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The Responses of Young People to Their Experiences of First-Episode Psychosis: Harnessing Resilience

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Abstract There is a burgeoning literature on first-episode psychosis, the focus of which is early intervention. Little emphasis has been placed on the responses of young people to their experiences of psychosis. This study, therefore, aimed to describe and explain the responses of young people to their first episode of psychosis. Data obtained from ten young people who attended a community early intervention recovery program in Perth Western Australia were analysed using a grounded theory method. The results revealed that the basic psychosocial problem experienced by participants was loss of control resulting in disrupted lives and that the core variable, harnessing resilience, accounted for most of the variance in their behaviour to overcome this problem. The resultant framework described and explained how participants resiled and established direction in their lives. Although there are limitations with this qualitative study, such as the small size and the demographics of the sample, the findings have potential implications for approaches to service provision and phase specific interventions.

Keywords Resilience · First-episode psychosis · Grounded theory young people

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Introduction

Research into first-episode psychosis (FEP) has largely focussed on the stages of illness, early intervention and the importance of reducing the duration of untreated psychosis (DUP) (Killackey and Yung 2007; McGorry et al. 2003, 2006; McGorry and Yung 2003). This has created considerable debate in the literature over a number of years mainly because young people are faced with a critical period of development during which, changes occur biologically and socially (Crockett and Petersen 1993). Rosenman and Anderson (2011) opined that "signs of psychosis seem to be innocuous at least in terms of progression to illness" (p. 511). In addition to clinically driven research a number of qualitative studies have explored the subjective experiences of psychosis in young people (Leiviskä Deland et al. 2011; Boydell et al. 2010; Lam et al. 2010; Tranulis et al. 2009; Morgan et al. 2006; Hirschfeld et al. 2005; Etheridge et al. 2004; Norman et al. 2004). These studies, however, focussed on describing the meaning of the psychotic experiences of young people and family involvement. Only Judge et al. (2005), in a pilot study of pathways to care, briefly discussed the responses of young people with a diagnosis of schizophrenia, schizophreniform or schizoaffective disorder. They reported, as with Norman et al. (2004) that it was more likely that a family member rather than the person with a psychosis noticed the changes and initiated help-seeking. In a retrospective study of the same sample, they expanded on the responses to early psychosis, but again without developing an explanatory framework (Judge et al. 2008). Going beyond exploring the experience of psychosis of young people, Lester et al. (2011) used, what they referred to as, a constructivist grounded theory method to explore the value of Early Intervention Services from the perspective of

service users. They reported that services users valued the support of service providers and family members. Support from service providers included: help to come to terms with their illness, identifying early warning signs and to understand why they had become unwell. This study provided a useful insight into the importance of support in assisting young people to gain an understanding of their psychotic experiences but again did not explicate their responses.

The purpose of this study was to build on existing knowledge and explore the responses of young people's experience of a first episode of psychosis from the time their psychosis was detected until our contact with them. In this way we aimed to develop a substantive theory with the potential to describe and explain the behaviour of young people with similar circumstances, and inform practice.

The research commenced after receiving approval from the University of Western Australia Human Research Ethics Committee.

Method

We collected the data using the grounded theory method originally described by Glaser and Strauss (1967), and modified by Charmaz (2000), which was underpinned by symbolic interactionism (Blumer 1969). Data was analysed using the constant comparative method to discover what the participants experienced as being the Basic Social Psychological Problem (BSPP), and identify the Basic Social Process (BSP) around a core variable, which accounted for most of the variance in participant behaviour. Before conducting the interviews we bracketed our prior practice and research experiences which involved recovery from severe enduring mental illness. This was to ensure that we did not force the data to fit our views. Field notes were written during and directly after each interview to record the immediate interpretations of the interviewer and act as a reference during the analysis.

Participant Selection

We placed an advertisement in not for profit organisation (NGO) newsletter and flyers were posted in not for profit organisation offices inviting young men and women aged 18–30, who could communicate well in English and were willing to share their experiences of psychosis, to contact us. People in Australia are considered to be adults at the age of 18. Participants were selected using purposive sampling. Purposive sampling required that participants have the ability to give a coherent account of their experience of the phenomenon under study (Glaser and Strauss 1967). A total of 10 people responded, all of whom met the inclusion criteria. They ranged in age from 19 to 28, seven were male and three were female, they had either completed tertiary education studies or were enrolled in a tertiary education course, those not studying were employed, of the 10 participants only two lived alone, six of the ten participants were born in Australia, one in Croatia, one in Zimbabwe and one in Vietnam. The length of time between the onset of symptoms and receiving treatment—duration of untreated psychosis (DUP)— varied between the participants; three had DUP of 1 month, two a DUP of 2 months, one a DUP of 3 months, one of 12 months, two of 18 months, and one of 24 months. The longest period of time between the onset of psychosis and the interview was 36 months. In addition to attending the recovery program with the NGO nine participants received follow up from a government community mental health clinic and one from a private psychiatrist. When asked if they had been given a formal diagnosis, two said they had been subsequently diagnosed with schizophrenia.

