Understanding the development of narrative insight in early psychosis: A qualitative approach

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(Received 28 June 2013; accepted 21 October 2014)

The primary objective was to understand the process of insight development in early psychosis, using narrative analysis and grounded theory. Given the growing interest in “narrative insight”, the study’s use of a qualitative research design was deemed appropriate for shedding light on this emerging phenomenon. Twenty-four data-gathering sessions were conducted; 12 participants from a Vancouver, BC early psychosis clinic wrote a narrative of their pathway into care, and were then interviewed. The results of the analysis, which used qualitative research, consisted of four “doorways” to positive insight development: “becoming demoralized”, “finding a fit”, “experiencing an impact”, and “envisioning illness in the background” of life. The “core process” of narrative insight development in early psychosis thus involves “coming to an acceptable, adaptive explanation” of one’s problem. The implications are that interventions should seek to help people find an explanation that resonates with their psychosis experience, and which is appraised as relevant to restoring their envisioned life trajectory.

Keywords: early psychosis; insight; recovery; qualitative research; narrative; pathway to care

Introduction

Building insight in people with psychosis has been recognized as an important but elusive clinical challenge, given the complexity of the phenomenon (McGorry & McConville, 1999). Insight is a particularly important challenge in early psychosis. Despite the importance of intervening early in the course of psychosis, young people may be relatively difficult to engage (Thompson, McGorry, & Harrigan, 2001), suggesting that lack of insight may be hindering recovery.

The question of insight is problematic, however, given that accepting a diagnosis can be experienced as being either a facilitator or impediment to quality of life. This phenomenon, known as the “insight paradox”, may be explained by the fact that for some, taking on a psychiatric label also entails adopting harmful societal stereotypes (Lysaker, Yanos, & Roe, 2009), and an awareness of loss (Buck et al. 2013). Thus, as will be discussed below, the challenge of insight development may be better framed as building a narrative of one’s experience that promotes recovery, rather than creates more pain and dysfunction.

It appears that clinical, neurocognitive and psychological factors all play a role in the formation of insight, either separately or in combination (Cooke et al. 2005;
Some research specific to the early psychosis phase has investigated the various factors. For instance, attention has been directed to the relationship between insight and psychological adjustment to receiving a diagnosis. Both clinical experience (McGorry, 1995) and research (Thompson, McGorry, & Harrigan, 2003) suggest that insight improves as symptoms diminish after initial treatment; however, some individuals may later “fl(ee) into health”, and away from treatment settings before eventually coming to terms with illness. The authors argue that behaviour that appears less insightful is in fact part of a process of normal psychological adjustment to the difficult experience of receiving a diagnosis. This finding accords with Tait, Birchwood, and Trower (2003), which demonstrates the tendency of some individuals, at least initially, to “seal over” the psychosis experience.

This interest in psychological factors has extended into sociocultural influences (Kirmayer, Corin & Jarvis, 2004; Judge, Estroff, Perkins, & Penn, 2008). In a related development, a distinction has been made between narrative and clinical insight (Roe, Hasson-Ohayon, Kravetz, Yanos & Lysaker, 2008; Tranulis, Freudenreich, & Park, 2009). In the latter, the clinical perspective on the illness is taken as “the gold standard” of reality; insightfulness thus requires the individual to agree that they have an illness, and that their psychosis experiences are symptoms, the treatment of which will have a helpful impact on their lives. In contrast, Roe et al. (2008), arguing for the concept of narrative insight, assert that insightfulness entails developing a meaningful and useful narrative about one’s experience. When deriving meaningful accounts, people draw from a culturally informed repertoire of possible explanations, which may or may not include the notion of illness. Dolson (2005) demonstrated this phenomenon of cultural “bricolage” in their interviews of people experiencing early psychosis, showing how individuals attempt to make meaning of anomalous experiences using the metaphors available to them (e.g. attributing what others may see as symptoms to religious experience).

In the narrative view, then, what would traditionally be considered to be lack of insight could actually be the result of a disagreement with an explanation (i.e. illness) that doesn’t “make sense” or which “doesn’t work” for the person, although it might fit the clinician’s perspective. Arguably, insight development is essentially pragmatic; that is, a process of coming up with a version (or “story”) of events to achieve certain personal ends, such as improving quality of life, and improving one’s sense of control (D. Roe & Kravetz, 2003).

Ko, Yeh, Hsu, Chung, and Yen (2006), using narrative analysis of patient accounts in an early psychosis context, produced qualitative evidence that supports this notion. They showed that insight formation began after their psychosis became “unbearable”, and was furthered when the treatment was experienced as helpful; they also showed that patients made comparisons between their experience and that of others, and were more likely to be insightful in traditional terms when their own experience corresponded to that of others in the treatment setting. In other words, participants came to understand the notion of illness as relevant when it was perceived as helpful, and when it fit or made sense to them.

