

**UNDERSTANDING INSIGHT DEVELOPMENT IN EARLY PSYCHOSIS:  
A NARRATIVE APPROACH**

by

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## ABSTRACT

Intervening early in the course of psychotic illness (e.g. schizophrenia) may significantly improve prospects for the recovery, both in medical and psychosocial terms, of the individuals who experience these conditions. Engaging such individuals in care, however, remains a challenge. One barrier to engagement is lack of insight, or the low illness awareness that is considered to be a typical characteristic of people who experience psychotic illnesses, particularly in their early phases.

The dominant view of this phenomenon is that it is primarily related to the illness itself and thus is biologically based. There is reason to believe, however, that understanding the psychosis experience is also an interpretive process, and that the meaning of this experience for the individual arises out of dialogue between the person, mental health professionals and significant others. There is also reason to believe that the relationship between insight and recovery may not be as straightforward as presumed. While the dominant view sees insight as a crucial condition for recovery, emerging evidence suggests that insight once gained may lead to depression and demoralization.

Insight thus may be understood as an interpretive, dialogical process that is fundamentally narrative in nature, the consequences of which may be divergent. Using qualitative methods (constructivist grounded theory complemented by narrative analysis), the present study sought to understand the process by which insight developed in early psychosis, and sought to explore the relationship between insight and the early stages of illness management and recovery, as reflected by the written and oral accounts of twelve individuals who were within the first three years of illness.

Overall, the results suggest that insight development in early psychosis can be conceptualized as the process of coming to an acceptable, adaptive explanation. More specifically, the results first of all suggest that insight development involves finding or negotiating an account of illness that fits or can be accommodated with the individual's own story of the psychosis experience. The process also involves finding an account of illness and its treatment that can be envisioned as a helpful rather than disruptive aspect of the individual's future biography.

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**For Catharine, Ben & Oliver**



# CHAPTER 1: INTRODUCTION

## Background and Significance

Schizophrenia and other psychotic illnesses have been historically devastating and disabling conditions for those who experience them, as well as for their significant others. Within the last few decades, however, some hope has emerged in the form of evidence about the improved prospects for recovery, both in medical and social terms. One promising strategy in particular is early psychosis intervention<sup>1</sup>, with emerging evidence showing that timely and appropriate interventions – both medical and psychosocial in nature – can significantly improve the prospects of people with these conditions for living fulfilling lives in the community (Killackey & Yung, 2007; Malla *et al.*, 2005).

The ideal scenario motivating the field of early psychosis intervention is that a young person<sup>2</sup> experiencing the early stages of a psychotic illness can be persuaded to accept help in a timely manner and that the support offered will confer upon the individual a sense that he or she can live successfully with or despite their health condition. Ironically, while people early in the course of psychotic illness may benefit most from support, they may be amongst the hardest subpopulations to engage and may show a lower degree of insight into their illness relative to people with a more established illness history (Schimmelmann *et al.*, 2006; Thompson *et al.*, 2001) While insight or awareness of illness has traditionally been seen as a prerequisite of recovery, it may in fact have divergent and apparently paradoxical impacts: for some it apparently provides a stepping stone to an improved quality of life, but for others it may lead to less positive results (Paul H. Lysaker & Buck, 2007). For instance, those who exhibit insight in the early stages of their illness may become depressed or demoralized, negatively impacting their prospects for illness management (Birchwood, 2003; Jackson *et al.*, 2005).

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<sup>1</sup> the phrase “early psychosis intervention” refers to an intervention that is initiated without the prolonged treatment delays (typically averaging a year) that have been the norm for people experiencing psychosis. Psychosis refers to the loss of contact with reality and symptomatology often associated with illnesses such as schizophrenia, schizoaffective disorder, and some affective disorders, especially bipolar disorder.

<sup>2</sup> though most often appearing in the late teenage years, the onset of psychosis is typically anywhere between the ages of 13 and 30.

This scenario places the need to understand the concept of insight into the foreground of efforts to optimize the potential of early psychosis intervention service development, and thus promote illness management and recovery. Insight as traditionally defined has to do with the degree to which an individual views her or his illness experience as problematic, sees the problem as a defined illness, and is willing to pursue treatment and support for it (David, 2004). Conversely, a person who lacks insight may not see a problem or if he or she does, will refuse to attribute the problem or its symptoms to an illness, and/or refuse to pursue a plan of treatment and support that others see as a positive step. Once viewed as a categorical “all or none” concept, insight is now viewed as being constituted of the dimensions just mentioned, not all of which need be present for a person to be considered insightful. For instance, an insightful individual may identify a problem, but not necessarily adhere to a treatment plan.

Investigating how to produce insight has been an increasing focus of research, but has lagged behind work seeking to understand the factors that might account for its absence. The dominant strand of research suggests that *lack* of insight has to do with a neuropsychological deficit that is largely biological in origin, and an intrinsic aspect of the illness (Amador & Kronengold, 2004; Torrey, 2004). However, there has been a growing appreciation of the etiological complexity of the phenomenon as well. As a review by Cooke *et al.* (2005) outlines, lack of insight has been explained in a number of ways: as the result of psychopathology, as an underlying neuropsychological deficit, and as a psychological process of protective denial (i.e. a coping strategy adopted to minimize distress) (M. A. Cooke *et al.*, 2005). Evidence has also been produced suggesting lack of insight can result from a combination of these factors (Startup, 1996). Recent cognitive formulations posit the importance of meta-cognitive functions in maintaining insight (i.e. cognitive flexibility enabling a person’s willingness and ability to generate, consider and evaluate alternative explanations about one’s experience) (Beck & Warnham, 2004). Finally, others (Laurence J. Kirmayer *et al.*, 2004) have argued that lack of insight may also (or instead) be viewed as a process of contestation about the meaning of experience wherein the professional’s view, (i.e. the illness model), has traditionally but unreasonably been seen as the “gold standard” against which other interpretive frames are measured and found to be lacking. In other words, lack of insight may be understood as

a term applied to individuals who disagree with the professional perspective about what their experience means and what should, in turn, be done.

As mentioned, there is growing awareness that obtaining insight may not always promote positive emotional adjustment, nor does it necessarily set the individual off on the path to illness management and recovery. For instance, Birchwood's research suggests that perceived entrapment by the illness and its symptoms may be one "pathway to emotional dysfunction" for people experiencing early psychosis (Birchwood, 2003). Similarly, relevant research on both physical and mental illness suggests that individuals who, upon learning of their illness, appraise their conditions as being chronic, less controllable and having more severe consequences, tend to cope more poorly and have worse outcomes, irrespective of the actual nature of their health condition (F. Lobban *et al.*, 2003a; Watson *et al.*, 2006). There is also some indication that individuals experiencing early psychosis may "seal over" (McGlashan, 1987) their initial experiences and avoid contemplating them, a style of coping which may lead to disengagement from care (Tait & Birchwood, 2004). This research is consistent with another line of investigation which suggests that individuals may only begin to more fully adopt the illness label as they start to develop a sense of control over their disorder, and in so doing begin to reclaim valued aspects of self despite having an illness (Roe & Davidson, 2005). In this view, acceptance is seen as a gradual process wherein the individual more fully accepts the illness as he or she becomes able to deal with its impacts on day to day life.

## **Theoretical Framework**

While the biomedical and psychological approaches discussed above have contributed to a growing understanding of the process of insight development and its relationship with illness management and recovery, there is a compelling theoretical argument that a more comprehensive understanding requires an interpretive, narrative perspective. In contrast with a psychological perspective (which to some extent is also interpretive and seeks to understand the link between appraised meaning, illness management, and health outcomes), a narrative one sees the process of understanding and dealing with illness experience(s) as an evolving and interactive process, shifting across social setting, circumstance and over time.

Research from various interpretive traditions has suggested that the initial stages of insight development in psychosis involve attempts at interpreting a changed phenomenological reality by drawing upon “common sense” notions available within the wider culture (Jenkins, 2004). The concept of “demoralization” (Frank & Frank, 1993) may then help to explain why the individual, alone or in concert with significant others, may subsequently seek help – that is, when the original understandings no longer work. Once in the mental health system, the matter is not one of simply agreeing with the medical view of the problem, attaining insight, or accepting<sup>3</sup> a problem. Rather, it may involve negotiating an explanation that is congruent with the individual’s own interpretive frame and with relevant social contexts, whether therapeutic, family, or those of a broader cultural milieu (Laurence J. Kirmayer et al., 2004; Roe & Davidson, 2005). Upon encountering a specific diagnosis, people with mental illness may also attempt to deal with the envisioned “biographical disruption” posed by the illness (as do people experiencing other chronic illnesses) (Bury, 2001; S. J. Williams, 2000). Thus, acceptance may involve coming to understand the illness and its proposed treatments as potentially relevant and restorative to one’s envisioned life trajectory.

In sum, insight may involve finding, or being persuaded to find, an explanation that makes sense and that works for the individual in the context of his or her own world of meaning (J. D. Frank & Frank, 1991; Laurence J. Kirmayer et al., 2004; Wampold *et al.*, 2007). The alternative theoretical framework guiding this study is one that sees the process of insight as both essentially pragmatic and ultimately dialogical and social. This framework is in keeping with symbolic interactionism (Charon, 1995), in that it takes the view that the individual gains insight in dialogue with others and in doing so draws upon available discourses (or “interpretive frames”, as explained later) in search of a fitting explanation that enables him or her to achieve certain pragmatic ends and to live with the condition in keeping with his or her values. As explained further below, the chosen methodology is congruent with this view of the issue.

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<sup>3</sup> the term “acceptance” comes laden with theoretical baggage having to do with the presumed “stages of denial” that the present research treats as an open question

## **Objective/General Research Questions**

As noted, the relationship between early intervention and successful recovery or self-management is predicated on the assumption that a given individual acknowledges that some problem exists and needs to be addressed on an ongoing basis. The argument presented above suggests the importance of investigating the interpretive process by which this awareness may come about. It also highlights the importance of understanding the conditions under which such a process may lead to positive emotional adjustment and illness management, rather than increased demoralization.

Given the above, the present research seeks to understand in narrative terms both the process of insight development in early psychosis and its relationship with recovery. As outlined below, the study methodology is qualitative in nature, and combines narrative analysis (Mishler, 1991) with constructivist grounded theory procedures (Charmaz, 2006) to examine the main study questions:

- What is the process of insight development amongst individuals who have recently experienced psychotic illness for the first time?; and,
- What is the relationship of illness awareness to self-management and recovery?

An underlying question also present is “what is the role of narrative in the process by which the individual appraises the illness experience and attempts to act in the face of that experience?” In other words, “what is the story that individuals tell themselves and others about their experience and its significance in their lives?”

## **Research Setting/Context**

The study sample was recruited from clients at the Vancouver Coastal Health’s Early Psychosis Intervention (EPI) program, where the research was based, and where one of the co-investigators (DI) is a staff psychiatrist. The EPI program is a multidisciplinary intervention which offers assessment, medical treatment, psychosocial rehabilitation, and other forms of ongoing community support. The program serves youth and young adults

between the ages of 14-30<sup>4</sup> in Vancouver and Richmond, who have recently<sup>5</sup> experienced their first episode of psychosis. It offers support for up to two years before referring individuals to other parts of the mental health system, if needed.

The rehabilitative component of the program consists of a structured Day Program wherein participants attend daily interactive classroom-style sessions teaching symptom and stress management skills, as well as providing support designed to help young people eventually succeed in vocational, recreational, and/or educational settings. The community clinic provides case management, education and support on a weekly basis. The clinic also runs education and support groups for youths under 18, young adults up to age 30, and their family members.

Mental health professionals on staff include psychiatrists, psychiatric nurses, occupational therapists, social workers, and youth and family therapists.

The Team works from three separate venues: an inpatient/outpatient unit and a rehabilitation day program, both in the VGH University Hospital, and a community clinic on Commercial Drive in Vancouver.

## **Methodological Framework**

### ***General Strategy of Inquiry***

The research employed a constructivist grounded theory (GT) strategy of inquiry (cf. Charmaz, 2006) complemented by narrative analysis (Mishler, 1991) and guided by a symbolic interactionist (SI) theoretical framework. Its purpose was to examine the above-mentioned main study questions: what is the process of insight development amongst individuals who have recently experienced psychotic illness for the first time?; and, what is the relationship of illness awareness to self-management and recovery?

The approach is influenced by Clarke's argument (A. E. Clarke, 2005b) that, at an analytic level, grounded theory should become more explicit about examining the

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<sup>4</sup> The sampling frame included only individuals within the adult system (i.e. 18 and over), as this age group is more typical of the general population of early psychosis program participants.

<sup>5</sup> For reasons explained later, the study sample will consist of individuals who experienced their first psychotic episode or have received a diagnosis of psychotic illness within three years of participation in the study.

discourses or narratives that impinge upon the interaction and process issues that GT traditionally looks at. As suggested by Mishler's (1991) notion of structural, textual and pragmatic functions, and in keeping with the general theoretical framework described above, the overall analysis considers how, in drawing consciously or tacitly from an available "toolkit" of interpretive structures and resources<sup>6</sup>, the individual makes sense of and communicates his or her experience, and in doing so comes to an interpretation that apparently makes sense and works within the relevant settings. While consistent with a traditional grounded theory analysis in its interest in action and process, as explained below, the methodological approach seeks to understand how the expressed narrative either consciously or tacitly influences those processes as the individual achieves some insight.

In keeping with this focus on narrative, the first step of data gathering was to elicit a written story from study participants describing what happened, and indicative of the "interpretive frames" used to make sense of their experience prior to entering the mental health system. A follow up interview then focused on the individual's evolving understanding during the post-entry period and asked about the kinds of things (i.e. interactions, interventions, information, etc.) that helped participants understand and manage their illness. In the course of conducting these semi-structured oral interviews, the interviewing strategy was to probe for the tacit understandings suggested by the interpretive frames, and by various other aspects of the linguistic repertoire employed in the written accounts.<sup>7</sup> In other words, the follow up interview sought to understand how the individual's narrative as represented by the elicited written story may have changed or evolved, and how these changes may have contributed, if at all, to the individual's ability to envision the illness as an acceptable aspect of his or her ongoing life story.

### ***Research Paradigm***

The research takes place within an interpretive framework rather than within the traditional positivistic scientific paradigm. An implication here is that rather than being

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<sup>6</sup> Interpretive resources are elements of the linguistic repertoire the individual draws upon consciously; interpretive or narrative structures are those that influence the individual's constructions unconsciously and which may reflect power relations within a given discursive context.

<sup>7</sup> guided by discourse-based approaches, in particular as suggested by Holstein & Gubrium (2001); and by Goswami & Odell (1983).

monolithic and static, the reality of a given situation is appreciated as dependent on the shifting perspectives of the actors within that context. Within the interpretive framework, the meaning ascribed to a given situation is presumed to guide action, rather than isolatable variables that the positivistic tradition would seek to measure. In the present context, the implication is that understanding the perspective individuals hold about their illness experience is crucial to understanding their subsequent action(s), in particular, their decisions about whether to actively engage with an illness management plan.

As opposed to traditional quantitative research on insight which proceeds from what could be termed a professional-centered perspective, the present research is consistent with research and policy-making trends associated with health promotion and the recovery philosophy of mental illness – namely, that interventions must be grounded in an understanding of the experiences of those who use those services (Chadwick, 1997; Roe & Lachman, 2005). More specifically, the present research proceeds from the assumption that understanding the experiences and perspectives of people with mental illness in regards to their own experience and how they choose to act upon it (i.e. on the topic of insight) will lead to the development of more effective interventions.

As described below, however, it should be emphasized here that, while paying particular attention to how participants construct their situations, the constructivist grounded theory approach employed in the present study seeks to move beyond a description of individual experiences to understand underlying patterns relating those constructions and subsequent action(s): These patterns may remain tacit to individual participants.

### ***Brief Data Analysis Plan***

As suggested, an interpretive frame analysis is applied to the written narratives, then a more traditional grounded theory (GT) analysis is used on the follow-up interview data, looking at the kinds of interactions or strategies that affected the insight and adjustment process, but also paying attention to how the interpretive frames identified earlier evolved over time subsequent to the interactions experienced by the individual once he or she has entered the mental health system. As explained below, the data analysis approach as a whole follows constructivist grounded theory (Charmaz, 2006), which provides a way of



integrating the narrative analysis into the later stages of a traditional grounded theory approach, should the narrative elements prove relevant to the emerging theory.

In terms of its narrative aspect, the present approach adopts Goffman's notion of interpretive frames, pre-existing notions that help the individual understand experience and suggest a course of action (Goffman, 1959). The analysis adapts the "core narrative" approach as used by Mishler (1991) as a way of identifying the interpretive frames employed by the individual. In particular, the approach used here focuses on two "core" narrative features, known as "complication" and "resolution" sequences, in order to bring relevant interpretive frames into relief. For instance, the core narrative of one participant featured the idea that her problems (the complication) were due to "demon possession." As a result she sought the help of a friend to expel the demons (the attempted resolution).

Grounded theory analysis entails using inductive methods (constant comparative analysis) to identify emerging themes characterizing overt action and underlying process represented within the data. It should be noted that in general there is a tension between narrative analysis and the techniques of grounded theory. While in analytical terms the latter (GT), given its emphasis on induction, has historically professed and privileged attempts at understanding social reality in "blank slate" terms, it has also focused methodologically on the observed or described actions of research participants, rather than upon the interpretations that may be guiding those actions. In apparent contrast, a narrative perspective implies that perceived reality is influenced (either constrained or enabled) by the very narrative forms that are employed by actors, researchers and participants alike, as each seeks to interpret and act within social situations.

Given the importance of narrative in guiding action presumed here, the present study applies a constructivist version of grounded theory (Charmaz, 2006). This approach pays particular attention to how participants construct and express experience and to the relationship between these constructions, the subsequent actions the participants describe, and to the processes that may be inferred from these. According to Charmaz and others, the form of induction guiding GT analysis, "analytic induction" is not inductive in the commonly understood sense of a method which derives concepts purely from the bottom up. Analytic induction assumes instead that observation, while grounded in specific situations, is essentially theory-driven by an investigator who, ideally, seeks to avoid

privileging one potential explanatory concept (or story of events) over another, in the manner described below. In an attempt to maintain some “theoretical agnosticism” (Dey, 2007), the present research adopts a number of strategies, including delaying the formal literature review conceptual and framework development stages until after the analysis had been completed, and being transparent about the professional and personal interests influencing the investigation by articulating these at end of the present chapter.

### ***Overview of the Constructivist Grounded Theory Analysis Stages***

In an attempt to avoid premature imposition of theory, the first stage of analysis, “initial coding,” stays “close to the data” and labels the events under study in descriptive terms, using codes which depict action, in other words – what is going on in the context. The next stage, “focused coding,” identifies repeating themes or categories of events which appear to be significant, and explicitly documents or memos the researcher’s hunches about significant patterns and the reasons for their presumed significance. During the final “theoretical coding” stage, only those categories judged by the researcher to be of apparent significance to the emerging theoretical process are identified. As Charmaz suggests, the narrative elements of the analysis, which up until this stage had been identified in a parallel analysis, can be integrated into the final theory, assuming that they are relevant to the overall grounded theory that emerges, and they “earn their way in” to the analysis. In other words, the narrative elements are included to the extent that they influence the observed process by which participants come to understand their illness. As mentioned, this parallel analysis involves categorizing the written narratives in terms of the complication and resolution sequences depicted in the stories, thus highlighting the individual’s interpretive frames that may ultimately influence the process of insight development identified within the overall grounded theory analysis.

## **Implications**

To date, few studies have sought the patient perspective on the process of insight development and its relationship with recovery from psychotic illness. By seeking to understand how people with these conditions narrate their experience, the present study

thus seeks to provide a missing aspect of research on a contentious concept with apparently paradoxical impacts on emotional adjustment and illness management. In particular, the findings may shed light both on the interactive processes that lead to insight, the conditions under which insight has either positive or negative consequences for psychosocial recovery, and the context in which individuals may adjust constructively to initial negative consequences of insight.

The anticipated findings – in relation to the wider literature – may help to increase theoretical understanding of the insight development process in relation to key illness management- and well-being-related outcomes. Consequently, they may be considered as informing important aspects of a potential logic model or “intervention map” (Bartholomew *et al.*, 1998) for future program development aimed at achieving insight in the first episode context in a way that promotes rather than forestalls recovery.

The research may also shed light on the applicability of the self-management service delivery model to people with psychotic illness who were formerly presumed to lack insight and deemed not capable of actively managing or recovering from their conditions. At the same time, the research may shed light on approaches to acceptance and self-management in the early phases of other chronic conditions.

## **A Note on the Researcher’s Personal Perspective on the Topic**

While this chapter has until now discussed the potential significance of the topic and the stance taken towards it from an academic perspective, in this final section, switching to a first person perspective, I will discuss from a personal and professional perspective what I sense to be the wider significance of this topic and what would perhaps be a tacit lens I bring towards its analysis. This is a perspective that could both hinder or help, but which is necessary to make clear for the purposes of the transparency of this qualitative research, where as the saying goes, “the researcher is the instrument.”

First of all, my background as both a family member of people with mental illness and a mental health researcher is in some sense a check on potential blind spots that could arise from a study that relies on the perspectives of people with mental illness. While

people with mental illness obviously have more privileged access to their respective phenomenological worlds, they, like anyone else, but perhaps more so, may have difficulty perceiving the impact of the actions that may flow from that experience, in other words, seeing themselves through the eyes of others.

At the same time, I've come to believe through my interactions with people close to me who have mental illness (or through the course of my work) that they possess unique insights into what mental illness *is*, and how these conditions can be ameliorated. While in seeking to understand and improve mental health services I rely strongly on my professional background, but it is from people with mental illness themselves that I have personally gained the most trenchant insights. For instance, I remember clearly the time when I heard Pat Capponi, self-described "survivor" of the mental health system and author of *Upstairs at the Crazy House*, speak at a conference: commenting on the seemingly interminable series of blind alleys mental health researchers of all varieties (clinical, biomedical, services, etc.) had wandered along, she expressed surprise that none of these investigators had ever asked her simple questions such as "what helps?" and "what *doesn't* help?"

While I have kept this comment firmly in mind as I've proceeded along my own career path as a researcher, as a participant in the family sector of the community mental health movement I've been familiarized with an opposite view which in its most extreme version goes as follows: people with mental illness are sick, they have brain diseases, and thus possess *no* insight into what helps. As a family member myself, though certainly gaining in understanding from my relationship, I've experienced times when this appeared to be true. Both as a participant in the family movement and as a researcher, I've heard numerous accounts of lives seemingly ruined by psychotic illness, set against a backdrop of a person's refusal to seek treatment that could possibly help restore his or her life.

In my professional career, I have seen the two poles of the continuum (that people with mental illness have unique insight into what helps, or that they have no insight whatsoever) play out in debates over involuntary treatment legislation and translate into battles amongst people and groups both for and against coercive treatment. I have seen a

tremendous amount of emotion, energy and thought go into this debate over an issue that has been framed almost exclusively as a legislative one, while the discourse within this social movement continues to devolve into opposing ideologies and dogma. I have also sensed the rumblings of these ideologies within what is considered to be the touchstone academic text, *Insight & Psychosis* (Amador & Strauss, 2003), especially in certain chapters calling for policy and legislative changes that sit uncomfortably upon what most authors recognize to be a shifting base of evidence.

When I undertook the research that led to my Master's degree, a central question I asked family members who described their metaphorical pathway into and through Ontario's mental health system was: "what worked, and what didn't?" What people told me was that their relatives had taken months, years and even decades from the time they first experienced psychosis to the time they finally accessed care. While legislation was certainly mentioned as a barrier (namely, the criterion that someone is a danger to themselves or others) that kept people who were reluctant to seek help out of care, there were other equally significant reasons keeping people out: some were stigma, lack of trust, trauma and fear resulting from past experiences with treatment. On the other hand, the reasons why people eventually *did* seek help usually had nothing to do with legislation: negotiating through a trusted relationship or developing literacy about how the system worked, thereby helping people "learn the ropes" and get the help they needed (Macnaughton, 1993).

The experience gained through my research, I found later, was consistent with other emerging research showing similar things: people with psychotic illness took years to get into care, inaccessible systems were part of the problem, and that while insight (or lack thereof) was a problem, the fact was that people in the earlier stages of psychosis often did seek help, only to be turned away because they were assessed as "not sick enough" (e.g. Lincoln & McGorry, 1996). The same people then returned, often treated against their will, when they were fully psychotic, a point when insight obviously *was* problematic and perhaps not achievable in the short-term.

This body of research and the movement that both accompanied and followed it, led to the growing development of specialized early psychosis services predicated on

emerging findings that when people with psychotic illnesses such as schizophrenia were engaged early on in the course of illness, they tended to recover more quickly, both in medical and social terms (Killackey & Yung, 2007). To people within the broader mental health community, early psychosis intervention represents a possible way around the fight over insight, in the sense that the philosophical orientation of these services is to respond to people who seek help voluntarily rather than wait until they are fully psychotic and require treatment under coercive circumstances. Nonetheless, people with psychosis are understandably often still reluctant to seek help and are often mystified or demoralized by what transpires once into the system. Insight thus remains a contested concept that is crucial to understand in the search for answers about how to engage young people before they become disconnected from their social networks, fall off the paths they hoped their lives would follow, and lose touch with the dreams they formerly expressed.

## **Key Terms and Definitions**

Key terms and definitions have been articulated in footnotes to this chapter.

## **Overview of Dissertation Chapters**

The thesis will be laid out in the following way. The next chapter (Chapter Two) reviews the relevant literature and elucidates the theoretical framework, thus setting the stage for the research study. Chapter Three describes the actual methodology employed to define research questions, gather data and perform the analysis, including a description of how the methodology evolved in the course of its practice. Chapter Four presents the findings of the research. Chapter Five discusses the significance of the findings to the various practical, service delivery, policy and theoretical issues upon which those findings impinge. This final chapter will also provide a conclusion, summing up the key findings and suggesting options for further research.

## **CHAPTER TWO: LITERATURE REVIEW & THEORETICAL FRAMEWORK**

### **Chapter Outline and Summary**

In broad strokes, Chapter One outlined the nature and significance of insight development in early psychosis, and then discussed in general terms the strategy of inquiry to be adopted in attempting to understand this process. The present chapter explores the literature on this topic in more detail: After examining traditional definitions of insight, the chapter then examines the major theories that seek to explain the etiology of insight or the lack thereof, as traditionally defined. The chapter then articulates an emerging understanding of the process of insight development. First, it looks at insight as a social process whereby individuals come to understand the psychosis experience and its implications within the context of one's own conceptions of life problems and presumed solutions. Next, it questions whether, as suggested by the traditional model, insight leads to generally positive illness management ability and well-being. It does so by examining a synthesis of previous literature indicating the divergent, apparently "paradoxical" consequences of insight; this suggests that for some, acceptance of the label confers a sense of control, while for others it may result in demoralization and lead to depression or the adoption of avoidant coping strategies that are ultimately unsuccessful (Paul H. Lysaker & Buck, 2007). A final part of the literature review discusses the possibility that individuals may come to more fully accept the illness as its controllability becomes evident and the consequences of having it appear less catastrophic than originally imagined. In keeping with this emerging literature, the last part of the chapter develops an alternative theoretical framework of an interpretive, narrative understanding of insight development and argues that this provides a sounder basis for a comprehensive understanding of the topic. The discussion in this chapter will thus set the stage for a more involved discussion of the methodology presented in Chapter Three.

It is important to note that, following the methods of constructivist grounded theory (Charmaz, 2006), the literature presented below was synthesized after and in light of the

data analysis and the emergence of the grounded theory<sup>8</sup> presented in Chapter Three. The literature is thus reviewed as a means of identifying extant concepts that appear to be most helpful in explicating this emerging grounded theory as an eventual basis for locating the emergent results within this literature; the review also provides a way to identify areas where the dominant theoretical understandings of insight (both in terms of its process and outcomes) may need to be adapted or transformed. Similarly, the alternative theoretical framework developed in this chapter, while consistent with the initial theoretical perspective held by the researcher at the study proposal stage, was more fully developed only after the analysis came into view. In keeping with the constructivist grounded theory approach, the analysis represented is not to be taken as an inductive process in the commonly understood sense of being derived de novo; instead, the analysis should be understood as an interplay between observation and theoretical perspective, which, though unavoidably present, as Dey (2007) suggests is held in abeyance and used in eclectic fashion in order to help inform the emerging analysis.

## Literature Review

As noted, the literature discussed below first outlines the traditional definition of insight, then discusses how it has evolved over time. For the most part the conceptualizations underlying these definitions have viewed illness awareness or lack thereof as biologically determined; the dominant paradigm has also tended to equate insight development with improved prospects for medical and social recovery. However, the respective notions that insight can be explained purely in biomedical terms, and that its development is sufficient for recovery, are being called into question. As will be explained further below, insight development appears to require an opportunity for dialogue and reflection which does not always exist within mental health service delivery settings; the reappraisal of experience that occurs upon reflection need not lead to the replacement of earlier beliefs with the illness model, but may instead lead to an accommodation of different views. Further, the impact of illness awareness on subsequent illness management capacity and recovery appears to depend on the unique

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<sup>8</sup> Theory in this sense connotes a systematic understanding of the process by which participants come to understand the illness.



meaning that the illness has for the individual; this may depend on the individual's "common sense" model of illness (Leventhal, 1997) and on the envisioned, often divergent or "paradoxical" (J. T. Lysaker, 2007) connotations the notion of illness may have in the lives of different individuals. Finally, it appears that in some cases individuals with psychosis may "seal over" (McGlashan, 1987) the experience, or exhibit a kind of partial awareness featuring attempts to cope with the illness by avoiding any contemplation upon it. Fuller acceptance may happen as individuals come to perceive the illness as more controllable and as having less catastrophic consequences on their lives (Roe & Davidson, 2005).

## ***The Dominant View of Insight***

### ***Definitions***

The conceptualization of insight in psychosis has evolved over time: while originally seen as a one dimensional, categorical (all or none) concept, insight is now seen to involve a number of dimensions; it has also come to be understood as a continuous variable, that is, potentially present in various degrees (Amador & Kronengold, 2004). The most common definition of insight describes the concept as having three aspects, all of which may or may not be present to some extent at the same time: these are the awareness of illness, the ability to re-label symptoms as part of illness, and an appreciation of the need for treatment (M. A. Cooke *et al.*, 2005; McGorry & McConville, 1999; Osatuke *et al.*, 2008).<sup>9</sup> Being able to discern a change following treatment and attributing this change to the medication have also been put forward as key attributes of the insight development process (Amador & Kronengold, 2004; David, 2004).

In other words, a fully insightful person sees her or his anomalous experience or problematic behaviour as an indication that something is wrong; further, he or she is also able to correctly interpret the problem and its symptoms as attributable to illness rather than as due to some other cause ; finally, the person is also able to understand the need

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<sup>9</sup> There also appears to be a temporal dimension to insight, in that attribution of past experiences to illness, or past insight, is usually more frequently done in comparison to attribution of more recent experiences (Rusch & Corrigan, 2002)

for treatment in abstract terms and more specifically, is able to appreciate the concrete benefits of continued participation in a treatment or rehabilitative plan.<sup>10</sup>

In the traditional view, the importance of achieving insight is related to putative evidence of the relationship between improved insight, treatment adherence, and quality of life. Its significance also has to do with the apparent relationship between lack of insight, potential violence, repeated hospitalizations, and the consequent need to use coercive treatments (Torrey, 2004). More specifically, in first episode psychosis, lack of insight has recently been shown to predict relapse and rehospitalization (Drake *et al.*, 2007). In general, insight has been assumed to be a stepping stone to recovery or increased well-being. As discussed later, however, the assumption about a straightforward relationship between insight and recovery is increasingly being called into question.