Data Collection

We telephoned the ten participants to arrange a time and location for the interview. During this phone conversation we gave an explanation of the research and advised that their written informed consent was required. Of the ten interviews, nine were conducted at a club house and one interview took place at a participant's home. When we met with the participants, we provided them with a copy of a participant plain language statement explaining the research and their rights. All of the participants signed a form giving their informed consent. The participants did not receive any financial benefit for their participation. Data were collected using unstructured face to face interviews. The interview commenced by asking the participant to describe their experience of psychosis and how they responded. Each interview, which lasted approximately 60 min was recorded on an audio digital recorder and then transcribed verbatim. Both writers were present during the interviews—AH conducted the interviews while AC took detailed notes.

Data Analysis

We analysed transcripts using substantive and theoretical coding and the constant comparative method. This involved extracting all incidents that were apparent in the transcripts to develop preliminary categories, concepts and properties. The categories were given a title based on a term used by the participant or one fashioned by the writers. The categories were then checked with transcript codes for emerging themes enabling the identification of what we saw as the basic social problem, and core variable.

These emerged as the loss of control with resultant disruption of lifestyle and the harnessing of resilience respectively.

All transcripts were coded by A.H. and also independently by A.C. The two sets of codes were then compared to ensure that interpretations were consistent and corresponded with the data. Analysis then proceeded according to the constant comparison method—data were compared across individuals, and the relationships between codes were explored. We examined the properties of the emerging concepts for exemplars and non-exemplars; concepts were then labelled and grouped together to form categories which were also compared with the data obtained from each subsequent participant. Frequent comparisons were also made to the literature.

In order to ensure the trustworthiness and credibility of the data an independent researcher familiar with the grounded theory method but not involved in the research analysed and coded the data. The codes that they identified were consistent with those of A.H and A.C.

Once the core category was recognized we used selective coding to look just for the core variable and related categories that had been identified in the interviewee's responses. We then built this into a theoretical framework. By introducing these concepts to participants we were able to sharpen the theoretical framework enhancing the credibility of the findings. This process was aided by compiling memos. The purpose of the memos was to record early interpretations and note embryonic patterns emerging from solid realities. The memos served as a link between the data and emergent theory and acted as a record of the process we undertook to develop the framework.

To ensure that the concepts we developed where generated from the data and not from our preconceived ideas we used the process of theoretical sensitivity (Glaser 1978). A diary was kept of our reflections of the data for any potential bias. This process ensured that the problem and its solution were discovered from the data and not from our prior knowledge or experience.

Data collection ceased after interviewing 10 participants when we found that no new information was being presented and the categories were saturated. At this point we were confident that our findings of the Basic Social Problem, loss of control resulting in disruption, and core variable, harnessing resilience, both fitted the data and worked.

Results

The purpose of this study was to describe and explain how young people responded to their experiences of a first episode of psychosis. Loss of control resulting in disrupted lives emerged as the Basic Psychosocial Problem (BPSP). The core category which explained the responses of the participants emerged as a Basic Social Process (BSP), which we termed harnessing resilience. Loss of Control was described in the following ways. Participant 4 explained, "I just felt increasingly out of control and paranoid. I'd started driving recklessly, and you know. I wouldn't necessarily seek harm, but I would be indifferent to my safety or to the safety of other people". Participant 5 explained: "I got into a lot of arguments and stuff. Then I had like a whole year, all I did was stay home, mainly, because I didn't want to have anything to do with other people". Participant 8 described the following experience "I was thinking oh my god! My life is like ended, you know? Yeah, I didn't have control over it, I couldn't do anything. I'd be ok if I didn't have to do anything like go to uni or didn't have to work."

Initially, only one of the ten participants identified their psychotic experience as out of the ordinary and sought help. The remainder did not respond as they did not perceive a problem. The length of time it took from the initial psychotic experience to identifying it as such varied from 1 to 3 months for six participants and 12–24 months for the other four. Participants did not respond to disruption in their lives, this was mainly because they were unaware that their experiences were abnormal and required any intervention. Their naivety also extended to family members, but eventually their behaviour became too obvious to ignore, either by themselves or others. When this happened, they and others around them did not know how to respond. The following excerpt from participant 9 provided an example of this. "…, so all this started to build up and get out of hand. And no-one knew what to do when it did get really serious."