**Objective**

Given the importance of insight for engagement in the early psychosis phase, and given this emerging understanding of insight development in this phase as involving
an active construction (or “storying”) of the psychosis experience, there is a need to understand, from a first-person perspective, how individuals make sense of the early psychosis experience. Hence, the current study used qualitative methods, in particular a constructivist grounded theory approach (Charmaz, 2006), to understand the phenomenon of narrative insight in early psychosis. The underlying research question was: what is the process of narrative insight development in early psychosis from the person’s perspective?

Methodology

Setting, sampling and recruitment
The study was conducted at an Early Psychosis Intervention (EPI) program based in Vancouver, Canada, and involved participants of the Rehabilitation Day Program and Community Clinic. Within both settings, all participants participated in evidence-based illness management and psychosocial recovery interventions (Mueser et al. 2002), informed by the international early psychosis practice guidelines. The recruitment strategy ensured that the sample was representative of people within the first three to five years, or “critical period” (Edwards, Harris, & Bapat, 2005) of early psychosis, because participants from the community clinic tended to be earlier on in the illness, and those from the Day Program were further on in this period.

The sample consisted of people who were currently engaged in the EPI program, and who were judged by the clinician researcher as being clinically stable and having relatively developed insight and illness management capacity. This was verified by both clinical and self-ratings of insight, where participants were asked questions which aligned with the Birchwood Insight Scale (Birchwood et al. 1994). Although the initial target was 12–16, recruitment stopped after data from 12 participants had been analysed and reached the point of theoretical saturation (i.e. no major categories or subcategories continued to emerge).

Recruitment and informed consent procedures
Initial information was provided during recruitment by the clinician researcher, who referred interested and eligible people to the main investigator, who provided thorough information. During the consent process, participants were assured that the research was voluntary and their participation would not affect clinical care. The study was approved by (University of British Columbia) Behavioural Research Ethics Board.

Sample characteristics
The 12 participants were evenly split by gender. Regarding diagnosis, two (17%) had schizoaffective disorder, three (25%) had schizophrenia, four (33%) had psychosis (not otherwise specified), and three (25%) had bipolar disorder with prominent psychotic features. The sample thus reflects a relatively good balance between psychotic illnesses with and without prominent mood features.

Ages ranged between 20 and 32, with the median age being 26 years. As measured by the median, participants had typically been in the mental health system or been diagnosed 7 months prior to study participation, ranging from 2 to 36 months. Seven (58%) of the participants had not experienced a second psychotic episode,
and the other five (42%) had experienced at least one relapse; two (17%) had never been hospitalized. Eight (67%) were from the Day Program, and the other four (33%) were from the Community Clinic.

Four (33%) participants were from Anglo-European ethnocultural backgrounds, four (33%) had East Asian heritage, three (25%) were of non-Anglophone European descent, and one person had a South Asian background. The sample thus reflects the diverse ethnocultural diversity typical of a large multicultural centre.

Data-gathering and analysis
Given the potential synergy of narrative and grounded theory (Dey, 2007), the analytic approach integrates narrative analysis within the overarching approach of constructivist grounded theory (Charmaz, 2006). The first author gathered the data. In keeping with the focus on narrative, the first step was to ask participants to write a story describing what happened, and how they made sense of their experience prior to entering the mental health system. Similar to the study by Ko et al. (2006), the core narrative approach (Mishler, 1991) was used to bring participants’ initial interpretive frames (Goffman, 1974) into relief. Following narrative coding of the written stories, participants were then interviewed in order to ascertain how the individual’s understanding may have changed upon entering the mental health system. All material, including the coded data from the written stories and follow-up interview data, was then included in the constructivist grounded theory analysis that is described next.

Following Charmaz’s approach, the first stage of analysis, “initial coding”, gave descriptive labels to participants’ actions. During “focused coding”, we identified repeating themes or salient categories of events, and used memos to record hunches about potentially significant patterns. During the final “theoretical coding” stage, we identified categories of apparent significance to the emerging grounded theory, including the relevant interpretive frames identified in the analysis of the written stories.

In order to maintain theoretical agnosticism, the full literature review and development of theoretical framework were delayed until the final stages of the analysis. Other steps taken to ensure the credibility of the analysis (Guba & Lincoln, 2005) included using successive interviewing (both written and oral), peer debriefing (returning transcripts to participants to ensure accuracy), and triangulation of analysis (involvement of an academic researcher reference group including clinicians). Using a team approach helped guard against potential biases present, given that the interviewer was the lead coder.

Findings
The results of the analysis consisted of four inter-related main themes or “doorways” to positive insight development: “becoming demoralized”, “experiencing an impact”, “finding a fit”, and “envisioning illness in the background”.

