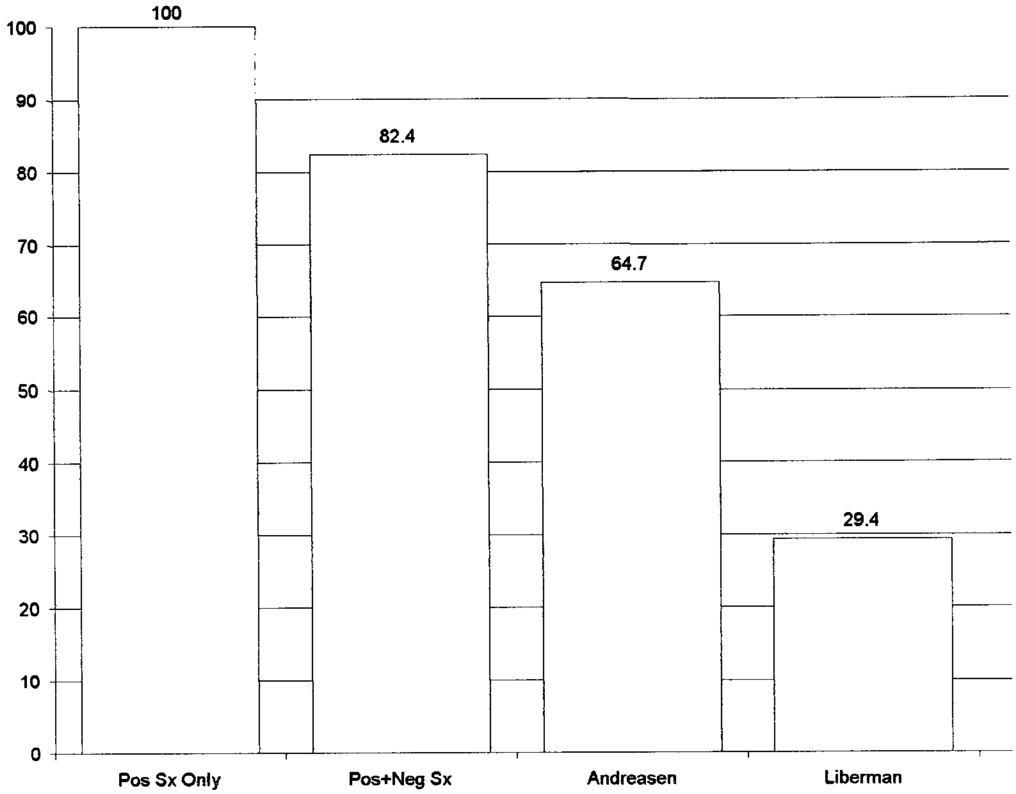


Figure 4: Objective + Subjective non-recovery congruence

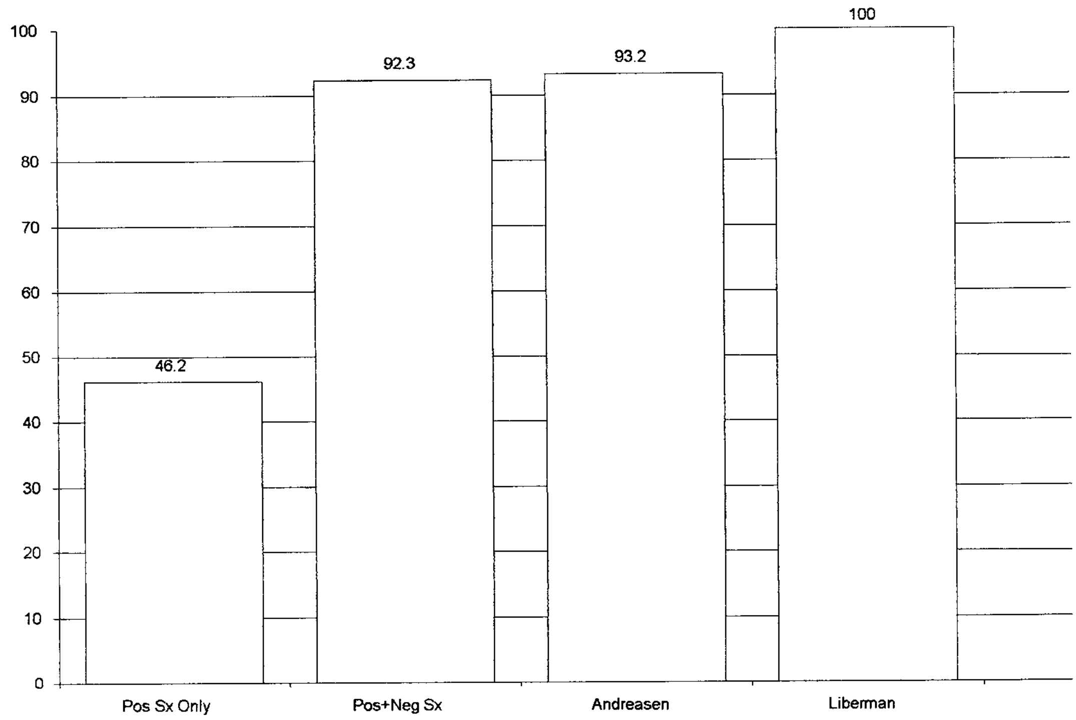


Figure 5: Recovery category distributions

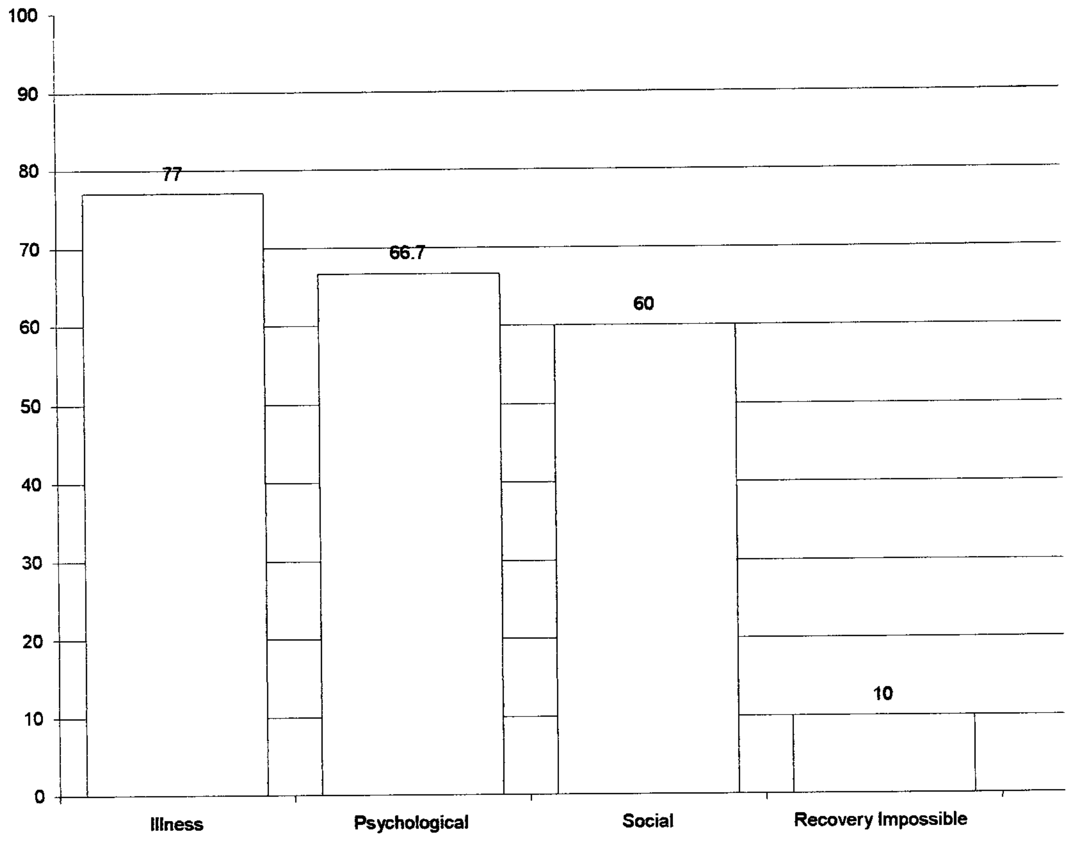
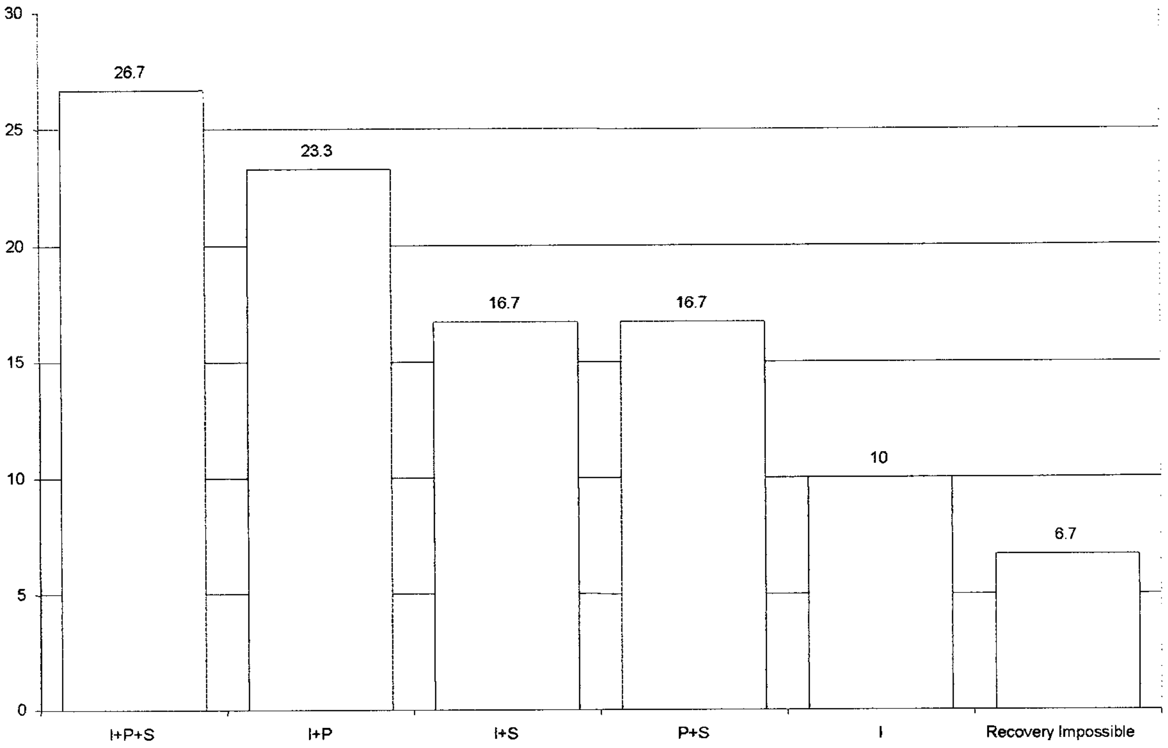