Having identified the BPSP the task was to identify the core variable which described and explained how participants responded to overcome the problems they faced. The core variable emerged as a Basic Social Process (BSP), which we categorised as harnessing resilience. This accounted for most of the variation of participant behaviour which resolved the BPSP. Harnessing resilience was comprised of the following phases: acknowledgement, help-seeking, acceptance, regaining control, and resiled. It was not until participants acknowledged that their behaviour was out of the ordinary that they took action. This is exemplified in the experiences of participants 4, and 10.

Participant 4:"Yeah, I was sort of vaguely aware that I wanted to see someone but I found it hard, because I didn't accept that I had a condition." And participant 10 "I didn't want to accept what they (family) said. Acknowledge, I think that's the word…."

Acknowledgement led to help-seeking, with implications for various pathways to care. Participants sought help from family members, their general practitioner (GP) or

through admission to hospital. This is reflected in the experience of Participant 7 who stated.

> Yeah. Um, I sort of realised that… something was very, very wrong and so I told my mum I need to see a doctor. My mum didn't know what to do so she called a friend, who was known to me, and she's like a lovely friend of the family and she said 'I think she needs to go to hospital'.

Participant 8 consulted his GP who recommended that he go to his local general hospital, which he did and was subsequently admitted as a voluntary patient.

It was largely through the help of others that participants transitioned from acknowledgement to the third phase in the process—acceptance. Participant 7 for example, acknowledged her psychotic experience and sought help she but did not accept it. It was only following hospitalisation and effective treatment that she progressed to the third phase of acceptance: "I took a lot of convincing. So it's not just having insight about it, it's actually being able to do something about it as well." Participant 10 described acceptance in the following way, "I realise the condition is going to play a significant part in my life for a long time, but I can do a lot and that gives me the drive to get myself around it."

Once a person had accepted their experiences as part of a psychosis and engaged in treatment they were able to transition to the fourth phase in the process—regaining control. Participant 4 explained: "I went onto antipsychotics, which really changed everything a lot, I guess. I could think clearly again and my thinking patterns changed. But it was good because I really enjoyed feeling in control again." One participant experienced what we termed "control paradox". In this case the participant admitted herself to hospital, thereby relinquishing control over her life and largely turning it over to the staff. However, as the course of her treatment continued and she came to the view that, as much had been done for her as could be, she took control back and discharged herself against medical advice.

When participants gained the confidence to be self-determining and regain control they transitioned to the fifth and final phase we termed resiled. The main property of resiling was the ability to regain control over disrupted psychosocial functioning and pursue chosen directions in life in spite of continuing to experience some symptoms. Participant 1 stated "I haven't recovered, I'm resilient." and participant 8, "I was resilient and able to ride out the storm." Participant 5 stated "I think I have full control now. I just feel it doesn't matter what your diagnosis is … you have the right to do everything you want, as long as it isn't at the expense of other people's happiness." Participant 3 exemplified taking control and resiling in the following way.

> I'd been in hospital an exceptionally long time and I told my doctor that I'm leaving. The voices had gone during the day but it gets to about three o'clock and they start up again. I worked really hard to learn strategies to put them away. …. I wasn't ready to go back to uni but worked for my mum and dad because we have our own business. I want to do nursing so I've been looking at a nursing course.

Explaining the Process

Two styles of resilience emerged from the data, first tenacity requiring effort over a period of time and second rebounding by springing back. Tenacity was reflected in the experience of Participant 3 who stated: "It's been a long, hard road. And it's taken ages, but I've just tried my hardest, with everything that's been put in front of me." Rebounding was described as getting on with life. Participant 7 was an artist and in addition to her own work established an art course for young people. She explained: "Yeah, I met Anna (pseudonym), through Early Intervention, and we started running the course. … I sort of had the drive to be able to do it and to be able to get over any sort of insecurities."

The process of harnessing resilience was further explained, by two related mechanisms; first internal resources and second environment resources. Internal resources included: determination, adopting an at-risk role which involved self-pacing, balancing roles and taking control. Environmental resources related to the participants' interaction and relationships with others evidenced by welcome support. However, they also described unwelcome support, which had a negative impact on them. In addition to the quality of support experienced by the participants they also described the importance of being prescribed the right medication, which we included as a property of welcome support.