### ***Theories Concerning the Etiology of Insight, or Lack thereof***

Traditionally, lack of insight was seen as intrinsic to the psychopathology of psychotic illness and a distinguishing characteristic between psychotic and so-called neurotic illness (David, 1990). However, it eventually became apparent that insight was not always related to a reduction or elimination of symptoms; that is, people experiencing active psychosis who lacked insight often did not acknowledge the presence of illness once the symptoms were ameliorated by treatment. At the same time, other individuals who actively experienced psychosis *were* aware of the illness (David, 2004). Given that active psychosis could not necessarily be equated with lack of insight, some psychoanalytically oriented researchers theorized that lack of insight might be caused by “protective denial.” The more accepted explanation, however, was advanced by more biologically oriented researchers who theorized that the phenomenon might instead be due to an underlying neuropsychological deficit (known as anosognosia) that remained present regardless of the presence or absence of active symptoms (M. A. Cooke *et al.*, 2005). This deficit was not only considered as preventing people from recognizing a

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<sup>10</sup> Of course, the multi-factor, dimensional concept of illness suggests that most people need not achieve this ideal in order to be considered as having some insight; for instance, a person could have awareness of illness but not adhere to treatment or could take medication while remaining unsure about the presence of illness.

problem, but also from appreciating the objective benefits of treatment; that is, not only did the deficit make it unlikely that individuals could appreciate the existence of illness, it also made it difficult for them to acknowledge the benefits of the treatment as observed by a clinician (Amador & Kronengold, 2004).

Despite the evidence marshaled and the arguments made about possible mechanisms which explain the insight deficits in neuropsychological terms (Laroi *et al.*, 2004), a recent meta-analysis shows that lack of insight does have a modest relationship with active symptoms<sup>11</sup>, as well as with a relative diminishment of neuropsychological function that may be consistent with the notion of insight loss due to anosognosia (A. R. Mintz *et al.*, 2003). This meta-analysis also showed a relationship between the presence of insight and depression, thus providing indirect evidence that lack of insight may play a protective psychological function. While proponents of the neurological deficit theory have questioned this link, emerging evidence discussed further below (see “Insight and Avoiding Coping”) suggests that psychological or interpretive functions may indeed play a role in determining whether or not an individual actively considers illness as a possible explanation for his or her problems, and if actively accepted, in determining how successfully he or she manages the illness (Michael A. Cooke *et al.*, 2007; M. A. Cooke *et al.*, 2005).

In summary, whether conceived of as related to psychotic symptoms or an underlying neuropsychological deficit, or some combination of the two, the dominant view is that lack of insight is an intrinsic aspect of psychotic mental illness, with a biological basis. From this perspective, biomedical interventions are considered of primary importance for producing insight, which in turn is necessary for continued compliance; treatment adherence then purportedly enables the individual to achieve control over symptoms and maximize quality of life. In other words, in this framework, achieving insight is seen as a necessary and crucial condition for achieving the control necessary for illness management and recovery.

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<sup>11</sup> Frese suggests the possibility that reduction of certain types of positive symptoms, (e.g. disorganized, bizarre delusions) may be more associated with insight (Frese, 2004).

## ***Emerging Views of Insight and Its Relationship with Illness Management and Recovery***

The dominant understanding of insight, however, is being called into question, and contested as something that has perhaps less to do with deficits *in* the person, as the biomedical view would imply, and at least as much to do with a process that is interpersonal and interpretive (Dolson, 2005; K. Doubt, 1992; Laurence J. Kirmayer *et al.*, 2004; White *et al.*, 2000). As discussed in the next section, cross cultural research suggests that what appears to be lack of insight may, in fact, reflect a mismatch between the explanations used by doctor and patient about the nature of the problem. As discussed further below, lack of insight may also reflect divergent expectations about what constitutes a successful outcome of treatment. The next section also provides evidence that insight may have divergent impacts on recovery depending on the connotations of the illness for the individual in question. While for some these may be positive, for others insight may lead to depression, demoralization, and avoidant strategies for coping; acceptance may become easier as the illness becomes perceived as controllable and as having less catastrophic impacts.

### ***Lack of Insight as a Mismatch in Interpretation***

Researchers looking at insight from a cross cultural perspective noted a tendency for clinicians to ascribe lack of insight to people from diverse cultural backgrounds more often, relative to the dominant culture; this suggests that lack of insight may in part relate to a mismatch between different interpretations held by doctor and patient (Johnson & Orrell, 1995), which could reflect a tendency to avoid appraising experience in a way that may be highly stigmatized within a given cultural milieu; it could also reflect a tendency to ascribe psychotic experience in terms of culturally current organizing metaphors or idioms which appear to be employed by people of all ethnocultural backgrounds (Jacobson, 2001; J. A. Larsen, 2004; Ridgway, 2001; Saravanan *et al.*, 2005; Vanthuyne, 2003). Another relatively recent study highlighted a mutual avoidance occurring in clinical situations, such that when people tried to discuss the reasons behind their unusual beliefs, mental health professionals tended to become uncomfortable and avoid the type

of normalizing dialogue that could have helped the clinician and patient negotiate a potentially more helpful understanding of the experience (McCabe *et al.*, 2002).

Taken as a whole, this evidence critiques the notion of insight as the process of logically interpreting problematic or anomalous experiences as attributed to illness, suggesting instead that other explanations may be equally plausible, if not more desirable than that of mental illness. The evidence also indicates the discomfort felt by mental health professionals when confronted by these seemingly idiosyncratic views. As Doubt argues, while lack of insight has been construed as a failure by individuals to see themselves as others see them, the challenge of insight may arguably also reflect a systemic disinclination or inability to understand people with psychosis in their own terms (Keith Doubt, 1996).

### ***Lack of Insight as a Mismatch between Expectancies and Subjective Impacts of Treatment***

As mentioned, another aspect of the insight concept is the notion that insightful individuals must necessarily recognize the objective benefits of treatment they have experienced. Based on a synthesis of studies looking at medication compliance in first-episode psychosis, Drake *et al.* (2007) suggest that compliance may depend on the attribution of psychotic experiences as symptoms and the recognition of the benefits of medication (also see Perkins *et al.*, 2006). This evidence, however, instead of indicating that insight involves an appreciation of objective treatment benefits, may instead suggest that the individual may evaluate the benefits of treatment according to values and subjectively perceived needs and impacts. Indeed, this conclusion is suggested by the results of another study (Ko *et al.*, 2006) showing that patients became insightful in hindsight after they noticed the impacts of medication and linked these benefits to the distress or problems in life created by their symptoms. Other evidence suggests, too, that people appear more inclined to pursue a course of treatment when they experience its benefits (Perkins *et al.*, 2006; Warner *et al.*, 1994) and the impact helps, rather than hinders, them in performing day to day activities or roles that are of value to them (Carling, 1995). Thus, what appears to be lack of insight may, in fact, reflect a mismatch between the felt impact of the treatment and the individual's "expectancies" (Leventhal,

1997), in turn reflecting biographically or culturally influenced values about costs and benefits. On the other hand, insight may come about as the individual notices the impact of treatment and comes to see that it helps them solve a particular life problem that they consider to be associated with their condition.

In summary, the traditional notion of insight assumes that the medical explanation of events is the only plausible, objective one, and that a person who disagrees with it or fails to see the objective benefits of treatment necessarily lacks insight. As opposed to viewing insight as a logical response to an objective fact of illness, critics have pointed out that people may interpret problematic or anomalous experiences in various ways that may be equally, if not more, persuasive, depending on the unique biographical, interpersonal or cultural context of each individual. This emerging view also suggests that if people accept the illness and do pursue treatment, they may judge and eventually reject or accept its benefits according to the expectations that flow from the context of their own lives, rather than as measured from the so-called objective standpoint of the professional.

### ***Insight and the Divergent, Paradoxical Impacts on Recovery***

As noted above, the dominant conception of insight tends to view its creation as a positive occurrence; in this view, insights leads to treatment adherence, control over the symptoms of illness, and helps the individual better his or her quality of life to the greatest extent possible. An emerging line of inquiry suggests, however, that illness awareness and treatment adherence in and of themselves may not have positive consequences for the individual's subsequent health and quality of life (M. A. Cooke et al., 2005; Hasson-Ohayon *et al.*, 2006; A. R. Mintz et al., 2003; Roe & Kravetz, 2003; Simon *et al.*, 2004). As discussed below, in early psychosis, awareness of illness may lead – at least initially – to poorer emotional adjustment, when individuals appraise the illness or its specific symptoms as involving “entrapment” (Birchwood *et al.*, 2000). The section also discusses emerging evidence that emotional adjustment in early psychosis (e.g., Watson *et al.*, 2006) may be seen within the context of the wider body of literature exploring the impact of illness perceptions on the outcome of chronic illness (see Hagger & Orbell, 2003). There is some indication that, as a whole, the impact of insight on emotional adjustment and well-being may be divergent: depending on the individual and

his or her construal of the impact of illness, the effects of insight may be either positive or negative (J. T. Lysaker, 2007)

As mentioned, emerging evidence indicates a link between insight in early psychosis and depression (Alisa R. Mintz *et al.*, 2004; Saeedi *et al.*, 2007), suggesting the possibility that increases in illness awareness may cause demoralization (Birchwood, 2003) and heighten the risk of suicide (Crumlish *et al.*, 2005; McGorry & McConville, 1999). While there are various possibilities explaining this link,<sup>12</sup> recent studies suggest that depression follows increased awareness rather than the reverse (Birchwood *et al.*, 2000; Drake *et al.*, 2004; Jackson *et al.*, 2005; Saeedi *et al.*, 2007). These studies suggest further that depression may in fact be related to feelings of entrapment by persistent, non-responsive symptoms and, more generally, depression may also relate to feelings of demoralization about the new, unwelcome reality of illness, and to fear about the inability to reclaim valued aspects of one's identity (McGorry, 1995).

This line of investigation is consistent with a wider body of research which looks at the impact of appraisals on successful coping with chronic illness in general. (Jolley & Garety, 2004) It also suggests that how the illness is appraised may have direct impact on how specific conditions are managed. In particular, this body of research indicates that these appraisals are mediated by the "common sense model" of the health condition held by the individual, also known as "illness perceptions" (Hagger & Orbell, 2003; Leventhal *et al.*, 1992). Built up through experience and enculturation, these involve the person's beliefs pertaining to the perceived identity, consequences, duration and controllability of the health condition in question. A meta-analysis of the relevant research suggests that individuals who appraise their conditions as being chronic, less controllable and having more severe consequences tend to cope more poorly and exhibit more distress and symptomatology, irrespective of the actual nature of the health condition (Hagger & Orbell, 2003). Some research also suggests that people who view their identities as indistinguishable or enmeshed with illness may have relatively poor emotional adjustment (Sharpe & Curran, 2006). In sum, the illness perception literature highlights

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<sup>12</sup> For instance, some research (E. T. Taylor & Brown, 1988) suggests that individuals with psychosis are depressed to begin with and, like other depressed individuals, may be less disposed to engage in protective denial and less inclined to interpret their personal situations in a way that casts themselves in a favourable light.

the importance of developing a concept of illness that does not overwhelm one's sense of identity; it also implies the need to develop a realistic sense of efficacy in relation to the illness, either through effective treatment or self-care strategies.

While the earlier cited psychosis research was shown to be analogous to the illness perceptions literature, recent research more explicitly explores the relevance of common sense models of illness to psychosis. Though in its early stages, this line of inquiry shows the following results: beliefs or attitudes about specific treatments and their appropriateness can positively impact help seeking (Haley *et al.*, 2003) and subsequent compliance (Quillams & Addington, 2003), either positively or negatively; and beliefs related to psychotic illnesses (and appraisals of specific symptoms thereof) can impact on symptom distress and outcomes related to emotional adjustment (Birchwood, 2003; Jolley & Garety, 2004; Kinderman *et al.*, 2006; Fiona Lobban *et al.*, 2003b; F. Lobban *et al.*, 2004; Watson *et al.*, 2006).

This evidence has led some researchers to the conclusion that creating an “adaptive profile” of illness perceptions may be equally significant to helping create illness awareness in and of itself (Jolley & Garety, 2004). Certain authors also suggest that illness perceptions (Jolley & Garety, 2004) or stigma (P. H. Lysaker *et al.*, 2007) may account for what appears to be the “paradoxical” impact of insight, whereby for some individuals, insight (or acceptance of the mental illness label) can be associated with feelings of control and improved quality of life, while for others, accepting the label may lead to feelings of demoralization, depression, engulfment and avoidant coping. In sum, the foregoing suggests that insight is not sufficient for recovery. Awareness of illness may have different meanings and thus different consequences for the individual's recovery depending on past circumstances and the unique connotations (or common sense model) the illness possesses for each individual.

### ***Insight & Avoidant Coping***

The sections above identified the possibility that denial of illness could play a psychological function by protecting the individual from the unpalatable consequences that would otherwise be brought to consciousness if the illness was directly acknowledged. The above-mentioned link between insight and depression has been taken



as indirect evidence in support of this theory. A body of research suggests that rather than denying illness altogether, some individuals with psychosis actively “seal over” the illness experience and seek to avoid contemplating it or exploring its consequences upon their lives (McGlashan, 1987; Tait *et al.*, 2003; Thompson *et al.*, 2003). Some research also indicates that this tendency may be related to past adverse experiences and suggests that individuals who had developed resilient responses to past adversity may be less inclined to adopt such evasive coping strategies (McGlashan, 1987; Stewart, 2006; Tait *et al.*, 2004); conversely, those who adopt sealing over strategies may have negative “self-schemas,” worse outcomes than “integrators” (Thompson *et al.*, 2003) and may be less inclined to maintain engagement in services over the long term (Tait *et al.*, 2003).

Other work, however, suggests that the tendency to seal over or “bracket” (Charmaz, 1997) experience may be a situational response adopted by many people who experience various chronic illnesses, including early psychosis (Hirschfeld *et al.*, 2005; J. Larsen, 2007b; Thompson *et al.*, 2003). It is possible that this tendency has to do with a reasonable disinclination to contemplate dealing with a condition that is perceived as having potentially negative consequences, but which in an early psychosis context may not in fact be long term. Recent qualitative research on the experience of recovery from an initial episode of psychosis indeed suggests that being in a state of diagnostic limbo – and perhaps wishing to push the possibility into the background after the initial episode of psychosis – may result in young people rushing back to reclaim their previous lives. Without taking the necessary steps to minimize their vulnerability, these young people may be confronted by relapse (Stewart, 2006); how the relapse is interpreted (*i.e.*, whether it is seen as an opportunity for learning or a source of demoralization) may determine whether or not the individual becomes caught in a negative cycle of avoidance, recurrence and demoralization, whereby illness (rather than wellness) advances “into the foreground” of the person’s life (Paterson, 2001).

The discussion above suggests that individuals may avoid contemplating the possibility of illness when that condition is perceived as uncontrollable and having negative consequences over the long term. However, the notion of illness at some point may come, at least notionally, to be more acceptable. Indeed, research looking at the process of recovery from serious mental illness suggests that individuals may

increasingly accept the illness label as they come to understand its consequences as less catastrophic (P. H. Lysaker et al., 2007) or as they see the diagnosis and treatment as offering them a sense of control over their lives (Carling, 1995; Deegan, 2007). In turn, being able to reframe one's perceptions may relate both to how one understands one's own strengths or resilience as well as to how one understands the illness and its potential controllability in relation to those strengths. For instance, research on the recovery process from serious mental illness suggests that as the individual takes stock of the strengths preserved in the face of illness and successfully puts these into action, initial successes (or "small wins") make it easier for the individual to accept mental illness without it engulfing one's sense of self (Davidson & Strauss, 1992; Lally, 1989). As the individual continues to make gains and reclaim aspects of a previously healthy self, the notion of illness may become increasingly less dominant and thus easier to accept. Other research on recovery shows that beliefs about the consequences of illness may be powerfully influenced by contact with other individuals with mental illness, and that acceptance can be affected for better or for worse depending on the image of illness conveyed through these "social comparisons" (Pettie & Triolo, 1998). Acceptance of illness may also become easier when doing so is not perceived as leading to social exclusion, which suggests that positive perceptions and expectations of significant others is of integral importance to the acceptance process (Fisher, 1999).

In sum, this research suggests that acceptance of illness may relate to the extent to which one can envision being able, through treatment, effective self-care, or through one's own resilient qualities, to control its potentially disruptive impact on one's life. It may also relate to the ability or opportunity to reappraise the envisioned consequences of the illness (e.g., for one's goals or social connections) in a less catastrophic way. Rather than supporting a theory of psychoanalytic denial, this body of research may instead support a theory of pragmatic acceptance; that is, rather than being unconsciously denied, a given explanation may be actively set aside or "sealed over" until the point where that explanation appears adaptive relative to other competing explanations. Helping a person gain insight in psychosis, then, may be more akin to the process of motivational interviewing approaches typically adopted in the field of addictions, which seek to help individuals consider whether a certain change (in this case, a change in attitudes and

behaviour in relation to the notion of illness and treatment) is consistent with his or her values and best interests (Rusch & Corrigan, 2002).

### ***Literature Review: Overall Summary***

The literature reviewed above suggests that insight, or the lack thereof, may involve a complex mix of factors which appear to be both biological and interpretive in nature. While the traditional medical paradigm suggests that lack of insight involves a failure to recognize a problem as a result of illness and unwillingness to adhere to treatment, an emerging view suggests the importance of understanding the individual's socially and biographically mediated view of the problem, as well as its expected solution. This suggests the need, when assessing insight, to ascertain potential mismatches in the way problems are defined and impacts are perceived, valued and attributed by patient and professional. Producing insight thus appears to involve finding a way to accommodate these different perspectives about the problem and how it should be addressed. Beyond the issue of congruence, the literature review points to the need to ascertain the unique meaning of illness for each individual. It suggests that the perceived controllability and envisioned consequences of the illness (including the perceived consequences for identity) may be unrealistically negative, and that such maladaptive "illness perceptions" may lead to demoralization and depression or to avoidant strategies of coping with the illness. On the other hand, as the individual draws on his or her resilience, gains a sense of control over the illness, and comes to see the condition as less catastrophic, he or she may begin to more fully accept the need to more consciously address the condition. This suggests a reciprocal relationship between insight and successful illness management: though insight may lead to illness management, perceived efficacy over the illness (a facet of illness management (Marks *et al.*, 2005)) may increase acceptance. It appears that, without consideration of the individual's perceived abilities to deal with the condition, achieving illness awareness in the short-term may be detrimental to emotional adjustment, successful recovery, and active acceptance of illness over the longer term.

## Theoretical Framework

Within the traditional paradigm of insight, noticing a problem, interpreting that problem as an illness, and pursuing treatment to gain its apparent benefits are viewed as self-evidently rational decisions that the individual is unable to make correctly due to illness. In keeping with the implications of the critique articulated in the previous section, however, the following section of the dissertation articulates an alternative theoretical framework within which insight development is viewed as a narrative and dialogical process. Such a framework suggests that insight can be viewed as coming to one of, or an accommodation between, a number of possible explanations (or stories) that may be plausible and functional to the individual. As explained below, coming to such an explanation can be looked at as a process of negotiation to find a version of events that is resonant within the person's day to day social world; insight development can also be seen as a process that the individual and significant others pursue together in order to find a version of events that is acceptable in the context of the individual's envisioned "self-story" or biography and seen as relevant to solving problems within that life story.

The theoretical framework to be developed below arises out of a synthesis and reappraisal of the literature review. By drawing upon and highlighting certain elements of the previously reviewed literature, the following section will present narrative as an interdisciplinary concept bridging these elements and forming the basis for a perspective from which a more comprehensive understanding of insight and its development can be gained using the methodological approach articulated in the following chapter. As explained at the end of the present chapter, this theoretical framework can be seen as ultimately related to symbolic interactionism (Charon, 1995), which is generally seen as providing a coherent "theory-methods package" with grounded theory (A. Clarke, 2005a), the strategy of inquiry chosen for the present study. While a chosen theoretical perspective is inevitably linked to a researcher's own store of knowledge and sensitivities, the research followed a recognized methodological approach (constructivist grounded theory, described in Chapter Three) to ensure that the framework was not imposed on the data. As noted, in accordance with the precepts of analytic induction (see Dey, 2007), the framework evolved as the analysis took shape which, as Dey suggests,

represents an interplay between the emerging results and the theoretical concepts that appeared useful for explaining them.

This interdisciplinary overview presents a contrast to the traditional psychiatric and psychological literature that explores a concept of insight using variables which are essentially static entities; the overview suggests instead that insight development can be understood as a process that evolves over time. It suggests that the process begins along the “pathway to care” (C. Lincoln & McGorry, 1995) as the individual’s initial attempts to frame a plausible, workable story of events break down. The process then evolves as the person subsequently interacts with mental health professionals in attempting to come to a “shared image” (Aaltonen & Rakkolainen, 1994), or story, of the experience. A final aspect of the process occurs as the person attempts to make sense of the new interpretive framework that comes out of those interactions, and then “contextualize” it (J. Corbin & Strauss, 1988) or mentally incorporate the illness as an adaptive aspect of the envisioned trajectory of his or her life.

As explained below, narrative may be seen to play a role and provide a potentially useful analytical framework within each of the three stages (breakdown of the initial story along the pathway to care, seeking a shared story of events, and contextualizing illness and life). Also, as articulated in each of these sections, the theoretical framework raises a number of key issues about the insight development process in early psychosis, each of which is illuminated by the study results discussed in Chapter Three, and will be discussed further in the final chapter of the dissertation.

### ***Breakdown of the Initial Story: Traveling the Pathway to Care***

Anthropological research suggests that in the early aspects of insight development, the individual uses culturally available discourses explain the anomalous and problematic experiences that typically occur in the very beginning phases of psychosis (Laurence J. Kirmayer et al., 2004). The research on pathways to care within the health services literature suggests, too, that during this phase, individuals may draw upon common sense psychological explanations, initially in an attempt to “normalize” the experience and later to guide their attempts in seeking outside help (Judge *et al.*, 2008). Given that in the beginning stages of psychosis, individuals may apparently draw upon different kinds of

discourses, the question arises as to why an individual might choose one type of explanation over the other, and at what point might he or she choose an explanation that implies the need for outside help.

There is some indication that individuals may consider new explanations and seek professional help upon becoming “demoralized” – i.e., when their original interpretive framework breaks down and comes to be seen as no longer adaptive (J. D. Frank & Frank, 1991). Consideration of new alternatives may be mediated by prototypes (Dey, 2007), that is, by comparing attributes of experience to stories of previously encountered instances which have come to represent a given concept (e.g. having a psychotic illness). While Hunter (1991) has elucidated the significance of prototype mediated (or case-based) decision-making within the medical profession, others have discussed how laypersons may recognize illness similarly (Hacking, 1995; L.J. Kirmayer *et al.*, 1994). Given its narrative framework, the present study may shed light on how people come to consider the notion of illness as potentially relevant to their own experience. It is possible that story- or case-based information may in fact play a role in illness awareness in an early psychosis context; further, this type of information can be more salient by comparison to the abstract knowledge typically delivered through psychoeducational interventions or by mental health literacy campaigns (Jorm, 2000) targeted to individuals coming into contact with mental health services for the first time.

### ***Bridging Perspectives and Negotiating a Shared Story***

After entering the mental health system, an apparent need arises to bridge potentially competing explanations that the individual may be struggling to reconcile. Of apparently equal importance is the need to find a “shared image” (Aaltonen & Rakkolainen, 1994) of the problem (Leventhal, 1997), or to find some accommodation between the various accounts by which doctor, patient *and* significant others conceptualize the psychosis experience. Achieving a shared story can then help all parties collectively move forward and develop a plan for managing the condition. There is some indication that people may hold apparently contradictory explanations (e.g. seeing experience as religion and illness) without apparent ill effect, and that this may indeed be adaptive (Good, 1994). At the

same time, various members of the individual's family may hold divergent, sometimes conflicting, interpretations.

Given this potential complexity of perspectives, a question arises as to how the individual can accommodate or bridge new understandings with previously held interpretive frames. Despite the literature apparently showing such divergent explanations to be potentially adaptive, it is unclear how such differences come to be accommodated in a way that *is* adaptive rather than confusing for the person. The question also arises as to how the individual's understandings might be influenced for better or for worse by significant others and what kinds of interactions *do* lead to a consensus about how to move forward. The present study presents an opportunity to understand more fully how these accommodations may play out: at the individual level, as the individual seeks to accommodate his or her original account of experience with the medical version; and at the interpersonal level, as the individual and his or her significant others seek to find a shared story.

### ***Contextualizing the Illness: Illness as Restoration, Illness as Disruption, and Biographical Work***

Once individuals come to reinterpret their experiences as illness-related, this revised version of events may provide divergent impacts and outcomes. In the literature review, the concept of "insight paradox" was identified (i.e., becoming aware of the presence of illness may constitute radically different scenarios to different individuals) (Greenfeld *et al.*, 1989; P. H. Lysaker *et al.*, 2007). While apparently providing some individuals with a perceived opportunity for restoration or for "reskilling," or reinterpreting past negative experience in a different light (Schneider, 2003), for others, awareness of illness evidently leads to demoralization or to attempts to seal over the illness, or avoid consciously addressing it. Thus, a final important issue is the manner in which the individual, both initially and over time, "contextualizes" the illness (Juliet Corbin & Strauss, 1985), and comes to see it as an acceptable part of his or her life.

The experimental social science literature provides some suggestions about how the acceptance process may happen. As mentioned, the literature on illness perceptions suggests that acceptance and positive coping may require re-appraising and finding a

more “adaptive profile” of the condition with respect to its perceived controllability, consequences, and impact on identity. Parallel research on the concept of self-efficacy and recovery from serious mental illness suggests that acceptance may be facilitated as the individual draws on personal strengths and reclaims non-ill aspects of the self with support from others. As argued below, a narrative theoretical perspective provides a way to understand how these disparate processes may work together to facilitate positive acceptance of illness by helping the individual reclaim self and reframe illness at the same time.

Within the sociological literature on chronic illness in general, such conditions have been acknowledged as potentially representing a “fundamental biographical disruption,” meaning that they may fundamentally change the individual’s envisioned life trajectory in unpredictable ways. Here, the concept that Corbin & Strauss call “biographical work” (J. Corbin & Strauss, 1988) appears to be particularly relevant to the process of adjustment and acceptance of illness. This notion encompasses the interpretive work that may be necessary for the individual to see the illness and its treatment as potentially reconcilable with one’s envisioned life story. It entails reclaiming valued aspects of self, or if this is not possible, reconstituting one’s identity. It may also involve reframing the meaning of illness, for instance, by discovering value or benefits from the experience (J. Corbin & Strauss, 1991).

Herndl uses different terminology to suggest that in the process of contextualizing illness into biography, individuals may adopt discourses offering various different “ways of being” with a chronic or threatening illness (Price Herndl, 2006). Other authors have suggested that these may involve using different “illness narratives” such as leaving the illness behind or “beating it,” seeking to coexist with it, or interpreting it as a transformative life event (A. W. Frank, 1993; Sharpe & Curran, 2006)<sup>13</sup>. In general, Sharpe & Curran (2006) argue that facilitating adjustment to illness “could be facilitated by encouraging patients to construct a narrative that integrates the experience of illness within their life story....” As will become apparent when the results of the current study

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<sup>13</sup> As will be explored later in the dissertation, Frank refers to these different ways of storying the illness (envisioning “beating” the illness or, alternatively, seeking to co-exist and potentially learn from the experience) as “restitution” and “quest” narratives, respectively.



are presented, the notions of illness as disruption and biographical work are evidently relevant to explaining how individuals may come to more positively accept the presence of psychosis in their lives.

## **Summary and Conclusion: A Narrative Theoretical Framework on Insight and its Consequences**

In summary, a narrative perspective of insight suggests that the meaning of the illness experience in general is conveyed in storied accounts which are chosen from within a number of possible versions of the experience. From this perspective, insight development initially involves exploring common sense explanations and seeking alternative perspectives or “interpretive frames” (Goffman, 1959; Snow & Benford, 1988) in the face of demoralization (J. D. Frank & Frank, 1991) once these no longer work. Upon entering the mental health system, the insight development process appears to entail achieving an appropriate fit between the individual’s view of the problem and the solution offered by the professional and achieving some accommodation between potentially competing views of the experience held by the individual. Beyond the issue of achieving fit or congruence, the nature of the narrative taken up may itself constitute an important aspect of the individual’s ability to manage or recover from the impacts of the illness. Depending on how the condition is storied, radically divergent connotations for the individual’s envisioned life trajectory may emerge, presenting implications for the individual’s inclination to address his or her condition directly (or avoid it), or more generally, for how the individual envisions and goes about living with the illness. Being able to “narratively reconstruct” (G. Williams, 1984) one’s identity and one’s illness appears to facilitate acceptance by helping individuals imagine and realize a scenario in which they can live meaningfully with and despite a serious illness.

Overall, the discussion suggests that a fuller understanding of insight development requires recognition of what appears to be a process that is essentially interpretive, social and pragmatic. In other words, as suggested by Roe & Kravetz, insight can be considered to be the story the individual tells oneself about the psychosis experience; it should be judged not by its congruence with the biomedical version of events, but by pragmatic considerations, such as whether it helps the individual maintain a healthy sense of

identity, connections with others, and a sense of his or her life as meaningful. The authors refer to their view as the “multifunctional narrative approach” of insight (Roe & Kravetz, 2003). As will be developed more fully in the final chapter, this theoretical framework is consistent with the notion advanced by Wampold *et al.* (2007) that insight involves coming to an “acceptable, adaptive explanation.”

The theoretical framework articulated above can also be seen as consistent in general terms with symbolic interactionism (Charon, 1995), which has been described together with the chosen strategy of enquiry, grounded theory, as a coherent “theory/methods package” (A. Clarke, 2005a). Symbolic Interactionism (SI) is a theoretical framework that seeks to understand how individuals and groups interpret (or symbolize) and act or interact in relation to some situation (Charon, 1995). While understanding action in a given situation is a primary concern for SI, it also seeks to understand several things: first, how the interpretations or perspectives leading to action are socially constructed through discourse; the factors which influence how individuals choose the particular perspective that guides action in a given situation; how individuals negotiate meaning as they attempt to bring shared “lines of action” together; and finally, how those perspectives are maintained, modified or discarded based on the consequences of the actions guided by the perspective taken (Lal, 1995).

This perspective is evidently consistent with and appropriate to understanding the problem as set out above; namely, how individuals, in dialogue with others, drawing on available discursive resources, come to a “shared story” which enables them to understand and deal effectively with the experience of psychosis. In the next chapter the methodology which follows from this theoretical perspective will be set out, combining grounded theory with narrative analysis, an innovation that Adele Clarke argues is necessary to take grounded theory around the “postmodern turn” and bring it closer to the theoretical roots of what is the essentially interpretive framework of symbolic interactionism (A. Clarke, 2005a).

As will be explained more fully in the next chapter, this framework forms the epistemological basis for a strategy of inquiry which employs narrative analysis (Mishler, 1991) within the overall context of constructivist grounded theory (Charmaz, 2006).

# CHAPTER THREE: METHODOLOGY

## Introduction

The previous chapter reviewed the literature on insight in psychosis and articulated the need for an analytical perspective consistent with symbolic interactionism, arguing that such a theoretical framework provides a basis for moving towards a more comprehensive understanding of the insight development process in early psychosis. The following chapter describes how the overall strategy of inquiry adopted in the present study – grounded theory complemented by narrative analysis – will be undertaken in a way that is consistent with this theoretical framework. First, the chapter discusses the methodological approach in general terms, articulating the value of using the chosen methodology for adequately understanding its topic of inquiry. The chapter then goes on to explain the specific steps taken to address the overall study questions, with respect to sampling and recruitment, data gathering and analysis, and representation of the results. The final section of the chapter talks about the steps taken to ensure methodological rigour of data gathering, analysis, interpretation and representation of the findings.

## Methodology: General Approach

As mentioned, the research uses the “core narrative” form of narrative analysis (Mishler, 1991; Reissman, 1993), carried out within an overarching strategy of inquiry which employs constructivist grounded theory (GT) (cf. Charmaz, 2006) guided by the symbolic interactionist (SI) theoretical framework, to examine the general study questions:

- what is the process of insight development amongst individuals who have recently been diagnosed with psychotic illness for the first time?; and,
- what is the relationship of illness awareness to self-management and recovery in the early stages of psychosis (known as the “critical period” of the illness)?

In more general terms, the study seeks to understand the process by which individuals come to understand their illness in a way that increases, rather than decreases, effective illness management and leads to increased well-being. Expressed in terms of the study's narrative theoretical perspective, the underlying question is how, in interaction with significant others, participants draw on available discursive resources and come to frame their experience in terms of a narrative that is acceptable and adaptive to them. The section below discusses both grounded theory and narrative analysis, explains the rationale for combining the two, and articulates the means by which the present methodology achieves their integration. The chapter then goes on to discuss the specific steps taken within this overall approach.