Figure 6: Distribution of these recovery definition accounts



CHAPTER 4 – MANUSCRIPT 2
"The Experiences of Early Recovery among Individuals Treated for a First-Episode of Psychosis"

The Experiences of Early Recovery among Individuals Treated for a First-Episode of Psychosis

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Abstract

Background: There is evidence to suggest that the processes that can lead to chronic difficulties in multiple domains begin from the very onset of a psychotic disorder. Examining the subjective experiences following a first-episode of psychosis can enhance our understanding of the critical change processes and experiences that prevent chronicity and promote positive outcome, offering new and important insights by which to improve early intervention services and practices.

Objective: The primary aim of the present research is to explore both commonalities and variations in early recovery experiences for individuals who received early intervention care following their first-episode of psychosis.

Methods: Semi-structured interviews were carried out with thirty individuals in early recovery following a first-episode of psychosis. Interpretative Phenomenological Analysis was used to examine the subjectively identified important processes and turning points over the early course of illness.

Results: Seven common early recovery processes were identified. Variations between individuals in the magnitude of described self and social functioning disruption, duration of the illness-acceptance process and the treatment engagement process greatly influenced the experience of recovery.

Conclusions: Differences in illness acceptance trajectories have important implications for understanding psychological adjustment to the experience of psychosis, its diagnosis and treatment, and emphasizes the importance of assisting individuals with the construction of meaning following the initial illness experience. The subjective importance of role resumption and relationship engagement emphasizes the need to encourage and assist young adults in meeting their social recovery goals.

The Experiences of Early Recovery among Individuals Treated for a First-Episode of Psychosis

The naturalistic outcome of schizophrenia may actually be much better than previously assumed, with positive outcome for approximately half of individuals diagnosed with the illness (for a review see Calabrese & Corrigan, 2005). This relatively more hopeful view of course of illness has encouraged a recent interest in recovery from schizophrenia. There is also emerging evidence that specialized interventions are highly effective in producing better symptomatic and, less often, functional recovery following a first-episode of psychosis (Harvey et al, 2007). An optimistic and personally empowering model of recovery put forth by the consumer recovery movement has also contributed to the burgeoning interest in recovery from schizophrenia and related psychotic disorders (Anthony, 1993).

Most research on the subjective experience of recovery report variations on acceptance of illness, having a sense of hope about the future, cultivating a sense of agency, taking control of the illness and finding a renewed sense of self (Davidson, 2003). The individual is likely to play an active role in coping with, adapting to, and promoting his/her recovery from both the disease related experiences as well as its secondary personal and social consequences (e.g. Corin & Lauzon, 1992, 1994; Kotake Smith, 2000; Mancini, 2007; Marin et al, 2005; Roe et al, 2004). Research on experienced recovery reveals that recovery occurs amid a complex interplay of subjective, psychological, environmental and social contexts (e.g. Ochocka et al, 2005). There may be significant implications for service delivery from themes derived from subjective recovery descriptions (e.g. Cohen, 2005; Pitt et al, 2007).

The vast majority of investigations of the subjective experiences of recovery have been undertaken with individuals many years after onset of the illness and may only be representative of recovery experiences of individuals with a relatively chronic illness course who remain in the treatment system over many years. Individuals who have recently experienced a first episode of psychosis represent a more heterogeneous group regarding potential outcome trajectories, encompassing the breadth of outcome more closely representative of recovery experiences, and therefore represent a unique opportunity to examine early processes and influences that may promote (or prevent) positive outcome from psychosis.

The current understanding of various prognostic indicators does not fully account for this variation in trajectories of outcome or the mechanisms involved. How the individual experiences a psychotic illness may influence the trajectory of recovery (Davidson, 2003; Estroff et al, 1991). For example, perceptions of illness and recovery differ depending on duration of illness (William & Collins, 1999). The adaptation to the experiences of psychosis during the early phase of illness may involve difficult realizations and profound changes in the self and relationships (Baxter and Diehl, 1998; Billings et al, in preparation; Hirschfeld et al, 2005; Spaniol et al, 2002; Williams & Collins, 2002), resulting in potentially serious long-term negative impact on the individual's sense of self and engulfment in the illness and patient role (McCay & Ryan, 2002). There is evidence that this adaptation also influences the future course and outcome of the illness (Tait et al, 2003; Thompson et al, 2003), and that the ways in which early illness perceptions are formed has an important influence on the individual's attitudes toward service use (Judge et al, 2008).

Therefore, there remains much to be learned regarding subjective experiences in the context of the development of the course of illness during the early critical phase. While a considerable amount of quantitative research on outcome following a first-episode of psychosis has been reported, there is a real need for recognition of the importance of exploring the experiences of the individual during this critical period (Hirschfeld et al, 2005; Judge et al, 2008; Larsen, 2004; MacDonald et al, 2005; Werbart & Levander, 2005; Woodside et al, 2007), including the experience of specialized early treatment (Larsen, 2007a, 2007b; O'Toole et al, 2004). The subjective perspective of individuals early in illness course offers a unique opportunity to investigate the various ways that individuals experience and respond to the initial episode of a psychotic illness (Billings et al, in preparation) and how treatment initiation is experienced and negotiated (Chen et al, 2005; Judge et al, 2008; Larsen, 2007a, 2007b). An enhanced understanding of these variations in critical early and potentially trajectory-forming processes has the potential to inform the development and refinement of effective early intervention services, potentially aiding in the identification of critical opportunities and methods for encouraging and enhancing positive outcome.

The purpose of the present study is to examine the subjective experience of early recovery for individuals who receive specialized early intervention (SEI) care following their first-episode of psychosis. It explores the evolution of the recovery experience over the 3-5 year period following the onset episode, and to shed light on similarities and variations between individuals in terms of the lived experience of early recovery from psychosis.

Method

Participants

Participants were receiving follow-up care subsequent to specialized early-intervention treatment in the Prevention and Early Intervention Program for Psychoses (PEPP) in London, Canada for a period of two years following their first episode of psychosis. The nature of this early intervention program and assessment protocol has been characterized elsewhere (Malla et al, 2003; www.pepp.ca). Participants were consecutively recruited from a cohort of patients enrolled in a long-term outcome study 3-5 years following initial program entry. The inclusionary criteria for the source study were: treatment for two or more years in the early-intervention program, diagnosis of a psychotic disorder, 16 years of age or older, competence to provide informed consent, and no evidence of mental retardation. Of those individuals approached, 30 (90%) individuals agreed and completed the interview. Participants provided informed consent as approved by the University of Western Ontario Ethics Board for Health Services Research.

Participants were interviewed at the time of entry to the program using the Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I: First et al, 1995). Clinical and demographic information are presented in Table 1. Participants ranged in age from 19 to 42 years (M = 25.9 years, SD = 5.3). Just over three-quarters (76.7%) of participants were male and 90% were single. The vast majority of participants (86.7%)

remitted following their first-episode of psychosis, and twelve of those individuals (40%) had not relapsed following their remission from their first episode. Participants had an average of one (M = 1.08, SD = 1.29) relapse following their first-episode of psychosis, ranging from zero to five relapses until the time of interview. The number of psychiatric hospitalizations since the onset of illness was approximately two (M = 2.07), and ranged from zero to five hospitalizations among participants.