Internal Resources

Participants explained how adopting an at-risk role and self-pacing contributed to harnessing resilience and regaining control. These two mechanisms centred on maintaining mental health and avoiding the risk of a relapse or exacerbation of symptoms. By reducing stress in this way participants were able to exert some control over their lives. Participant 10 explained "Every time I'd come out of hospital I was relapsing almost immediately because there was just too much activity. So I needed shut off time." Similarly participant 8 said: "I knew I could control it, if I had no other things to do, didn't have to go to uni or didn't have to work. Yeah, I mean, I just don't want to stress out too much. I do keep in mind that I do have a

mental health concern, so I don't want to overburden myself."

Environmental Resources

Environmental resources included support from others. Participants, however, identified two types of support, these being welcome support and unwelcome support.

Welcome support referred to offers of support made by relatives, friends and or health care workers, which the participants valued and were prepared to act upon. In welcome support there was a sense of a reciprocal relationship. This was exemplified in the experience of participant 4. "Yeah, I think if I wasn't on Clozapine I think they'd be there permanently. Medication's played a huge part, but working with MIFWA (The Mental Illness Fellowship of Western Australia) has played an even bigger part." The experience of participant 9 reflected the welcome support he received while an inpatient."…(I) enjoyed being there, like,… I thought everyone was there for me." Similarly participant 5 stated "the nurses treated me well and yeah I got a sense of comfort and it was almost like I got me freedom back." These examples demonstrate welcome support received from service providers. Participant 8 received support from family. "I go to my godmother's house and you know have a chat with her and her brother and stuff. Yeah, they live down the road and they support me very much."

Unwelcome support referred to offers of support, which the participants did not value. Participant 2 described the following experience of unwelcome support. "She (mother) wanted me to go home to the farm, and recover there. Yeah, I had to like stop them from helping me the way that they wanted to help me."

Thus, harnessing resilience emerged as a process which, consisted of one of two resilience styles, either tenacity or rebounding. The ability to transition the process was facilitated by internal and external resources. Harnessing resilience enabled the participants to resile which, we defined as having adjusted or come to terms with a psychotic experience, and the ability to take control over and pursue chosen directions in life, including: employment, relationships, education and accommodation.

Discussion

Our grounded theory study resulted in a framework, which described and explained the responses of young people to first episode of psychosis. The main elements included; loss of control resulting in disrupted lives, this was resolved by harnessing resilience facilitated by internal and environmental resources, which resulted in the ability of participants to resile. Although a number of qualitative studies investigated the experiences of young people with a first episode psychosis, we found only one, Judge et al. (2008), which explored the responses of young people, but only in relation to help-seeking. We were unable to find any reference to a process, a frame work, or model associated with the responses of young people to psychosis by which to undertake a comparative analysis with our findings. There were, however, similarities with qualitative studies, which described various models of recovery from severe enduring mental illness, particularly acknowledgement and acceptance (Henderson 2011; Andresen et al. 2006).

The concept of loss associated with various types of mental illness had been reported in previous research and supported our findings. Leiviskä Deland et al. (2011) using a grounded theory method found that young people who had experienced a psychotic episode felt they had little control over their circumstances during the psychotic phase of the experience. Tait et al. (2003) opined that loss of control contributed to difficulties in social relationships and autonomy in a sample of persons who were depressed.

In order to respond to loss of control and disruption, it was important for participants to acknowledge their experiences as psychotic in order to seek help. The experiences of the participants in our study echoed the literature. Norman et al. in their study of understanding the delay in treatment for first-episode psychosis reported that 35 % of their sample did not seek help even when symptomatic. And when they did seek help it was at the instigation of a family member. Etheridge et al. (2004) identified lack of information as being the main reason why people did not seek help, with the least reported reason being not realising they were ill. Tranulis et al. (2009), using a case study method, described how a young woman with a first episode psychosis did not seek help because she did not know she was ill. She functioned well at work and in her home life, so much so that even her husband was unaware that she experienced psychotic symptoms. It was a colleague who eventually recognised she was unwell and suggested that she should seek help–which she did. Within the mental health literature, the ability to overcome various losses had been conceptualised primarily as recovery. A significant finding of our research was that participants stated that they had not recovered but rather were resilient.