### ***Grounded Theory***

Consistent with its roots in the SI framework, grounded theory (GT) seeks to understand the actions or interactions of individuals as they “process” (Holton, 2007), or attempt to solve a basic social or psychological problem in a given situation. It involves a systematic approach to data collection, as well as specified techniques for data analysis (Dey, 1999). While different versions of GT exist, the common features involve the following : simultaneous data collection and analysis (involving theoretical sampling, guided by the emerging analysis); questioning the data for actions/interactions that can be observed therein (breaking down the data); using comparisons in order to categorize the observed incidents and to “raise” the data to a more abstract conceptual level; and exploring the emerging analysis to identify a theory that represents a latent process (basic social or psychological process) which encompasses and integrates the categories that are observed and induced (Charmaz, 2002a). In other words, all approaches to grounded theory analysis isolate meaningful incidents from within the data, group them into categories which appear to share a conceptual similarity, then explore the interrelationships between categories. The overall analysis ultimately leads towards a theoretical understanding of the process in question (in this case, the process of insight creation and its relationship with self-management and recovery in the early phases of psychotic illness).

A point of contention exists, however, between two major schools of grounded theory on the appropriate use of a pre-existing theoretical coding framework in arriving at a novel understanding of the phenomenon in question. “Classic” grounded theorists have been criticized as “forcing” (Glaser, 1993) both the use of any preconceived theoretical framework, and the use of the standardized “axial coding” (Strauss & Corbin, 1990) approach to raising the data<sup>14</sup>. While in the original version of grounded theory analysis, emphasis is placed on letting categories “emerge” inductively from the data (Glaser, 1993), other approaches to GT acknowledge the useful and inevitable role of sensitizing concepts (e.g. disciplinary or substantive theories) as the researcher builds a theoretical understanding of the subject matter (Dey, 1999). As explained further elsewhere, the present approach adopts what can be looked at as the middle-ground approach taken by Charmaz’ constructivist grounded theory; this approach avoids axial coding, but recognizes the inevitability and potential value of employing a transparent theoretical framework, should these concepts “earn their way into the analysis” (Charmaz, 2006).

A criticism of grounded theory as practiced today is that it gives short shrift to issues of perspective and meaning, and thus is not fully methodologically congruent with its roots in symbolic interactionism (Charmaz, 2005; A. E. Clarke, 2005b). As mentioned, within the SI framework, language or narrative is seen as the tool by which discrete perspectives can be brought together into a shared perspective that shapes a coherent “line of action” towards a given situation. With this in mind, emerging approaches to grounded theory guided by symbolic interactionism recognize that in order to understand the basic social or psychological processes used by participants to address their concerns, one must be able to identify the language and narratives being employed to interpret situations and to guide the actions within those situations (Charmaz, 2002c; A. E. Clarke, 2005b; Dey, 2007).

The present methodological approach thus takes its initial cue from one of these approaches (situational analysis, see Clarke, 2005), suggesting that narrative analysis can identify such things as the narrative “elements” of the analytic situation, which can later

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<sup>14</sup> Axial coding is an approach to examining the relationships between initial categories. It seeks to find these relationships in terms of pre-set “coding families”, for example, by looking at whether one initial category might be a cause or context for a specific action or interaction.

be incorporated within a standard grounded theory analysis. While relying on Clarke's theoretical arguments, the present approach draws on Charmaz' constructivist grounded theory (Charmaz, 2006), which provides an approach that is both theoretically and practically suited for the present purposes. It is theoretically consistent given its emphasis on the importance of understanding the meanings and discourses influencing how participants construct their experience and exploring how these constructions relate to subsequent actions.

In terms of its practical aspects, Charmaz' approach, used together with discourse-based interviewing (Odell *et al.*, 1983), provides a concrete way of employing narrative analysis within the steps of an established grounded theory approach. First of all, discursively oriented listening and probing provides a way of attuning the conversation within traditional semi-structured interviews to the use of the linguistic repertoire employed within the written narratives and to its possible impact on the recounted events (Odell *et al.*, 1983); further, Charmaz suggests that a parallel narrative analysis provides a way of identifying elements which, if warranted, can be included in the final theoretical coding stage of the overarching constructivist grounded theory analysis, should they prove relevant to the emerging theoretical understanding; she argues that the narrative aspects are included together with the other emerging categories of the overarching grounded theory analysis which also earn their way into the final grounded theory of the phenomenon in question. The specific steps of constructivist grounded theory and the way in which narrative analysis – using Mishler's core narrative approach (1991) – is integrated within these steps will be described further below (see "Data Analysis"), after the general approach to narrative analysis adopted in the present approach is explained.

### ***Narrative Analysis***

Charmaz and Clarke provide compelling theoretical arguments as to why narrative analysis is an appropriate complement to grounded theory, and also provide some practical guidance as to how these approaches can be integrated; neither, however, provides prescriptive advice as to which among the many forms of narrative analysis may be appropriate to employ. The following section provides an overview of narrative

analysis, thus setting the stage for the discussion of the form of narrative analysis that will be employed by the current study.

Narrative analysis in general focuses less on content (or *what* participants' accounts refer to) than on *how* and to what ends participants convey those accounts (Lieblich *et al.*, 1998); this follows in part from the precepts of narrative epistemology, wherein the correspondence between the content of the narrative and some external objective reality is less important than the function the narrative plays in achieving some underlying personal, interpersonal, or social function (Roe & Kravetz, 2003). In the narrative view, then, what might be considered to be a unitary, objective truth could be storied in different ways depending on the setting, the audience, and the purposes of the narrator. For instance, what could be considered as the same experience could be construed as illness or religious epiphany, depending on the individual or the context.

Narrative analysis is recognized as being less developed than other approaches, such as grounded theory. The relative lack of development or consensus concerning narrative analysis in part reflects the diversity of approaches referred to under the narrative analysis rubric. Understanding narrative analysis first requires a discussion of what is meant by the term "narrative" itself. There are a bewildering number of definitions of "narrative" and "narrative analysis", none of which is entirely comprehensive. For the present purposes, a synthesis definition based on various accounts is offered wherein narrative is defined as the purposeful (meaningful) recounting of a temporally related and/or thematically coherent sequence of events with a beginning, middle and end related from a specific point of view to an audience (either actual or implied); the narrative typically makes use of a recognizable form or structure to convey the emergence and resolution of some complicating action or event (Chase, 2005; Norman K. Denzin, 2001; Mishler, 1991; Ochs, 1996).

Analysis of narratives (e.g. as contained in novels, films, etc.) has moved out of the humanities and into health and social science research, as stories elicited in the course of research interviews, and even voluntarily offered despite the strictures of more structured surveys, have been accepted and analyzed as narratives (Chase, 2005). Within the social sciences context, narrative analysis has been used as a term to categorize a family of

approaches that concern themselves with meaning making and its relationship with the narrative elements mentioned above (Chase, 2005; Lieblich et al., 1998). For instance, in a health context, one form of narrative analysis (congruent with the present approach) has been used to examine how specific health complications are framed in terms of underlying features of core narratives (e.g., characters, setting, plot complications, etc., as explained below) and how these accounts may affect the resolution of the concern (Reissman, 1993).

Mishler, based on his review of the analytical approaches used by literary scholars, suggests that, regardless of the form of narrative analysis adopted, these approaches generally consider structural, textual and pragmatic considerations, placing more or less emphasis on each depending on the particular approach (Mishler, 1991). That is, they focus to a greater or lesser extent on the underlying structures that may influence the narrative<sup>15</sup>; or they may concentrate on the narrator's conscious choices of literary repertoire made within a text<sup>16</sup>; and/or they may concentrate on the function of these choices, for example, what social goals the narrator is trying to achieve in a specific inter-personal context (e.g., presentation of self in a certain kind of light). In a health context, Murray points out that, depending on the researcher's purposes, narrative analysis may focus on different levels of analysis (i.e., personal, interpersonal, or more societal) (Murray, 2000).

In the context of the present study, which concerns itself more specifically with the personal (and to some extent inter-personal) level(s), the foregoing implies that the analysis should look at how an individual draws upon, or is influenced by, existing discursive structures or resources in order to make sense of a situation and to achieve a certain personal or interpersonal (or pragmatic) function. This formulation can be seen as consistent with the theoretical framework adopted towards insight development, in which

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<sup>15</sup> For example, Arthur Frank's form of analysis has looked at how the accounts of cancer patients can be discerned according to a typology of accounts, which include "restitution" narratives (wherein the accounts describe the actions or wishes to beat or overcome the illness), "quest" narratives (seeking to learn from or gain from the experience) or "chaos" narratives (where no clear attempt has been made to ascribe meaning to the illness) (A. W. Frank, 1995).

<sup>16</sup> For example, Mattingly, drawing on Frye's notion of "emplotment" (Frye, 1963) describes an approach wherein rehabilitation professionals seek to help brain injured clients frame their experience of recovery in terms of a "healing drama" (Mattingly, 1998).



the individual is seen to make sense of his or her experience of psychosis using available discursive resources in order to understand and communicate that experience in a way that makes sense and is adaptive within a given social context.

### ***Integration of Constructivist Grounded Theory and Narrative Analysis: The Present Approach***

As explained further in the next section, the present approach uses a form of narrative analysis to discern the “interpretive frames” (described below) employed by individuals to understand or story their new reality; simultaneously, using grounded theory analysis, it seeks to explore the subsequent process of insight development and the consequences of the individual’s evolving understanding for illness management and well-being. The specifics of the present approach are discussed in more detail below.

Using the notion of interpretive frames set forth by Goffman (Goffman, 1959), and as described in Della Porta & Diani (Della Porta & Diani, 1999), the present approach performs an interpretive frames analysis using an adaptation of the core narrative approach articulated by influential narrative analysis texts written by Mishler (1991), and Reissman (1993) to bring these frames into relief.<sup>17</sup> Interpretive frames are pre-existing notions that allow individuals to understand and act in the face of unfamiliar experience or situations. They can be seen as stories providing guidance as to how the future might unfold, and within that light, how to deal effectively with a given situation. While there are a variety of similar formulations conceptualizing how individuals story their illness experience<sup>18</sup>, the notion of interpretive frames was chosen because of its heritage within the symbolic interactionism tradition.

With this notion in mind, Mishler’s core narrative approach was chosen, since its methods were recognized by the present researcher – in particular, the “complication”

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<sup>17</sup> As explained by these authors, the approach is derived from an approach used by Labov (Labov, 1997), who in turn drew upon techniques used by Vladimir Propp to analyze Russian folk tales.

<sup>18</sup> Such terms include prototypes and “organizing metaphors” (L.J. Kirmayer et al., 1994), illness perceptions or common sense models of illness (Leventhal *et al.*, 1992) and explanatory models (Kleinman, 1988).

and “resolution” sequences<sup>19</sup> that form the core of the narrative – as providing a way of bringing the interpretive frames employed by participants into relief, both as the experience of psychosis evolved, and as the individual came into contact with the potentially competing frames encountered within the mental health systems.<sup>20</sup> While consistent with a traditional grounded theory analysis in its interest in action and process, as explained, the methodological approach is also consistent with a narrative, symbolic interactionist perspective; this latter seeks to understand how narrative either consciously or tacitly influences those processes as the individual achieves to find a pragmatic interpretation of his or her experience. The full range of steps will be explained below (see “Data Analysis”).

As described below, in keeping with the focus on narrative, the first step of the chosen analytic strategy was to elicit and understand, using narrative analysis, written accounts articulating how participants experienced and made sense of their emerging psychosis.

After identifying the narrative elements of the situation in these terms, the analysis then sought to understand from a grounded theory perspective the process by which insight is created in a new context of interaction: that is, to understand, upon entering the mental health system, how the individual’s understanding may be modified through interactions with health professionals and others associated with the care setting (e.g., other individuals with mental illness, family care givers, etc.) and how that understanding may be affected by other information available in and through that setting. The grounded theory analysis also sought an understanding of the impact of insight for self-management and recovery in the early stages of psychosis; in other words, it examined the relationship between changes in understanding and the individual’s ability to manage

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<sup>19</sup> The term “resolution” should not be taken to imply that narratives always function to produce acceptance of one particular interpretive frame; as discussed later in the dissertation, narrative may also function in the service of accommodating a “multiplicity” (Lewis, 2006) of views.

<sup>20</sup> It is interesting to note that after the present approach was chosen, the research uncovered other similar studies employing similar approaches, including Bell’s study which investigated how D.E.S. daughters constructed their experience and upon seeking medical help eventually juxtaposed (often in opposition) these interpretations against medical interpretations (Bell, 2000). The core narrative approach was also used by another study investigating the formation of insight in people with schizophrenia (Ko *et al.*, 2006).

the emotions and symptoms associated with the condition, and the challenges these create in the context of the individual's day to day life.

Before moving on, it should be noted that by eliciting written narratives (or in conducting interviews) that the research process itself may influence the research participants' understanding, and thus could be considered to change the reality of the phenomena which it seeks to study (insight and self-management), and could be seen as constituting a type of intervention. Within an interpretive ontological framework, however, this methodological approach is consistent with a more accurate view of reality wherein illness awareness may change across circumstance, rather than one in which one's degree of insight could be measured in a way that pins it down once and for all. It should then be emphasized that the present research, while potentially having an impact on those who participate in it<sup>21</sup>, is not intended as an intervention, but as a way of developing a more thorough understanding upon which to develop more sophisticated interventions in the future.

## **Setting, Sampling & Recruitment**

### ***Setting & Sampling Strategy***

As explained earlier, the study was based at the Vancouver Coastal Health Authority's Early Psychosis Intervention (EPI) program, in particular at the Vancouver/Richmond EPI Day Program, at the Detwiler Pavillion of Vancouver Hospital, and at the community clinic of the EPI program, on Commercial Drive in Vancouver, Canada. Within these settings, all participants would have experienced psychoeducational interventions consistent with recognized evidence-based approaches for achieving illness management and psychosocial recovery (Mueser *et al.*, 2002); the EPI practitioners are also part of a provincial network of early psychosis services and are conversant with the international practice guidelines specific to the early psychosis context.

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<sup>21</sup> Pennebaker's research, for instance, shows that narrative writing may help emotional adjustment to traumatic experiences (Pennebaker, 2000), as does the research of Bernard *et al.* in an early psychosis context (Bernard *et al.*, 2006).

Participants were recruited from both settings of the EPI program in accordance with the following theoretical sampling strategy: in general, the rationale behind the theoretical sampling strategy was to seek participants who were within the “critical period” of psychosis, a three to five year period following the onset of the illness during which early psychosis intervention is posited to be of maximal effectiveness (Edwards *et al.*, 2005). For two reasons, however, the sampling frame was subsequently narrowed. In order to ensure potential participants had achieved sufficient distance and reflective understanding of their experience, only those participants were recruited who had been judged by treating clinicians to have achieved clinical stability<sup>22</sup>. The general guideline used was to recruit people at least two months from their first episode. At the upper end, in order to ensure that people’s accounts were not hindered by memory difficulties, participants were generally less than three years from their first episode, or from their first diagnosis; three years from entry into service also roughly reflects the upper limit of eligibility for early psychosis program in Canada. Sampling from both program settings ensured that the overall sample was representative of the overall sampling frame sought, since participants from the community clinic tended to be earlier on in the illness, and those from the Day Program were further on in the critical period being investigated. Although participants were expected to be within a specific age range given their early psychosis status, age was not a specific criterion. While gender and cultural background were also not explicit criteria, as described in more detail below, the sample was also roughly even by gender and featured the ethnocultural diversity that would be expected from a service situated within a large urban centre.

The exclusion criteria included the following:

- individuals with active and problematic substance abuse; and
- people with non-psychotic illnesses.

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<sup>22</sup> Clinical stability in this context meant that the individual had not been recently hospitalized and was not experiencing symptoms that were distressing, presented cognitive barriers, or which otherwise interfered with their ability to carry on a conversation and participate in day to day activities, e.g. pursue their regular educational, vocational, or rehabilitative activities.

The criteria with respect to clinical stability and active substance abuse were necessary to ensure all participants were competent to give informed consent and to ensure the safety of both the client and the researcher. A de facto criterion was the selection of those who were currently engaged in treatment and who participated regularly in therapeutic and rehabilitative aspects of the EPI program; this, plus the presence of clinical stability, means that the analysis reflects on the processes of those with psychotic illnesses who are relatively successful in terms of developing insight and illness management capacity. As part of the demographic and service utilization data collection, participants were asked to provide self-ratings of their insightfulness and self-management capacity. The characteristics of the sample on these and other parameters are presented later.

Generally, in theoretical sampling, recruitment choices evolve as the analysis takes shape. In the present study, the emerging theoretical categories generally did not conform to demographic variables upon which one could make sampling decisions. As the analysis proceeded, however, the importance of achieving maximal variation within the sampling frame on the variable of time from entry into care was recognized<sup>23</sup>, and this realization guided the subsequent recruitment strategy. (Apart from maintaining maximal variation sampling, the emerging theory was also explicated by varying the way participants and data were questioned.)

The study initially sought to recruit between twelve and sixteen participants. Recruitment stopped after data from twelve participants had been analyzed to the point at which the overall grounded theory analysis had emerged and had become sufficiently saturated; in other words, the recruitment stopped once the grounded theory had emerged sufficiently so that all major categories and subcategories had been identified and fleshed out by the analysis.

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<sup>23</sup> In particular, because of its importance in ensuring sufficient data was available to flesh out, at the earlier end of the sampling interval, the focused code of “being in diagnostic limbo”, and at the upper end, to define the focused codes of “pushing illness away” and “being confronted” by relapse.

## ***Recruitment***

The following steps were taken to recruit participants:

- distributing and making available a “consent to be contacted” sheet by/with the Early Psychosis Team receptionist/administrator (Appendix A);<sup>24</sup>
- having the researcher (EM) do a brief talk about the study during EPI Team (staff) meetings, during which the sampling strategy was explained;
- having staff distribute the consent to be contacted form to interested and eligible participants;
- having staff ask potential participants for permission to pass on contact information to the researcher in order to hear more information; and
- fully informing potential participants and asking individuals to indicate their consent (see Appendix B).

Recruitment steps were taken in accordance with ethical considerations; thus it was emphasized to participants in all recruitment information and during the consent process that their participation or non-participation in the study would in no way affect their clinical care. The research methods were approved the Research Ethics Board of the University of British Columbia, and by the Vancouver Coastal Health Authority (see Appendices C and D).

### ***Sample Characteristics***

As noted, participants were asked about demographic and service delivery characteristics which were anticipated to be potentially relevant to the analysis (see Appendix E). The participants were evenly split by gender. By diagnosis, of the twelve participants, two (17%) had schizoaffective disorder, three (25%) had schizophrenia, four (33%) listed their diagnosis generically as psychosis, and the remaining three (25%) had

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<sup>24</sup> The sheet included general information about the study and what it entailed as well as a signature line where the individual indicated their consent to be contacted by the researcher to receive further information and a line to leave a contact phone number. In accordance with instructions from the researcher, in cases where the consent to be contact was passed on to the receptionist/administrator, the form was kept in a confidential, secure place.

bipolar disorder. The sample thus reflects a relatively even split between psychotic illnesses with and without prominent mood features.

Participants' ages ranged between 20 and 32, with the mean and median both being approximately 26 years old. Participants had typically (as measured by the median) been in the mental health system or been diagnosed seven months prior to their participation in the study, ranging from 2 to 36 months. Seven (58%) of the participants had not experienced a relapse of the illness, and the other five (42%) had experienced at least one re-hospitalization; two participants (17%) had never been hospitalized. Eight participants (67%) were from the Day Program, and the other four (33%) were recruited from the Community Clinic.

In terms of their living context, seven (58%) lived with family, four (33%) lived on their own (or with a roommate), and one (8%) lived in supportive housing. Four (33%) participants were from an anglo-European ethnocultural background, four (33%) were of East Asian heritage, three (25%) were of non-anglophone European descent, and one person was from a South Asian background. The sample thus reflects the diverse ethnocultural background typical of a large multicultural centre.

Finally, participants were asked to rate aspects of insight (i.e., agreement re "problems", degree of adherence to care, and self-management ability) by rating various statements – listed below – according to the criteria "agree", "not sure", or "disagree". All agreed with the statement "I agree that I've experienced some problems", and all but one participant agreed with the statement rating adherence: "I generally agree with what my mental health professional(s) think is the problem, and with what they recommend I should do about it." The participants thus represent a relatively insightful population by the traditional definition of insight, according to their own ratings (and as judged by their behaviour of participating regularly in care). However, participants who were presently insightful had not necessarily gained insight quickly; as mentioned above, nearly half of participants had experienced at least one relapse, and as discussed later, were often ambivalent for lengthy periods of time about the notion of illness and its treatment.

In terms of their self-management ability, seven (58%) of participants agreed with the statement "I generally feel that I'm able to deal effectively with my problems," with the other five circling "not sure". Seven (58%) had completed high school; 42% held either

a university degree or college diploma. Seven (58%) worked or went to school part time; two (17%) attended school full time; thus, 75% of participants worked or went to school on a full or part time basis. Four (25%) attended the Day Program full time. The participants thus reflect a group of people that are able to manage their illness to the extent that they can participate in community life on a relatively full basis, compared to older individuals with psychotic illnesses.

## Data Gathering

In keeping with the focus on narrative, the first step of data gathering was to elicit a written narrative from participants describing what happened and how they interpreted or framed their experience prior to entering the mental health system. A follow up interview then focused on the individual's evolving understanding during the post-entry period, and asked about the kinds of events (i.e., interactions, interventions, information, etc.) that helped participants understand and manage their illness. This sequence of asking participants to write an autobiographical narrative and performing a follow-up interview was suggested by a study done by Kralik *et al.*, which looked at how participants "incorporated the consequences of [arthritis] into their lives" (Kralik et al., 2004). As noted, it is also consistent with an approach known as "discourse-based interviewing"<sup>25</sup> (Odell et al., 1983); that is, in the course of conducting the semi-structured oral interviews, the interviewing strategy was to probe for the tacit understandings suggested by various aspects of the linguistic repertoire employed in the written accounts. This strategy allowed elements of the earlier narrative accounts to be explored during the oral interview for their subsequent influence on the participants' evolving understandings of their experiences.

The researcher took field notes for each participant; notes initially recorded in a notebook were subsequently transferred to a computer field note file kept for each participant based on a common template created by the researcher (see Appendix F). Participants were also given the opportunity to review and reflect upon their respective interview transcripts and upon an interim summary of the data analysis. Their responses

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<sup>25</sup> It is also consistent in a general way with a research procedure known as a "Questerview" (Adamson *et al.*, 2004), which also combines written and oral approaches for eliciting data.



to these were also noted and included as part of the emerging analysis. As noted, basic demographic and service utilization information (gender, age, number of episodes, time since first episode, etc.) was collected following the interview.

For the elicited written narrative, the participant was given general guidelines about relevant topics to address (Appendix G), and was given an estimated time period for completion. The guidelines emphasized that the written account was to focus on events *prior* to when the individual entered the mental health system, and that the accounts should be written in prose. The participant was also given the option of reading a variety of published narratives to orient him or her to the nature of the task at hand. They were also given the option of composing on a laptop computer or writing longhand in a notebook; the latter was preferred by two participants.

The content of the oral interview guide was consistent with topic domains identified through an initial literature search (see Appendix H for interview guide protocol) and, as mentioned above, was modified in order to explicate the emerging analysis in accordance with grounded theory procedures. Three participants were interviewed during a pilot phase of the inquiry in which the initial version of the interview guide was tested for response burden, length, face validity and perceived relevance of the questions, and for any question ambiguity leading to inconsistency and unreliability of responses. No significant modifications of the data gathering process were made following the pilot phase, and all material gathered during this stage was included in the final analysis.

The written narratives were typically about 800 and 1000 words in length or about 2 and 2.5 typed single-spaced pages (as judged by the median and mean lengths respectively). These ranged between 400 and 3400 words, and generally took between 30 to 60 minutes to complete. The transcribed oral interviews were typically about 18 pages in length (median length, double spaced 12 point font) took between 35 and 55 minutes, and produced between 13 and 44 pages of transcribed material. In total, the interview data gathered resulted in 283 pages of transcribed material.

## **Data Analysis**

The general aspects of the data analysis procedures were described above. The specific steps are outlined in more detail below, including an explanation of the main narrative analysis steps, as well as an explanation as to how the narrative analysis was integrated within the constructivist grounded theory approach which overarched the analysis. The coding procedures described below were carried out using a template file in which narrative analysis and grounded theory codes for each participant were recorded. As mentioned, a file was kept for each participant using a common template, within which observational field notes, codes, and initial memos reflecting on the methodology and emerging analysis were kept. More detailed memos recording hunches about emerging codes and categories were kept in separate files, beginning with the focused coding stage of analysis. Memos were also kept recording reflections on the emerging methodology, and were used to produce the description that follows.

### ***Narrative Analysis***

As mentioned, the narrative analysis stage followed the core narrative model as explicated by Mishler (1991), in order to identify the interpretive frames employed by individuals to make sense of their experience. Initially, this entailed examining and coding the written narratives for the following elements:

- abstract (or what the story is about, in literal terms, or basic plot);
- orientation (or the main characters, timeframe, key scenes, settings, and relationships);
- complication (the key events around which the plot of the story revolves);
- resolution (or how the characters dealt with those events); and
- evaluation (or what the story is “about”, or figuratively or thematically speaking, what the “point” of the story is).

As the analysis proceeded, it became clear that two features, that is, the complication and resolution sequences of the narrative, were of particular importance in capturing the interpretive frames of participants; it was in examining how participants plotted these

core aspects, and in identifying what discursive resources were employed in doing so, that the interpretive frames became evident.<sup>26</sup> One other thing that became clear was the importance of the capturing and documenting images, known as “prototypes”, that participants employed to relate their initial understandings of what adopting the interpretive frame of illness would mean. Prototype images were evidently used throughout the stories of participants to describe imagined ideas about what the experience of mental illness is like, what a person with mental illness is like and imagined “future selves” associated with mental illness (L.J. Kirmayer et al., 1994; Markus & Nurius, 1986). As the analysis proceeded, it also became apparent that the experiences expressed by participants were often consistent with Arthur Frank’s typology of illness narratives; these include “restitution” narratives (wherein the accounts describe the actions or wishes to beat or overcome the illness), “quest” narratives (seeking to learn or gain from the experience), or “chaos” narratives (where no clear attempt has been made to ascribe meaning to the illness) (A. W. Frank, 1995).

Taken as a whole, the first stage of the strategy, narrative analysis, identified the discursive elements presumed to play a role in helping participants make sense of the initial stages of psychosis in terms of the interpretive frames employed, and the prototypes sometimes used by participants to represent the notion of illness, and to consider what adopting this explanation might mean. As explained below, grounded theory analysis was then applied to the oral interview transcripts in order to understand how participants acted upon their situations and to understand how the identified interpretive frames may have influenced that action, either consciously or tacitly. As mentioned, discursive analysis was also applied to the interview transcripts to study the continued influence of the narrative elements identified earlier, or to note new discursive elements (e.g. quest or restitution narratives) that came into play.

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<sup>26</sup> For instance, the participant may have explained the complications created by their psychosis as “being demon possessed”, and their attempts to resolve the situation as “trying to expel” the demons; in more general terms, participants used interpretive frames involving spirituality, special “powers”, technology, and also used common sense terms linked to professional theories, such as “stress” and “phases”. They also used various interpretive frames to describe not just specific experiences related to the experience of psychosis, but also how their overall life was going, for example, “going off the rails”.

## ***Grounded Theory Analysis***

As mentioned, the grounded theory strategy follows the constructivist grounded theory approach set out by Charmaz (2006). As explained below, the steps of this were:

- initial coding (questioning or examining the data in order to identify segments of transcript text with similar thematic content; labeling these segments using gerunds; beginning to group these segments into more explicit categories; beginning to further define the categories by specific elements thereof, and by breaking categories into sub-categories);
- focused coding (grouping codes into higher level conceptual categories, identifying what appear to be the most significant or frequent categories, identifying and verifying subcategories by comparing and testing codes against further data, and fleshing out and beginning to verify relationships between and amongst categories and subcategories);
- memoing (making written notes for the purpose of more explicitly defining the categories and exemplifying them by linking the definitions with specific examples from the transcripts; dating memos to establish an audit trail of the emerging analysis);
- conceptual mapping (drawing diagrams to visually represent the main categories – both focused codes and narrative codes – and their interrelationships);
- using the map as a basis for memoing potential relationships between focused codes (e.g. possible temporal, causal or contextual relationships), and memoing relationships of influence between focused codes and narrative codes in order to explicate the overall grounded theory; and
- theoretical coding (to identify a common core category or process that integrates or relates the categories and subcategories, and to derive a theory which explains the action in the data).

Given the iterative approach of grounded theory, the stages of data analysis and data gathering, while described separately, in practice can not and should not be done separately. In the present study, this meant that the analytical hunches emerging from early interviews were documented, which then influenced how the analysis of subsequent interviews was carried out. Another implication was that the narrative analysis of the written material also came into play as the analysis proceeded. For instance, a preliminary analysis of each written account was done prior to the face to face interview with each participant. This allowed the researcher, at appropriate parts of the interview, to probe into terms used during the written accounts or the interview itself, seeking to understand how these interpretive frames (or “linguistic repertoire”) may have influenced the described events, either consciously or without the awareness of the participant (Gubrium & Holstein, 2001; Odell *et al.*, 1983).

In accordance with the grounded theory approach, means of ensuring that the emerging analysis is credible and transparent included the following:

- use of memoing to document emerging hunches and theoretical ideas/codes;
- triangulation of analysis, that is by considering the perspective of others in the emerging analysis via use of the thesis advisory committee and by presenting the analysis for feedback at two conferences;
- use of member checking to verify the analysis (i.e. returning the transcripts and emerging analysis to study participants to solicit their feedback); and
- triangulation of data sources and analysis (use of successive narrative analysis and grounded theory, cf. Clarke 2005).

Other techniques for ensuring the transparency and credibility of the analysis and for ensuring rigour are described below.

## **Rigour/Limitations**

Key issues relating to the rigour of the analysis have to do with methodological coherence (Morse *et al.*, 2002), quality of the data (Kvale, 1989), transparency and trustworthiness of the data analysis process (auditability), and credibility and fittingness (Chiovitti & Piran, 2003) of the results (N.K. Denzin & Lincoln, 2005; Lal, 1995; Y. S. Lincoln, 1995). As also discussed, the chosen narrative analysis/grounded theory strategy also suggests specific criteria for rigour to be addressed, some of which have been discussed in the previous section.

### ***Methodological Coherence***

The chosen strategy of inquiry – grounded theory supplemented by narrative analysis – was conducted within the theoretical framework of symbolic interactionism (SI) (Lal, 1995). The criterion of methodological coherence (Morse *et al.*, 2002) suggests that the data gathering and analysis strategy should be an appropriate fit with the given theoretical framework. In the present case, then, the implication is that the chosen data gathering and analysis methods should provide an appropriate means of addressing the issues of action, interaction, meaning and context as suggested by the SI theoretical framework. The SI framework suggests that while interactions and actions are the ultimate data, a true understanding of these requires an understanding of the meaning-making process that guides the action. The current study appropriately addresses this by choosing a data collection strategy (i.e. written narratives and interviews) that elicits descriptions of interactions as well as elicits how meanings are derived within the relevant interactional contexts.

### ***Quality of the Data***

Eliciting high quality data hinges on the appropriateness of the research instrument, on the listening skills of the interviewer and the ability to make effective use of the probes and follow-up questions to pursue topics which are significant to the participant and to the emerging theory (Kvale, 1989). The nature of the research instrument has been discussed above, as have some of the strategies that were pursued to ensure that it possessed relevance, face validity, and avoided undue response burden for the participant.

(These strategies included pilot testing, ensuring appropriate question ordering, and the use of active listening skills.) Researcher reflexivity is necessary for ensuring the researcher is aware of the impact of the interview process on the data elicited, and for ensuring this role is used constructively. This notion is consistent with the precepts of narrative analysis and more recent versions of grounded theory, whereby data is viewed as “co-created” by the researcher and research participant (Hall & Callery, 2001). Steps taken included reflecting on the process using field notes, periodic checking with participants about their comfort level, and conscious attempts to establish and maintain a conversational rapport and flow throughout the interview sessions. High quality data was also ensured by checking recording equipment, using an experienced transcriber, proof reading transcriptions, and using field notes to restore interview context and to ensure reflexivity. It should be noted that in accordance with a narrative perspective, the accounts of individuals are presumed to vary across setting and over time. However, it was expected that people very early on in the course of their illness would not have gained the opportunity to form any coherent version (or versions) of their experience. Because of these concerns, the study sample included only those individuals whose accounts could be expected to have greater chance of achieving such perspective.