Measures

A semi-structured interview guide was designed to elicit in-depth accounts of the individual's subjective experience of psychosis and recovery from time of first onset. The interview was designed to explore the following topics: the meaning of psychosis, illness self-identification, the meaning and important processes of recovery and experiences of treatment. The goal of the interview was to retrospectively explore changes in these themes over the relatively short time since onset of illness and initiation of treatment. Individuals were asked to identify critical turning points in recovery. Turning points consist of self-reported life events that cause lasting change and are useful for understanding subjective experience rather than an objective truth (Clausen, 1998).

Procedure

Diagnostic and clinical terms (e.g. "psychosis") were not used in the interview unless mentioned by the participants, and instead the terms used by the participant were adopted by the interviewer. Interviews were conducted by the first author at the time and place of convenience to the participant. The length of interviews ranged from one to three hours. Interviews were audio-taped and transcribed verbatim.

Analysis

The data were analysed using Interpretative Phenomenological Analysis (IPA) procedures outlined by Smith and collaborators (1999). The IPA researcher's goal is to develop an in-depth understanding of the meanings used by informants to make sense of their experiences as it relates to a particular topic. This is attempted through a subjective and reflective process of interpretation of the individual's account by the researcher (Smith et al, 1999). IPA is not a prescriptive approach, but instead provides a set of flexible guidelines that can be adapted for specific research purposes (Smith & Eatrough, 2007). While IPA typically retains an idiographic focus with small samples, larger samples are useful for the exploration of one phenomenon from multiple perspectives, enabling a more detailed and multifaceted account of that phenomenon (Smith et al, 1999). We chose to include a large sample size (by IPA standards) of 30 participants due to the known variation in recovery experiences and the intent to explore patterns of similarity and difference in recovery experiences within the group. Smith and colleagues (1999) outline a specific framework and guidelines for conducting IPA with a larger sample sizes. These guidelines were followed in the present analysis.

The transcripts were initially examined individually, first noting preliminary observations of important ideas described by the individual, followed by transformation of these ideas into higher-order themes representing the individual's concerns on the topic. These higher-order themes were then examined extensively across cases for patterns and connections between ideas, as well as contradictions and tensions, identifying thematic linkages in an attempt to identify general broad categories. Once general categories were identified, the source text from each transcript for each category was amalgamated and more intensively reviewed; each extract was examined to elucidate shared aspects of the participant's experience in relation to the general theme. Throughout the analysis, constant reflection and re-examination of the verbatim transcripts were utilised to confirm that constructed themes were meaningfully and closely connected to the source material.

Results

The experience of psychosis

The experience of psychosis was described as one of overwhelming confusion and incoherence, leaving individuals feeling powerless and alienated. Individuals typically described having no sense of what was happening to them at the initial onset and most did not recognize changes as indicators of mental illness.

The meaning of psychosis

In this sample, an overwhelming majority (93.3%) of participants identified their condition to be mental illness, although two cases described considerable ambivalence and contradiction regarding the application of an illness framework to their experiences. The participants who did not identify themselves as having a mental illness contested the meaning of mental illness and were ambivalent about agreeing with an illness model:

> *"Ill" is a weird word -- I've had it explained to me if you had diabetes you take your needles every day, and it's just a different organ that's ill. I don't know... the brain is such an important part of your being and I just hate to say that my brain was sick -- I don't like thinking I'm sick, I just like thinking I have a different state of mind.*

This individual was reluctant to place his experiences into an illness framework, although he was clearly aware that he had experienced an anomalous mental experience, one that he continued to be vulnerable to it happening again, that was detrimental to him, and for which medication was helpful. This young man is therefore a clear example of the complexities of what is meant by "insight" into illness, and how the subjective experience of illness "awareness" and "acceptance" is complex, often contradictory.

Another individual indicated that he didn't want to contextualize his problems as mental illness because people with mental illness were "looked down on by everyone," and because "once you're mentally ill you can't ever not be mentally ill." Clearly the meaning of illness identification in terms of personal and social consequences is extremely influential, and is described further in this analysis by those individuals who described a prolonged period of reluctance in illness identification.

Recovery processes

Seven general categories that reflected subjectively important processes of recovery as experienced in the first few years following a first-episode of psychosis emerged from the analysis, illustrating a course of recovery that was multidimensional and that changed greatly over time. The seven processes commonly identified in recovery descriptions were: 1) eliminating symptoms, 2) reckoning and reconciling meaning, 3) regaining control, 4) restoring self, 5) resuming roles, 6) social reengagement, and 7) negotiating and accepting treatment. See Table 2 for distribution of general categories and respective subthemes.

1. Symptom recovery

The "symptom recovery" domain encompasses the subthemes of "improvement" and "relative distress." Thematic analysis of the recovery narratives revealed that 90% of participants described symptom-related improvement in their descriptions of recovery. Descriptions of illness recovery for many individuals were not exclusive to symptoms of psychosis, but included numerous affective (e.g. mood, anxiety), cognitive (e.g. concentration), and negative symptoms (e.g. motivation). Turning points described in the illness recovery domain reflected either an attenuation or elimination of psychotic and/or affective symptoms.

1.a. Improvement. A relief from distressing symptoms was described by many as the initiation of their recovery, and 53% of the participants identified illness-specific (psychosis and/or affect) turning points, which occurred at various time-points in recovery, ranging from within weeks of initiation of treatment to three or four years later:

> *I look back at myself and go, "You know, I was thinking that, but that's not true." At the time, it felt like it was true or it sounded good to me, but it wasn't a real thought -- and it wasn't until I could actually say, "No, that's not true" that I reached that turning point.*

Some individuals identified more than one illness turning point in their recovery narrative. While for some individuals the elimination of symptoms was experienced as sudden and complete, for many it was experienced as an incremental process:

> *I went to Seroquel, which started to work pretty well. At that point...I probably would've said then that I was recovered. But when I went to Clozapine, it was like another level.*

The theme of finding the "right" medication was commonly associated with symptom turning points. Improvement in symptoms was nearly always attributed, at least in large part, to medication:

> *...the first time they put me on Seroquel -- it was such an unbelievable change. I went from being delusional and having hallucinations to being free of that in two weeks.*

1.b. Relative distress. Additionally, the subjective experience of symptom improvement depended on the relative distress that different symptoms caused the individual, and often non-psychotic symptoms were more saliently distressing. It was evident that the subjective experience of the symptom, not the fact of it, was typically the most important in recovery experiences:

> *The panic attacks were the worst, I think. By far. 'Cause you didn't really feel like you could do anything about it. And my symptoms were – I don't know if they're different than most people. When I was hearing the voices or whatever... that never really bothered me at all.*

This was especially true for the individuals who described their struggle with depression as causing the most subjective distress in their recovery:

> *Um, see the – the, the depression was the worst. It's really hard to get motivated to do anything at all. Let alone something difficult... the depression was the hardest part.*

2. Reckoning and reconciling meaning

The category of "reconciling meaning and acceptance" reflected the turning points and processes of "recognizing" a psychological problem and "reconciling" the personal meaning of the experience. These processes were described by most individuals as essential before moving forward in recovery. The descriptions of the experience of resolving the explanation-seeking and sense-making processes revealed differences between individuals, with some moving through these experiences relatively efficiently, while others struggled at length to recognize and/or reconcile the illness experience.

2.a. Recognizing problem. The "recognition" turning point in personal recovery was described as a realization that something had changed within himself or herself. This often followed an initial period where the psychotic symptoms were normalized until an awareness that something more serious was happening, often described as realizing "something was wrong." This turning point of recognizing psychological problems was described as occurring through various experiences, including perceived psychological changes retrospectively once symptoms subsided, or by noting discrepancies between expectations (driven by delusional thinking) and actual experiences, often in confluence with messages from other people that they had changed. Logically, this awareness of change and identification of the change as psychological in nature was crucial for the initiation of explanation (and help) seeking. This period of time between believing whole-heartedly in the reality of psychotic symptoms and recognition of a psychological problem varied greatly between individuals, ranging from near immediate recognition (within days or weeks), to a prolonged period of many months, or in some cases, years.