Becoming demoralized
Participants typically attributed initial phenomenological changes of psychosis to some plausible explanation that was relatively benign, in an attempt to minimize or normalize the experience. For instance, one participant, despite feeling that her
friends were “pulling a plot” on her, felt it “was just depression”. Another person talked about feeling “really paranoid”, but attributed this to having “an emotional problem”, which he sought to deal with through psychotherapy where he “talked about his mother”. Still another began “feeling split from reality”, but thought it was a “passing phase”. Even relatively bizarre thoughts could be normalized, as the following passage illustrates:

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.

Generally, participants didn’t actively consider the possibility of illness until they experienced significant distress, were “not themselves”, and had run out of less threatening explanations for their predicament. For instance, one young woman described changing jobs and friends, seeking help from her family doctor, psychotherapists and naturopathy, and wrote:

“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 … 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”.

Once in the mental health system, participants began to arrive at a new understanding of their condition.

Experiencing an impact
Initially, people may come to infer the applicability of illness as explanation after experiencing a positive impact of the medication. As one young woman explained: “when the medication works … the thing is: the type of difference it makes, makes you doubt your previous state. You start to [wonder] … maybe that wasn’t real.” Another said:

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.

While these phenomenological changes appear to allow the individual to infer the presence of an illness, the medication is not always experienced as having any impact, and the clinical experience of one co-author (DA) suggests that some individuals may not be able to connect observable changes to the medication.

Finding a fit
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 experiences and the information about illness they eventually come across through their interactions with mental health professionals, and through their interactions with other people to whom similar diagnoses have been applied. Initially, the information may be unconvincing, given the salience of the psychosis experience. As one person said: “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.” The scepticism may also relate to the meanings ascribed to the notion of illness. For instance, one young man, a brilliant student, because of his experience with other family members with mental illness, thought of people with schizophrenia as “low functioning and frazzled”, and “not like (him) at all”. Others overcame their unwillingness to consider the notion of illness after some period of reflection. Thus one participant explained:

[Initially] I just kind of thought it was something unique to me […] (and) 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 and over time I came to the conclusion that it was probably an illness.

Reframing past experience as illness was relatively straightforward for some, especially those who came to see their psychosis-related ideas as “bizarre” and easily given up for the alternative explanation offered by the notion of illness. Others, however, sought to accommodate or blend their earlier interpretive frames (e.g. spirituality, limit identities, etc.) with the notion of illness. For instance, one woman’s experience of psychosis was entangled with her sense of self as “perceptive” and “intuitive,” which went hand in hand with her strengths as an artist. Her solution, like other participants, 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”.

**Envisioning illness in the background of life**

Participants 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 they had an illness. As one young man wrote: “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.” For these people, the diagnosis represented a chance to get their lives back.

For others, however, the diagnosis was profoundly upsetting and threatening. As one young woman wrote: “I was afraid I would lose myself and my identity if I took medication. All my ‘special’ feelings and sensitivity would go away.” Another said: “At that time I was so hopeless, I thought that my future was ruined.”

Regardless, all participants experienced some conflicting emotions, which were often accompanied by ambivalence about the possibility of illness. As one young woman explained: “initially I wanted to push the idea away that I had a mental illness”, which lead to a relapse. Being able to “address illness head on” (rather than avoiding it) generally required reframing what the notion of illness meant, including the sense of isolation, that they were the “only one” that had these kind of experiences, and their sense of agency. As one young woman said:

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.
After reframing illness, participants became increasingly likely to acknowledge and manage it, with the expectation that by doing so it would recede to the background of their lives in the long run.

Discussion

Within the standard view – i.e. what Roe et al. (2008) describe as “clinical insight” – the inability to accept illness is primarily determined by neurological factors and part of the illness. The alternative perspective supported by the present findings – and consistent with Roe et al.’s notion of “narrative insight” – is that participants actively choose whether to accept the notion of illness, and use creative strategies for making this notion relevant and palatable to them. Like Ko et al. (2006), this study shows that participants avoid outside help until they can “no longer get by”, and then become more willing to consider alternative explanations, especially if these are experienced as fitting their experience.

While nominally having gained “clinical insight” in the sense of accepting a label, our participants often actively incorporated their earlier narratives into their understanding of illness in a way that made it uniquely their own. Also, our study, like Tait et al. (2003), suggests that participants, even after some initial insight (in its clinical sense), still tend to “push away” the distressing possibility of illness, until they can reconceptualize what the psychosis experience means to their life. In other words, clinical insight or lack thereof depends on an active choosing process, involving considerations of whether the narrative in question offers a plausible, helpful, and hopeful explanation of their predicament.