### ***Auditability and Trustworthiness of the Data Analysis***

The rigour of the data analysis process relates to the extent to which methodological steps are documented and to which decision-points regarding the choices made during the process of analysis are justified with the use of a documented audit trail, in order to ensure the transparent, explicit use of established data analysis techniques (Chiovitti & Piran, 2003). The data analysis steps that were followed in this case were consistent with a recognized approach to grounded theory (cf. Charmaz, 2005) and are supplemented by an approach to narrative analysis that has been justified and documented above, and whose emerging process was explicated in methodological memos. During the course of the data analysis, the researcher used analytic memos to document and define emerging categories and to explain decisions as to how emerging categories and subcategories are linked. Transparency of the analysis was also furthered by documenting the researcher’s own preconceived notions. As explained, this was done by presenting the documenting

the researcher's perspective (see Chapter 1), and using memos and a notebook to document field notes and hunches.

Use of memoing helped auditability and also helped ensure the trustworthiness of the analysis (and credibility of the results, as discussed in more detail further below) by showing how the researcher's emerging analysis was guided by explicit and logical steps that reflected accepted data analysis techniques. As mentioned, these steps included making clear, explicit links among aspects of the analysis as the emerging theory was articulated. It also involved attempting to contextualize or falsify the emerging theory by taking active steps to look for disconfirming evidence in the course of doing the analysis.

The trustworthiness of the analysis was furthered by making appropriate use of theoretical sensitivity (Glaser, 2003) in a way that did not privilege certain theories or hunches about the meaning of the data. As mentioned, the current approach to avoid unduly imposing prior theoretical notions included delaying a full literature review until the later stages of the data analysis; also, the theoretical framework, though specified in general terms during the proposal stage, was not fully articulated until the later stages of analysis.

As suggested further above, the trustworthiness of the analysis also hinges on some assumptions regarding the nature of the data generated by interviews with people with mental illness, namely that people can adequately tap into their experiences while experiencing psychosis, and that they are motivated to credibly narrate these experiences. Earlier research done in an early psychosis context suggests that people with mental illness have better access to their earliest illness experiences than do their family members or professionals, but that the latter group may have superior recall or insight into behaviours or actions during the period leading up to diagnosis (Hambrecht *et al.*, 1994). Another study suggests the capacity of people with serious mental illness has been generally underestimated: assessments of mental health inpatients showed similar levels of capacity as compared to other matched populations with chronic illnesses (Appelbaum & Grisso, 1995). The research in question showed that only a small subpopulation of people with schizophrenia had significantly impaired decision-making ability. A final argument in support of the trustworthiness of an analysis based on data from people with



mental illness is consistent with the theoretical framework of the current research. Within the symbolic interactionist framework, it is assumed that one cannot understand actions (in this case, for example, decisions about whether or not to pursue engage in treatment) without understanding the meanings that guide them. By using the narrative approach, the present study thus fills a gap in the research enterprise on insight, which with few exceptions seeks to understand this phenomenon without consideration of the experience of those with psychotic illness.

### ***Credibility/Relevance/Transferability***

The credibility of a study refers to its ability to consider perspectives of the multiple stakeholders that may be impacted by its findings. In this respect, a limitation of the current study is that the perspectives of other relevant players, such as professionals and caregivers are not sought within face to face interviews, and no direct observation of “real-time” clinical or program situations were made (Silverman, 1998); given this lack, comments made by participants about their interactions with professionals and significant others cannot be verified. The results of the study therefore need to be contextualized within research that does include the perspective of these other stakeholders.

While the perspective of persons with mental illness represented by the study constitutes a strength, future research using a narrative approach would be strengthened by attention to the experiences of the other key actors in the situation, namely, family caregivers and mental health professionals. The study methodology may address this to some extent by virtue of the fact that members of the supervisory team bring the perspective of family member (EM), and mental health professional to the analysis (DI, JF, EM).

Relevance refers to the ability of the results to provide practical solutions to issues that are meaningful to potential research users. Ideally, relevance would be optimized by the use of participatory action research methods wherein the research process addressed the needs of all stakeholders and provided a way to feed back the findings within the service delivery context where they were derived. However, given the limited time frame of the current research, its relevance relates mainly to characteristics of the investigator (EM), who as a researcher and participant in the community health

movement for the past 20 years, has drawn upon that experience to define a question that addresses an important issue of perceived significance to people with mental illness, their families, and to policy members in general. In retrospect, the study may have benefited by using focus groups of the above mentioned stakeholders to help orient the research instrument and to consider ways of adapting services in light of the studies' results.

Transferability refers to the possibility that meaningful results can be applied to settings other than the current research setting. This notion relates in part to the theoretical generalizability of the findings beyond a current early psychosis program setting to the issue of early psychosis in general. This was maximized by attempting to integrate the findings with other relevant studies within a broader early psychosis context, and with adjustment to other chronic illnesses.

### ***A Note on Representation of the Analysis***

Mishler (1999) suggests that not only the data analysis but the representation of the data (i.e. how the findings are presented) should reflect the theoretical framework of the research. Seen within the theoretical framework of the present study, construction of meaning (or interpretive frames) is a dialogical process done in conversation with significant others or with discourses drawn from the wider culture. Similarly, the analysis of these meanings is to some extent jointly constructed both by the participant and the researcher who seeks to understand the participant's perspective before making an interpretation that also makes sense to the participant. As the reader may note in the following chapter, the assembled quotations reflecting a given theme usually exhibit the following pattern: early on, the presentation of a portion of a participant's written narrative or interview comments (citing the relevant passage of text, and whether it is from the narrative "n", or transcript "t"; e.g., **ln 141: n**); and later, passages within which participants and researcher discuss a particular interpretation and where the researcher may seek the participant's view about that interpretation. The choice to represent the data this way thus reflects the theoretical framework of reality as a co-construction, in this case between participant and researcher (Mishler, 1999). At the same time, in using this representational strategy, the investigator seeks to make the interpretive choices made by the researcher as transparent as possible.

As the reader will note, the various aspects of the analysis are illustrated with a relatively exhaustive presentation of quotations. These are presented in such a way to fully explicate the theme in question, its specific properties, and relationships with other themes or categories within the analysis as a whole.

## CHAPTER 4: RESULTS

### Introduction

The results will be presented in three sections. The first provides an analysis of participants' narratives describing their pathway to care; this is the metaphorical route participants travel as they attempt to make sense of and deal with changing experience, drawing upon common sense explanations or interpretive frames. The first section ("Traveling the Pathway to Care") also describes how, in interpreting their changing phenomenology<sup>27</sup>, participants seek to achieve certain pragmatic ends such as achieving a sense of control, protecting identity, and maintaining a semblance of social equilibrium. In doing so, participants may be able to struggle by for some time, until these initial interpretive frames break down and the individual becomes unable to perform valued social roles or "selves." The results suggest that, ultimately, when the individual can no longer tolerate the distress of the experience, he or she moves in to the formal mental health system and comes directly in contact with medical understandings and treatment of the psychosis. This first section thus illustrates that what has been conceived of as the beginning stages of a deteriorating biological sequence is a process that is also essentially interpretive, involving attempts by the individual to find some interpretive frame that works. It is also a process that is intrinsically interactive in the sense that, for better or worse, these attempts at sense making and coping are negotiated within the person's social network and the wider cultural milieu that surrounds him or her.

The second section of the chapter ("Pathways to Initial Insight") describes how, once in the mental health system, participants arrive at a new understanding of their condition, and describes the process by which this new understanding evolves over time. The analysis suggests that the process whereby people come to this initial insight involves two mutually reinforcing aspects: "experiencing an impact," and "finding a fit." That is, people may come to infer the presence of an illness after experiencing a positive impact of the medication; participants may also come to accept the notion of illness as a plausible explanation when they make comparisons and sense a fit between their own

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<sup>27</sup> The term phenomenology, as in "changed phenomenology" is used here and throughout to mean the changing inner experience (e.g. heightened perceptions, misperceptions, changed sense of self, etc.) common to the early stages of psychosis (Mundt, 2005).

experiences and the information about illness they eventually come across through their interactions with individual mental health professionals, within educational interventions and material, and through their interactions with other people with mental illness. In some cases, participants sense only a partial fit between their experience and the new interpretive frame, and more fully accept the illness after going through a process of “making accommodations” that reconcile competing interpretive frames (e.g. experience as psychosis versus experience as artistic inclination or spiritual awakening). “Finding a fit” and “experiencing an impact,” while manifesting themselves as distinct processes, appear to act in complementary fashion: for instance, it appears that participants become more apt to actively make comparisons with the new framework as they experience or envision the positive impacts or consequences of adopting it.

The final section (“Negotiating the Path to an Acceptable, Adaptive Explanation”) illustrates the challenges faced by participants as they adjust to the emotional impact of arriving at some initial insight. The results presented in this chapter suggest that those impacts, depending on the context, can be widely divergent, ranging from relief to shock, with most participants, even those whose overriding emotion is relief, initially going through at least some period of emotional ambivalence. The relative ease with which participants eventually come to a fuller acceptance of the illness appears to depend on the way in which the illness is interpreted; that is, on the extent to which the person initially sees the illness as something that provides a possibility of restoration (or even transformation) or as something that seriously disrupts their envisioned life trajectory. While participants in the former category accept the illness fairly readily, participants who initially fall into the latter appear to go through a process of what could be termed “negative acceptance,” which involves seeking to “push away” the illness from consciousness and attempting to reclaim their previous lives, only to be confronted by a return of the illness. The final part of the chapter describes a subsequent process participants go through as they begin to see the illness as an “acceptable, adaptive explanation.” This part of the analysis depicts a cyclical process that will be called “positive acceptance,” and describes the interpretive work participants go through as they reframe their notion of illness and its relationship with themselves, and come eventually

to envision the illness and its management as something they can adapt to and live with successfully in the “background of their lives.”

The process of insight development in psychotherapy has been described as a process of persuasion, by which people come to a more “acceptable, adaptive explanation” about their experience<sup>28</sup>. This implies a process that is intrinsically social and one that involves dialogue and negotiation. It also suggests a process that is pragmatic in a thoroughgoing way: one that involves not just coming to the realization of some objective fact of illness, but as coming to a version of it that makes sense and works for the individual within their social context, in terms of the values and vocabulary that are resonant within the “lifeworld”<sup>29</sup> of the individual. As hinted at by the nomenclature adopted earlier in this discussion, the argument will be developed, in the final chapter of the dissertation, that this notion of insight – with some important modifications – is an apt description of how people who experience psychosis come to understand and learn to deal with their new reality. It thus provides a lens through which the various themes presented in the present chapter can be understood as a whole; in other words, all of the various processes described throughout the chapter can be understood in terms of an *overarching* persuasive process by which people arrive at the notion of illness as something that makes sense and as something they can live with.

It is beyond the scope of the present discussion to fully explore the theoretical implications of the concept of insight as “coming to an acceptable, adaptive explanation,” but for the present, the broad strokes will be applied so that the reader can begin to view the discussion that will follow later in this chapter within this larger picture. As noted above, the analysis suggests that participants actively consider the illness frame when it provides an acceptable “fit” with their experience. As will be discussed later, they come to more fully sense this fit when they find in the illness framework a language that explains their condition in terms that also makes sense in the terms of their own phenomenological lifeworld. Throughout this chapter, the analysis also foregrounds the

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<sup>28</sup> Wampold, B., et als.(2007). “Insight as a Common Factor,” in. L.G. Castonguay & C.E. Hill, *Insight in Psychotherapy*, (pp. 119-), Washington, DC: American Psychological Association Press.

<sup>29</sup> This is a term employed by other social scientists Eliot Mishler and Ellen Corin (Corin & Lauzon, 1994); having a long history in phenomenological philosophy, it connotes the experienced reality of a given individual and the way the person makes sense of events given a phenomenological perspective that is unique and at the same time influenced by his or her social and cultural milieu.

importance of “adaptiveness” to the process of insight development in this broader sense. That is, people appear more inclined to accept a new interpretive frame not only when it appears to fit, but when they see it as useful in solving the problems that they see as most important to their lives. Overall, the themes discussed in this chapter illustrate a process by which people come to incorporate the illness story into their lives; this apparently happens as they begin to understand the new interpretive frame as being resonant to (and fitting with) their experience, and as they reframe their initial understanding of “illness as disruption” (cf. Bury, 2001) and come to see the new explanation as providing a means by which they can reclaim their lives.

The analysis also suggests that this persuasion process takes place in the context of various interactions occurring at multiple levels; first is a cultural level wherein the individual draws upon what appear to be apt and convincing explanations for her or his experience; then, at an interpersonal level, participants negotiate these meanings, successfully or otherwise, with those closest to them; and at an institutional level, once individuals enter the formal mental health system, they experience treatment, they come into contact with new information about illness and experience different sorts of interactions with other people with mental illness. As the results will illustrate, all of these interactions may persuade participants that the notion of illness is an acceptable, adaptive framework.

Before moving on, it should be noted that, due to the limitations of representing complex experience in writing, the processes described in this Chapter may appear more linear and neat than their actual occurrence in the lives of the study participants. For instance, while the notional transition from negative to positive acceptance is described as successive stages of forward progress, the analysis may not adequately convey the struggles often occurring within the interval wherein this process happens, nor does it fully portray the fitfulness or potentially cyclical nature of the events. At the same time, the reader should keep in mind that the accounts feature the experiences of individuals who, for the most part, *have* apparently arrived at an understanding of their condition that enables them to participate regularly in care and be more active and connected within the wider context of their lives. As mentioned previously, the analysis thus represents an account of how this success has been achieved through the individuals’

struggles, aided by the support and encouragement of those around them, on the path towards an acceptable, adaptive explanation of their experience.

## **Traveling the Pathway to Care**

### ***Introduction and Outline***

This first section describes the process by which participants attempted to understand and deal with their initial experiences of psychosis and how, for better or worse, they made use of common sense explanations to interpret and cope with this new life situation. It then describes the context within which the individual (and/or those around her or him) sought outside help from the formal mental health system as the initial explanations no longer proved adequate and the individual could no longer function adequately in the social roles most important to him or her.

As the following analysis will make clear, the process that is traditionally conceived of as “losing insight” and as a matter of malfunctioning biochemicals is also an interpretive, interactive process; in other words, it has to do with how the individual makes sense of a new phenomenological reality. It is also a process that is mediated by explanatory tools (or “interpretive frames”) that are available in the culture surrounding the individual, and played out in social interactions that can either worsen or forestall the emerging psychosis (as explained in “Interpreting a Changed Reality”). By employing these interpretive frames, individuals maintain both some sense of control in their lives as well as a healthy sense of self (see “Consequences of the Interpretive Process”). Their views of reality, however, may eventually lead to conflict, isolation and exacerbation of the worsening psychosis (as explained in “Negative Interactional Cycles”). As illustrated in the subsequent section (“Seeking Help”), study participants tended to seek psychiatric help (and/or have help sought for them) when they were no longer able to struggle by in valued social roles (see “Failing Performance of Self”) and/or when symptoms, though initially tolerated, became significantly more distressful to the point where participants couldn’t go on (as explained in “Worsening Distress”). Seeking help in voluntary situations was facilitated by effective interactions with trusted others, which enabled the participants to share their concerns (see “Breaking the Negative Interactional Cycle”). In



the absence of such interactions, the individual may have deteriorated to the point where help was sought in the context of chaos and breakdown.

### ***Interpreting a Changed Reality: Drawing on Common Sense***

The traditional notion of insight loss conceives it as a gradually deteriorating awareness of reality which generally occurs as the individual develops psychosis. In contrast to what would be expected based on this notion, the experience of participants appears to be more accurately conceptualized as an active attempt to make sense of changes in their phenomenological world. Participants appear to use common sense explanations to interpret these experiences and decide how to act in the face of them; in the early stages of psychosis, they often employed explanations that would normalize or minimize their problems, often seeing these as externally caused or, if seen as internal, as temporary or not serious. In minimizing their problems, participants often employed popularized versions of professional mental health concepts (e.g. “emotional problems,” “just depressed,” etc.) or, when the problems became more extreme, used culturally available ideas to interpret their “limit-experiences”<sup>30</sup>; and at the most extreme level, participants constructed an elaborate delusional world which either engulfed their previous reality or operated in parallel to it, thus becoming seduced more completely into the world of psychosis. (Though initially perceived as unsettling, participants could eventually come to see these ideas as normal.)

### ***Normalization & Minimization***

The passages below illustrate how participants initially explained their experience in a way that often normalized or minimized their concerns in terms of explanations more familiar and/or less threatening than the notion of psychotic illness.

I had been born and raised as a Jehovah’s Witness and now my religion was making me ill ... [in other words, I thought] it was that my religion was the reason for my problems, the reason for conflict... [since] my parents imposed it so strongly onto me that I had no freedom to do what I wanted.

**P5 (ln 17: n; ln 15: t)**

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<sup>30</sup> Drawing on various French philosophers (e.g. Foucault), Ingram uses the concept of “limit-experiences” as an alternative term for the psychosis experience (Ingram, 2005). Wikipedia defines it as a “type of action or experience which approaches the edge of living in terms of its intensity and its seeming impossibility.”

I would be sitting in class, and would suddenly feel detached from myself... I thought it would pass.

**P1 (ln 11: t)**

When I first realized things starting to change, I felt like people around me were pulling a plot on me. [...] They seemed to be able to read my mind. [...] As a result, I got paranoid about my secrets being spread publicly. I read books about hidden cameras and equipment. I even climbed up the roof of my house to check if there were hidden cameras in my house. [...] I didn't think I was really sick; I thought maybe I had depression, but not schizophrenia.

**P2 (ln1;ln 4;ln 6: n;ln 77: t)**

I was seeing a psychologist at that time... because I ... felt really paranoid, ... but still I didn't feel that there was something wrong, I just thought I was being kind of, I was having some emotional problem [...] I basically talked about my mother.

**P7 (ln 150; ln 168: t)**

I [was in class] watching a film ... and [found] myself entering a headspace, a "split from reality" that made me feel highly spiritual.

**P8 (ln 13: n)**

I thought I was demon possessed because I could not explain to myself what was going through my mind or what was happening to my mind. I asked ... the girl who lived with us if she would expel the demons. I was never demonized because that didn't make my mind feel better. She had said a prayer and urged the demon out, but there was no demon to come out.

**P5 (ln 184: n)**

At first I found it hard to [accept], but slowly I was learning that I was the Prophet of the entire World. I would send text messages to my friends telling them to read certain passages of a book because I was The One.

**P1 (ln 25: n)**

My thoughts started to become so rapid and nasty and I was afraid because people could hear my thoughts and I thought that I was superhuman and that there was no treatment by modern medicine.

**P10 (ln 27: n)**

Throughout these past few years I was constantly reaching into other peoples words, reactions, comments towards me as a "sign" to follow certain "orders" that I could never quite figure out. [...] I eventually, to make sense of my paranoid delusions, came up with a rationale that my head (mind) was the centre of a[n] on-line reality show that prayed on my deep sense of intuitiveness. [...] Obviously when this began I was very afraid, self conscious and the like, but eventually [I] accepted [this] as normal.

**P6 (ln 15; ln 21; ln 29: n)**

## **Summary: Normalization & Minimization**

The quotes above suggest an interpretive process whereby people “interact” with available cultural discourses or categories to explain their changing and perplexing experience. As noted, the categories may be professional concepts that have made their way into popular culture and are then drawn upon by the individual to normalize the problem (e.g., “emotional problems,” passing phases, conflicts over parenting, etc.); or, in the case of more extreme or “limit” experience, people may draw on ideas broadly available in the cultural zeitgeist which resonate with their experience, such as religious quests, the notion of paranormal powers, surveillance technology, and the construction of elaborate *Truman Show* worlds,<sup>31</sup> all of which may resonate with a sense that was common to study participants of “reading in” or “being read,” (i.e., either that they could read others’ thoughts, or vice versa).

It also should be noted that the particular interpretive frame employed was associated in the individual’s mind with specific consequences. For instance, the idea of being demon possessed led to an unsuccessful attempt to expel the demons; the sense of anointment as a prophet spurred an individual to share his revelations with others; the notion of powers, though distressing, was initially perceived as untreatable by medicine; the notion of starring in a reality show carried with it the imperative of adequately performing this role. Some interpretive frames (e.g., “emotional problems”) implied the need for psychological help that proved ineffective. As will be explained and illustrated later, these interpretive frames apparently served to protect individuals from threats to identity by externalizing the problem and, in some cases, also served to maintain some functional equilibrium. In doing so, participants also tended to delay decisions to seek outside help, particularly when alternative explanations were perceived as threatening, as explained immediately below.

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<sup>31</sup> The *Truman Show* is a 1998 movie starring Jim Carrey about a man who imagines that his life is being broadcast as a form of reality TV show.

## Considering Mental Illness & Prototypes

In some cases, the pattern of experience or specific salient symptoms (hearing a voice, for instance), may lead the individual (or someone close to him or her) to think about the possibility of psychotic illness. The passages below suggest that people with previous knowledge about mental illness, especially those whose pre-existing “prototypes”<sup>32</sup> of illness are negative, appear inclined to avoid the possibility of psychotic illness as a potential explanation, at least until they have exhausted other less threatening options.

I think that there’s a greater chance that I probably would know something was wrong now (I: um hum), definitely if I hallucinated I would probably realize that there was something definitely wrong.

**P7 (ln 607: t)**

I thought in terms of schizophrenia [before entering the mental health system]. Because I heard voices, I knew *something* was up, and when I was [living at the place] the guys [would talk in terms of schizophrenia], and they would mention that the world was schizophrenic, it was the natural state; like things are fractured, so are people, and so is life, that’s the norm, what do you expect considering the history of the world and where we’re at. Again, I moved back here from a smaller town, so a lot of emphasis [where I lived] on the other, the Edward Said type of thing [i.e., the idea of “othering” as leading to cultural schisms] That was pretty huge, because when I walked through the street I’d realize the inherent racism,

**P8 (ln 70: t)**

**I:** and what about [when your mother showed you the information about schizophrenia]...what about the idea that you had [it] or what about the notion of schizophrenia. Did that mean anything to you at that time...like...?

**P:** I knew what it meant...it scared me because I see other people who are sick from that and like it didn’t look good, so...but it kind of went on the back burner for me. I really didn’t make anything of it.

**I:** Right. Like that wasn’t like...that wasn’t like high up in your mind...

**P:** No...it wasn’t... I had a tenant and stuff who had like schizophrenia or like he was always talking to himself and something like that and it scared me like I wanted nothing to do with that; I didn’t want to think that I had it...and he was drinking a lot and stuff like that...just bad...

**P10 (ln 52; ln 76: t)**

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<sup>32</sup> Prototypes are mental images which represent the individual’s accumulated understanding of what a person with psychotic illness (either particular illnesses, or in general) is “like” (i.e., what such a person looks like, how they behave, what kinds of experience they have, and perhaps how such persons would experience or live their lives). The accumulation of the prototype appears to occur through experience of salient “cases” of psychotic illness, either in relatives or those known somehow to the individual or his or her network, or those experienced indirectly through the media. The notion of prototypes is discussed in the following works: (Dey, 2007; Hacking, 1995; Hunter, 1991; L.J. Kirmayer et al., 1994).

The passages suggest that even if a certain illness (e.g. schizophrenia) is suspected, it, too, may be normalized, minimized, or altogether denied. As will be discussed later on (see the section “Pushing Away”), even once people have received a certain diagnosis, they may still continue to push this interpretation to the “backburner.”

### ***Consequences of the Interpretive Process***

By interpreting their experience in certain ways, participants appear to be achieving, or attempting to achieve, certain pragmatic outcomes. As the passages directly above suggest, in seeking to normalize or minimize the significance of the experience and in seeking to ascribe its significance to something external or temporary, participants appear to be attempting to maintain a sense of themselves as healthy and trying to fend off threats to their sense of self (in some cases, experience is interpreted in such a way that the participant adopts a transformed, exalted sense of self). Also, as the quotations below illustrate, in attempting to place a perplexing experience into an understandable framework, participants may be gaining a sense of psychological control. As will also be shown, the individual’s interpretive framework may eventually begin to have negative consequences, leading, for instance, to depression, a sense of entrapment, and other unhealthy coping strategies like substance use; the interpretive framework and its consequences can apparently then fuel the emerging psychosis. As illustrated further below (see “Interactive Interpretive Cycles”), participants’ attempts to make sense of their situation may also lead to interpersonal conflict and social isolation, which may serve to further exacerbate the emerging psychosis.

The first thing was I didn’t want this notion [of schizophrenia] attached to me. The second thing, I want to feel that I’m a somewhat worthwhile person, so I tried to make sense of those adversities, I tried to... yeah, I guess there were a few downs in my life... but I tried to make sense of the situation to make myself feel better **P2 (ln 112: t)**

Well, what was going on...they said that I was scared and stuff and so I had like all these...like the remote controls and the wires and stuff like that and they gave me like a comfort...kind of like made me feel safe. **P10 (ln 266: t)**

**I:** OK and at this point you talk about how your delusions kind of kicked in or went into a different scale, like you started to think that, about, you started to think that these events [your friends trying to hurt you] were part of a movie, and within the movie that the police were protecting you (**P:** yeah) and um did the, so within the plot of the movie, did you feel, did that make you feel safe? Safer?

**P:** yeah, it did, yeah, I, yeah, it did because I thought that they were on the other side of the street from my apartment so I didn't feel like I was in danger at that time, (I: um hum), so I did feel safe then... **P6 (ln 137: t)**

These times were extremely exhausting as I would spend all day and night pondering whether or not I was doing the "right thing" at a given time... and I would just sit there and talk to myself all night about what was going on, (I: um hum) so it was a very lonely time as well ... (I: um hum) so I guess the only way to get through the stress of that was to intoxicate myself

**P6 (ln 18:n;ln 103: t)**

So as time passed on, I was in and out of this [reality show] delusion. I figured that I had better change my ways [stop using substances] or else they would never set me free ... My thinking was that when four years was up, I would be set free, granted I showed steady improvement. I felt I had this past October but I was not released. This was devastating as it felt I'd be stuck, with my entire life on display forever. **P6 (ln 39; ln 42: n)**

Every summer since Grade eleven, I had been visiting my uncle [and aunt] in the jungles of Cacaluta, Mexico. They taught that Jesus was the only God, that angels do exist, and that we must read a book called "Urantia." I read it, ecstatically, and the information in that book (the history of the world as told by aliens) fueled my psychosis when it came.

**P1 (ln 33: n)**

The sensitivity that had allowed me to be perceptive and intimate with spirituality had flipped. It felt like I was entering a "dark side." I felt like people were following me, or talking about me; strangers were out to get me. **P8 (ln 45: n)**

People seemed to be able to read my mind [...] [as a result] I felt injustice about my [loss of] privacy [...] I felt unsafe and created distance around people. I thought the purpose of feeling injustice was to prepare me to be a public figure to speak for the poor and needy [...] I studied criminology with success. I was able to read people in ...negative term[s] easily. However, this negative evaluation of people did not help with social interaction. **P2 (ln 6; ln 25; ln 42; ln 46: n)**

### **Summary: Consequences of the Interpretive Process**

In sum, by attempting to make sense of their experience, participants *did* manage to achieve some sort of equilibrium despite that experience and, to some extent, managed to cope with their situation for an extended period of time. As will be discussed in the next section and further below (see "Seeking Help"), these attempts to manage often persist until the person is finally no longer able to withstand the distress or suffering being

experienced, becomes unable to fulfill the social roles most important to her or him, and/or the tenuous equilibrium within existing social support networks breaks down.

### ***Negative Interactional Cycles***

Again, in contrast to traditional notions of insight loss which define the problem as intrinsic to the individual's illness, the experiences of the present participants suggest an interactive process. As described above, people "interact" with socially available cultural categories as they draw upon common sense notions to interpret their experience. Their experience is also interpreted and negotiated within their day to day social worlds with other individuals in their social sphere. The consequences for insight (i.e. whether the individual's views stray further from consensual reality), can depend on the nature of these interactions. Frequently, participants' attempts to share their experience lead to conflict, mutual avoidance, isolation, and more obviously idiosyncratic thinking (what could be termed a "negative interactional cycle"). While acknowledging the difficulty of communication, participants suggested that such a cycle was not inevitable. As discussed further below ("Breaking the Negative Interactional Cycle") if the individual is able to share her or his experience with trusted others in a non-judgmental way, the negative cycle may be broken; the participant may thus avoid being seduced more fully by the world of psychosis and may more easily reach out for help.

I had countless friends in Grade 12, but slowly I began to lose contact with all of them except my very spiritually minded friend G.

**P1 (ln 12: n)**

**I:** ...so, and friends had kind of fallen by the wayside, and was there anybody that was saying, maybe there's something else going on here, or you...?

**P:** well I wasn't very open with it, (I: right) cause, like I thought these people were a part of, (I: um hum) the people close to me were a part of the conspiracy, so to speak, uh, so I didn't really, there was times when I actually confronted them (I: um hum) about the situation, but they would just deny it ... I think a lot of the time I was looking for someone to put me in my place so to speak (I: um hum) you know what I mean, and having a direct conversation about what I was going through ...

**P6 (ln 113: t)**

I thought the reason why my friend didn't call me back was because she had started a rumour about me and spread it all over my work. I called her boyfriend and told him what

she had done to me. He became angry and called me crazy he said that she would never do something like that. I didn't believe him. I thought he was in on it too. **P7 (ln 23: t)**

**I:** **[question to P7:]** I'm wondering if you think your experience fits this pattern [that others have talked about] ...where the person first shares their experience kind of openly, and then after others, you know, don't know how to deal with it, you know those people pull away, and then the person gets more suspicious and less willing to talk about it, and you know when they do talk about it , it's more confrontational and um which makes the friends less comfortable, and there's this kind of cycle that's set up, and I'm just wondering if that seems to kind ...

**P:** yes, yes, that's exactly, exactly what happens cause once you start sharing things with people and they start sort of rejecting your ideas you feel like, it makes you feel more suspicious because you think these people are not believing me because they're part of the conspiracy or they're out to get me as well, it's sort of, their rejection of your ideas sort of enforces, creates more problems... **P7 (ln 248: t)**

**P:** [What makes it easier if] you know...[can] talk about it. I think it's easier ...with people you're close with...

**I:** Like if you can be open mostly with people that you trust.

**P:** Be open and communicate, that's a big help.

**I:** As opposed to holding...

**P:** Holding it all in and thinking all the time, like...well, my problem was I was thinking...I was analyzing everything and thinking way too much...right. And I kept everything in and it just blew up and...

**I:** So, if you had been able to feel that you could communicate, then that would have maybe...things would have been easier.

**P:** It would have been...maybe if they would listen to what I had to say...right...first and then make their point. You know what I mean. Like maybe what I'm seeing doesn't make sense...right but I don't know that... **P10 (ln 700: t)**

It is noteworthy that when experiencing this type of interaction, two participants interpreted a rejection of their ideas as a personal rejection. Thus, it appears that part of the challenge in "breaking" the negative interactive cycle (as illustrated below: see "Breaking the Negative Interactional Cycle") is finding a way to communicate with the person in psychosis that maintains some degree of trust.

## Seeking Help

In general, participants attempt to achieve an interpretive framework that allows them some functional or social equilibrium. In many cases, they appear to successfully achieve such an equilibrium and are able to struggle by for many months or even years while experiencing significant psychotic symptoms. At some point, however,



participants may begin to feel that they can no longer carry on in their social niche, or break down to the point where they can no longer perform their preferred social roles and identities (described below as “Failing Performance of Self”).

The individuals (or others) may notice that they no longer feel like themselves and may reach the limit of their ability to tolerate their experience. Often, it appears that it is not symptoms per se that are problematic to people, but those that are (or which increasingly become) disruptive and salient. For instance, symptoms that were once tolerated or minimized may increase suddenly and become more noticeable, increasing to the point where the person “can’t go on” or can no longer function. In the course of these struggles, some participants may have no idea about mental illness or its potential relevance for their respective situations. Others who do know may progressively run through and eventually exhaust a range of less threatening explanations, including those that involve seeking outside help from mental health professionals (though not for psychosis). Running through the options unsuccessfully leads these participants to feel that something more is going on, as illustrated below in “Running Out of Answers and Having Enough.”