2.b Reconciling meaning. The experiences described under the theme "reconciling" included processes of differentiating between the illness and the self, forming a coherent explanation and reconciling the personal meaning of the experience and implications for the future. The processes of seeking an explanation and forming a coherent account for the experience were critical in early recovery. This quest to "understand" the experience was highly individual, depending on personal notions of mental illness, messages received from influential others, and direct illness experiences. Participants described an initial period of uncertainty and flux as they struggled to "make sense" of what happened to them and why it had happened, thereby considering, ascribing and combining various explanations:

> *But just wondering why it happened to you is one of the big things, too. Wondering why there aren't other people, like there isn't anyone to compare to, like it didn't happen to anybody else in my family. Wondering why that is.*

The reconciling process also frequently involved teasing out what was "real" from what was "not real," as well as delineating what aspects of the experience were attributable to personality, illness or medication side-effects. Seeking information about the illness from various sources was an important activity in this process. Individuals described refining their explanation over time as new information and experiences were introduced, eventually developing an account for the experience that was relatively coherent and relevant to the individual's experience:

> *When I would talk to [case manager] we would go over symptoms like, are you hearing voices? These make sense, because…when someone describes what you're feeling, then you feel, yeah, that's my problem and that's why I picked up on the fact that I have psychosis.*

An explanation for the experience did not come fully formed nor did it remain static thereafter, as changes to the explanation were described as continually shifting over time. Instead, it seems that an adequate, albeit somewhat tentative, explanation was necessary to begin to move forward in recovery. Reconciling the meaning of the illness (often described as "acceptance") generally included accepting one's potential long-term vulnerability to relapse. Therefore, for some individuals, shifting from conceiving of the experience as an isolated event to that of an enduring illness was an essential experience in the recovery process. Therefore, for many individuals, the experience of relapse was an important turning point in accepting the fact of enduring vulnerability and acceptance of the experience as an illness:

> *After I relapsed I'm thinking, "Huh, ever since I took the Olanzapine, all that went away after all, just like it did when I took the Risperidal." And I was like, "Oh, it's an illness." That was actually the, the pinnacle –But it took awhile for me to get…to realize that.*

In this way, the reconciling process included adjustment not just to having had a psychotic episode, but to the idea of having a mental illness and all of the perceived ramifications on personal and social identity. Therefore, inherent in this acceptance experience was recognition and "coming to terms" with the various losses associated with accepting that one has a psychotic disorder. While grieving the loss of a "normal" identity was commonly described, constructive acceptance of illness was especially difficult for a subset of participants. Some individuals described experiencing feelings of powerlessness and multitude of losses associated with the experience. These feelings sometimes overwhelmed the individual and resulted in a period of depression, and at times a prolonged period of severe demoralization:

> *And I had this huge, uh, breakdown because I thought that here I was living for, like... two years and I thought I knew who I was but then it's like... that idea is... not true, so then you have to rebuild who you are all over again.*

The participants who struggled for a considerable period of time before reaching this point of constructive acceptance of illness inevitably identified and emphasized this process as an essential turning point in their recovery:

> *I think I was just putting the schizophrenia aside. And I wasn't dealing with it. I think the reason why I relapsed was, I still hadn't dealt with acceptance -- a big part of turning things around for myself was no longer worrying about -- the stigma.*

There was remarkable variation between accounts regarding the subjective difficulty, distress and duration of this process. Once a coherent explanation of the experience was developed and the individual had resolved (at least in part) the meaning of the experience, the subsequent self-recovery experiences were possible. The account for the experience frequently influenced the nature of other personal recovery processes. For example, the explanation for the experience influenced the perceived avenues open to the individual in influencing his or her recovery.

3. Regaining control

This recovery process encompassed the subthemes of "discovering agency" in influencing the illness experiences, and "developing personal strategies" for promoting and protecting recovery.

3.a Discovering agency. The turning point of realizing that one can act upon one's illness and circumstance in order to promote positive change was commonly identified. "Regaining" turning points involved becoming aware that change is possible and taking personal responsibility makes changes happen. Many individuals described a conscious decision to confront the illness and surrounding circumstances:

> *That's when I thought, you know, I've got to do something about this. I said, okay, I'm going to do it. I've got to get out of this. I can't let this bring me down.*

3.b. Developing personal strategies. The ways that individuals took responsibility depended on individual ideas about illness (perceived possible avenues for illness control) and the resources available to the individual (options afforded to the individual). In general, these strategies were both internal, by changing one's "mindset" toward a positive and hopeful outlook, and behavioural, by taking deliberate action to promote recovery, prevent relapse or preserve progress:

> *I decided to, to change my attitude. So that was one part of it, and the other part of it was that I changed, my living conditions -- that brought my mood up and that was able to help me change my outlook on life.*

These strategies were derived from personal observations and experiences of symptom-behaviour interactions as well as suggestions received from others. Information seeking was an important part of coping strategy development. Individuals described "experimenting" and "testing limits" to discover the ways in which they could enact their power over their experience. The results of these experiments enhanced what individuals frequently referred to as their "self awareness." Regardless of the specific strategy, the process of modifying attitudes and behaviours appeared to enhance recovery by renewing one's sense of hope and enhanced a sense of control:

> *This stuff needs facts... they made a little chart as to the chances of relapse and how if you stayed away from the drugs, stayed on your meds, the chance of relapse is zero. That was like, wow, I can actually be healthy for the rest of my life if I make the right choices.*

Therefore, the themes within this domain include both a deliberate, self-initiated choice and precise behavioural descriptions. These behaviours were described as reflecting the individual's wholehearted commitment to the goal of recovery, prioritizing recovery above all else:

> *So recovery -- what it means to me is doing what you have to do -- you've gotta stop hanging out with certain people, stop doing certain things. It was a big change - it's not something that you want to do, but you have to -- balance it against your lifestyle...*

The common behavioural recovery themes encompassed a variety of lifestyle decisions, and the elimination of drug and/or alcohol use was an essential turning point in recovery for some individuals. One very common strategy for managing illness was taking responsibility for treatment participation, by attending appointments, choosing to disclose experiences to treatment providers, and/or regularly taking medication. Many individuals indicated that although they were cautious about relapse risk, they believed that any subsequent experiences of psychosis could not possibly be as confusing or alienating as the first episode, now that they could understand what was happening to them and had knowledge of what they could do to recover:

> *Well…when you get a relapse…it kind of puts it back to where you were, but still having these skills that you've learned along the way helps you rebound that much quicker.*

4. Restoring self

The "restoring self" category encompasses various processes of self-enhancement, whereby individuals rebuilt a positive identity. The two subthemes were "enhancing self-concept" and "redefining self."

4.a Enhancing self-concept. Reconstructing a positive sense of self (rebuilding self-confidence and self-esteem) was an integral experience in recovery for many informants. The variability in describing recovery experiences of rebuilding a sense of self appears congruent with the variations in the magnitude of the impact of the psychotic experience and diagnosis on the individual's sense of self:

> *I know many people, their self-esteem got shot when their illness came on, and that can be a huge blow -- you're put in that crazy category -- so getting my self esteem back…*

Individuals described the importance of pursuing experiences that enhanced their self-esteem. This was accomplished by engaging in activities that held a high likelihood of success, and/or adjusting notions of "success" to new limitations. The rediscovering of previous abilities or positive traits in a current context often promoted a positive self-concept, enhancing a sense of worth and accomplishment, and providing linkages between "pre-illness" and current identities. The discovery of new abilities or positive traits, often as a result of the illness experience, was also described as beneficial for self-regard and self-confidence.

4.b. Redefining self. Some individuals described turning points in recovery when the meaning of the experience for the self was resolved, and it no longer remained a dominant focus of the individual's thoughts, feelings and identity. For some individuals, this point in self-recovery included putting the illness experience into a wider perspective:

> *I'm getting to know people, and you know what? Everybody suffers at one point or another. You know, with cancer or diabetes or whatever. Something will happen to you... it's all a matter of how you see things, I think.*

Many individuals described the experience as having changed them for the better, either making them a more mature person who takes their responsibilities more seriously, or a change into a wiser, and/or more compassionate individual:

> *I feel like I've grown and I feel like a better person -- I think before I was just letting life go by and living for the next party. I've grown -- and I've found a new passion.*

5. Resuming roles

This category encompasses subthemes of "role resumption," "critical role events," and "seeking independence." The experience of role loss was described as very difficult for many individuals, having a detrimental impact on their sense of self. The loss of this aspect of identity was acutely experienced, perhaps magnified by the developmental stage of most participants, when role participation and development is crucial to identity formation:

> *...it just feels wrong to live in a low stress environment, because everyone else is handling so much stress, you don't feel like you're part of society. That's something I had a problem with when I first got sick -- I felt that I wasn't contributing, that I was underachieving.*

The sense of being "behind" peers in achieving developmental goals was acutely felt by many of the young adults:

> *Um, well, I missed out on a lot of school, so... it's still holding me back. I'm trying to get into college and... move on... but I'm sort of behind everyone else, so, it's harder.*

Over half (60%) of individuals identified a return to role as an integral part of recovery. Twelve individuals (40%) indicated specifically that return to role (work or school) was a critical *turning point* in recovery:

> *So it was when I started doing things again, you know went and got a job, started filling my day full of stuff that it brushed right off. Things started falling into place, you know?*

5.a. Role resumption. Role resumption often took many months, and for many it took at least a year post onset of treatment before reengaging in roles, suggesting that successful role resumption depends on a number of other critical recovery processes that preceded role reengagement. Approximately a third (30%) of participants returned to their pre-illness role, approximately a third (36.7%) made partial attempts to resume roles, and a third (33.3%) did not attempt role resumption in the period following the onset of their first episode of psychosis.