Through our comparative analysis with the resilience literature, we found much debate about the concept of resilience, particularly around individual resilience and environmental resilience. Luthar and Cicchetti (2000) defined resilience as "…a dynamic process wherein individuals display positive adaptation despite experiences of significant adversity or trauma". Bonanno (2004) drew a distinction between recovery and resilience stating that

recovery "…connotes a trajectory in which normal functioning gives way to threshold or sub-threshold psychopathology… and then gradually returns to pre-event levels" (p. 20) whereas "Resilient individuals, by contrast may experience transient perturbations in normal functioning … but generally exhibit a stable healthy trajectory of functioning across time" (pp. 21)." This distinction differed from the psychiatric recovery literature, which described recovery as finding new meaning and purpose in life and participating actively in community life without necessarily returning to "pre-event" levels (Liberman 2008; Anthony 1993). Recovery in this context seemed to be an admixture of resilience and recovery. Bottrell (2009) argued for a move from an individual concept of resilience and elevating the concept of environmental resilience. Both Luthar and Cicchetti's and Bottrell's concepts of resilience resonated with our findings and provided confirmation for the construction the framework—harnessing resilience.

Within our study, internal resources of: determination, at-risk role and self-pacing were consistent with an individualistic concept of resilience. The concept of internal resources extended the concept of determination associated with rebounding to include tenacity whereby participants were able to pursue a particular direction in life albeit slowly and with some effort. Henderson (2011) had previously drawn a distinction between tenacity and rebounding in his study of recovery from enduring psychosis. Dyer and McGuinness (1996) associated resilience with the ability to rebound toward a direction in life, acceptance of what had transpired in one's life and determination with resolve, this latter point supported the tenacious style of resilience in our study.

In addition to internal resources, participants described the importance of external resources such as welcome support—this reflected Bottrell's concept of environmental resilience. Environmental resilience in the form of welcome support was also highlighted by Lester et al. (2011), in what they referred to as relationality, defined as, "a positive relationship between service users and key workers and family support…" (p. 884). Research has demonstrated that the longer the association with an educational institution the more accepting people are of offers of assistance. Antonucci and Jackson (1990) for example reported that "… increased education is associated with a greater likelihood of having more reciprocal relationships" (p. 188). They also opined that reciprocal relationships may influence a persons' ability to cope with life, thus contributing to a person's resilience. This is important for our study as all of the participants had either completed or were in the processes of completing a tertiary education qualification. This may well have accounted for their co-operation in seeking help and willingness to participate in treatment.

External resources—environment resilience—had an impact on participants: acknowledging their psychotic experiences as out of the ordinary, seeking and accepting help and accepting the need to adjust their lifestyle. Internal resource—individual resilience—provided the determination to pursue their chosen direction. Both of these concepts explained the responses of young people to the experiences of first episode psychosis and their ability to transition from acknowledgement to resiling—the process of harnessing resilience.

Summary

The BPSP, Loss of Control, was associated with the participants misrepresenting reality, for example suspicion and paranoia, which led to disruption of their lives. The core variable—harnessing resilience—emerged as a Basic Social Process (BSP), which accounted for most of the variation of participant behaviour and which resolved the BPSP. Harnessing resilience was comprised of the following phases: acknowledgement, help-seeking, acceptance, regaining control, and resiled. Two styles of resilience emerged, first tenacity requiring effort over a period of time and second rebounding by springing back. Participants explained how adopting an at-risk role and self-pacing contributed to harnessing resilience and regaining control. Environmental resources also contributed to the resilience of the participants in particular welcome support from others.

Limitations

The main limitation of the study was a sample of ten young people who self selected for participation. They all had a tertiary education, a good command of the English language and although they were of mixed ethnic backgrounds they all identified with the Western urban society in which they lived. The results, therefore, are only relevant to a similar population and are not applicable to other populations or cultures. Second, was the absence of data relating to the resiliency of the participants prior to experiencing a psychosis, it may well have been the case that the interventions they participated in contributed to the resilience styles reported in the findings.

Conclusions

To the best of our knowledge this is the first study to describe and explain the responses of young people to their experience of a first-episode of psychosis. Although the

study comprised a select sample, it extends our understanding of how young people overcome the impact of psychosis; primarily by distinguishing between recovery and resilience and what this meant for the participants. Resilience was the key which enabled them to get on with their lives. Resilience involved not only the personal characteristics of the participants but also environmental resources. Being mindful of the limitations of the study, the findings of our study suggest that first; service providers could assess the resilience of people with a first episode of psychosis and how they overcome the difficulties they experience; second identifying appropriate interventions which promote resilience, and third, guiding phase specific psychosocial interventions. Further research, however, is required to identify if the framework fits and works for young people who experience a first episode of psychosis with a different demographic profile.

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