### ***Failing Performance of Self: Struggling By and Becoming Unable to Function***

As mentioned, the comments of participants indicate that prior to seeking help, individuals are often able to struggle by for months and years while experiencing psychotic symptoms. Eventually, however, these individuals become unable to function.

- I:** OK so, you mentioned you were, kind of in and out of the delusion about the reality show, or just sort of that way of thinking for, in and out for 4 years, and I just wanted to ask, during the 4 years, like how were you getting by, like how where you kind of functioning?
- P:** uh well I wasn’t functioning very well [...] like, uh I guess I wasn’t moving forward (I: um huh) in any way, like I wasn’t looking into school, I wasn’t, I stayed at a job for many years, (I: um hum) because I was afraid to move on and take on more challenges (I: um hum)
- I:** but you were able to work
- P:** I was able to work, yes
- I:** you were able to keep going despite
- P:** despite the fact that I was dealing with these delusions and paranoia **P6 (ln 74: t)**

As the passage above illustrates, this young man was able to struggle by at a job for “several years.” He was able to do this despite believing his colleagues were conspiring against him and eventually believing his life was being broadcast over the internet as part of a “reality show.” This was a delusion he “went in and out of” for years until, after having reached a point where he felt trapped in the world he had created, he finally became suicidal, stating that “it would never end, it would just be madness forever.”

The story of another participant (P2) also illustrates this pattern of struggling by for years before eventually becoming unable to function. In fact, this individual experienced psychosis for several years, during which she “studied criminology with success” for a couple of years, and then worked as a security guard. Although she maintained some friendships, for the most part she “creat[ed] some distance” between herself and other people, “spending most of her days on the beach or some quiet place” and “reading philosophy or criminology books.” Finally, after being traumatized by an event at her job, she experienced intolerable bodily hallucinations, threw out personal belongings she believed to be contaminated, and was unable to “calm herself down.” Her friends, being concerned, urged her to return to her parents, who then sought help for her.

### ***Worsening Distress: Running Out of Answers and Having Enough***

As the comments above suggest, and as the passages below more fully illustrate, not only did participants become unable to function in preferred social roles, they may have also have reached the point where they could no longer tolerate the distress of their symptoms and had run out of answers. That is, help-seeking was often initiated when participants were distressed, had difficulty functioning, and had exhausted their internal coping resources or those of the individuals in their social network.

As the passages immediately below illustrate, P8, P10 and P11 (who will be referred to as Shiran, Rob, and Dennis) struggled by until they had reached the limit of their ability to tolerate what was going on, all the while searching for potential answers.

Shiran wrote that, after changing jobs and friends, after seeking help from her family doctor, psychotherapists and naturopathy: “I couldn’t take it anymore; the paranoia, the isolation, the feelings of dread, the anxiety, all collided and knotted inside my core until I

wanted to die... I had a friend in the past who had been in a psych ward for a year, and when I knew her she seemed OK, although she had stopped taking meds and smoked a lot of pot. I decided I needed to give it a try. I got on a bus, alone, and went to the emergency ward at the hospital. I checked myself 'in.'

**P8 (ln 94: n)**

Referring to a similar pattern, involving quitting one job, starting another, all the while seeking help from his family doctor, a psychotherapist, and calling a help line, Dennis stated: "I wasn't productive in my life...like my thinking...the way I was thinking was irrational, I wasn't getting stuff done that I needed to get done. I just knew that I was like...I can't live like this...I need to get help and you can't lead a productive life and be having psychosis and not getting it treated...you know. I just don't think you can.

**P11 (ln 205)**

The following passage illustrates how Rob, who had previously wanted "no part of" the information about schizophrenia offered by his family, finally readily accepts the possibility of the illness, after going two months without sleeping, all the while investigating for and ruling out a number of other possibilities, such as allergies and epilepsy, and being "dragged" to doctors appointments by his mother numerous times.

**P:** they thought it might be schizophrenia or something and then I was all down with that.

**I:** So, can you say a bit more about that...why you were okay with coming here?

**P:** Because, at that point, I realized there's like got to be something...right, and I guess it was at the last...last thing because everything else...because they couldn't find anything else.

**P10 (ln 216-217; Ln 228: t)**

### ***Summary: Seeking Help***

In summary, there is a combination of factors – failing performance of self, reaching the limit of tolerance, and the exhaustion of interpretive options – that leads the individual to consider seeking outside help from the formal (psychiatric) mental health system. That is, when the individual feels he or she can no longer struggle by, no longer feels like oneself, "reaches the limit" of his or her ability to tolerate symptoms, and feels like he or she is "out of answers," thereby seeking help (independently, or more commonly, with the encouragement of others; see "Breaking the Negative Interactional Cycle" below ) from the mental health system.

## ***Breaking the Negative Interactional Cycle***

As mentioned, the early stages of the insight and help-seeking process are intrinsically social and mediated by interactions with others close to the individual. Seeking outside help thus often involves the intervention of others in a way that breaks or forestalls the negative interactional cycle spoken of earlier and defined by conflict, mutual avoidance, isolation and worsening psychosis. For instance, it is often through a conversation with a trusted other that the individual agrees to consider seeking outside help from the formal mental health system after he or she has made the decision to “open up” and share the psychosis experience rather than holding it in. It may be an outsider who notices that something is “not quite right” or that person is “not themselves” and persuades the participant that a problem exists and outside help is required.

As discussed earlier in the chapter, conflict with others can worsen the “negative interactional cycle” in some cases. However, in other cases, these interactions turn out differently. For instance, in two of the instances illustrated directly above (P2, P10), it was the concern and intervention of people within the participants’ immediate social network that convinced the individuals to seek help or led them into care. The example below illustrates the type of effective interaction that helps break the negative cycle.

### ***Effective Interactions***

I text messaged my roommate (I: um hum) and said I know what you’ve done to me, and I’m going to burn all of your things, and like yeah there was obviously something wrong because if I was well I would never do anything like that (I: um hum) so she, she called my dad and she called my sister and was basically was like there’s something seriously wrong with G. ... [When my sister arrived] she was pretty firm with me and she just said no, like this isn’t what’s going on (I: um hum), there’s something else going on here, like you’re mistaken, N. would never do that, so basically after like 20 minutes she finally convinced me and I was like OK yeah something’s wrong, what’s going on, what *is* going on with me, why would I think that? So, at that point I didn’t think that other stuff before, but I did think that there was definitely, I had done something, something had happened, that day.

**P7 (ln 184: t)**

### ***Opening Up***

While in the above case, breaking the cycle depended on the skilful communication of a trusted person who helped the individual recognize that his or her actions were out of character or “not me,” in other cases, the participant initially made a conscious decision

to share what he or she had been experiencing. This “opening up” is what then allowed the cycle to be broken.

When I went home, I told my parents about people and colleagues not being kind. My parents were very concerned about my health as well, so they called the mental health team and sent me to the hospital.

**P2 (ln 70: n)**

Well...at that time I was kind of feeling like ‘Okay...I need help.’ Like I felt like a weight was being lifted off my shoulders...right, so I told him all the symptoms I was having...right. I was like ‘okay, it’s better to get it over with now’ and he’s the one that sent me here. Because I actually told him...I got the nerve to tell him everything...right.

**P10 (ln 627: t).**

In summary, breaking negative the negative interactional cycle can involve effective interventions carried out by trusted others, and could also involve the efforts of the individual him or herself to gain the courage to disclose problems.

### ***Traveling the Pathway to Care: Concluding Comments***

The individual voluntarily appears to seek help with the assistance of others once the initial interpretive frames no longer provide a means of helping the individual function in the course of his or her day to day life, or when these interpretive frames are cast in doubt by alternative explanations. When done voluntarily, people seek help with the intention of finding a better way or a more adequate explanation that will enable them to navigate their lives in the face of this experience. On the other hand, in the breakdown or absence of such relationships (and in the context of an expanding sphere of influence of psychosis or paranoia), the person may reach a point of complete breakdown and utter chaos, leading to involuntary hospitalization or help-seeking in more coercive circumstances. Such individuals may be forced into considering psychotic illness as an option; they may not have a sense, like other individuals, of having exhausted less threatening interpretive options; nor may they have a sense of having ceased being able to function, or have developed as clear a sense that their life has gone off the rails.

# Pathways to Initial Insight

## *Introduction*

The previous section discussed how people's initial interpretive frames break down as they move further along the "pathway to care." The following section describes how insight develops as individuals enter the mental health system, experience treatment, and learn about the possibility that they were experiencing psychosis. Insight development in early psychosis can also be conceived of as a pathway which has two initial, mutually reinforcing entry points. The first involves "inferring through impact," or coming to understand the presence of illness through the impact of the treatment. The second involves participants "finding a fit" between their experience and what may be a better interpretive framework; this may involve a further sub-process of "making accommodations" which allow potentially competing interpretive frames to become complementary.

The process of insight development in psychotherapy has been described as "coming to an acceptable, adaptive explanation" (Wampold *et al.*, 2007). What this section describes is how people in the present study appear to come to some *initial* insight into their condition. This understanding, however, may not initially be conceived of as "adaptive."

As participants come to reframe their experiences and begin to gain insight, the initial emotional impacts can be quite divergent, as some individuals in particular sense the notion of psychotic illness to be alien and/or disruptive. Thus, moving more closely towards insight in the sense defined above involves more work and a further process of adjustment which entails performing the "biographical work" (J. Corbin & Strauss, 1988) necessary to envision the new explanation as relevant and adaptive to the individuals' lives. As the third section of the chapter will discuss later, in coming to insight, ultimately, what people apparently seek is an explanation congruent with their general style of making sense of their experience, and which they see as helping rather than hindering them in their envisioned life trajectory.

## Initial Entry Points along the Pathway to Insight

Initially, participants appeared to enter the pathway to insight through one of two entry points: as mentioned, the first involved inferring an illness from the impacts of treatment (hereafter referred to as “inferring through impact”) and the second involved a process of making comparisons and finding a fit between their experience and a relevant diagnostic framework (a process which will be hereafter referred to as “making comparisons”). Making comparisons appears to involve a conscious deliberative process to explore whether the new frame may represent a more apt and adaptive explanation than what was previously believed, leading to a decision to try on, as it were, the illness frame or explanation. Inferring through impact, as implied by the term, involves accepting or beginning to accept the illness by a process of reverse logic: in effect, this entails accepting the presence of an illness because of the perceived helpfulness of the treatment even though the individual had not previously made any deliberate decision to entertain the notion of the illnesses’ presence. The two processes may be mutually reinforcing: for instance, after experiencing a positive impact, an individual may discern a fit which validates his or her sense that illness is an acceptable explanation; or when medication relieves cognitive confusion, it may enable the individual to reflect and make such comparisons.

### ***Inferring through Impact: Experiencing Positive Impacts of Treatment***

The following passages illustrate the notion of “inferring through impact”:

Insight arrived like the dawning of the light. I was standing by my desk in hospital, and suddenly, the voices faded, and I thought “Wait a second, these voices aren’t real, everything everyone has been telling me is the truth. I am sane again, I am sane again!”

**P1 (ln 45: n)**

**P:** [although one thing] I had a lot of trouble believing was that the demons that I had fought with when I first got sick weren’t real, no matter how many times people told me that, even when I got a little bit better, I still thought that those demons were real, because they were such a real experience.

**I:** Right. So, even though the voices dimmed and the experience didn’t seem as real, that particular part of the experience, the demons, they remained real.

**P:** Exactly

**P1 (ln 127: t)**

**P:** I think that the more I denied my illness, the more I tried to make sense of the illness but it could always be helped by antipsychotic drugs; once I took the anti-psychotics, my paranoia was gone, when I watched TV, I didn't feel there was secret messages from the TV, when people talked to me, I didn't [have] second thoughts about what they were intending to say; I got less serious, less stressed out, so yeah, once I accepted I have an illness and I need to take medicine, than the stress went away.

**I:** Right, and also part of being able to accept it, was seeing that the medication worked

**P:** Um hum

**P2 (ln 160: t)**

**P:** ...It was a very good experience in the sense that I got my treatment very fast and I was lucky that I responded to the treatment and...yeah.

**I:** Great. Okay. Well, I guess just the follow-up question is just the fact that you responded to the treatment. Like some other people have mentioned that as an issue...like something that's made it easier for them to accept that something was wrong and there is an illness, is that the medication works so they think 'Okay...the medication works...that makes sense that it's an illness.' Can you...does that...?

**P:** Well, the medication worked...well...when you change when you take your medication then it does make you doubt your previous state. And when the medication works...I'm sure medication would make a difference to everybody but the thing is the type of difference it makes, makes you doubt your previous state. You start to doubt about that...maybe that wasn't real.

**I:** Right...so it just removes the belief that...

**P:** Yeah.

**P9 (ln 228: t)**

**P:** I still get the occasional thought that it could be going on [the conspiracy], but it's really significantly different than before; it was just, it's not weighing on me as heavy (I: um hum), and I'm on anti-psychotics so I, obviously part of it, a lot of it's from that, but...

**I:** [...] so can you kind of separate what was the impact of the meds and what was the impact of what you learned? Did the meds have an impact first, and then you, or was it

**P:** I think the medication had the impact first cause it relaxed me, (I: um hum) it kind of, what my doctor explained to me is that the medication is designed to, for you to be able to filter out what's *for* me and what's *not* for me (I: um hum) you know as far as taking in information, so I was able to, (I: um hum) it cleared my head... and when I was in the hospital all I was doing was resting, and I was with people who were going through the same thing as me (I: um hum) ...so that part allowed me to relax, and as I've been coming here and learning about mental illnesses, it uh, it gave me, it gives you knowledge and understanding about what I'm going through from a medical point of view

**P6 (ln 149: t)**

**P:** Well...I kind of brought it up [...] but nobody really...it was kind of dismissed, it's not really looked upon that...by the medical community...right. Like people



hearing what you can think. So, it was kind of like just dismissed...like as nothing like.[...]

**I:** [...] the people I've talked to just in these interviews, they...like they do talk about that kind of sense that either they can read other people...other people can read them but in a lot of cases, they'll see it as part of the...part of the illness. It's something that their brain is...the illness is just...

**P:** I think it was part of the brain doing something else.

**I:** Yeah.

**P:** Cause as soon as you get the meds, it changed the chemical composition or whatever...like it stopped...right.

**I:** Right...that's right. What you were saying before...it stopped. Yeah...okay. So you can sort of...because of the effect of the medication, you can kind of say 'Okay...

**P:** It's gone.

**I:** It's gone and it was something to do with my brain but yet it's still sort of mysterious.

**P:** Exactly...exactly...that's exactly what I was thinking. **P10 (ln 538: t)**

### ***Summary: Inferring through Impact***

The passages above suggest that participants may discern phenomenological changes in the volume or “heaviness” of the previous ideas or in the conviction associated with bizarre beliefs, thereby allowing the individual to question these ideas or to set them aside. The medication may also dissipate paranoia and somehow reduce the impetus to “read into” or look for hidden meanings in various forms of communication. As suggested above, experiencing these phenomenological changes appears to allow the individual to infer the presence of an illness. At times, however, the individual may have trouble attributing an experienced change with the impact of the medication and may remain ambivalent about certain experiences which still retain a strong sense of phenomenological reality. As the individual's cognitive confusion or distress clears, the individual becomes better able to consider information that enables him or her to evaluate the experience in terms of the new interpretive frame provided by the illness. The process of “inferring through impact” thus appears to work both independently and in tandem with the evaluative process of “making comparisons and finding a fit” described in the next section.

## ***Making Comparisons and Finding a Fit***

The passages below suggest that people initially compare their experiences to sometimes inaccurate “prototypes” of illness and that subsequently encountered information and interactions may help the individual reframe these notions and find a fit. As will be explored further below, people may be more inclined to make comparisons and find a fit when the illness frame becomes interpreted as providing a relative advantage, pragmatically speaking, when compared to earlier notions. Finding a fit also seems to depend on participants having a sense that the new interpretive frame is resonant at a phenomenological level.

- I:** OK, and when they said you had schizophrenia, what did that mean?
- P:** It didn't mean anything to me. I just thought the doctors in Westernized medicine don't acknowledge me having spiritual revelations.
- I:** OK, so it didn't make sense to your experience, what about the term schizophrenia, did you have any previous understanding of what it meant?
- P:** I knew that my uncle and that my aunt had it, and I didn't want to have it and didn't want to be told that I had it, and I thought they were just wrong, because I'd spent some time in the jungle with my [other] aunt and uncle who were very, very spiritual who believe in spirits and they believe in angels and they believe in this book called the Urantia ... and I'd read this stuff and I had it all in my mind and I thought I was the next prophet and the second coming. ...
- I:** OK, so the relatives on your dad's side, was there any, what did you think about schizophrenia, given their experience, what did it mean to you?
- P:** I thought they were very low functioning kind of frazzled, sick people. And I never thought of myself as being like that
- I:** Right
- P:** ... because I still had my philosophy and my poetry and stuff like that, and I had the ability to think and speak...so I totally stigmatized them, and it was totally alien to me...  
**P1 (ln 16: t)**
- I:** Right, so when you were told the diagnosis, did that change your understanding of what was going on?
- P:** yes, everything makes sense to me now, like I've a fear of persecution; it's like [of] authority figures invading my privacy, um; I have thought intrusions that makes me want me to climb up the roof and check out if there's hidden cameras, and I study all about this in my psychology courses, but in the past I just refused to accept I had schizophrenia; it's so hard on me that I wouldn't want to think I had schizophrenia[...] Now [...] I accept the diagnosis and I guess I start to realize that it's kind of a relief, because I was really stressed out by hallucinations and paranoia; I tend to feel relieved that those positive symptoms are not real; it helps me to be normal.  
**P2 (ln 49; ln 81: t)**

[...] I was still not sure when I got out of the hospital the first time that I had OCD, because I don't have any hand washing or checking, or anything (I: right), but when I went to the Mental Health Team they explained that I get infatuated with this girl, and I think a lot about her, and they gave me some examples [...] [that] I could identify with [...] and I was kind of more sure that I had OCD[...] someone told me that [the doctor] initially thought that I had schizophrenia, uh...but I don't have any hallucinations, just obsessive thinking, right...

**P3 (ln 11; ln 17: t)**

**I:** [...] what else were you told about the illness that was helpful in shifting your kind of perspective about what was going on?

**P:** well it was, like a lot of the delusions that people get are things like having your thoughts broadcasted, and being followed and conspiracies and being wanted by the CIA, and delusions of grandeur, those kind of things, so, I just kind of thought it was something unique to me [...]When I first got admitted into the hospital I didn't feel that I had an illness, so, I just sat there and kinda soaked in what was going on around me, and comparing it to what I was going through (I: right) and over time I came to the conclusion that it was probably an illness, yeah, definitely, so I was in denial for a bit there, (I: um hum)

**I:** and when you compared what you were soaking in to what you'd been through, was there anything in particular that, kind of fit, like you mentioned the thought broadcasting as something that fit, (**P:** um), was there stuff

**P:** actually I didn't hear anybody talking about that per se, (I: um hum) but uh delusions, like uh when I was there I noticed a lot of uh strong religious beliefs amongst people that were maybe a bit, you know overblown, like you know (I: um hum), so stuff like that, um a lot of coincidence type of stuff (I: um hum), that kind of thing, so, I knew to some extent I was you know relating to these people (I: um hum) so that gave me some comfort I guess

**P6 (ln 176; ln 206: t)**

**P:** so when they said OK well we feel that this is bipolar disorder that really, really made sense to me especially after I sort of thought about my experience like the depression, and feeling really good, and like this idea to write this book,

**I:** which was better than Harry Potter, th[at] is with big ideas (**P:** yeah, yeah), about the book

**P:** so, I mean I felt that that was the right diagnosis for me, um, and I feel , I feel confident that I have been given the right diagnosis, and I feel that that fits, because of my previous history as well with depression

**P7 (ln 400: t)**

**I:** Can you talk...describe any particular moments or turning points when you shifted your understanding or came to a better understanding of what needed to be done?

**P:** I guess that would have been when I went to the doctor at UBC and he was talking about schizophrenia and I also had a book...I got a book, right and it had something with schizophrenia and all the symptoms that I was experiencing were

inside, psychosis...whatever. [...] The book was like...we had it in storage and I took it out and I was reading about it and it was just talking about like thoughts and there was a bunch of stuff about the same symptoms that I was having.

**I:** So you looked at it and just thought there was a sense of fit between what it said and what you were experiencing.

**P:** Yeah.

**P10 (ln 596; ln 611: t)**

It was the wellness education course, basically psychoeducation [that made a difference, as the doctor] would say this is what drinking [or stress] does to you, so I could see how my brain had shifted, so I was getting an explanation for my symptoms [...] and I could see a big picture that was making sense [...] [and] I find myself more functional in that framework

**P8 (ln 213: t)**

[...] when I was in hospital I was still adamant that my friends were spreading rumours about me and that they were trying to hurt me, but it wasn't until a couple months later after I'd been on medication that I had still sort of like OK yeah, that didn't happen, it was more like looking at the other things that I have accepted and just sort of saying OK there's obviously a problem here, and now that I'm on medication and my brain is healing I was more able to say, look at the fact that, I've acknowledged there's a problem here, so I think there's a problem there too, so, but then I would talk to my other friends about it, and they said yeah, I think that you're right, I don't think that anything was going on there

**P7 (ln 497: t)**

### ***Summary: Making Comparisons & Finding a Fit***

The passages presented above suggest, first of all, that people may size up their own experience and sometimes fail to find a fit with illness prototypes that are not entirely representative. As mentioned earlier, prototypes are derived from instances of the illness experience encountered within the individual's personal sphere or through the media. These are often unrepresentative: for example, they may entail seeing all people with schizophrenia as frazzled and low functioning people or seeing schizophrenia as necessarily involving hallucinations. Reframing illness prototypes (for instance, by providing a positive, accurate example with which the person can "identify") may lead the person to eventually discern a sense of fit. As will be discussed more fully elsewhere, people compared their experiences with a number of sources of information in addition to illness prototypes (whether accurate or not); this included knowledge gleaned through interactions with individual professionals, learned through psycho-educational courses or groups, and comparisons with others, either directly or indirectly, in the form of stories.

The ability to reframe experience also depended to some extent on the availability of what could be termed “reflective space”; that is, an environment where there is an opportunity for dialogue about new perspectives with professionals and peers; in one example related above (P6) the hospital provided such an environment. In other instances, however, the hospital experience was a “really scary experience” and “very confusing.” **P8 (ln 137: ln 173).**

The passages also suggest that willingness to consider fit to some extent depends not only on the aptness of the available information, but on pragmatic considerations as to whether the new explanatory framework provides a relative advantage over the old one. For instance, whereas P2 had previously “pushed aside” the possibility of schizophrenia, she came to see it as an explanation that “makes sense” at the same time as when she realized that the treatment could help her “be normal.” Similarly, P10 had initially “wanted no part” of the information on schizophrenia provided by his family; however, after exhausting a number of other potential explanations, he came to sense that the diagnosis “fit” and assented to the possibility that “maybe they can do something.” The implication here is that the process of making comparisons and finding a fit is not necessarily a linear, direct process; people appear more inclined to consider and favourably evaluate such comparisons when the consequences of doing so (e.g. the opportunity to become normal) becomes less threatening.

Also noteworthy is that participants frequently mentioned certain terms within the new interpretive frameworks that appeared to resonate or provide a sense of phenomenological fit with their experience. For instance, the term “thought broadcasting” appeared to resonate with some participants’ feelings of “being read,” and thus adequately replaced earlier interpretive frames such as paranormal “powers.” As comments by P8 and others suggest, people make comparisons not only with specific terms, but also with an explanatory framework that illustrates a “big picture” of what they’ve been experiencing. They may become more likely to adopt it when they “become more functional in that framework.” Overall, when making comparisons, individuals appear to evaluate both the aptness and relevance of the overall “big picture,” but also its resonance to specific aspects of their experience, which depends on whether

the information provided within the framework is rich enough to provide a potentially resonant comparison point for the individual.

As the final quotation in this passage suggests, an inclination to explain certain aspects of one's recent experience as illness-related does not necessarily imply that all other experience in the individual's more distant past will be seen that way. This participant (P7) had to revisit past experience and reinterpret it in light of the new explanation. Other quotations in the passage above (e.g., P1's comment about the reality of the "demon" and P10's comment about "other people being able to hear his thoughts") also suggest that despite attaining insight, certain experiences remain "mysterious" and difficult to assimilate into the illness framework. The next section illustrates how, in certain contexts, people must perform a considerable amount of "interpretive work" in order to successfully accommodate alternative, potentially competing interpretive frames. Before moving on, it should be emphasized that not all participants entered the path to insight by this doorway. Some participants *did* apparently go through a proactive, deliberate process of considering the possibility of mental illness; for others, however, finding a fit apparently happened retrospectively, after they had experienced a positive impact of the medication.

### ***Accommodating Illness with Previous Frames***

After experiencing some initial insight, a significant source of tension for some participants was reconciling the notion of illness with their previous and potentially competing understandings of their experience. As will be described in the next section of this chapter (see "Coming to an Acceptable, Adaptive Explanation"), the individuals and their families may also struggle amongst themselves to reconcile their views. In some cases, this was not a significant issue. Particularly when the initial ideas were seen as "bizarre" and "not making sense" at all, the earlier frame was quickly discarded for what seemed like a "better explanation." In other cases, however, there was considerable tension, particularly when the initial interpretive frame involved spiritual explanations of limit experiences as well as challenges to the identities often developed in tandem with those interpretations. What the participants in the study apparently did was attempt to reconcile the previous identities and beliefs with the notion of illness and, in general

terms, seek to accommodate their previous interpretive frame with the illness frame. This involves reframing past experience as related to illness in a way that does not *reduce* or eliminate its earlier significance. It can also involve reframing the illness frame in a way that makes it more resonant with the spiritual one.

- I:** So...the interesting symptoms or experiences that you were having seemed to fit what their explanation of psychosis is?
- P:** Yeah.
- I:** Okay. Can you say why there was a sense of fit?
- P:** Well...because I also lost my touch with reality; I mean I had paranoid thoughts, I had delusions and I just saw myself in that picture. [...]What I just believed about myself was so bizarre that what they said was better and they basically said that I'm losing my touch with reality and I believed them.
- I:** Okay. Cause basically because it was...it was a much better explanation than what you'd come up with.
- P:** Yeah. **P9 (ln 133: t)**

I never had [auditory] hallucinations, just thoughts that I determined were not my own and therefore had to be those belonging to [a presence that I knew as] Dameon. Thoughts, feelings, and a presence that seemed to be constantly with me. [...]I thought I was demon possessed because I could not explain to myself what was going through my mind or what was happening to my mind

- I:** [...] so you say that it's taken you quite a while to kind of shift your views from demon possessed to schizophrenia (**P:** yeah), so can you tell me or talk about what kinds of things got in your way from kind of seeing this other way of seeing things?
- P:** Religion did, (I: um hum), like when I would watch Jesus movies, and I would see parts in the Jesus movies where the child or the person was demonized, (I: um hum) my body would start moving like that, like almost as if I was demonized but now I believe that it was just the strength of the illness itself, the power of belief. I've read up on the power of belief and that's a very strong, strong power, so that also gives me validation to realize that I have schizophrenia, like religion was the only thing that really stood in my way, of it all, believing in Jesus meant believing there's a devil (I: right), and knowing that once upon a time, if they don't anymore, people were demonized, and um, and then just the other day I read a scripture in the Bible that says Jesus not only expelled demons, but he also cured the insane, so that helps me even more to accept the fact that it's a mental illness, it's not demonic, because insanity existed back then too (I: right), it wasn't all blamed on the demons. **P5 (ln 5; ln 184: n; ln 226: t)**

- I:** you've talked a lot about the medication and how difficult the idea of taking meds was for you, but what about the diagnosis, was there anything that helped you accept that?
- P:** Dr. X. talked about dopamine and opium and I could see a big picture that was making sense, that's why I'm less decided about the spirituality [...] I just believe

that just hearing Dr. X.'s stuff and making the connections for me, and I guess my philosophy or way of seeing things [made a difference]. I really think that flight or fight stuff makes us highly intuitive – being in the west, I don't know how applicable intuition is [...] [but] this is the way this place works for the most part, so you may as well sink or swim. And it's actually freeing [...] to have this feeling that I'm not here for this higher reason, you're good to be with someone because you just want to be with them [...] I'm a bit of a realist so it makes it easier and I still look at the sunset and it makes it peaceful and I see it as kind of a biological thing, like my mind producing good feelings and enjoying it... Dr. X.'s class... made me think of what is the ideal state of mind. **P8 (ln 215; ln 272: t)**

There is an old joke: One guy is sitting at a bus stop looking really miserable, the other guy asks him: "What's wrong?" "I just got let out of the mental ward." "So, that is wonderful!" "Yesterday I was Napoleon, king of half the world, now I am nothing."

It took some getting used to, not being the Messiah. This is where the magic of insight began to burn [...] Now after a year and a half since my first hospitalization, I am seeing the light in a new way; I have increased compassion for all beings, humility within my heart, and I am grateful for this existence at every moment. I can honestly say, I had rather be alive now, and with all these symptoms than to never have lived at all.

- I:** [...] you mentioned that it was difficult to, once you stepped away from your original beliefs, it was difficult to not think of yourself as the Messiah. [How did you get through that?]
- P:** I just stopped believing in all that, and I felt very inadequate because I used to think I was the centre of the universe, and then I realized that I was not that important at all. And what got me through that time was the love of my family and explaining that I was still special, even though I wasn't the Messiah.

**P1 (ln 46: n; ln 221: t)**

### ***Summary: Accommodating Interpretive Frames***

Once an individual comes to accept, to whatever degree, that they have an illness, the person then is confronted with the question of whether his or her earlier interpretive frames (e.g., spirituality, limit identities, etc.) are completely worthless, or worth saving in some way. For instance, P1 wrote about the good news/bad news joke – being cured and getting out of the hospital, but no longer being Napoleon – as a way of conveying the void of meaning that the illness created. In interpreting the illness, however, he appears to have integrated the illness and spiritual frames, viewing the process of "gaining insight" as experiencing personal self-realization (fittingly, he titled a similar narrative to the one completed in the course of the study "My Schizopoetic Soul"). Similarly, P7 had a sense of herself as "perceptive" and "intuitive," which went hand in hand with her



strengths as an artist. Accepting the illness thus threatened those aspects of identity that were inextricably bound to the illness experience. Her solution, like P1's, was to "make connections" between her illness and the sense of herself as perceptive and spiritual, for instance, seeing the action of neurochemicals as enhancing sensitivity under "fight or flight" situations and understanding the medication as helping her achieve an "ideal state of mind."

Reframing past experience also involves seeing that illness was in fact resonant with the phenomenological nature of one's previous experience. P9 and P11 both saw their illness-related ideas as relatively "bizarre" and easily given up for the alternative explanation offered by the illness. For others, however, the process is not so simple and earlier interpretive frames are not given up so readily. After two or three years of involvement with treatment, P5 was still ambivalent about whether she had a mental illness as opposed to being "demon possessed." As illustrated in the passage above, a turning point that allowed her to accommodate her new and old interpretive frames happened when she came across an article that helped her see that the bodily experiences she attributed to "possession" could actually be related to "the power of belief" and thus be related to the illness.

### ***Pathways to Initial Insight: Concluding Comments***

It should be emphasized that, while defined provisionally as distinct processes, experiencing an impact and finding a fit can be seen as interacting and as part of a more general process of decision-making, one that involves both comparing or testing for a fit between one's experience and the illness frame, as well as evaluating the consequences of adopting that interpretive frame. For instance, as discussed earlier (in both "Pathway to Care" and the present section), it appears that individuals generally begin to consider potential fit once the *imagined* consequences of the new interpretive frame are positive, at least in relation to the original explanation; the *actual* experienced consequences of "taking on" the frame then may either reinforce or question the initial sense of fit. At the same time, people who initially inferred the illness through the treatment's impact may retrospectively evaluate their experience in terms of its fit with the new frame, which

may in turn serve to reinforce the sense that the notion of illness constitutes a valid, or at least plausible, explanation for their experience.<sup>33</sup>

Before proceeding, it should be noted that, in order to consider fit or accommodate old and new frames, people generally require some opportunity to reflect in order to more fully consider the implications of the illness to their past experience. For instance, for some, being able to retreat from a stressful work situation provides an opportunity to reflect and reconsider the validity of the paranoid thoughts the individual may be entertaining about their co-workers (P6). At the same time, being in a hospital or other treatment environment where they feel safe allows the distance necessary for reflection, although a hospital environment that is experienced as traumatic may exacerbate the situation and make reflection impossible (P7). The impacts of medication, such as providing relief from bombardment by stimulation and amelioration of cognitive confusion, may in so doing also provide an opportunity to reflect and make comparisons (P6, P7, P11). Finally, being able to discuss the meaning of their experience with a trusted other may also provide the possibility for reflection. As mentioned, and as will be explored further in the next section, reflecting, appraising and reconciling alternative explanations is a process that involves the individual, his or her significant others, and mental health professionals.