The individuals who were able to reengage in the same role (same job or school program) after a relatively brief period of leave valued the sustained availability of prior-to-illness role:

> *...and then I went back to work and it wasn't bad at all. Like, I actually think it made me realize, you know, work's not that bad of a place. That other jobs probably would've fired me or... made it harder. With [company] it was really easy -- they were good there that way.*

Interestingly, those individuals returning to post-secondary studies spoke with passion about the importance of this role resumption to their recovery:

> *School was a pretty good turning point too -- sort of gave me something to concentrate on, focus on and look forward to going to the next week.*

The desire and motivation to retain this role was clear, seemingly because it provided an intact sense of continuity, social identity and hope for retention of life goals and expectations for the future:

> *...we were trying to figure out if I should go back to school, or if I should go part-time, or if I should go back at all. And I thought...what? You're not going to let me go back to school? I'm going to miss a year of school and not graduate with my friends? Nah, that's not going to happen...I'm not going to miss a year -- I said I'm going to school, forget it!*

For other individuals, the trajectory of role resumption consisted of repeated, partially successful (in either duration or quality of role performance) attempts, sometimes eventually leading to sustained performance in a role. For others, unsuccessful attempts led to the relinquishment of the goal for at least the foreseeable future. Most individuals who had not engaged (at all or sustainably) in a role still maintained hope, if not confidence, that this could change in the future, and expressed a clear desire for improvement in this area:

> *I just want to get my medications straightened out first. I'm doing better, but I'm not feeling better. But I do want to work again, for sure. I want to get back into the workforce.*

5.b. Critical role events. Positive role-related events were frequently identified as important turning points in recovery. These included getting a job, returning to school, receiving a raise or promotion, and for many individuals it included school graduation. The emphasis on the latter event seems to indicate that the attainment of developmentally appropriate and meaningful goals had a strong and important influence on recovery, namely in increasing a sense of self-esteem and self-confidence:

> *...going back to university was difficult. But...I got through it and I have the degree to show for it -- and you can't take that away from someone -- it's gonna stay with you for the rest of your life. It makes me stronger knowing that I graduated and got through it.*

5.c. Seeking independence. For some individuals, recovery entailed establishing independent adult living. The individuals who described family independence emphasized independence as a sign of success, competence and maturity as a young adult. However, living with family was also often described as a helpful condition of recovery, and a *return* to living with family was an important positive turning point in recovery for a subset of individuals. Conflicting feelings regarding the perceived need for and benefit from family support in contrast to the perceived benefits of and desire for independence were described. The individuation process in development, which typically involves risks, uncertainties and trade-offs between the benefits and burdens of independence, appears to be intensified in the early course of recovery from psychosis for some individuals.

6. Social reengagement

All types of relationships were identified as important in social recovery: peers, parents and extended family members, coworkers, romantic partners, and service providers. The importance of participation in fulfilling relationships was omnipresent in retrospective descriptions of the recovery process. The social losses that were described as part of the experience of psychosis were loss of relationships, loss of trust in others, and loss of social confidence, social competence, and social worth. The themes of social recovery included "relationship repair and reengagement" and "restored social confidence, competence and worth."

6.a. Relationship repair and reengagement. Participation in peer relationships was very important for many individuals. The effect of the illness experience on peer relationships was highly varied, ranging from minimal to severe social disruption. Significant disruption in peer relationships appeared to be the result of the individual's actions (e.g. withdrawal) or through the rejection of the individual by their peer network (or parts of their peer network) following diagnosis and treatment for psychosis. Therefore the tasks of social recovery varied according to experienced social consequences of the illness experience, and included re-engaging in friendships, repairing damaged friendships and/or initiating new friendships.

Some individuals (23%) described an initial response of uncertainty from peers, where friends were initially tentative in their initial reengagement with the person. Interestingly, this situation was successfully resolved for most:

> *...Because a lot of the people didn't understand what I was going through so they were kind of, like, questioning me and you know backing off a bit. A lot of my friends were scared and weren't talking to me as much, because they thought I was crazy and stuff like that. But they got over that, just by seeing me, like, that I wasn't like different from everyone else.*

In contrast, some individuals experienced little to no disruption socially, though the extent to which the illness was disclosed and discussed in the retained friendships varied depending on the individual's perception of the social meaning of their illness. Finally, a subset of individuals described a self-initiated complete overhaul of their peer group due to the illness experience. They described these old friendships as an obstacle to recovery and their desired recovery-promoting lifestyle. In these cases, participants described new peer groups emerging from their social network periphery. While fluctuation in peer membership and participation was common, the desire for and goal of social inclusion was paramount for many individuals.

Relationships with family often played a crucial role in recovery, and were frequently described as having changed due to the illness experience. This most often involved an initial disruption while the individual's unusual behaviour alienated and strained family relationships, but was almost always followed by eventual reintegration. Reengagement in these relationships was a very important part of the recovery process for many individuals. Many individuals described having greatly enhanced family (parents or spouse) relationships compared to experience even prior to the illness experience, and that family members were now more supportive, tolerant, sympathetic and even more loving towards them:

> *I think it has made my relationship with my family stronger on the whole, and it's through... having hard times with them... they understand me better as a person. I think I've been able to get closer to them.*

Romantic involvement was a frequently identified important part of recovery, and themes of challenges and successes in romantic relationships emerged strongly in descriptions of the recovery process. For some individuals, the illness disrupted relationships held at the time of onset. The initiation of romantic relationships was described as very challenging, and success was a frequently identified turning point in recovery:

> *I changed for the better after – when I met my boyfriend. That's when I had more… love for life. It's like… I was feeling so messed up, but after I met him, it was like I had someone to live for.*

6.b. Restored social confidence, competence and worth. Restoration of social confidence was described as a critical process of recovery for many individuals. The experience of psychosis left some individuals shaken and uncertain regarding their worthiness as a family member, friend and romantic partner. According to these individual's descriptions, perceived discrediting experiences were a frequent detrimental influence on diminished social confidence, sense of self and social worth:

> *I was singled out and nobody would listen to me… when I was trying to have a conversation or trying to say something, they would ignore me. It kind of made me feel like a little geek or something. Rejected.*

The initiation of new friendships was perceived as a considerable challenge:

> *Like the first like year and a half to two years it was impossible to even think about talking to anyone new. It was really hard, because I felt like that was the only thing I had to talk about… what was on my mind.*

Even when friendships were retained, individuals often experienced a reduced capacity to socialize for a period of time early in recovery. The reasons for this varied, and the relevant factors described included continued psychotic symptoms, a necessary inward focus due to feeling overwhelmed by their struggle making sense of the experience, the experience of socializing as draining or stressful, and/or the subjective feeling that social competency or social worth was compromised.Some individuals described a loss of confidence regarding their comprehension and execution of socially appropriate behaviour that was distressing and socially prohibitive:

> *I kind of felt different from others, and uncomfortable being around people. I was just feeling very insecure about interacting with people and my opinions and asserting myself.*

This sensitivity was typically described as improving slowly as the individual strategically increased their social exposure in confidence enhancing contexts. Therefore, active social participation and perceived social worth and confidence were described as reciprocally reinforcing. This restored social confidence was a very critical component of recovery for many informants:

> *That's the biggest thing since I've been ill - my confidence has gone way down. I'd let people push me around. I'd avoid conflict and confrontations... and I worried a lot about what people thought. Now my confidence...I started to get my confide-, happiness back.*

7. Treatment negotiation and acceptance

Negotiating meaningful and active participation in treatment, while avoiding engulfment in the patient role or label, was an important process in recovery for many individuals. The subthemes of the "treatment negotiation and acceptance" category included "engaging with provider(s)" and "negotiating medication." The trajectory of change in treatment perceptions and attitudes in the period following onset of illness differed greatly between individuals. Treatment turning points reflected a turn towards treatment, and included engagement with treatment, disclosure of problems and experiences, events that engendered trust in the treatment provider(s), a change of medication, or sustained medication adherence/acceptance.

Individuals reflected on changes they had experienced in their perceptions and attitudes toward medication over time since onset of illness and treatment, describing coming to terms with the need for medication as a critical and sometimes difficult and prolonged process. Negotiation of positive medication-related perceptions was described as especially difficult when initial medication was not effective in reducing symptoms, when side-effects interfered with other valued states (e.g. alertness) or activities (e.g. cognitive performance), or when the individual experienced difficulties reconciling the meaning of the illness (acceptance):

> *I think it wasn't so much taking or not taking the medication that was my biggest concern, it was my pride and -- the stigma that comes with schizophrenia that was my biggest challenge. So as soon as my mood and my perspective dealing with*

schizophrenia turned around, the next step was to just start taking the meds, and that was very easy.

Acceptance of medication was described as a process of weighing various perceived costs and benefits of medication. Participants emphasized that the messages from the social milieu regarding the need and meaning of psychiatric medication enormously impacted their medication perceptions and actions of individuals.

Recovery Trajectories

Two distinct trajectories emerged from the retrospective recovery narratives relating to the themes of reconciling meaning and acceptance of illness. Some individuals described a relatively prompt recognition of a problem, with acceptance of illness taking little time and involving minimal disruption of the self (prompt group), while others described a prolonged struggle to recognize self-changes and/or in accepting an illness framework for their experiences (prolonged group). In addition, the latter individuals often described a recovery experience that involved considerable difficulty recovering from perceived losses in personal and social worth, sometimes leading to a period of significant demoralization. The "prompt acceptance" group and "prolonged acceptance" group each comprised about half of the total sample (53% and 47% respectively).