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 effectively to guide their lives (Frank & Frank, 1991). In accordance with the Franks’ ideas, the present analysis suggests that in the early stages, people come to consider illness, in the words of the participants, after they’ve “run through the [interpretive] options” until these no longer suffice.

Building on the Franks’ notion of demoralization, and speaking of the psychotherapy process in general, Wampold and his colleagues 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, Imel, Bhati, & Johnson-Jennings, 2007). They argue further that insight could involve accepting various alternative accounts, the objective “truth” of which is less important than the extent to which a given story provides 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 of one’s predicament, which they suggest is a “common factor” to all successful forms of psychotherapy or healing.

As work by Lysaker et al. (2013) suggests, however, creating a workable story (or what they call an “enriched narrative”), may be challenging, and may hinge on being able to remediate the (often impaired) metacognitive abilities that appear to be necessary for doing so: evaluating alternative interpretations of one’s psychosis experience, having the flexibility to construct more coherent, relevant narratives, and the perspective-taking ability to ensure these narratives are understandable to others.

On the one hand, our results point to the narrative competence of our participants, and appear contrary to this line of research, which implies the need for
specialized intervention to address metacognitive deficits. Our findings suggest that people in the early psychosis phase do possess the reflective capacity to construct fitting and workable narratives, which they often do independently; the findings also suggest that narrative insight development process can be construed as similar to what happens in psychotherapy for less severe conditions. On the other hand, our results suggest that insight development can take a considerable amount of time, and like people later on in their illness, younger people do benefit from having what could be called a “reflective space”, where they can be helped to make meaning of the difficult experience of psychosis. Below, we discuss the practical implications of our findings for creating such a space, in order to help young people with early psychosis develop fitting, workable narratives of their experiences that help them move forward in their lives.

**Practical implications**

The present study suggests that one crucial aspect of the core process of insight development involves being able to compare one’s experience with various possible explanations and discern a fit. The ability to reflect on “fit” in part relates to the availability of accurate information that can help the individual reframe previously incorrect notions of illness. A key need, however, is to provide the opportunity for dialogue and reflection to people whose earlier interpretive frames remain convincing despite psychoeducation and adequate treatment. Consistent with the Open Dialogue approach for early psychosis (Seikkula, Alakare, & Aaltonen, 2011), people need an opportunity to consider how divergent accounts could be accommodated or bridged, using approaches based on what Henriksen and Parnas (2014) refer to as “phenomenologically informed” accounts of insight in early psychosis.

As noted, another 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 of self, or as a possibility for restoration. In other words, clinicians must pay attention the “paradoxical” (Lysaker et al. 2007) emotional impact of insight development, and help individuals envision recovery rather than inevitable loss. Along these lines, Gumley and Clark (2012) suggest that a therapeutic relationship sensitive to distress may help individuals experiencing early psychosis to develop more integrative accounts of their experience. The results of Roe et al. (2008), however, remind us that narratives need not explicitly acknowledge illness to be functional.

Some literature emphasizes the need to develop specialized psychotherapeutic approaches to build insight (Lysaker et al. 2013; Rusch & Corrigan, 2002). While we don’t disagree, our results suggest that one valuable approach may be relatively more straightforward: of particular helpfulness to our participants was the opportunity to meet others who had experienced similar difficulties, and who had recovered and achieved goals they valued. We further suggest that such peer-to-peer dialogue may contribute to the effectiveness of relevant group-based approaches that seek to build insight and counter stigma (e.g. NECT: Yanos, Roe, West, & Smith, 2012) for similar reasons as discussed: i.e. by allowing people to compare psychosis experiences (and discern fit), and by helping them accept these stories as workable and hopeful. Limitations and future directions.
The possible limitations posed by the relatively small sample size (12) should be kept in mind, as should the possibility that our sampling strategy, which sought relatively insightful individuals, may have excluded people with significant metacognitive deficits. Whether narrative insight development entails a similar process for people with more serious metacognitive deficits, and/or further along in their illness is an open question.

One value of qualitative research is in opening up possibilities for further exploration. Thus, it would be valuable to develop and test an intervention informed by the present findings: a “dialogical” approach to positive insight development, grounded in an understanding of the individual’s phenomenological world and envisioned life with psychosis. Building on psychotherapeutic approaches for insight development currently under study (Lysaker et al. 2013), such an intervention could be aimed at those early on in the course of illness. By paying explicit attention to insight development, and developing and evaluating targeted strategies to develop and enhance it, existing evidence-based early psychosis interventions may be able to improve and accelerate the positive outcomes for the young adults they seek to support.

Acknowledgements
The authors would like to thank Dr. Judy Segal of (University of British Columbia, Department of English) for her involvement in the project, and the participants of the study for sharing their insights.

Funding
This project was funded by the Canadian Institutes of Health Research.

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