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<sup>33</sup> Taking on a frame can thus be seen as analogous to scientific inquiry in the sense that the frame the individual tries out can be seen as a hypothesis to be tested. The process can also be seen in narrative terms, whereby the theory constitutes a “plot” or a metaphoric understanding that suggests how a given reality will play out. In science, as in life, the validity of the theory, the plausibility of the plot, or the productiveness of the metaphor, is judged in terms of how well it helps the individual anticipate and act in the face of that experience.

# Negotiating the Path to an Acceptable, Adaptive Explanation

## *Introduction*

As the next section discusses, after coming to some initial insight, participants often faced considerable challenges adjusting emotionally and coming to insight in its broader sense of arriving at an “acceptable, adaptive explanation” (Wampold *et al.*, 2007). The amount of adjustment required appears to depend on the initial impact associated with gaining insight, which in turn depended on how the illness and its treatment were initially interpreted and its consequences for the individual’s future were envisioned. That is, the emotional impact depended on whether the illness and its diagnosis was seen initially as a potential answer to past struggles (“illness as restoration”) and greeted with relief; believed to potentially “ruin the life” of the person (“illness as disruption”); or viewed as something still ambiguous (“being in limbo”). Even participants whose initial reaction was relief invariably expressed some conflicting emotions, and individuals cannot be fitted neatly into these three categories. Perhaps the distinctions are thus better seen as way stations along a continuum, or a pathway which people move along as they adjust, become able to reframe this sense of disruption, and come to see the illness as something they can live with, or even as something that presents the possibility for personal transformation.

Before making such adjustments, however, participants who experienced an initial sense of disruption typically had emotional difficulty. Some also displayed what could be a form of “negative acceptance,” that is, even though aware of the illness, these individuals sought to “push” it into the background of their lives and delayed “addressing it head on” until they were confronted by a return of symptoms or relapse. Before being able to actively adopt the necessary self-care strategies (both medical and psychosocial), participants typically had to go through a process that could be termed “positive acceptance” (Davidson & Strauss, 1992). That is, they needed to reframe their notions of illness and come to see it as something that could be lived with and managed; they also

had to reframe their notions of their own ability to deal with it. As implied above, they may also have come to see the illness as an experience that could be gained from.

Overall, the section below discusses the process by which people more fully come to an “acceptable, adaptive explanation.” The discussion immediately below more fully illustrates the varied emotional impacts of insight associated with the divergent appraisals or stories of illness mentioned above. The subsequent section then illustrates the sequences and processes by which participants re-imagine the originally envisioned consequences of illness for their lives and, in so doing, move from “negative acceptance” to “positive acceptance.”

## **Initial Impact of Insight**

As noted, the emotional impacts of gaining insight were divergent depending on the person’s interpretation of the illness. As illustrated directly below, the impact could be generally positive; this pattern is described as “illness as relief or restoration”; as illustrated further below, the illness could be upsetting or confusing (described in the sections “illness as disruption” and “being in limbo”).

### ***Illness as Relief or Restoration***

On the one hand, those people who saw (or came to see) the illness and its treatment as potentially restorative appeared to adjust more easily, often describing their initial reaction as “relieved.” Generally speaking, these were the people who initially saw the illness as a “fitting” explanation from the outset (compared to their earlier “bizarre” beliefs), who saw their lives as “going off track” for a considerable period of time before receiving the diagnosis, who experienced considerable emotional and social suffering before coming into treatment, and who may have exhausted other interpretive options before considering mental illness. For these participants, the diagnosis readily provided a better explanation for past struggles, a prospect of relief from suffering and isolation, and an opportunity to “right the ship.”

I figured if it kept going the way I thought it was then it would never end, it would just be madness forever [...] I finally sliced both my wrists, blood everywhere [...] Within minutes police and ambulance arrived and escorted me to the hospital. I ended up staying there for three weeks. Began meds, and the EPI program where to my surprise learned

that there were many people who were suffering just as I had been. I never even considered that I had a mental illness, but the education I've received since then has reassured me that I indeed do suffer from schizophrenia. I don't know if anyone was as relieved as I was to find out that I was ill, because my previous reality was Hell on Earth

**P6 (ln 56: n)**

**I:** what were you told or what did you learn about what your situation was or what might be going on?

**P:** Well...it was a big step...like I'd been given a name 'psychosis'...like an illness that you can suffer from so I kind of had a name to what was going on; before I had no idea and so that was important and...yeah.

**I:** that was helpful...that seemed to make...seemed to make sense. (?)

**P:** Yeah...it was a relief, coming in and getting help and to know that I was in the right place.

**P11 (ln 221: t)**

Because I slowly just skipped school more and more and students [were] think[ing] I'm weird [because I went] from [being] outgoing [and suddenly became] very quiet and [having] a strange look on my face all the time. The strange look on my face [was because I always tried] to widen my eyes so they look nice [so I could try to avoid the] loneliness and unpopular[ity] and sometimes mean[ness] from people that think I'm weird. I made a conclusion that I have a natural[ly] evil face, especially the eyes, and this has lasted until the 2<sup>nd</sup> time I was hit hard with schizophrenia in year 2007[...] and when I went back to hospital I planned to tell this to the doctors because I f[ound] I have no more chance in life cause of the evil eyes. So after telling the doctors, they said no it has nothing to do with your eyes, [and] after hearing that I underst[ood] that every time I s[aw] someone I had] the [delusional] thought of [having] evil eyes which makes me look evil, [and realized] if I just remember I'm a ordinary person, people will smile back; so that's how I started living and life now is pretty good; most people smile at me and I know I have a normal face, so I'm very happy now.

**P12 (ln 10; ln 21: n)**

As these passages illustrate, for some individuals, particularly those who had experienced prolonged suffering and perplexity, developing insight lead to a feeling of relief, and offered the possibility of reclaiming a better life.

### ***Illness as Disruption***

On the other hand, as illustrated by the next passages, people who saw the diagnosis as potentially disruptive to their lives or identities had a difficult time emotionally and had more difficulty putting the illness "on the front burner" and staying with the treatment. Such individuals typically had not given up on previous interpretive frames, continued to have high hopes for their lives, and envisioned the illness as potentially

catastrophic to these hopes. They may have also seen themselves in terms of “limit identities” (such as artist, or spiritual seer) that were potentially negated by the illness identity.

...It’s a big life, it definitely changes your life, it sets you back I guess, because you know when I could have finished school back in 2005 or whatever I couldn’t. I was held back because of my illness [...] At that time I was so hopeless, I thought that my future was ruined.

When I received my first diagnosis, of bipolar disorder, I was in complete shock

**P4 (ln 34; ln 60: t; ln 101: n)**

There is an old joke: One guy is sitting at a bus stop looking really miserable, the other guy asks him: “What’s wrong?” “I just got let out of the mental ward.” “So, that is wonderful!” “Yesterday I was Napoleon, king of half the world, now I am nothing [...] and after I stopped being delusional I [also] had to deal with not having my old self back. I felt like I’d kind of fallen into a hole, and I had to climb back into the light, and...I did and I have, but through that process there was a lot of coming to terms with not being as versatile and healthy as I once was.

**P1 (ln 50: n; ln 78: t)**

I was afraid I would lose myself and my identity if I took medication. All my “special” feelings and sensitivity would go away. I’d look sites up on the internet that explained meds and people’s reactions and for the most part they were negative. People complained about weight gain, sexual dysfunction, spouses claimed that their medicated partners “just didn’t care anymore”

**P8 (ln 77: n)**

[...] I’ve had a big shock because, right now, I’m not able to accomplish the things the same things I used to be able to accomplish before I got ill, like, uh, working and going to school at the same time for example.

**P5 (ln 539: t)**

These comments illustrate the envisioned disruption (images of “ruined lives,” “lost identity,” etc.) and negative emotions that follow (shock, apprehension, demoralization, etc.). As the passage below illustrates, however, some participants were not sure what to think or feel about the implications of their experience.

### ***Being in Limbo***

Particularly for those individuals who had experienced their first episode of psychosis most recently (e.g., within the past six months) , there was some discomfort or unease associated with the position of being in diagnostic limbo. This was the period of time before it was too early to say if a definite diagnosis applied, and too soon to get further definitive answers about what had caused the psychosis and what could be done about it.

Some participants also struggled with the questions of whether he or she “would have to take medication for the rest of my life” and whether the illness would come back again. Some individuals also wondered more broadly about what the illness meant for her or his envisioned life trajectory.

When I came to [the early psychosis program], I talked to Dr. F., [and] she said um I agree with Dr. A. that you’ve gone through psychosis but the type of psychosis I’m not quite sure yet what you have, so at that point I was sort of confused because I wanted to know what was wrong with me, like I wanted to know what my mental illness was, so at that point it was a little frustrating for me [...] I mean it’s just, I didn’t know what was wrong with me, so, and when like when I’m explaining things to people, like I had to explain to my friends who I thought were trying to hurt me, what was wrong with me, it’s like OK, I went through psychosis ... like what *is* that, what does that *mean*, and I just felt like I was basically telling them OK like I went crazy for a little while, but I don’t know why.

**P7 (ln 346; ln 390: t)**

**P:** Well...for a long time they didn’t have a diagnosis so I really couldn’t understand my illness until now actually. Now I know it’s a bipolar disorder but for a long time they didn’t know what it was and...but from the very beginning they explained a lot.

**I:** So...not having a diagnosis, did you find that difficult?

**P:** Hard.

[...]

**I:** And so, did you have any previous understandings about what bipolar meant or does that...?

**P:** No...I never heard of it before.

**I:** Okay. So...and what about schizophrenia? Did you have any previous understandings about that?

**P:** Well...my uncle is schizophrenic but I don’t know him very well.

**I:** And did you find that...was schizophrenia...like did you find that a threatening label in anyway compared to bipolar?

**P:** Yeah. My thinking was that schizophrenia was much more scary than bipolar...that their lives are ruined and they can’t work, they can’t do anything.

**I:** And so bipolar in that sense is more...gave you a better kind of sense of being able to...

**P:** Yeah...better.

**P9 (ln 179: t)**

**I:** can you say anything more about what you were told about what psychosis was and, or...?

**P:** There was a lot of uncertainty about...like questions that...like I mean...I think there’s still...I don’t know...there was still kind of like...like I asked questions like how long would it last or you know, am I going to be permanently like this and they couldn’t tell me, so I had a lot of questions regarding that...my future and what it

was going to mean for me to have psychosis and they couldn't really...like certain questions they couldn't answer those questions.

**I:** Because it was sort of too early in the ballgame.

**P:** Yeah...too early.

**P11 (ln 225: t)**

**I:** And did being upset about having it...were you also upset about what might happen in the future or was it more about what you could have done in the past or both?

**P:** I think it was both. Like in the future, too. I could have a relapse or something. That scares me.

**I:** Okay. So, it's more about can you actually control...I've got this and can I actually control it coming back again.

**P:** Yeah.

**I:** Okay.

**P:** Without...and I also don't want to be on meds the rest of my life...right.

**I:** Right.

**P10 (ln 328: t)**

As these comments indicate, participants were uncomfortable with being in diagnostic limbo because of the uncertain implications for their lives, but also because they desired more information about what caused the condition and how it could be controlled.

### ***Summary: Initial Impact of Insight***

In summary, participants as a whole described a range of emotional responses to their initial awareness of the possibility of illness. In general, those whose lives were perceived as going off track and who had exhausted alternative explanations were more inclined to be relieved upon learning that they were experiencing a problem for which a potential answer existed; to these people, the illness and its treatment represented a possibility for restoration and a chance to get their lives back on track. For others, however, the diagnosis was upsetting and represented a threat to present identity and to their envisioned future biography. Still, others were in an uncomfortable position of limbo, where their future prospects remained uncertain.

### **Adjusting to the Initial Impact of Illness**

Generally speaking, all participants, regardless of their initial emotional reaction, experienced some conflicting emotions. For instance, initial relief from entrapment or suffering may have been quickly followed by feelings of uncertainty about the future.



All participants thus go through the process of adjusting to insight in the broader sense of reframing its meaning as they struggled along the path towards an acceptable, adaptive explanatory framework. A considerable amount of effort may be involved in coming to this point, however, depending on the extent to which the individual interprets the illness as disruptive after first gaining insight. As illustrated in the next section, before coming to a revised understanding, however, the individual's stance towards the illness may be a form of "negative acceptance" involving a tendency to "push illness away," only to be confronted by its return and then experiencing the resulting demoralization. After reframing one's relation to the illness, though, participants eventually came to see the illness, as one participant put it: "something I could adjust my life to be with." As will be discussed further below, this process of reframing illness as disruption apparently initiated what could be termed a "positive acceptance cycle." In this process, initial hope enabled the individual to take an active role in managing the illness, allowing the person to reclaim valued aspects of his or her identity, and to begin envisioning "illness in the background" of one's life; this begat more acceptance and confidence, in turn setting in motion an upwards spiral of recovery.

### ***Negative Acceptance: Pushing Illness Away***

Individuals whose understanding fit the "illness as disruption" pattern were inclined to accept the illness, but to do so while harboring conflicting feelings or experiencing ambiguity. Because of its perceived disruptive nature, people often saw the presence of the illness as a cause for mourning losses. As mentioned, individuals in this category often attempted to mentally "push away" the notion of the illness, hoping it was short-term, and subsequently rushed back in an attempt to quickly "get back on track"; in so doing, people sometimes went off their medication or ignored self-care strategies. Such individuals were then typically confronted by a return of the illness. While a relapse and confrontation might have led at least temporarily to demoralization, often participants spoke about the experience as something that led them eventually to "get a grip" on their illness, put mental health on the "front burner," and "take an active stance" towards the illness. The following section illustrates the process of negative acceptance and also exemplifies the confrontation with illness which could act as a positive turning point. It

will do so by looking at concise case studies of three participants (P3, P5, P6) whose accounts exemplified the process. For the purposes of these case studies, rather than continuing to use such clinical labels, these young people will be referred to as Jessica, Jenna, and Nicholas. The subsequent section more fully illustrates the factors involved in what apparently is a process of positive acceptance, wherein the individual begins to reframe his or her notions of self in relation to the illness.

- I:** [...] some people have said that accepting a problem is the first step to moving on, what do you think about that?
- P:** I totally agree with that, because when you're in denial, you're just ...either you put the problem aside because you want to avoid it, or you ...or you can't even tell that there's a problem going on  
**Jessica (Ln 228: t)**

This passage identifies the pushing away/addressing head on dynamic as experienced by Jessica, whose story is a good illustration of this overall pattern. As noted earlier, she stated the diagnosis was a “complete shock” (ln 103: n), and saw bipolar illness as “something that would ruin [her] life forever” (ln 58: t), and which might prevent her from realizing her long term vocational goal. After recovering from her initial episode, she returned to school full time, went off her medication near exam time, and suffered a relapse. After a period where she described herself as “mourning” and “having nothing,” she entered a vocational rehabilitation program, and eventually “realized that it’s not something that I can really take away, but I can learn to manage [...]” (ln 152: t).

The next passage describes another variation of the pattern, as experienced by Jenna.

- I:** what about when you first came to the day program, what did you think about other people who ...
- P:** well, honestly and initially I wanted to push the idea away that I had a mental illness (I: um hum), so coming to the day program and recognizing that everyone else in the day program has a mental illness too, makes me have to accept the fact that I have a mental illness. I wanted to just be with say normal people, or otherwise healthy people (I: um hum) thinking that’s what will make me well, but I’m realizing now, you know maybe it’s time that I should admit that I have a mental illness, and maybe it’s time I should come to grips with the fact that I have to deal with my mental illness

**Jenna (Ln 332: t)**

After her first episode of psychosis, Jenna stayed on her medication for quite some time, while continuing to experience symptoms. All the while, however, she was ambivalent about her initial diagnosis of “stress induced” and “drug induced” schizophrenia, and held on to the notion that she was “demon possessed,” and to the hope that the condition would be short-term. Some time after the symptoms abated, she with her fiancée’s encouragement, decided to go off her medication and had a bad relapse.

After the relapse, and until entering a rehabilitation program, she was reluctant to associate with other people with mental illness. During the course of the interview for this study, Jenna recalled her mother's apprehension about a stuffed animal that a man with schizophrenia had given to her as a child at their church, fearing that the man's "demons" would be passed on to her children through the gift. She suggested that this incident could explain her wish to avoid the idea of mental illness and people who experience it: "I think that plays a part in how I view my illness, but now I'm getting better at viewing as just an illness" (ln 389: t).

Despite generally fitting the "illness as restoration" pattern, Nicholas, who described his entry into treatment as relief from "Hell on Earth," nonetheless experienced some fear about the potential consequences of a psychotic illness such as schizophrenia for his life. After some "pushing and pulling," he relatively quickly came to see the illness and its management as a "chance to move forward" with his life.

- I:** so it's a matter, if you find yourself thinking that way ["pushing and pulling"] it's a matter of talking to yourself, giving yourself a talk?
- P:** yeah, it's reassuring myself that even though, it just, it's hard to do the right things in life you know, and it's just, you're, it's far more challenging to tackle the things that aren't correct to yourself, so by nature you're always going to go the other way once in a while, but you gotta stay forward, focused and move forward, and just deal with the problems head on  
**Nicholas (Ln 375: t)**

### ***Summary: Negative Acceptance Cycle***

In summary, participants who initially story the illness as disruptive or as fundamentally uncertain tend to experience demoralization or fear; as an apparent consequence, they push away the notion of illness and avoid contemplating its presence, or taking the steps (treatment and/or self-care) that would be required to effectively manage it. When confronted by relapse, these individuals may be persuaded, by the return of symptoms, that the illness is indeed real and worthy of their active attention. As the next sections describe, however, certain steps are necessary before the individual can begin to restory their notion of illness and begin to address it "head on."

### ***Positive Acceptance: Addressing Illness Head On***

As mentioned, the overall process whereby people initially address the illness head on can be seen as a "positive acceptance cycle" in which the hope that flows from seeing the illness in a new way allows the individual to address the illness directly, leading to actual success in terms of reclaiming valued aspects of life. As participants experience these

benefits, they eventually come to envision the illness as a less dominating and defining part of their identity in the short-term. This, in turn, leads the individual to envision the illness “in the background,” in other words, as a less dominating and thus a more acceptable part of life over the longer term; this begets further confidence, success and acceptance in recursive fashion. The section below will illustrate this process and the steps that appear to facilitate it.

Being able to “address illness head on” (or take an increasingly active role in managing it in a way that mitigates the emotional consequences of doing so) generally entailed a number of aspects, especially for those individuals who were originally inclined to view the illness as a disruption to their lives (or who may have been inclined to reject it as a possibility altogether). As the sections below illustrate, the process involves reframing the illness, reframing one’s sense of self-efficacy in relation to the illness, experiencing gains, envisioning “illness in the background,” and coming to see the illness, or the experience of going through it, as an opportunity for transformation.

### ***Reframing Illness***

First of all, participants came to see the illness as a potentially manageable entity, as something that was experienced by other “normal” people, and whose potential future impacts were not as catastrophic as originally envisioned. As the passages below illustrate, reframing the illness came about through various means, including experiencing reassuring interactions with mental health professionals and learning new information about the illness. It appears that a particularly powerful way of reframing is through normalized interactions with other people with mental illness, particularly those who had experienced similar things and had achieved a significant degree of recovery.

**I:** What’s the best way of helping somebody come to terms their illness?

**P:** um, at the hospital there were other patients and there was street people and I get really scared since I get the diagnosis, because I’m afraid that some day I would be on the street, because I’m mentally ill, [...] I think they make my life easier when I see my Day Program colleagues, start to make friends with them, and I see them, they are quite normal people as well (I: um hum), that has started to [offer me] way less worry about me being ill, because people couldn’t tell they’re ill, and I’m quite relieved by that

**P2 (ln 90; ln123: t)**

**I:** Was there anything that helped you realize that the illness wasn't so bad?

**P:** When I first came to the day program I was still pretty sick, like I wasn't like, I still had all these things, lack of concentration, I was still feeling hopeless, you know, it wasn't until; well, no, I wasn't feeling hopeless all the time, but like certain times I would be, but then you know seeing how far others had progressed, like in the Day Program you know, some who they went back to school, they went back to work, um, it just gives me hope, you know, the fact that you see others who once were as sick as you were getting back to you know getting back to how they were before they got ill, definitely did something [...]

**P4 (ln 185: t)**

**I:** you talked about how difficult that was kind of emotionally to accept that [you had thought your friends were trying to hurt you], was there anything that helped you deal with the emotions of accepting that

**P:** um, well, I mean, I was coming to EPI every two weeks (I: um hum), so I mean they really helped, and there were some things that I was really, really upset about, and they really helped me, just, it was sort of just the explanation that what I'd experienced and how I'd acted was normal, for, I mean for someone who experienced psychosis, was sort of the thing that made it easier for me to accept because at first I was very, very embarrassed, just that reassurance that this is an illness and you don't need to be embarrassed about it, and everything you experienced is normal for someone who experiences psychosis and has that same sort of illness [...]

**P7 (ln 527: t)**

I just kind of thought it was something unique to me, and now that I know that a lot of people suffer from this; it just made me realize that I was silly, well not silly, not to put it down or anything, but it's just, it's not something that I have to hang on my head anymore. I know that it's not real, that it's treatable my condition, so that kind of gave a relief.

**P6 (ln 184: t)**

I was quite resistant to the meds, I was taking them and he could tell, I wasn't I was sort of doing it reluctantly, but he just said keep going to program, keep participating, and being around other people taking meds too and experiencing similar stuff was helpful too, and kept checking with him and asking is this as good as it gets, and he'd say no, everyone's at different stages, and I'd keep asking ... and he'd look at me and see I wasn't doing well, and he'd say I think I can make things easier for you, and he said, I want to make you feel you're in control of your life, those words made me feel better, and think here's somebody that might have an answer.

**P8 (ln 202: t)**

Yeah...I've gone to many group sessions here at EPI, just to know that there's others out there and to talk about medication...just to chat about that and to realize that other people have the same issues that you have and they're all just like regular people off the street...like anybody can get it kind of thing. Makes you realize that you know...you're not the only one out there.

**P11 (ln 464: t)**

As noted above, one common sense in which the illness becomes interpreted differently is that it becomes seen as something one can “live with.” Another noteworthy theme from the quotations is that reframing the illness involves normalizing it in the sense of becoming able to see that one’s experience does not mean total isolation, that it is something experienced by other “regular” people, and that it is not a cause of shame or a legitimate reason for being ostracized.

### ***Reframing Self and Sense of Efficacy in Relation to Illness: Putting Wellness in the Foreground***

After beginning to reframe the illness, participants typically began to reframe the meaning of their own actions in relation to treatment, in the sense that things previously seen as resigning themselves to illness, and which were interpreted as losses or threats to identity (e.g., making lifestyle changes, participating in a treatment and rehabilitation plan, etc.), were increasingly seen as active choices that the individual made to avoid relapse and reclaim valued aspects of their lives.

[...] I think during the second hospitalization um... (pause of several seconds) when I just for whatever reason when I realized that it’s not something that I can really take away, but I can learn to manage you know if I take my medications and I keep my stress under control  
**P4 (ln 151: t)**

I had to accept that I’m not going to be able to make my mind better on my own power, except by doing things like the day program [...] now that I’ve come to realization that I have an illness, I realize you know what, as sad as it is that I can’t have a full course load right now... I can still go to school some day, and I just have to do stress management like deep breathing and relaxation exercises...  
**P5 (ln 595; 605: t)**

[...] I didn’t know [...] that I had to live my life somewhat differently or I had to change my life to be with this illness  
**P2 (ln 90: t)**

**I:** once you saw that you had to adjust your life, was that a difficult thing to kind of get your head around, or?

**P:** no, because I was so traumatized by what had happened, that I wanted to do whatever I could to ensure that that would never happen again, or to minimize the chances of it happening again, so like I said I took a very active role (I: um hum) in my recovery and basically tried to do whatever it took to get better, and now I pretty much do whatever it takes to make sure that I don’t become ill again [...] it’s like any illness, you have to adjust your lifestyle to deal with the problem

**P7 (ln 640; ln 630: t)**

[...] it made me feel like I wasn't alone to have those presences with me, but now I'm giving healthiness a chance to take over and I'm being strong enough to say you know what I'd better be well, and I'd better get in touch with reality, because it's not fair to life, it's not fair to me, it's not fair to reality to be, living in that dream world (I: right) and who knows what other dreams would come if I was still in that dream world, because I can't control what dreams come

**P5 (ln 281: t)**

**I:** can you describe a typical day and tell me how your illness might come into play, like your symptoms or whatever might come into play and about the things you might do to cope just on a day to day basis?

**P:** well I think my day to day routine *is* coping (I: um hum) in general, and right now I'm just doing the types of things that I neglected before, like I'm going to the gym regularly, I'm getting fit, and I'm preparing my own meals now, I'm not, making sure I eat well, I wake up every day at the same time, so I'm getting just a nice steady routine, and that's building some structure into my life, and I guess my life is about coping now, it's not really uh, normal yet, I don't know if that's the right word, but I'm not really uh, you know, I'm not doing anything more than I can take right now, just getting some structure, coming to the day program, learning more about it, um, getting help from my OT to look forward to the future, what my strengths and weaknesses are, so I guess to sum it up, every day is a coping day. I'm learning how to live more productively

**P6 (ln 435: t)**

In summary, these passages illustrate how participants begin to reframe treatment and self-care activities as opportunities to reclaim valued aspects of life. As they do so, they come to see the value of putting the illness and its management in the foreground of their attention, in order to avoid setbacks, learn to live more productively, and look forward to the future.

### ***Experiencing Success and Making Gains***

Moving along, people's sense of efficacy in relation to the illness increases as they begin to experience and be mindful of the positive impacts of these initial choices on making actual progress with respect to managing symptoms, reclaiming meaningful roles and relationships, or even experiencing personal transformation.

**I:** OK, so the next question is can you describe any turning points (etc.) in the course of learning to deal with your illness?

**P:** ... Oh, my godmother's birthday party. I went over there and I was very worried that things wouldn't go well, and I had a beer and I took some Atavan and everything just flowed so beautifully, and I was so relaxed, and I could

communicate and I read my poetry, and I just felt like on top of the clouds. Everything was just so amazing. And, it gave me a lot of confidence and a lot of assurance.

**P1 (ln 100: t)**

**I:** so, um, given your current understanding of your illness and what it means, how do you see your life unfolding?

**P:** um, I see a lot of potential, I see a lot of hope, cause you know, well first of all, one of my goals from even the time when I *was* ill was to get back to school which I did, like I don't know, illness doesn't stop me from doing things I want to do, it doesn't seem to, at least not any more

**P4 (ln 285: t)**

[...] sometimes I take it for granted, [and think ] that [participating in the program] is not helping me, just because I was working and going to school [before, and now I'm not [...], but that's just me being stubborn, um, so I'm going to keep going on with this day program, and goal setting, to accomplish my goals, and do cognitive tasks, starting in January I'm going to do cognitive tasks (I: um hum). All of this is because I'm accepting that I have this illness, and I have to deal with it

**P5 (ln 611: t)**

[...] over time I just started realizing, there's just no way it could be happening, you know, so you know, finally I just forced myself, because I figured there's no way to move forward, hanging on to those thoughts [...] so I figured the only way, I was rock bottom at that point, so there's only one way to go, and I felt that maybe I should start cooperation and it was my chance to move on with my life, because I couldn't get in the real world, so uh, I had people that helped me and I decided to put my faith in it, hopefully you know, things have been better since I have

**P6 (ln 266;ln 273: t)**

**I:** Can you describe any turning points in the course of dealing with your illness?

**P:** [...] just watching the meds work, being able to focus, wow that's cool, the lights aren't bright, the traffic isn't too loud, it's ok to have someone brush up to you, you don't have to take them in – I choose how to connect and how long, so those are breakthroughs and that's huge; and school, that I can go to school and function, that's good, that I get to express myself, because I was worried about losing my identity, and motivation, because I was highly motivated

**P8 (ln 339: t)**

The comments above suggest a couple of things that are noteworthy: one issue that stands out is the importance not only of experiencing success, but of the significance of being *mindful* of the connection between this success and the self-care activities that participants chose to adopt; secondly, as participants experienced initial success – in managing their symptoms and in reclaiming valued aspects of their lives – their confidence level increased.



## ***Envisioning Illness in the Background***

As illustrated in the next section, when their sense of efficacy in relation to the illness increased, individuals began to experience and envision “illness in the background,” perhaps as a present but less dominant aspect of their lives.

**P:** I was suicidal when I first got out, but I fought it, and me and my mom worked through it, and I came out on top ...

[...]

**I:** OK, so, given your current understanding of your illness, how do you see your life unfolding?

**P:** That’s a good question. Well I hope to go into creative writing here at UBC, and I think I’m well on my way, and I hope to have a family one day. Dr. X says it’ll come to a point where I just have to take a pill at night time. That’s the only thing I’ll have to pay attention to with my illness. So I’m pretty confident that it’s up from here, it’s going to get better. I’ve been through the worst times.

**P1 (ln 93;108: t)**

**P:** I think schizophrenia plays a big part in my life, lots of down times, but since I’m on medication, I feel that it’s a small part; yeah, that’s what my doctor, Dr. X. says too

**I:** that’s great, and once it becomes a smaller part of your life, it becomes easier to accept and to deal with it? Is that...

**P:** yeah, much easier, and my life is much happier too

**P2 (ln 286: t)**

I’m still adjusting, just hope is what gets me through it (I: um hum) realizing that you know what my mind can be that well again some day, as long as I pay careful attention to it, and keep on doing what I’m doing

**P5 (ln 548: t)**

The doctor said that 70% of people eventually experience no symptoms. I hope to be one of those people.

**P12 (ln: t)**

**I:** Yeah. Okay. Anything else you can say about like how you...how you see your life unfolding and living with the illness kind of stuff?

**P:** I don’t want to live with illness anymore. The way I look at the future is not myself living with this illness. I see myself beating it...right. No meds...and that’s it. I don’t see myself thinking the way I did three years ago or [a few months ago] or anything like that [when I was in psychosis]. You know what I mean? Now I don’t know if you go off the meds, if its a trigger or if you get shot with a relapse, is it because your body’s out of chemicals or is it because your brain starts thinking or is it because of the thinking or is it stress or...I’m not sure...right?

**P10 (ln 882: t)**

As the last quotation suggests, people hold different perspectives when it comes to envisioning their future relationship with the illness. The idea of “illness in the

background” could thus connote a more peaceful co-existence or, for some, could entail the idea of “beating” it and leaving it completely behind. This sentiment appears to be the case particularly for individuals early on in the experience, who are in diagnostic limbo, and where the future course of the psychosis is not clear. Still, the participants as a whole appear to take comfort with the idea of illness in the background and appear to find viewing the illness in this way as more acceptable.

### ***Illness as Opportunity for Renewal or Transformation***

In some cases, after the individual moves along in their recovery, not only does the illness and one’s relationship with it become re-interpreted, the individual begins to adopt what could be called a “transformative” frame of reference towards one’s self and one’s relationship to the illness. That is, one begins to see oneself as a potentially “better person,” (as one participants expressed it) and value the illness as something that has helped bring this transformation about.

Now after a year and a half since my first hospitalization, I am seeing the light in a new way; I have increased compassion for all beings, humility within my heart, and I am grateful for this existence at every moment. I can honestly say, I had rather be alive now, and with all these symptoms than to never have lived at all. **P1 (ln 65: n)**

- P:** [...] [initially I thought] it was a very severe type of condition, and yeah I just didn’t want to have to deal with something like that... I don’t know, I think everything happens for a reason [...]
- I:** [...] yeah, so and the other thing you said that might relate to [coming to terms with your illness], I don’t remember if it was before you started, you said ‘everything happens for a reason’; was that part of it?
- P:** um hum, I think so, because um you know there’s still like great stigma around people who have mental illness, for example some people think that you know they’re violent, when you know many of them aren’t. I don’t know, I just, I want to become an advocate one day and help educate people who just don’t really know much about mental illness, and... yeah, so I think the purpose is helping others understand something, because I ‘ve gone through it myself [...]