Exploration of the described circumstances of "prolonged" illness acceptance experiences revealed two distinct groups: those individuals who experienced difficulties with recognizing processes (did not perceive changes as psychological) for a prolonged period of time (57% of the group), and those individuals who experienced difficulties with reconciling processes (contested the meaning of the changes) for a prolonged period of time (43% of the group). Turning points toward acceptance were often linked to medication (change or adherence) in the first group. The individuals (20% of the total sample) who did not proceed past the reconciling process for a significant period of time described experiencing a great deal of reluctance in the adoption of an illness framework for their experience, often citing the losses in social worth associated with such an identity as the reason for their resistance. The individuals in the prolonged group described considerable self biographical disruption and loss narratives, and negative illness perceptions pervaded their narratives:

> *I feel sometimes that I'm a bad person or, that there's no hope for me…I have these beliefs that I don't know why I have them -- I don't want to be a person with psychosis. I just want to be normal. I just want to be like everybody else.*

Relapse was a commonly identified turning point by the individuals who experienced a prolonged course of acceptance; individuals in this group described initially settling on a non-illness explanation for their experience of psychosis before the experience of relapse necessitated a revision of their explanation, returning them to the reconciliation tasks of recovery. Those individuals who described a belated acceptance turning point in recovery often described strong feelings of regret and guilt regarding the delay, adding an additional layer of losses associated with the prolonged period of time when the illness model was contested:

> *…but I stopped taking my medication – and that was actually more than the worst mistakes I've ever committed. I went through a rough ride to realize I really needed medication -- I regret it, because I could have had at least my degree and then could've been working…*

Discussion

The majority of participants in the present study identified their experience of psychosis as mental illness, and descriptions of recovery experiences and the meaning ascribed to them by individuals revealed seven critical processes common to most individuals: symptom improvement, reconciling the meaning of the experience, regaining control over the experience, restoring the self, resuming roles, restoring relationships and social confidence, and negotiation and acceptance of treatment. Overall, these findings are in keeping with many of the key elements of the recovery put forth in other recovery studies, and also provide important insight regarding the nature of recovery trajectories that follow the initial episode.

Seeking explanation and developing meaning

Congruent with previous research, the individuals in the present study described early efforts to make sense of psychotic experiences by integrating the experience into existing context of meaning (Webart & Levander, 2005), with experienced changes frequently assimilated into the self ("normalizing the experience"), rather than immediately recognized as an illness (Billings et al, in preparation; Judge et al, 2008). Descriptions of these attempts to understand the psychotic experience are consistent with research reports that construction of the meaning of the experience of a first-episode of psychosis involves the individual adopting various information strategies depending on their mental state and influences (Larsen, 2005), modifying awareness of the illness depending on the current experiences of the illness (Billings et al, in preparation; Larsen, 2004).

The vast majority of informants in this study emphasized the essential role of acceptance of illness. The contradiction in the literature about whether or not awareness and acknowledgement of a psychiatric disorder is necessary for recovery likely reflects the fact that both have significant risks associated with them (for a review see Roe & Kravetz, 2003). The struggle and ambivalence inherent in reconciling the personal significance and perceived long-term consequences of the experience confirm that the process of identifying oneself as mentally ill is a complex one, and is often approached and avoided over a period of time, depending on factors such as recurrent illness experiences (Williams and Collins, 1999). The meaning of the acceptance had to be negotiated to one that helped preserve one's identity in some way without completely relinquishing personal control over outcome and thus allowed for avenues of agency. The considerable variations in levels of difficulty experienced in this undertaking suggests that the impact of the illness experience on self-concept likely involves a confluence of interactive factors in the individual, their experience of the illness and perceived and experienced social consequences of the experience. The outcome of this meaning-making appears to have very important implications in terms of emotional consequences (e.g. consequent "emotional dysfunction") and behavioural responses (e.g. medication adherence). This development of meaning may, therefore, be critical in determining future course of the disorder. As these processes appear to be most fluid early in recovery, further research and clinical attention for understanding these change processes are likely to be beneficial in developing treatment initiatives to promote positive outcome.

Restoring self-concept

The self-restoring processes identified by many individuals in the present study are very much in line with previous reports on recovery that describe reconstruction of a positive and efficacious sense of self as an essential aspect of recovery from mental illness (e.g. Davidson & Strauss, 1992; Estroff, 1989; Jacobson & Greenley, 2001; Noiseux & Ricard, 2007; Ochocka et al, 2005; Pettie and Triolo, 1999). Reconstructing the self was typically described as a slow process that involved uncovering aspects of the remaining self and reconstructing a self that was acceptable and desirable to the individual. Individuals described the important role that identifying (or rediscovering) positive qualities or special abilities played in contributing to a restored sense of self. Seeking out and engaging in activities that featured or strengthened the individual's positive qualities or abilities were important for enhancing self-concept, particularly if these were identified as pre-existing characteristics, thereby providing a sense of continuity of the self. This process is described by Noiseux & Ricard (2007) as identifying "points of reference" for self reconstruction in recovery. Therefore, the changes in the self described by our participants are congruent with Provencher's (2007) assertion that the transformation of the self in recovery from mental illness encompasses both increased self-complexity (increased multiple cognitive representations of the self) and enhanced self-esteem (positive self-regard).

Regaining a sense of control

Descriptions of the importance of discovering and enacting control over one's illness and life ubiquitous in the present recovery narratives are similar to the umbrella term of "empowerment" reported in much of the previous literature on recovery. Exercising empowerment is frequently described as a central task in recovery (Cohen, 2005; Mancini, 2007; Ochocka et al, 2005). Fostering self-empowerment has been proposed as essential for substantial positive change in individuals with mental illness (Young & Ensing, 1999), including those in early recovery from a first-episode of psychosis (Pitt et al, 2007).

Resuming roles

The experience of role loss following the first episode was described as extremely damaging to one's sense of self by a number of individuals. It has been similarly noted in research with non-psychiatric chronic illnesses that the loss of role functioning at the onset of illness contributes to a disrupted sense of self (Asbring, 2000). Similar to the reports by Williams and Collins (2002), role transitions that followed may result in serious and long-term effects on feelings of competency. These findings emphasize the importance of the subjective experience of role disruption following onset of the disorder in potentially having long-term consequences for the individual's sense of self.

The participants in the present study described the engagement in roles as important for enhancing subjective self-confidence and self-efficacy, a sense of social relevance and worth, and ultimately provided an expanded and multidimensional identity. This confirms similar evidence that work has a remarkably positive impact on the self in recovery (Mancini, 2007; Provencher et al, 2002). The described importance of a good fit between the individual's needs and goals and the social environment of the workplace is congruent with previous observations that particularly beneficial work climates for individuals with mental illness are those where positive messages are conveyed regarding the individual's performance and potential (Krupa, 2004; Woodside et al, 2006).

Many participants described with considerable passion the importance of returning to school, and it appeared that the return to this role enhanced self-esteem and self-confidence, as well as offered a supplemental personally and socially valued dimension for their identity reconstruction. This is in line with similar recent evidence of the immense value that education participation provides in enhancing sense of self among individuals with mental illness (Kris-Mathews, 2007; Mansbach-Kleinfeld et al, 2007). These findings emphasize the critical importance of developing and implementing interventions that encourage and assist with successful and meaningful role resumption following a first-episode of psychosis.

Social recovery

As previously observed (MacDonald et al, 2005), flux in friendships was common following onset of the disorder, and at times the result of non-illness factors. This seems to reflect the typically amorphous nature of early adulthood peer groups, although changes were often the result of the formation of new values and priorities that had been developed through the illness experience, and were therefore indirectly influenced by the disorder.

A period of loss of relationships during the initial and acute phase of the illness was common (e.g. Lipton et al, 1981), but once that phase had passed, many (though not all) individuals pursued engagement in friendships, including reconnecting with former relationships and/or forming new and reciprocal relationships (Breier and Strauss, 1984; MacDonald et al, 2005; Topor et al, 2006). The continued isolation experienced by a subset of individuals was frequently described as extremely painful. One individual, when asked what the most difficult part of his experience with psychosis was, succinctly replied "the problem of loneliness." This finding suggests that some individuals are vulnerable to prolonged social dysfunction following the onset of a psychotic disorder. Research on the social networks of individuals with long-standing mental illness suggests that isolation following mental illness can become enduring, as many individuals with schizophrenia report no friends or non-kin relationships other than superficial social contacts (Breier et al., 1991; Hirschberg, 1985).

There is evidence that kin and non-kin are differentially related to outcome, and that friendships may be beneficial in that they are more amenable to change with respect to the degree of emotional or physical proximity (Erickson et al, 1989; 1998). The subjective importance of friendships reported by participants in the present study is also in line with Beanlands and colleagues' (2006) finding that young people experiencing early schizophrenia describe supportive friends as important in moving "beyond the illness." Together these findings suggest that social rehabilitation in the domain of friendships is an essential area where creative intervention efforts can be focused in early recovery to potentially modify this trajectory of ever-entrenched isolation and its potential secondary influences on subjective well-being and illness course.

For many of these young adults, the goal of familial independence was desired, yet very difficult to achieve, hindered by a variety of internal and external barriers, and involving numerous conflicting emotions and needs. The difficulties typical for this individuation process appeared magnified by the illness experience and its personal and social consequences. This is in contrast to the findings of MacDonald and colleagues (2005), who also found that individuals early in the stages of recovery desired independence, but did not experience a heightened impact on this struggle due to the presence of a psychotic disorder. This discrepancy may reflect the greater range of experiences in the present study compared to relatively restricted sample (six participants) assessed by MacDonald and colleagues. Alternatively, it may reflect an influence of duration of illness on individuation experiences, as participants in MacDonald and colleagues' study were interviewed only one year after their first hospitalization for psychosis. However, our findings were congruent regarding the subjective importance of close relationships with family, and the immense value individuals placed on preserved family relationships, and their care and perseverance.