**P4 (ln 52; ln 157: t)**

- P:** well, I think it, any time you get some of that kind of adversity it can be liberating, if you, because it will make you open your eyes to what’s important in life, it’ll make you reflect and see what’s going wrong and it can put more of an emphasis on you know righting the ship and being a better all around human, I guess uh doing what’s important in life, valuing life a little bit more instead of taking it for granted
- I:** so OK, so adversity, as an opportunity (**P:** absolutely), that you can help people to see what’s important and get things going in the right direction

**P:** that's right)

[...] I think it's [also] kind of brought everyone [in my family] closer together, and it's made us more of a family

**I:** so again, if they, it's seeing illness as an opportunity

**P:** as an opportunity, yeah, absolutely, to you know, it's a starting point to something better  
**P6 (ln 355; ln 519: t)**

I feel renewed, like I've been given another chance, I hate to talk in clichés but it's true, but I'd wish I'd done it a lot sooner, and I see people now, and you see people who I wish I could help.  
**P8 (ln 368: t)**

One issue that becomes clear is that reframing one's self in relation to the illness is not a purely personal process despite the implication of specific comments made by participants. For instance, while in some cases, participants may speak of gaining acceptance and control of the illness with comments such as "I came out on top" or by making comments that envision "beating" the illness, a closer reading of the text suggests a more nuanced view of how people adjust. For example, the same participant who spoke of coming out on top also specifically emphasized how the support of people close to him had helped him regain confidence and eventually become a "more compassionate" person. Another person who talked about the illness making him a "better all around human" at one point, at another point talked about the crucial importance of the acceptance he'd experienced from his immediate family. In general the comments suggest that adjusting to a more acceptable and adaptive interpretation of the illness is a fundamentally social process involving the acceptance and hope of others.

### ***Summary: The Positive Acceptance Cycle***

In summary, and as noted above, those individuals who came to see the illness and its treatment as potentially restorative (and even transformative) often talked about what could be conceptualized as a "positive acceptance cycle." That is, after adopting the new interpretive frame, the person experienced positive consequences such as gaining an explanation for past struggles, finding relief from present suffering, and discovering an opportunity to get life "back on track" and achieve important goals in the future. As they experienced positive consequences from treatment for their various selves (past, present and future), they began to envision a time when the illness and its treatment would be the

background of their lives and a less pervasive part of “who they were.” By experiencing positive consequences and envisioning illness in the background, the illness thus becomes easier to accept on a long term basis. Because these participants were able to envision eventual progress, they were better able to accept the need to adjust and pace their lives in the short term.

In other words, when individuals could envision a time when they were better in the long term, they were able to interpret changes to their life in the short term (i.e. making lifestyle adjustments and pursuing a plan of treatment and rehabilitation) as actions that helped them move in this direction, rather than as losses that could never be recovered; illness management thus becomes reinterpreted as restorative rather than disruptive. By making these changes and being mindful of the experienced gains, participants become more confident of their abilities to manage the illness and are increasingly more accepting of the illness and their need to actively manage it as it becomes a less defining aspect of themselves over time.

## **Overall Chapter Summary**

In summary, the results of this chapter have helped start to formulate answers to questions that the study began with: specifically, how does insight develop and what are its consequences at the beginning stages of illness management for people with early psychosis. The results suggest that people become aware of the possibility of illness when the new explanation appears to fit their experience and when they are able to accommodate their previous interpretive frames with the new one. The results also suggest that people accept the notion of illness when they experience a positive impact of treatment which persuades them, in retrospect, that an illness is present. The findings suggest too that the two pathways to insight are inter-related. Namely, it is more difficult for participants to consider the fittingness of the new explanation when to do so would conjure up an envisioned narrative of disruption. Those whose initial understanding of illness fit this pattern tended not to fully accept the illness and sought to push it away. The return of symptoms that accompanied such avoidance then persuaded the individual that the illness was indeed present and did need to be managed. These individuals then became better able to more fully accept the illness as its consequences were perceived as

less disruptive and, in some cases, came to be envisioned as a positive or even transformative experience over time.

# **CHAPTER FIVE: INTERPRETATION, IMPLICATIONS, AND CONCLUSIONS**

## **Introduction**

The final chapter elaborates the argument introduced previously, namely, that insight develops in the face of demoralization (J. D. Frank & Frank, 1991) and can be conceived of as the process of coming to an “acceptable, adaptive explanation” (Wampold *et al.*, 2007). After explaining this general notion, the chapter then articulates how it constitutes the core concept of the emerging grounded theory; in other words, how the notion provides a unifying framework for explaining the study results and analysis as a coherent whole. In doing so, the chapter situates the findings of this theoretical understanding within relevant empirical and theoretical literature. It then briefly considers the broader policy implications of the studies’ findings on “biographical work” (Juliet Corbin & Strauss, 1985) for the management of other chronic conditions in their early phases. Next, the practical implications of the findings are considered by articulating a logic model that could help form a basis upon which to develop interventions for assisting individuals with early psychosis to become more insightful. In light of the study results, the process to be discussed entails two key aspects: first of all, helping individuals and their significant others find congruence between their own story of the illness experience and the medical version; and secondly, helping people “contextualize” their understandings of illness and its treatment as an adaptive feature of their envisioned biographies. The theoretical, practical and policy implications of the study must be understood in light of the limitations of the research. The final section of the dissertation discusses these as well as identifying issues that require further study.

## **Insight as Coming to an Acceptable, Adaptive Explanation**

The following section describes Wampold *et al.*’s conceptualization of insight, thus laying the foundation for an exploration of its relevance for the present study. The discussion first traces the development of the concept, starting from its basis in Frank & Frank’s notion of demoralization, the idea that people seek professional help to explain

life problems when their original interpretive frameworks prove inadequate in solving these. The results of the present study suggest that demoralization is apparently relevant to the beginning stages of insight development. As will be discussed, participants (often with the help of family members) seek outside help after their initial attempts to understand or story the psychosis experience no longer prove functional. Developing insight in its broader sense appears to entail finding a new narrative for the experience that is acceptable and more adaptive than the original one. After discussing this notion of insight, the chapter then goes on to illustrate its relevance in the context of the present study.

### ***Demoralization, Help-Seeking and the Early Stages of Insight***

Within the dominant view, developing insight entails being able to attribute anomalous and problematic experience to illness despite biological factors that may hinder the individual from recognizing a reality that, it is assumed, would be self-evident to a person without the illness. In this view, no consideration is given to the individual's appraisal of the experience of psychosis prior to entering the mental health system. The alternative perspective supported by the present findings is that prior to seeking help, people make active attempts to make sense of an experience that could be plausibly "storied" in a number of ways. As described previously, findings from the anthropological and health services literatures outline the different interpretive options that may be considered, including culturally available "organizing metaphors" (L.J. Kirmayer et al., 1994) and common sense professional discourses that have seeped into the wider culture (Judge et al., 2008). An initial challenge faced by the individual performing this interpretive work, then, is in deciding between, or knowing how to, reconcile these competing explanations. The present study provides evidence supporting what this literature suggests, namely, that people initially seek to externalize or normalize the problem and find an explanation that offers some sense of control. Extending these findings, the present study suggests that when people begin to actively consider the possibility of psychosis (or that the problem requires professional help from the psychiatric profession), they do so only after the earlier less threatening explanations prove to be no longer functional.

Accordingly, Jerome and Julia Frank argue that people seek help from mental health professionals when their interpretive world has become fraught with “demoralized meaning,” and no longer functions to guide their lives. They thus argue that the function of therapy or “healing” broadly conceived is to “re-moralize” (or make more adaptive) the interpretive framework that helps people thrive. The Franks suggest that for people with psychotic illness, the initiation of the help-seeking process may be better conceptualized in more explicitly ecological terms, as a “social breakdown syndrome” wherein the individual no longer functions in her niche and the rest of his or her social ecosystem loses the capacity to help (J. D. Frank & Frank, 1991). The findings of the present study show that participants and their significant others often do explore various interpretive frames (e.g. “powers,” “spirituality,” starring in a “reality show,” etc.) and, consistent with the ideas of Frank & Frank, the analysis suggests that in these early stages, people come to consider illness, in the words of the participants, after they’ve “run through the options,” and can “no longer get by.”

In accordance with this notion of demoralization driven help-seeking, qualitative research on the process of managing chronic illness in general suggests that people become motivated to seek help as the result of “failed performances” (Charmaz, 2002b; J. Corbin & Strauss, 1988) and “identity shifts” (Kearney & O'Sullivan, 2003). That is, they seek help not because of symptoms per se, but because they are unable to “perform” the social roles and identities most important to them, and begin to feel that their sense of personal identity is threatened.<sup>34</sup> Recently, qualitative studies of the early psychosis period have put forward further evidence suggesting that people with psychotic illness seek outside help for similar reasons. In particular, a study by Ko *et al.* (2006) indicated that the first stage of insight formation happens when symptoms became “unbearable” to people, and “once they noticed that they could not function as well as they [once] could.” Similarly, Woodside *et al.* showed that people entered the mental health system because of “faltering personal capacities” that made it increasingly difficult for them to perform valued roles and participate socially (Woodside *et al.*, 2007). Consistent with Frank’s notion, then, it appears that in its beginning stages, the insight development process is a

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<sup>34</sup> Orona’s notion of an “existential coordinate,” a defining event after which the person is recognized as not being him or herself, may also be relevant (Orona, 1997).



search for an explanation that offers the individual a sense of control and potentially enables her or him to maintain or protect valued roles, relationships or identities. Framed in terms of narrative, the argument can be advanced that people (alone or with the help of significant others) seek specialized help when their original story no longer works and when they become ready to seek a new one, even despite its potentially threatening nature.

### ***Insight Development: The General Concept***

Wampold *et al.*, building on the Franks' notion of demoralization, argue that the insight development process essentially involves helping the individual transform what has become a maladaptive narrative into one that is more adaptive, and at the same time acceptable to their values and worldview (Wampold *et al.*, 2007). They argue further that insight could involve accepting various accounts, the objective "truth" of which is less important than the extent to which a given account offers a plausible, coherent account of the problem and its possible solution. These authors thus define insight as the process of coming to an acceptable, adaptive explanation which they suggest is a "common factor" to all successful forms of psychotherapy or healing. As seen within this framework, then, the insight process begins as the individual and therapist find a story of illness, or an explanatory framework defined in terms that are *resonant* to the individual (i.e., congruent with the language normally employed by the individual to explain the problem, or with her or his general values and worldview). It also involves finding a story that is *relevant* to the individual in the sense that it plausibly suggests the possibility of a solution to problems perceived as important within the person's day to day life.<sup>35</sup>

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<sup>35</sup> Drawing on Goffman's notion of interpretive frames, scholars of social movements operating within the symbolic interactionist tradition have used the terms "frame resonance" and "frame relevance" to account for the mobilization potential of rhetoric employed by movement leaders. Resonance refers to the congruence of the rhetoric with the values and beliefs of a movements' constituents; relevance refers to the congruence of the rhetoric with the day to day concerns of its constituents (Snow & Benford, 1988). As in psychotherapy, persuasion in this context depends on employing terms that can frame a given situation in terms of the acceptability and adaptive potential of adopting a particular frame of reference.

## **Coming to an Acceptable, Adaptive Explanation: The Core Process of Insight Development in Early Psychosis**

While this formulation was advanced in the context of psychotherapy in general, Appignanesi, in her historical account, makes a similar point about psychotic illness: she suggests that over time, patient insight regarding schizophrenia entailed gaining knowledge about different apparent influences on one's mental health (e.g., unconscious conflicts, interpersonal dynamics, need for medication, etc.); she also suggests that various conceptualizations of schizophrenia (e.g. Kraepelin's vs. Bleuler's) connoted different expectations for recovery, which may have been internalized by patients and subsequently influenced actual outcomes (Appignanesi, 2007). The following section suggests that the notion provided by Wampold and his colleagues evidently offers an apt way of conceptualizing insight development for people experiencing psychosis. As will be discussed below, in the context of psychosis, the resonance of the new interpretive frame appears to relate to the extent to which it provides an acceptable (or even better) fit with the experience of psychosis and with the individual's own story of that experience. The relevance of the explanation apparently has to do with the degree to which it is interpreted as having a positive impact on the individual's life, or the extent to which it can be envisioned to help, rather than disrupt, the person's envisioned life trajectory.

Overall, as will be discussed below, coming to an acceptable, adaptive explanation first involves discerning whether, in fact, there is a way to fit or accommodate the individual's own experience with the explanatory framework that the notion of illness provides; it then involves performing the biographical work necessary to contextualize the envisioned trajectory of the illness and its treatment within the individual's own envisioned life path.

### ***Finding an Acceptable Explanation: Making Comparisons & Finding a Fit***

In the present study, participants' comments made it clear that some individuals in particular quite readily saw psychosis in hindsight as a "better explanation" compared to their previous "bizarre" notions about what their experience meant; their comments

indicated, for instance, that they “saw themselves in [the] picture” that a specific diagnosis provided. Others, over time, came to understand that the new explanation provided a more useful overall “framework” for explaining what had happened, or came to see certain terms, such as “racing thoughts” or “thought broadcasting” as providing a useful frame of reference for specific experiences. Writing in the specific context of early psychosis, Larsen makes a similar case. He first presents evidence suggesting that certain aspects of the illness model (e.g., terms such as “racing thoughts”) may provide a way of objectifying experiences that might otherwise lead to delusional explanations (J. A. Larsen, 2004); in a later paper, he suggests that people eventually learn a “system of explanation” that allows them to accommodate their experiences within the illness framework (J. Larsen, 2007a). The study by Ko *et al.* (2006) shows that the comparisons people with mental illness make to the experience of others with similar illnesses helps them evaluate whether, in fact, their experiences fit the new framework.

As noted in Chapter Four, “finding a fit” was enabled when the individual came across new information in the course of clinical interactions through participation in psychoeducational programs or through independent exploration. Such information, however, came not just in traditional didactic or therapeutic form, but most significantly was embodied by other individuals with mental illness with whom participants came into contact. By meeting others and learning they were “normal,” “regular” people, participants became more able to consider whether or not they, too, had similar experiences and shared a similar illness. It was this information in particular that apparently helped reframe the original prototypes that represented illness and that appeared to mediate the initial comparison process for participants. These results are consistent with literature noted earlier, namely, with the theoretical writing of humanities scholars such as Hacking (Hacking, 1995) and Hunter (Hunter, 1991) and with cognitive psychology research (Dey, 2007) highlighting the integral nature of prototypes in conceptualization and decision-making. In particular, this work suggests that prototypes are built up through the accumulation of stories or instances (in this case, through stories of others known to have psychotic illness); further, it suggests that they come to represent the salient attributes of the concept in question; these then become the comparison points against which individuals initially evaluate their experience and subsequently decide

whether or not they locate their own experience (or see themselves belonging) within the illness framework. The study results are also consistent with evaluative research on anti-stigma interventions showing that the most effective way of changing attitudes or prototypes about mental illness is through positive interactions with a person known to have the illness (Rusch *et al.*, 2005). Another study, a qualitative investigation of the recovery process in serious mental illness, provides more direct evidence of the conclusion suggested by the current results, specifically, that accepting illness is enabled through positive “social comparisons” (Pettie & Triolo, 1998) which may change the individual’s illness prototype in a way that is more acceptable to him or her. A later section will discuss the implications of the foregoing, namely, that insight development interventions should make use of the story-based nature of learning that prototypes embody.

### ***Making Accommodations***

The above discussion suggests that finding a fit is one doorway leading towards the pathway to insight, through which some participants progressed relatively quickly. The results of the present study suggest, however, that in other cases finding a fit may be difficult because, at least initially, the notion of illness may be alien to the individual’s experience; illness thus may not constitute an acceptable explanation in the theoretical sense defined above. However, the analysis suggests that people often *are* eventually able to find a story that accommodates different interpretive frames, such as illness and spirituality. In the present study, individuals found creative ways of bringing these into alignment, for instance, by reframing their original notions of illness and spirituality. To consider some specific examples, participants in various cases came to see spirituality as being supportive *and* potentially an illness “trigger”; viewed treatment as helping to achieve an “ideal state”; realized that the Bible distinguishes between insanity and possession; and recognizing that the “power of belief” may contribute to symptoms. These participants appeared to be achieving for themselves what the Franks would describe as a function of therapy, which is to help find acceptable explanations by hermeneutically bridging different perspectives in a process that Larsen describes as “symbolic healing” (J. Larsen, 2007a). Within the early psychosis context, this

investigator used qualitative research to uncover the reasons underlying the efficacy of evidence-based psychosocial interventions which he came to explain as involving their ability to help clients find a complementary fit between professional and common sense models of interpretation available within their respective lifeworlds (J. Larsen, 2007a). Lewis describes a similar notion which he terms “narrative multiplicity” in the characters of Chekov’s *Ivanov*<sup>36</sup>, as they seek to understand the protagonist’s depression from multiple perspectives (Lewis, 2006).

Literature reviewed earlier has identified how common it is for people to maintain multiple apparently contradictory perspectives on their health conditions. For example, Byron Good highlighted this phenomenon in his cross cultural research on epilepsy, which he refers to as narrating illness in “the subjunctive mode” (Good, 1994) because of the hypothesized function of such accounts of opening up multiple possibilities for managing the condition in the future. While this author provides evidence suggesting a link between “subjunctivizing” (Bruner, 1991) and positive emotional adjustment, the question remains as to how maintaining multiple explanations could be adaptive rather than confusing for an individual. What is suggested here, however, is that in all of these formulations (narrative multiplicity, subjunctivizing, bridging, etc.), the key point is that rather than choosing one account over another or simultaneously employing diverse accounts, the person is able to use various interpretive frames judiciously, shifting between and bridging them flexibly, depending on their appropriateness in a given situation or purpose.<sup>37</sup> Further, the present study also suggests that being able to do so was accompanied by some interpretive work done in order to accommodate different notions with each other. For example, as mentioned above, participants who were able to see spirituality depending on the context as potentially an illness trigger *and* a resource to be drawn upon for mental health, also developed language to explain illness in terms congruent with spirituality (e.g., treatment as facilitating an “ideal state”). An

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<sup>36</sup> As Lewis’ article describes, Chekov, apart from being a writer and cultural observer, was also a medical doctor who suffered from tuberculosis and from what today would be diagnosed as some form of mood disorder. Reflecting these multiple perspectives, the play deals with depression from various angles, including depression as medical condition, as a reflection of cultural change and anomie, and as a product of the protagonist’s hectic lifestyle.

<sup>37</sup> This capacity is essentially what William James describes in *The Principles of Psychology* as “sagacity” (James, 1890/1983).

implication of the foregoing discussion is that health education interventions must retain some degree of eclecticism in terms of available explanatory frameworks, or that they must be able to help the person construct bridges between different illness narratives. As discussed next, the notion of bridging also applies to the need to find a story that is shared by the person and his or her significant others.

### ***Finding a Shared Story***

The present study provides some evidence that acceptance by the individual was influenced by the extent to which significant others held divergent or convergent views about the illness. When family members discouraged treatment or held other interpretive frames, it was more difficult for the individual to see the illness as an acceptable explanation; one participant, for instance, remarked on her parent's "deep distrust" of Western medicine, and another commented that it would have been helpful if others close to her hadn't believed she was "demon possessed" and agreed that "there was an acceptance process for (the family) as well." Conversely, in other instances, significant others were "always supportive," or helped achieve the kind of bridging talked of above. For instance, one participant related how his mother had helped him understand that even though it was not true that he needed to carry out a special spiritual mission, his personal characteristics of communication and compassion made him special in a more meaningful, equally spiritual sense. Other support for the importance of achieving a shared story between person, professional and significant others is suggested by the success of the "open dialogue" approach to psychosis in helping people achieve varied aspects of social recovery (Seikkula *et al.*, 2006). In this approach, the views of each member of the therapeutic team, including the person and his or her informal and professional caregivers, are treated as equally valid accounts of experience; building on these perspectives, the intervention then seeks to negotiate a shared view in order to provide a basis for managing the condition.

While the above discussion emphasizes the importance of achieving a shared account of past experiences of psychosis, the next section discusses an equally important issue – the significance of finding some rapprochement between the traditional medical story of illness and the narrative of illness as it is envisioned to play out in the future biography of

the person. As suggested by Leventhal's common sense model of illness (Leventhal, 1997), it is important to achieve a shared representation of the illness; however, it is equally important to envision the future biographical consequences of the illness and to achieve some consensus about how the condition can be ameliorated and lived with in some meaningful fashion.

### ***Finding an Adaptive Explanation: Narrative Reconstruction and Contextualizing through Biographical Work***

The adopted theoretical framework of insight development suggests that the process depends not only on finding an acceptable fit but also on the degree to which a given story of illness and its treatment is experienced or envisioned to impact the individual's life in a positive fashion (or at least to not significantly interfere with it). In fact, the study results suggest that insight for some arrives after the person experiences a positive impact of the treatment and thus infers the presence of illness. Similarly, accepting the illness is easier for people interpreting or envisioning the illness as having a potentially restorative impact on their lives. For others, however, the illness was experienced as what Bury would call a "fundamental biographical disruption" (Bury, 2001), that is, as something that cast their lives, as previously imagined, into doubt. For such individuals, accepting the illness (i.e. seeing it as something that possibly could be "lived with") appears to involve what Corbin & Strauss would call "biographical work" (Juliet Corbin & Strauss, 1985) leading to a "narrative reconstruction" (G. Williams, 1984) of the illness and what it could mean for their lives.

The next section explores these issues further and discusses the implications of these divergent understandings to the insight development process. As discussed in the following two sections, insight development appeared easier to people for whom the treatment achieved a noticeably positive impact and for individuals to whom the treatment represented the possibility to restore a life recognizably gone off track. As discussed further below, however, participants who envisioned the illness as significantly disruptive to their lives had more difficulty in accepting and actively addressing the illness. For these participants, doing so appeared to require biographical work enabling them to adjust (or reconstruct the narratives of) their notions of what the illness would

mean for their lives, and reframe their notions of how they could deal with it in a way that minimized its potential impact. As discussed at the end of this section, in coming to accept the illness, participants in some cases came to restore the notion of illness using discursive formulations (“illness in the background” and “illness as opportunity”) that Arthur Frank might refer to respectively as “restitution” and “quest” narratives; that is, not only was illness and its treatment envisioned as a possibility for restoration, but, for some people, it could be viewed as potentially transformative.

### ***Experiencing a Positive Impact***

As mentioned, making comparisons and finding a fit was one metaphorical doorway leading towards the path to insight development. Another relatively direct doorway opened for participants (including those who initially may have been reluctant or unable to seek help independently) as they experienced positive benefits from the medication. This was indicated, for instance, by comments that “the medication always worked,” that the meds made delusional ideas “less heavy” and easier to set aside, that the medication dissipated the sense of reality associated with certain beliefs, and that “I wasn’t always having to read into other’s comments [and that this] helped me be normal.” In all of these instances, participants came to infer the existence of illness from the benefits of medication. Some participants also came to accept the illness after experiencing a relapse, in effect being “confronted” by the relapse with the reality of illness. These findings are consistent with the recent study by Ko *et al.* (2006) that showed, using a similar methodology, that participants with high insight developed this awareness by recognizing, often over repeated episodes, the role of the medication on lessening distressing or overwhelming symptoms.<sup>38</sup> These results are also consistent with other studies showing that compliance (an aspect of the traditional definition of insight) follows from perceived medication impact (Hoge *et al.*, 1990; Lieberman *et al.*, 2005; Perkins *et al.*, 2006; Warner *et al.*, 1994); they also show how people with psychotic illness may infer the presence of illness through the experience of a relapse caused by non-compliance (David, 2004). In general, the results suggest that insight may arrive once the treatment is perceived as positively impacting a problem initially considered distressing

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<sup>38</sup> In contrast, participants with only moderate insight recognized that their symptoms had been relieved, but did not attribute the impact to medication.



or as preventing the individual from functioning effectively in important and valued life roles. As the next section explores further, while the immediate impact of treatment appears significant to insight, more generally, the notion of illness is more easily accepted when the treatment is experienced as potentially restorative of one's identity and helping get life "back on track" in the longer term.

### ***Illness as Restoration***

Despite the pervasive negative connotations associated with psychotic illness, accepting the label of psychotic illness appears to be relatively unproblematic for some. In the present study, for instance, some participants commented on how the treatment provided relief from an illness that was "hell on earth," noted the benefits of "getting a name" for their experience, suggested "[how the diagnosis can] give you a reason for something bad you wouldn't [otherwise] have done," and talked about how getting help was like "having a weight" lifted from their back. Similarly, Schneider shows how accepting even seemingly stigmatized labels such as schizophrenia can provide relief from perplexity or distress, as well as offer an apparent explanation and absolution for previous struggles or bizarre behaviour (Schneider, 2003). A study by *Kravetz et al.* also suggests how for some, accepting the label appears to provide a sense of control over inexplicable past experiences and provides guidance about how these might be controlled in the future (*Kravetz et al.*, 2000). Accepting illness in this context thus may, in fact, absolve one's "past self" of responsibility for a life of struggle or disappointment, may restore the possibility of "being normal," and offer an opportunity to get life "back on track" in the future. As will be explained in a later section, the treatment may also have been framed in terms that Frank would term a "restitution" narrative, or as an opportunity to put the illness in the background of one's life.

### ***Disruption, Biographical Work and Narrative Reconstruction***

For others, however, the notion of illness may initially entail a significant sense of disruption to their envisioned lives. In the present study, participants made comments about the illness "ruining their lives," being "not a pretty picture," as meaning "they would be homeless and on the street," or that they would be ostracized from families and

friends. Such comments are not surprising given the pervasive stigma attached to mental illness in popular culture. In light of these connotations and the position of diagnostic limbo they were in, it was not surprising that some participants sought to push away the notion of illness and attempt to reclaim their lives. As explored further below, the ability to “address illness head on” thus happened only once people came to understand the possibility of illness and its treatment as potentially adaptive; as the meaning of illness was reframed, they came to see treatment and lifestyle changes as strategies to reclaiming their lives rather than as losses or as giving up control. Being able to address illness head on may have also involved a shift in the participant’s own sense of efficacy in relation to the illness. As discussed in the next sections, for these participants, coming to see the illness as an acceptable adaptive explanation appeared to involve a considerable amount of interpretive work, leading to a fundamental shift in the way the individual understands his or her relationship to the illness and how its impact on one’s life is envisioned.

In *Doctor’s Stories*, Elizabeth Montgomery Hunter warns about the need to distinguish medical accounts of illness with the illness narrative of the patient (Hunter, 1991). As she explains, in acute illness this confusion usually does not arise because the medical treatment restores the individual to his or her previous life. As on medical television dramas like *House*, doctors’ stories feature detective work leading to the eradication of the villainous pathogen. In chronic illness, however, the story of illness does not stop being lived and told once the person leaves the clinic, and could play out and be plotted in numerous ways. In the face of the indeterminate nature of chronic illness, a seminal grounded theory study by Corbin & Strauss highlights the importance for family (i.e. individual with illness along with significant others) and professional to create a shared “trajectory scheme”; in other words, to create a shared notion of how the illness and its treatment may play out in the course of the individual’s life in a way that is meaningful to the ill person and significant others (J. Corbin & Strauss, 1988).

The process by which the initially demoralized study participants came to see the illness as an adaptive explanation appears consistent with theorizing about adjustment to other chronic and disruptive illnesses. As noted earlier, in Bury’s terms, such individuals initially appear to experience the illness not only as a biological illness, but as a fundamental biographical disruption. At the same time, people with mental illness may

see the illness or the *treatment* itself as threatening salient aspects of identity. For instance, Kay Redfield Jamison relates an account wherein the artist Edvard Munch, when questioned why he wouldn't pursue a treatment that could "rid him of his troubles," replied "because they are part of me and my art." (Jamison, 1993). Similarly, in the present study, one participant feared that the medication would "take away my sensitivity." While Dumit (Dumit, 2004) suggests that the notion of genetic, brain-related illness may help an individual reframe past negative behaviour as "not me" (or in the words of one participant "help me be normal"), Haslam points out that "lay conceptions" of mental illness are commonly "essentializing"; in other words, that most people still, at least initially, view a *mental* illness as a disease of the self (Haslam *et al.*, 2007).

Understanding the illness and its treatment as potentially adaptive thus requires undertaking what Corbin & Strauss would call the biographical work necessary in order to be able to contextualize the illness into one's life in a way that enables the person to envision moving forward and perhaps reclaim valued pursuits (as opposed to seeing the illness as negating selves, both present or envisioned). In the context of mental illness, Estroff *et al.* refer to a similar process wherein individuals use "illness-identity strategies" (such as normalizing the illness) in order to accept a psychiatric label as applying to them and their lives (Estroff *et al.*, 1991). In the present study, this work (or strategies) involve reframing one's notions of illness as potentially controllable and as having less dire consequences for identity, while at the same time, reframing notions of how one's life might play out. For instance, study participants commented about the realization "that it's not something that I can really take away, but I can learn to manage," conveyed the importance of "accepting my limitations" (at least temporarily), spoke about the realization that "I had to change my life to be with this illness," talked about catastrophizing less (for example, about eventually living on the street) after seeing that others with the illness "were quite normal people as well," and related experiences of finding hope from "the fact that you see others who once were as sick as you were getting back to how they were before they got ill."

Just as the interpretive work performed along the pathway to care involves cultural discourses, so, too, does biographical work entail drawing upon culturally available

discursive resources. In this regard, it is interesting to note how, in articulating the relationship between illness and biography, participants used rhetoric similar to that noted by Arthur Frank in his taxonomy of illness narratives, for instance, by speaking of the illness that could be either left behind or lived with and gained from (A. W. Frank, 1995). As the next section illustrates, not only was illness and its treatment envisioned as a possibility for restitution, but the illness experience may have also been seen as potentially transformative.

### ***Illness Story as Restitution Narrative***

In some cases, participants adopted terminology congruent with Frank's notion of a restitution narrative, a story in which the individual with the illness is returned to his or her original self. In this vein, several of the present study participants used language that envisioned the illness as being "in the background" of their lives. For instance, they made comments suggesting that illness "was a small part of my life now that I'm on medication," and conveying the illness as something that doesn't stand in the way or "stop me from doing things I want to." Similarly, participants at times also used language suggesting the desire to "push away" the illness, saying, for instance, that they initially wanted to "push the idea away that I had a mental illness" or "put the problem aside." This apparent similarity, however, reflected two separate envisioned scenarios. First, participants who spoke in terms of the latter acknowledged that their envisioned restoration constituted an avoidance of what they later recognized as a reality that must be met head on (in order to reclaim some semblance of one's past life). In the other cases, the envisioned scenario is one in which the individual does acknowledge a problem, and becomes able to manage the illness effectively enough to reclaim valued aspects of normal life; illness is thus imagined to be in the background in the sense that the person envisions a time in which either its symptoms or the effort taken to address their impact does not dominate the person's life.

It is interesting to note that this language is consistent with what has been termed the "shifting images" (Thorne & Paterson, 1998) or "shifting perspectives" model of chronic illness (Paterson, 2001). The research underlying this model called into question the traditional "stage" model of illness acceptance by synthesizing the results of numerous

qualitative studies; it also presented evidence suggesting that illness may move in and out of the person's awareness as opposed to being a linear process where "denial" is replaced by "acceptance" once and for all. In the present study, initial awareness, in some cases, leads to pushing the illness away from consciousness, which in turn leads to relapse and subsequent confrontation with illness. In being able to address the illness head on and beginning to reclaim valued aspects of self, the individual then begins to envision the illness in the background of her or his later life. The shifting perspectives model suggests, however, that over time, different circumstances serve to bring the illness (or wellness) back and forth into the forefront of consciousness and that its successful management entails being able to adjust to these contingencies. The model is also congruent with research into the long-term recovery process from serious mental illness, which suggests that while the overall trajectory may move in the direction of what, in the shifting perspectives model, would be known as "illness in the background," the process is not necessarily linear and should be expected to involve setbacks requiring periodic adjustments and possibly the need to start over (Davidson, 2003).