Bidirectional, positive influences between perceived competence and social re-engagement were described. Many individuals described a process of seeking and engaging in creative methods of social participation in efforts to bolster self-confidence, cultivating opportunities for confidence-enhancing feedback and attempting reengagement in protected contexts. This process of purposeful negotiation of engagement in "normal" ways of life that provided contexts for favourable change has been previously described and elaborated by other researchers (e.g. Corin, 1990).

Course of recovery and turning points

Typically, turning points in social recovery that involved role resumption or reengaging in relationships occurred after a period of time when the individual reported sorting out their thoughts and feelings about their psychotic experience, regaining a sense of control over the illness and self, and re-establishing the adequate self-confidence required for reengagement with the social sphere. This is very much in keeping with Strauss's description of a plateau period in the realm of functioning following the acute episode that he labelled the "woodshedding" phase (Strauss, 1989). It is important to note that many salient turning points, and sometimes even the initial turning point, in the individual's recovery occurred well after illness onset and treatment, at times two or more years later. This has important implications for considerations regarding optimal duration of service delivery in an early specialized treatment program.

Subjective turning points provided a unique and illuminative way to examine interactions at the point of change. Turning points appeared to reflect either important events (e.g. starting a job) or important realizations (e.g. need for medication), frequently in combination. The described context of turning points in recovery examined here reveals that, at least on an experiential level, the various dimensions of recovery were interactive and at times interdependent. The complex and bidirectional relationships between recovery components such as self-evaluation, symptoms, and social participation described by participants are supported by the increasing recognition of these dynamic and reciprocal relationships between recovery components in quantitative studies on recovery processes (e.g. Markowitz, 2001). There is growing interest in developing new theoretical frameworks for explaining the interactions between various recovery dimensions (Markowitz, 2005; Provencher, 2007; Rogers et al, 2005). The challenges of delineating and understanding such dynamic and complex interactions will require the development and use of appropriately sensitive and systematic methodologies, including careful longitudinal study of course unfolding from the onset of the illness, and possibly combining quantitative and qualitative methods of inquiry (e.g. Jenkins et al, 2005).

What is also evident from these recovery narratives is that individuals pursue recovery strategically, prioritizing areas of recovery that are of greatest subjective significance, depending on specific emotional and developmental needs. For example, a sacrifice in the area of social recovery, and therefore even the benefits of social recovery on the individual's sense of self, is made by some individuals in order to sustain wellness and protect symptom recovery. Conversely, some individuals choose to maintain familiar tasks and social roles over symptom containment. This latter phenomenon has been observed in research on (non-psychiatric) chronic illness (e.g. Townsend et al, 2006), and seems to reflect the complex and personalized ways that individuals navigate the various trade-offs and psychological threats that comprise the illness experience, depending on what is most "at stake" for the individual at the time.

Variation in recovery trajectories

Recovery trajectories in this early period of illness course varied between individuals, but general patterns were identified from retrospective narratives. Interestingly, just over half (54%) of the study participants described an expedited progression through recognition and reconciliation to the point of acceptance and integration of illness, describing minimal suffering and minimal biographical processes of revision in their recovery narratives. They also frequently described retaining social roles and strong social support networks. In this way, adjustment to the experience of the illness and diagnosis appeared to be associated with the extent to which the individual was able to maintain aspects of their previous identity and the activities that were associated with it. This is an important finding, as it contradicts the notion in the current recovery literature that the experience of psychosis requires complete revision of one's self, has damaging consequences in all of life's realms, and that recovery is necessarily an arduous and prolonged process. This finding may reflect a less disruptive and damaging experience of the illness experienced by some individuals that is not captured in the literature of recovery from the perspective of more chronically ill populations, and that was potentially positively influenced by early, developmentally-specific and individualized treatment. Therefore, these findings suggest that this would be a fruitful area for further investigation.

Not surprisingly, those individuals who experienced difficulty with task of "reconciling" the personal meaning of the illness also described related difficulty accepting a need for treatment. Treatment experiences described by these individuals were conflicted and involved multiple tensions and repeated approach-avoidance patterns. This indicates, perhaps not surprisingly, that individuals who experience difficulty reconciling the meaning of the experience are at high risk for service disengagement. This has important implications for service delivery and the challenge of finding ways to identify those individuals that are at risk of failing to construct a meaningful acceptance of the illness. Specific interventions designed to enhance individual's perceptions of illness controllability and to decrease the risk of internalizing stigma may serve to prevent the devastating demoralization and treatment avoidance that were described by a subset of individuals.

Limitations

There are three significant potential limitations in the present study. One potential limitation is the application of IPA methods for such a large sample size. As IPA is an idiographic method, the analysis of large data set risks a relatively superficial interpretation compared to spirit of idiographic inquiry, with potential loss of subtle nuances in meaning. Attempts to minimize this risk included careful observation of published guidelines for large-sample IPA analysis (Smith et al, 1999), and detailed consideration of each case, along with several repeated cycles of analysis. The second important limitation is that the change processes in early recovery were ascertained through retrospective reports. This is an important limitation, as it has been noted that ideas of recovery change over time (Estroff et al, 1991). Finally, an inter-rater reliability assessment among multiple researchers of the application of coding themes to the text was not completed.

Conclusion and future directions

The numerous recovery processes identified in the present study are in keeping with many commonly identified themes in research on the subjective experience of recovery of a physical or mental illness of a chronic nature. In addition to identifying commonly experienced processes of early recovery (e.g. adjusting to illness, negotiating treatment, etc.), this close exploration of the lived experiences of early recovery provides unique insight into the variation of recovery trajectories between individuals. Our analysis reveals that not all individuals suffer the same loses or are impacted by these losses in the same way, and therefore the meanings ascribed to improvement differ accordingly. Confirmation of the present findings using a repeated longitudinal design following the onset of a psychotic episode would be greatly informative.

The present study examined recovery experiences among individuals treated in a highly specialized treatment program. This may account for the high proportion of positive experiences during the early phase of recovery compared to the current literature on recovery experiences. While these findings may not generalize to the recovery experiences of individuals who do not receive early phase-specific treatment, they provide additional evidence for the effectiveness of SEI services. Future research comparing subjective recovery experiences between individuals who receive standard care versus those individuals who receive SEI services may shed further light on the impact of early intervention on the experience of recovery.

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Table 1

Demographic Characteristics of Participants

Characteristics	**n**	**Percentage**
Self-report recovery		
Yes	17	57
No	13	43
Gender		
Men	23	76.7
Women	7	23.3
Ethnicity		
Caucasian	27	90.1
Asian	1	3.3
African-Canadian	1	3.3
First Nations	1	3.3
Education		
Not graduated high school	9	30
Graduated high school	10	33.3
Attended some university of college	6	20
Graduated college	2	6.7
Graduated university	3	10
Marital Status		
Single	27	90
Married/Common-law	2	6.7
Divorced	1	3.3
Diagnosis		
Schizophrenia	16	53.4
Schizoaffective	8	26.7
Psychosis NOS	3	10
Substance-induced psychosis	2	6.7

Bipolar I with psychotic features	1	3.3
Employment and school participation		
Full-time	7	23.3
Part-time	3	10
None	20	66.7
Disability pension		
Yes	12	40
No	18	60
Living circumstances at interview		
Alone	4	13.3
With family	20	66.7
With spouse	3	10
With friends	3	10
Atypical antipsychotic medication at interview		
Yes	27	90
No	3	10

Table 2

Recovery Experiences Categories and Themes

Category	Subthemes
1. Symptom recovery	1.a Improvement
	1.b Relative Distress
2.Reckoning and reconciling meaning	2.a Recognizing problem
	2.b Reconciling meaning
3.Regaining control	3.a Discovering agency
	3.b Developing personal strategies
4. Restoring self	4.a Enhancing self-concept
	4.b Redefining self
5. Resuming roles	5.a Role resumption
	5.b Critical role events
	5.c Seeking independence
6. Social reengagement	6.a Relationship repair and reengagement
	6.b Restored social confidence, competence and worth
7. Treatment negotiation and acceptance	7.a Engaging with provider(s)
	7.b Negotiating medication

CHAPTER 5 – DISCUSSION AND CONCLUSIONS

It is increasingly evident that the period following the onset of the first psychotic episode is the most important time to focus interventions that promote positive outcomes. However, it is essential that clinical approaches likely to promote better outcomes be rigorously evaluated. Critical to this goal is consultation with individuals who have experienced the illness and treatment. Understanding how individuals make sense of their initial experience of psychosis and treatment, and what notions of recovery they hold, may facilitate understanding and communication between service-users and service-providers regarding subjectively meaningful outcomes and goals of treatment. It may also provide *criteria* by which to evaluate the effectiveness of clinical interventions in enhancing subjectively meaningful outcome(s). Additionally, consultation with service-users has the potential to enhance our understanding of the experience of processes of early recovery. Elucidating variations in individual recovery trajectories and the critical influences involved in promoting positive outcome in all domains early in the course of illness has the potential to inform service design and delivery to optimize recovery. In this regard, two important inter-related but distinct areas of research need to be explored. One concerns the *meaning* of recovery that is held by the individual, and the other deals with the experienced *processes* of recovery, including the identification of important change points and recovery-promoting experiences and factors. Enhanced knowledge in both areas would provide important insights for service design and evaluation.