### ***Illness Story as Quest Narrative***

In other cases, participants used discourses consistent with what Frank would call "quest" narratives, accounts of illness in which the protagonist gains something through the illness and the adversity it represents, either in the sense of developing strengths, of coming to a more accurate or authentic understanding of the important things in life, or in the sense of finding a positive meaning out of the experience, such as an opportunity to "give back." The reader may perhaps take it as striking that psychotic illnesses such as schizophrenia could come to be interpreted this way. These accounts *are*, however, undeniably present, and appear to signal not only the individual's acceptance, but active valuing of the illness as well. For instance, participants variously commented that "everything happens for a reason" (such as enabling the person to become an advocate for people with mental illness), suggested that the illness presented an opportunity to become a "better person" and conveyed that the illness experience had led to becoming more "compassionate." Research on adjustment to physical illness (Sharpe & Curran, 2006) and other threatening events (S. Taylor, 1983), including early psychosis

(McGorry, 1995), suggests that such interpretive work may help people reduce the distress or loss associated with such events and move on with their lives. Sharpe, for instance, in her review of adjustment to chronic illness, suggests that these stories function to preserve the individual's worldview despite the occurrence of illness or, in other words, help people maintain the notion that they live in a safe world where good things happen (Sharpe & Curran, 2006). She provides evidence that meaning-making, in this sense, can help emotional adjustment to chronic illness, as does Taylor in his theoretical framework describing how people adjust to traumatic and disruptive experience (S. Taylor, 1983). While these types of accounts in mental illness and in other illnesses provide a necessary counter-balance to dominant stories of illness which feature these experiences as inevitably traumatic and disruptive, their significance to the individual's ability to adjust emotionally and manage the illness over the long term should perhaps be taken as an ongoing question of inquiry (as should the question of whether this strategy would be equally available to all people). In the early psychosis context, literature reviewed in the literature review section of the dissertation suggested that adjustment of this sort may be easier for individuals who have developed resilience in the face of past adversity (Stewart, 2006; Tait *et al.*, 2004) and that those who haven't may be more inclined to "seal over" or "push away" the illness. The implication here is that helping young people to draw on past experiences of resilience in the face of adversity may help them adjust emotionally and more actively address the psychosis.

### ***Summary and Implications: Biographical Work, Narrative Reconstruction and Acceptance***

The foregoing discussion highlights the importance of understanding that the impact of illness awareness depends on the meaning of the illness for the individual in question. The notion of illness as constituting fundamentally different stories – that is, as absolution or "second chance" for some, and as significant disruption for others – may thus provide an explanation for the "insight paradox" mentioned earlier in the paper, whereby becoming aware of illness has divergent impacts: While for some, it provides relief, for others it results in depression and demoralization (J. T. Lysaker, 2007), leading in some cases to avoidance of necessary illness management strategies.

The discussion above also discussed the biographical work apparently conducive of more active acceptance and illness management. The apparent relevance of the concept of biographical work in early psychosis is also significant because it suggests that insight development in psychosis may possess some fundamental similarities to the ways in which people come to accept and deal with various chronic illnesses in their early stages. It also suggests that biographical work could be a useful concept for bringing into focus related processes that have been looked at through two separate theoretical lenses: one emphasizes the importance of self-efficacy (Bandura, 1977; Bodenheimer *et al.*, 2002), that is, of developing beliefs and skills leading to the attainment of a valued health related goal; the other emphasizes the centrality of illness perceptions – people’s common sense representations about, among other things, the controllability and consequences of a given condition (Hagger & Orbell, 2003; F. Lobban & Barrowclough, 2005). The results of the current study suggest that these two things need to be looked at as part of a coherent whole: that is, developing self-efficacy in relation to one’s condition depends on one’s general views about whether that condition is, in fact, controllable (which may in turn depend on pre-existing prototypes); at the same time, one’s views about the illness may change subsequent to actual experiences of success in managing the condition. Instead of looking at illness management through a lens that concentrates on the individual (self-efficacy theory) or on the illness (illness perceptions research), the results of qualitative research, including the present study, suggest that a better concept for explaining successful illness management (or lack thereof) would be “self in relation to illness” as implied by the notion of biographical work leading to “adjustment,” defined by Sharpe & Curran as “balancing the reality of illness within the self-concept” (Sharpe & Curran, 2006). Given their consistency with the biographical work process(es) involved in managing chronic illnesses in general, the results suggest, as was apparent in this study, that particularly in the early phases of chronic conditions, one’s notion of self in relation to the illness may be instrumental to whether or not the illness is accepted and actively addressed; this possibility bears further investigation. Given the unique features of psychotic illness, however, it is not suggested that the chronic disease management model could be applied without careful consideration in this context. The next section in

consideration of the study findings suggests the outlines of a logic model upon which interventions for developing insight in its broad sense could be mounted and evaluated.

## **Practical Implications of the Theory**

The discussion above has advanced a theoretical understanding of insight development in early psychosis, supporting the argument by showing how various aspects of the process are consistent with theoretical and empirical writing in the field of chronic illness management in general and early psychosis intervention in particular. The section below examines the practical implications of the findings and suggests a logic model that could provide a basis upon which people experiencing early psychosis could be helped to understand the illness in a way that provides a positive stepping stone to recovery in a broad sense. The discussion is focused on the notion of insight as an interactive process involving dialogue or reflection on multiple levels - at the level of the individual and at the level of the interaction between the person and mental health professionals and significant others. As will be discussed, any attempts at intervening must also take into account aspects of the environment both within the treatment setting and the wider culture at large which can facilitate or hinder the process of reflection. The overall process could be said to involve the notion of “reflective space” or “reflective capacity” which should be seen as an emergent property of the system as a whole rather than as confined to any particular level.

The traditional notion of insight hinges on the presumed ability of a healthy individual to reflect and discern, by means of introspection, whether a problem exists and, if so, of what nature. This implies that if individuals with psychosis are to become aware of an illness, they must be able to reflect upon and evaluate the meaning of that experience. According to the present study, the process of reflection does appear to hinge on individual factors but at the same time, depends more broadly on how the individual interacts with his or her environment. The present study suggests that one crucial aspect of the core process involved being able to compare one’s experience with various notions of illness and discern a fit, and indicated further that certain key resources or events could facilitate the following comparison process: medication that reduced the salience of psychotic symptoms and ameliorated (rather than exacerbated) any previous cognitive



confusion; a safe environment where the individual was removed from the stressful circumstances that may have provoked or exacerbated the psychosis; the opportunity to interact respectfully with significant others within one's formal or informal support "team"; and the opportunity for positive interactions with others with mental illness within a hopeful climate. The ability to reflect also had to do with the availability of information with which the individual could reframe previously incorrect notions of illness. This could include, as mentioned, the possibility for positive "social comparisons" and the provision of an explanatory framework within which the individual could be helped to locate specific experiences. A key process is the need to provide the opportunity for dialogue and reflection to people whose earlier interpretive frames remain convincing. Rather than replacing one explanation with another, the study results suggest that people be provided with an opportunity to consider how these could be accommodated or bridged and to explore the contexts within which each could be helpful.

Consistent with the motivational interviewing (MI) approach (Rusch & Corrigan, 2002), individuals may benefit from the opportunity to reflect upon values and goals and upon the potential impact of the psychosis and its treatment for achieving these. As noted, the other key aspect of the core process was being able to envision the illness and its treatment as potentially adaptive rather than disruptive to one's envisioned life. This implies that special attention needs to be paid to the individual's views of illness, for example, whether a given diagnosis is interpreted as an inevitable failure and loss, or as a possibility for restoration or whether a given treatment is seen as a threat to valued aspects of the individual's identity. Some of the resources and events described above as facilitating "fit" also apply here to the task of helping the individual reframe the notion of illness or its treatment as potentially adaptive; in particular, the opportunity to meet others who had recovered and achieved goals valued by the individual him or herself. Another key issue is the need to discern the subjective impact of the treatment on the individual, specifically, whether, in fact, the individual does discern an impact, attributes this impact to the treatment, and whether the impact in question is achieved in a domain which is deemed to be of key significance for the individual's identity or future biography. The person must not only be helped to consider this impact, but also be given

the opportunity to reflect upon and be mindful of the source of the impact, whether it be medication or other effective aspects of the illness management plan, including the individual's own strategies. On a broader level, insight development requires attention to the meanings of illness in the individual's wider milieu. This calls for awareness of potentially competing interpretations which may need to be reconciled by the individual or negotiated with her or his significant others.

Overall, the foregoing suggests that the individual and his or her significant others may benefit from being involved in a process in which three key aspects could be explored and negotiated: first are the stories of the psychosis experience as narrated by the individual (and significant others) in relation to the professional account; next is the envisioned life story of the individual in relation to the envisioned story *with* the illness; and finally is the story of illness as metaphorically "told" by the medication in relation to the individual's expectations for help. It should also be kept in mind that in the early psychosis context, the desire to put the illness behind one is a common and reasonable response to being in diagnostic limbo. Such a strategy, however, should not be interpreted in narrow terms as lack of insight, but seen as a learning opportunity for patient, professional and significant other alike.

### ***Limitations, Implications, Areas for Further Study***

When interpreting the results of the study, a few things should be kept in mind or addressed. First of all, one must consider the validity or epistemological status of the accounts of people with psychotic illness. As discussed in Chapter Three (methodology), concerns about these accounts have been allayed by research suggesting that, in the early psychosis context, people themselves more accurately report their experiences than do professionals and family members. The latter tend to provide more accurate accounts of behaviour of the individual in question and, as might be expected, on the inter-personal impact of that behaviour. Future qualitative research on insight development would thus benefit from inclusion of the perspective of significant others (who might have very different stories to tell) and by an attempt to achieve a greater understanding of their impact on the process. It should also be noted, as discussed earlier, that from a narrative perspective, the veracity of the accounts are less important than their pragmatic effect. In

the present case, the research sought out the perspectives of individuals who were engaged in care and who participated actively in the community. The research thus provided a picture of the narratives of illness that these individuals arrived at in relation to their earlier, less functional accounts of the psychosis experience. Also, it is unclear whether the process delineated in the present study might apply to individuals who were currently disengaged from care and whose functioning has deteriorated significantly from its past levels. Present study participants, however, may have gone through periods of being disengaged from care, both prior to and after their initial entry into the mental health system (for example, almost half of the participants had experienced a relapse). Thus, it cannot be assumed that the present study results apply only to individuals with a less severe form of psychotic illness.

A second important issue that must be considered is the validity of the conclusions or, as discerned in qualitative research, the trustworthiness of the study results and the methodological rigour (Chiovitti & Piran, 2003) exhibited in coming to their interpretation. These issues have also been addressed in Chapter Three. For the present purposes, however, it will be noted that the study results are consistent with another recent study (Ko *et al.*, 2006) also showing the fundamental role of comparisons and inferring illness through impact using a similar methodology (narrative analysis). Further, the present studies' findings about the role of biographical work and positive acceptance (i.e. that individuals more actively address the illness as they come to envision being able to manage its impacts on their lives and reclaim valued aspects of identity) are consistent with results found in key studies discussed earlier: namely, Corbin & Strauss' seminal qualitative study "Unending Work & Care" (J. Corbin & Strauss, 1988) on chronic illness management (which investigated a wide variety of conditions, including schizophrenia), and a study by Davidson & Strauss on recovery from serious mental illness (Davidson & Strauss, 1992).

## **Conclusion**

The present study has examined patient perspectives on the process of insight development, contrasting an analysis of the underlying aspects of this process with what could be considered to be a professional-centric version of insight. A final way of

emphasizing the relevance and significance of these results is to juxtapose the concept as defined in the Diagnostic and Statistical Manual (the official professional version) with an account by a person with schizophrenia who is also a clinical psychologist (Deegan, 2007).

As Amador & Kronengold (2004) point out, “the schizophrenia and related disorders section of the DSM IV-TR (American Psychiatric Association Press, 2000, p. 304) now states:

A majority of individuals with schizophrenia lack insight regarding the fact that they have a psychotic illness. Evidence suggests that poor insight is a manifestation of the illness itself, rather than a coping strategy. It may be comparable to the lack of awareness of neurological deficits seen in stroke, termed anosognosia. This symptom predisposes the individual to non-compliance with treatment and has been found to be predictive of...increased number of involuntary hospital admissions, poorer psychosocial functioning, and a poorer course of illness.

The final chapter develops the argument introduced previously that insight needs to be conceptualized differently as an interactive, interpretive, narrative process that evolves over time. As has been argued, it can be seen to develop in the face of demoralization and can be conceived of as the process of coming to an acceptable, adaptive explanation (J. D. Frank & Frank, 1991). Part of the process involves making comparisons and experiencing the positive impact of treatment on perceived day to day problems. The rest of the process is related by Patricia Deegan, a psychologist who has schizophrenia. The final part of this dissertation will be taken up by her words:

When I was first diagnosed with schizophrenia as a teenager, my psychiatrist told me I had an illness from which I could not recover, and that I would have to take neuroleptics for the rest of my life. In effect, I was given a prognosis of doom (...) I remember leaving my psychiatrist’s office and deciding that when I got out of the hospital, I would throw the medication away. Not long after discharge, I did just that(...) (Back) in the hospital, my psychiatrist framed my discontinuation of medication as “non-compliance,” and (...) he explained that I needed to gain insight into the fact I was ill and needed medication. He said my non-compliance not only reflected a lack of insight, but was also a symptom of my illness (...) (B)y throwing away the medication, I was rejecting the message of hopelessness and chronicity with which it was linked. From my side of the consultation room, it was the psychiatrist who lacked insight into my resilience and my hope for a better life.

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## APPENDICES

### Appendix A

#### Consent to Be Contacted Form:

#### Insight & Self-Management in Early Psychosis

Are You Interested in Writing and Talking about Your Experiences of Early Psychosis?

We are conducting a research study looking at the relationship between insight and self-management in early psychosis. Basically, what this means is that we want to examine how you came to understand that something was wrong. We also want to find out how your understanding of your illness experience relates to your ability to deal with your illness on a day to day basis.

We're looking for people that have experienced their first episode of psychosis within the past three years, and who are comfortable talking and writing about their experiences, and who would like to share their experiences and perspectives on the topics of illness self-management (or coping), and insight (or awareness/understanding), and on how the two relate to each other.

What's Involved?

If you become involved, you will be asked to write a short account of your experiences with psychosis, focusing on how you interpreted what was happening to you prior to entering the mental health system. You will then participate in a follow-up interview, where you will be asked to describe how your understanding of your experience has changed since you became involved with the mental health system. You will also be asked to describe how your evolving understanding relates to your ability to deal with the impacts of psychosis on your day to day life. Each of these activities (written account and interview) will take approximately 1 to 1.5 hours to complete. You may also be clarify or comment on a transcript of your interview that will be returned to you, and to comment on the analysis of the results.

Each participant will receive an honorarium of \$30 to make up for the costs of things such as transportation, inconvenience, or loss of wages (or a proportion of that amount for those participants that withdraw early.)

### How Can I Find Out More?

Please write your name, signature and contact information on the form, return it to an EPI team member, and the researcher will be in touch to give you further information about the study. Please keep the first page of this form for your own information. You are signing below to indicate that you are willing to be contacted by the researcher. If there is a better time to be in touch, please indicate that on the form.

Please note, if you prefer, you can contact the researcher (Eric Macnaughton) directly at 604 xxx xxxx.

Name: \_\_\_\_\_

Signed: \_\_\_\_\_

Phone: \_\_\_\_\_ (daytime)

Email: \_\_\_\_\_

A good time to reach me is: \_\_\_\_\_

Eric Macnaughton  
University of British Columbia  
604 xxx xxxx

Dr. Dave Irwin  
University of British Columbia  
EPI Day Program  
604 604 822 7125

Dr. Jim Frankish  
University of British Columbia  
604 822 2258





## **Appendix B**

### **Consent Form for: Insight & Self-Management in Early Psychosis**

#### **Principal Investigator:**

Dr. Jim Frankish, Centre for Health Promotion Research. Telephone: 604 822 9205

#### **Co-Investigators**

Eric Macnaughton, Ph.D. (candidate), Individual Interdisciplinary Studies Ph.D. Program.  
Telephone: 604 xxx xxxx

Dr. Dave Irwin, Department of Psychiatry, Early Psychosis Intervention Day Program  
Telephone: 604 822 7125

Dr. Judy Segal, Department of English. Telephone: 604 822 5652

Dr. Sam Sheps, Department of Health Care & Epidemiology. Telephone: 604 822 3081

#### **What is the study about?**

The purpose of this study is to examine the relationship between insight (or awareness/understanding of illness) and self-management (or coping) in early psychosis. Basically, we want to examine how you came to understand that something was wrong. We also want to find out how your understanding of your illness experience relates to your ability to deal with your illness on a day to day basis. You are being asked to participate because the researchers want to understand the unique perspectives of people with early psychosis about these two important topics, and about how they relate. (For the purposes of this study, early psychosis means it has been three years or less since you experienced your first episode of psychosis.)

#### **What will it involve?**

As part of your involvement in this study, you will be asked to produce a short written account of your experiences with psychosis, focusing on how you interpreted what was happening to you prior to entering the mental health system. You will be given a booklet with some guidelines, and

with space to write your account. (You will also be given the chance to type your account on a computer, if you prefer.) After this, you will then participate in a follow-up interview, where you will be asked to describe how your understanding of your experience has changed since you became involved in the mental health system, as well to describe how your evolving understanding has impacted your ability to deal with the impacts of psychosis on your day to day life. This interview will be audiotaped to ensure that your statements are recorded as accurately as possible.

We estimate that each of these activities (written account, and interview) will take between half an hour and one and a half hours to complete. After you've completed these activities, you will be given a copy of your written account, as well as a typed transcript of your interview, and you will be given a chance to make sure that the transcript accurately reflects what you said. You will also have a chance to comment and give feedback on the emerging analysis, as well as an opportunity to see the results in draft form to ensure that your statements are accurately and fairly represented. Once the study is complete, you will be given a written summary of the research results, as well as an opportunity to hear a verbal presentation of the findings. You will also be given information about how to obtain the full report, which will be produced as a publicly available document as part of Eric Macnaughton's doctoral thesis.

**What are the risks of participating? How might participation be beneficial?**

There is a small possibility that your participation in the study may cause you some distress and discomfort as you reflect upon your experiences. To ensure your safety, a mental health professional will be immediately available on site, in the event that you become distressed and are unable to continue your participation in the study.

You are being asked to participate so that your experiences may be used to make early psychosis services more successful for people who use these in the future. The knowledge gained through the study may also be of use to you personally. If you are interested in receiving a written version of the results, please write your contact information below. Alternatively, the study will be made available in a location that is accessible to you.

**How will the results be presented? How can I be sure that what I say is confidential?**

The results of the study will appear in written form within Eric Macnaughton's doctoral thesis; they may also appear in articles in published journals, and/or in public oral presentations. In order to maintain the confidentiality of the information and the anonymity of individuals involved, participants will not be identified by name in any reports of the completed study. Written data will be kept in a locked filing cabinet, and digital versions of the data will be kept on a password protected computer. Because the group of people participating in the study is relatively small, there is a slight chance that someone reading the study could identify you as having made a particular comment, even though the results will be presented without names and without details that would enable people to identify you.

**Will I be compensated for my participation?**

In order to make up for the costs of transportation/inconvenience/loss of wages, each participant will receive an honorarium of \$30. This will be paid out in two installments: the first after you have completed the written account, and second after you've participated in the interview.

Remember that you can withdraw from the study at any time. If you do so, you will still be paid a portion of the honorarium that reflects the amount of time you spent in the study.

**What if I have any further questions or concerns about the study?**

If you have any questions about the study, please contact Eric Macnaughton at xxx xxx xxxx, Dr. Dave Irwin at 604 822 7125, or Dr. Jim Frankish at 604 822 2258. If you have any concerns about your treatment or rights as a research participant, you may call the Research Subject Information Line in the UBC Office of Research Services at 604 822 8598.

**Consent**

Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time without jeopardy to your services within the Early Psychosis Team.

Your signature indicates that you understand what is involved in the study, that you consent to participate, and that you have received a copy of this consent form for your own records.

Participant Signature \_\_\_\_\_

Date \_\_\_\_\_

Please print name \_\_\_\_\_

Interviewer signature \_\_\_\_\_

Date \_\_\_\_\_

**Contact Information (to receive an overview of the results):**

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**Receipt of Honorarium**

Please write your initials and the date (to acknowledge receiving the \$15 honorarium for this session)

\_\_\_\_\_ Initials \_\_\_\_\_ Date



The University of British Columbia  
 Office of Research Services  
**Behavioural Research Ethics Board**  
 Suite 102, 6190 Agronomy Road,  
 Vancouver, B.C. V6T 1Z3

## Appendix C

# CERTIFICATE OF APPROVAL - FULL BOARD

<b>PRINCIPAL INVESTIGATOR:</b> C. James Frankish	<b>INSTITUTION / DEPARTMENT:</b> UBC/College for Interdisciplinary Studies	<b>UBC BREB NUMBER:</b> H07-00777
<b>INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:</b>		
<b>Institution</b>		<b>Site</b>
Vancouver Coastal Health (VCHRI/VCHA)		UBC Hospital
Vancouver Coastal Health (VCHRI/VCHA)		Vancouver Community
<b>Other locations where the research will be conducted:</b> Research interviews and data gathering will be conducted at the Early Psychosis Intervention program sites, at the Detweiller Pavillion University Hospital inpatient and day program offices, and at offices of the Program Site on Commercial Drive in Vancouver. (Note: the program is also sometimes referred to publicly, and in this application as the Early Psychosis "Team", or the Early Psychosis "Program".)		
<b>CO-INVESTIGATOR(S):</b> Samuel B. Sheps Judy Z. Segal David A.J. Irwin		
<b>SPONSORING AGENCIES:</b> N/A		
<b>PROJECT TITLE:</b> Insight & Self-Management in Early Psychosis: Exploring the Link		
<b>REB MEETING DATE:</b> May 24, 2007	<b>CERTIFICATE EXPIRY DATE:</b> May 24, 2008	
<b>DOCUMENTS INCLUDED IN THIS APPROVAL:</b>		<b>DATE APPROVED:</b> May 29, 2007
<b>Document Name</b>	<b>Version</b>	<b>Date</b>
<b>Consent Forms:</b>		
consent form - insight and self-management	1	April 19, 2007
<b>Advertisements:</b>		
recruitment poster - insight and self-management	1	April 18, 2007
<b>Questionnaire, Questionnaire Cover Letter, Tests:</b>		
interview protocol - insight and self-management	1	April 18, 2007
written narrative protocol - insight and self-management	1	April 18, 2007
demographics and service utilization protocol - insight and self-	1	April 18, 2007

management

**Other Documents:**

consent to be contacted form - insight and self-management	1	April 18, 2007
Vancouver Coastal approval	N/A	April 18, 2007

The application for ethical review and the document(s) listed above have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.

***Approval is issued on behalf of the Behavioural Research Ethics Board  
and signed electronically by one of the following:***

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Dr. Peter Suedfeld, Chair  
Dr. Jim Rupert, Associate Chair  
Dr. Arminee Kazanjian, Associate Chair  
Dr. M. Judith Lynam, Associate Chair  
Dr. Laurie Ford, Associate Chair

## Appendix D

### Vancouver Coastal Health Board Certificate of Approval

<b>INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:</b>	
<b>Institution</b>	<b>Site</b>
Vancouver Coastal Health (VCHRI/VCHA)	UBC Hospital
Vancouver Coastal Health (VCHRI/VCHA)	Vancouver Community
<p><b>Other locations where the research will be conducted:</b>                      Research interviews and data gathering will be conducted at the Early Psychosis Intervention program sites, at the Detweiller Pavillion University Hospital inpatient and day program offices, and at offices of the Program Site on Commercial Drive in Vancouver. (Note: the program is also sometimes referred to publicly, and in this application as the Early Psychosis "Team", or the Early Psychosis "Program".)</p>	
<p><b>CO-INVESTIGATOR(S):</b>                      Samuel B. Sheps                      Judy Z. Segal                      David A.J. Irwin</p>	
<p><b>SPONSORING AGENCIES:</b>                      N/A</p>	
<p><b>PROJECT TITLE:</b>                      Insight &amp; Self-Management in Early Psychosis: Exploring the Link</p>	
<b>REB MEETING DATE:</b> May 24, 2007	<b>CERTIFICATE EXPIRY DATE:</b> May 24, 2008

## Appendix E

### Demographics and Service Utilization Information Protocol

Current diagnosis \_\_\_\_\_

gender \_\_\_\_\_

age \_\_\_\_\_

number of hospitalizations \_\_\_\_\_

program where care being received (Please check the appropriate answer):

Day Program \_\_\_\_\_ Community Team \_\_\_\_\_ Other \_\_\_\_\_

family context I live with family \_\_\_\_\_ I live by myself \_\_\_\_\_

I live in supported housing \_\_\_\_\_ Other \_\_\_\_\_ (describe)

ethnocultural background (check all that apply) Canadian \_\_\_\_\_ Asian \_\_\_\_\_

Latin American \_\_\_\_\_ European \_\_\_\_\_ Aboriginal \_\_\_\_\_ Other \_\_\_\_\_

I've completed (please check those that apply):

high school \_\_\_\_\_ college/university \_\_\_\_\_

(If attending school, part time or full time) I'm enrolled in college/university, year \_\_\_\_\_

**For the following question, please circle and check the appropriate answers:**

I'm currently working part/full time \_\_\_\_\_ studying part/full time \_\_\_\_\_

I'm currently attending Day Program part/full time \_\_\_\_\_

Length of time (in months) since I first entered the mental health system:

\_\_\_\_\_  
Length of time (approximate number of months) between the first signs of my illness and when I entered the mental health system \_\_\_\_\_

**For the next three questions, please circle the answer that applies.**

I agree that I've experienced some problems (agree/not sure/disagree)

I generally agree with what my mental health professional(s) think is the problem, and with what they recommend

I should do about it (agree/not sure/disagree)



I generally feel that I'm able to deal effectively  
with my problems

(agree/not sure/disagree)

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## Appendix F

### FIELD NOTES and INITIAL CODING TEMPLATE

Participant Code #

Date - N

Starting Time:

Finish Time:

finish f/up t:

Date - I

Starting Time:

Finish Time:

#### A) FIELD NOTES

**Relevant background** (context, observations, pre-session info/comments re/by P)

**Preinterview goals for interview (including followup from narrative)**

**Location of interview** (& observations on setting)

**Interview climate** (Nonverbal Behaviours, comfort level, etc.)

**Personal reflections** (use of self, emotions, reactions, over-attention to issues?)

**Methodological issues** (process or “how it went”: strengths and needed improvements; issues for clarification or followup, or memoing)

**post-session comments of relevance**

#### B) INITIAL CODING TEMPLATE

**Interview or Narrative abstract/Summary (and highlights)**

*Narrative codes (abstract & chronology of illness; orientation, problem/resolution frames; evaluation)*

*Codes re textual or pragmatic functions of interpretive work:*

*Interview codes (open codes)*

*Notes re influence of frames on action or vice versa*

*Initial Analytic Impressions (from session, from read through) – re possible focused codes or theoretical codes*

**Questions for clarification or followup**

*from narrative*

*from interview* – f/up during transcript review or member checking

C) FOLLOW UP

**Technological Problems to address**

**Needed Followup from Sessions**

## Appendix G

### Written Narrative Protocol: Insight & Self-Management in Early Psychosis

#### *Introduction*

Story telling is an opportunity to make sense of difficult experiences, to place them in context with the rest of your life, and to help deal with those experiences. It is also an opportunity for you to explain to others how you make sense of and deal with your illness experience.

So, in the next while (probably between 30 minutes to an hour and a half) I'd like you, in writing, to tell me the story of what happened between the time when you first noticed that something was not quite right (or looking back, when things started to go wrong) and when you entered the mental health system for the first time.

When you're writing, please feel free to talk about whatever you think is relevant to describing what was going on, and how you made sense of it, and how you dealt with it, *prior* to entering the mental health system for the first time. If you're having trouble thinking of what to write, consider questions such as:

- what was happening in your life at the time when things started to change or go wrong?
- what was the experience like?
- what did you think was going on?
- what (if anything) did you think should or could be done?
- what kinds of things (past experiences, knowledge, relationships, interactions, etc.) might have influenced your thoughts and feelings about what was going on and what needed to be done?
- what kinds of things did you do to cope or to make things better (before seeking help from the mental health system)?
- what role did other people in your social network play during this period?
- how did you come to seek help from the mental health system?

When you're writing, here are a few other things to keep in mind:

- remember, your written account is for telling about what happened *prior* to when you entered the mental health system, up until when you entered care.
- don't feel you need to write a "masterpiece". The purpose is for you to describe what happened, and to provide a basis for our discussion in the follow up interview.
- if you're writing, please try to write as legibly as possible, because your experiences are a valuable part of the research, and they'll set the stage for the follow up interview.
- please write your experiences using prose (not poetry).

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- Finally, please remember that if you find that in the course of doing your writing that you feel uncomfortable about being part of the study, you can take a break, or you can choose not to continue participating (a mental health professional is available to help if you need it). If you have any questions, the researcher will be available to answer them.

Thanks you for participating in this part of the study!

## Appendix H

### Interview Protocol: Insight & Self-Management in Early Psychosis

**Introduction and Instructions:** The story you wrote for me helped you think about your illness experience prior to entering the mental health system, and helped me get a sense of how your illness experience fits into the context of your life. Now I want you to tell me about what happened when you entered the mental health system for the first time and you learned or were told about what was going on or what needed to be done (in other words when you received some sort of diagnosis or information about what the illness was about, and about what kind of support you were going to be offered to deal with it).

The interview is going to take between half an hour and one and a half hours. Please remember that if you feel tired or uncomfortable participating, you can take a break, or you can withdraw from the study at any time. There is a mental health professional on site who can help if you're feeling distressed.

#### **Part One:** *Questions about the nature of insight*

The first questions have to do with what you were told about your illness and whether you agreed with it, in relation to what you initially thought was going on. When you answer the questions, it might help to think back to your written account about what you thought was going on prior to entering the mental health system for the first time.

1. once you entered the mental health system, what were you told (or what did you learn) about your situation (that is, about what was going on, and what needed to be done about it)?
2. what did this information mean to you? (probes: did you have any previous understandings of the terms used to describe your problem or its treatments? did these shift once you learned more?)
3. please describe to what extent, if at all, what you were initially told changed your previous ideas about your situation

***Part Two: Questions about the Process of Insight Development***

The next questions have to do with how you might have shifted your understanding of what was happening to you, and the kind of things that helped you to do this, or that may have been less helpful.

4. what kinds of things got in your way (or get in your way) when it comes to accepting that something is wrong (or agreeing with others about what the problem is, or what needs to be done)?
5. describe any particular moments (or turning points) when you shifted your understanding or came to a better understanding of what was going on and what needed to be done.
6. tell me about any particular things that helped you make this shift (probe re: any specific information or type of information; any specific interaction or type of interaction with individual staff, with others with mental illness, significant others, etc.)
7. was there anything that might (have) help(ed) you come to accept or understand your illness more easily?
8. speaking in general, how do you think that people who are reluctant to acknowledge a problem can best be helped to do so?

***Part Three: Questions about the Consequences or Outcome of Achieving Insight or Illness Awareness***

The last part of the interview has to do with how your understanding of your illness relates to your ability to deal with it in the course of your day to day life.

9. speaking in general, some people have said that accepting you have a problem (or understanding your problem) is the first step to moving on. What do you think about that?
10. when you personally gained a better understanding of what was going on what was the impact of that on your day to day life? (probe: re emotions, managing different types of symptoms, role management, re sense of control)
11. I'd like you to describe a typical day for you, and tell me about how your illness might come into play, and about things you might do (either by yourself or with the help of others) to deal with its impact as you go about your business and try to live your life the way you'd like.

12. please describe any turning points (either things taking a turn for the better or for the worse) that you've experienced in the course of dealing with your illness.
13. given your current understanding of your illness and what it means, how do you see your life unfolding (probe: re ability to maintain a degree of autonomy, to maintain or establish meaningful relationships, to achieve any vocational or educational goals you might have?)
14. in general, where do you draw your strength and support when it comes to dealing with your illness?

**Wrap Up Questions:**

15. Is there anything that I didn't ask that you think is relevant and would like to talk about?
16. Is there anything else you'd like to add?