In this study we have first explored the meaning of recovery held by individuals early in recovery following a first-episode of psychosis and who were engaged in specialized intensive intervention for a period of two years and less intensive care in the subsequent one to three years. Our results suggest that individuals hold distinct and discernable ideas about what recovery means, and that there are both notable variations and general commonalities between individuals on such meaning. The subjective perspective regarding the role of maintenance medication revealed the concept of "recovery as cure" held by some individuals, although most individuals appeared to believe that it was possible to be "recovered" while remaining vulnerable to relapse. Participants were almost equally split in assessments of self-recovery. Examination of the congruence of self-assessed recovery to researcher-defined outcome along with interpretive analysis of subjective recovery definitions suggest that individuals include components of psychological and social recovery in addition to symptom experiences in their recovery definitions. Common domains of recovery identified by most individuals included illness (symptoms of the disease), social functioning (normative engagement in work/school and relationships) and psychological adjustment (developing an understanding of the experience, accepting the meaning of the illness, and restoring one's agency and self-esteem).

Secondly, in exploring the early recovery *experiences* as described by individuals following a first-episode of psychosis, we found that individuals experience common losses in the experience of illness, diagnosis and treatment, but that the magnitude of these losses varies considerably between individuals. As such, the "tasks" of recovery were similar between individuals, but the magnitude of the task at hand varied. Individuals described important early recovery processes as symptom improvement, seeking explanation, resolving the meaning of the experience, gaining a sense of control over the illness, reengaging in valued roles and relationships and negotiating the need for treatment. Considerable differences in trajectories of recovery emerged, suggesting that many individuals (47%) experience considerable difficulty negotiating the meaning of the experience and constructing meaningful acceptance of the illness. Perhaps not surprisingly, differences between participants in treatment negotiation appeared related to this process. Sizable variation in the magnitude of self-disruption and of social disruption (both roles and relationships) emerged, and also appeared related to the difficulty in negotiating the meaning of the illness; however, the exact nature of this relationship is unclear.

Together these findings suggest that the developmental stage (late adolescence/early adulthood) that represented most participants played an important role in both the meaning of recovery and in the critical processes of early recovery. In examination of the meaning of "being recovered," there was considerable emphasis among individuals regarding the inclusion of (normative) friendships, romantic relationships, role resumption (especially school-related achievements) and the notions of recovery tied to independence held by some individuals. Similarly, in examining the important processes in early recovery revealed a strong emphasis among many individuals on the importance of re-engaging in relationships, often with peers as well as romantic partners; on regaining social confidence; on role resumption with educational engagement emphasized by many individuals; and arguably, the need for "control" in treatment engagement.

Treatment implications

There are numerous insights by which to enhance treatment design and delivery that have emerged from these analyses. The findings confirm the subjective importance of some of the current standard treatments offered as part of early intervention care (e.g. psychoeducation), suggest important additions (e.g. social recovery interventions) and provide a better understanding of some of the factors and experiences that impact early treatment response and engagement.

Psychoeducation

McGorry and colleagues (1995) have described the three key goals of psychoeducation in early psychosis as: 1) negotiating "meaning" through constructive assimilation of the illness experience into the individual's worldview, 2) developing "mastery" by acquiring or enhancing the skills needed to exert control over the disorder and its effects, and 3) protecting self-esteem that is threatened by assaults on self-identity, social roles, relationships and future plans. The present study confirms the critical importance of all three of these goals, as respectively reflected by the common subjectively identified and emphasized importance of constructing meaning ("reconciling meaning") for the experience, of "regaining control" over the illness (finding and enacting strategies for control), and of enhancing self-concept and redefining the self ("restoring self") identified by many individuals. The themes of "psychological recovery" identified in subjective definitions of recovery ("knowing something is wrong," "understanding the illness," "being able to do something about it," and "back to being myself/feeling better about myself") also confirm the importance of these goals as representing subjectively meaningful outcomes. The recommendation that psychoeducation be provided during all phases of the illness (Ehmann & Hanson, 2004) is confirmed by the present finding of the enormous variation within and between individuals in responses to the illness over time. Adjustment to the experience appears to be a process that evolves incrementally over the first couple of years following the onset of the illness for many individuals. The finding that education is better received by individuals if it is integrated into their own experiences, and that eliciting the individual's explanatory model is therefore clinically important (Kilkku et al, 2003) is confirmed by the current exploration of recovery narratives of information seeking and integration. Results from the current study indicate that suggestions and information that was congruent with personal beliefs regarding the experience and personal experiences of the illness were described as most helpful and empowering.

Social recovery

Participants in the present studies emphasized the overwhelming importance of role resumption and social participation in recovery experiences, as well as representing important indicators of recovery. This suggests that interventions that encourage and assist individuals in reengaging in valued roles are critical to providing effective and meaningful recovery. Clearly, role participation allows for a host of secondary benefits in enhancing self-esteem and mitigating the risk of engulfment. The specific difficulties related to role resumption and functioning were highly individual and would likely be most effectively addressed in an individualized clinical context. Clinicians may need to be sensitive to the fact that for some individuals, role participation only benefits recovery if it is experienced as congruent with the individual's goals and self-concept. The balance between encouraging individuals to reengage in roles that are more suitable to their current limitations and not communicating messages of lower expectations is critical for enhancing the individual's efforts to reintegrate into the community in a way that is most beneficial to the individual.

Treatment engagement and adjustment to the experience

The significant challenge of accepting the illness described by many individuals in the present study supports the importance of interventions in early psychosis designed to help individuals understand their illness and that taking into consideration the personalized nature of the individual's illness experience and beliefs is most likely to enhance the individual's own agency in coping with the experience. From the current findings, it is evident that the process of psychological adaptation to the illness experience is very difficult for some individuals. It is currently unclear whether intervening to influence recovery attitudes in individuals who are avoiding in-depth discussions regarding their illness experience has a positive impact, or if it instead represents a useful strategy by which to reduce adverse emotional states and maintain psychological equilibrium during early recovery (Jackson & Iqbalt, 2000). Our findings, however, confirm that emotional responses such as fear and denial of illness are critical in understanding adjustment to early psychosis (Jackson & Farmer 1998), and that it is important to address psychological adjustment to psychosis in the context of treatment engagement (Tait et al, 2003). The personal descriptions of important turning points and processes in recovery suggest that it is likely that integrating the experience in a way that allows for a cohesive and empowered self is more beneficial in the long run than denial and avoidance of illness, but that negotiating this process is complex and highly individual. Clearly, the timing and content of interventions should take into account the very individual nature of the struggle to cope with the magnitude of the illness experience. The current findings suggest that the point of relapse is often the context of the turning point of acceptance, and may be a time when the individual is more open to considering the implications of the experience. Therefore, ongoing assessment of the psychological "readiness" of the individual to address these concerns would be prudent.

Jackson and colleagues (2000) propose a framework for "psychological intervention" in early psychosis that seeks to address some of these issues. Relevant to the current findings is the emphasis that they place on providing "personalised" psychoeducation that helps the individual understand their experiences and emotional responses in an individualized way that respects the individual's experiences, beliefs and recovery style, and not forcing a particular coping style onto the individual. Therefore, the clinician may need to assess each person individually and does not focus on the meaning of psychosis if it seems it would be undesirable to the individual. In this way, the necessary stage of distancing oneself from the experience that appears to be required by some individuals is respected and alternative interventions (e.g. activity and social-based interventions) encouraged instead. Jackson and colleagues also suggest as part of their intervention that "cognitions of entrapment" and feelings of helplessness are addressed in order to empower the individual's sense of agency and control, emphasizing the importance of facilitating autonomy and role and relationship participation. This type of intervention may need to be in line with the subjectively identified critical recovering process of "regaining control" and the "doing something about it" component identified under the theme of "psychological recovery" in subjective recovery definitions.

Recovery outcome definitions

The insights provided by the present findings benefit not only service design and delivery, but also provide important indications for subjectively meaningful outcomes by which to judge treatment effectiveness. The findings suggest that symptom improvement is an area of recovery that is valued by most individuals, and confirms the utility of these commonly employed outcome measures. The equal subjective importance of social integration as a critical outcome by which to measure meaningful treatment effectiveness suggests that recovery requires outcome assessment of multiple domains, and underscores the need to develop and implement socially and empirically validated measures of social and vocational functioning. These measures may be most meaningful if designed specifically to assess community integration among individuals recovering from a recent-onset psychotic disorder. Finally, the inclusion of various recovery outcome measures that reflect aspects of integration of the experience of illness, coping abilities, empowerment, engulfment and self-esteem should also be incorporated as meaningful goals of treatment and measured and evaluated as such.

It is evident that examining the subjective experiences of early recovery can yield important insights regarding the nature of recovery ideas and lived experiences of recovery. These insights provide a multitude of suggestions for enhancing interventions for a first-episode of psychosis. Subjective descriptions of complex and unique concerns specific to recovery from the initial episode emphatically confirm the importance of specialized early intervention services for optimizing full, meaningful and lasting recovery from psychosis.

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