Finding a way: a grounded theory of young people's experience of the pathway to mental health care

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KEY WORDS

Accessing care, first episode, grounded theory, analysis, mental health nursing, young people

ABSTRACT

Objective
The purpose of this grounded theory study was to explore how young people experienced the onset of mental health problems and to investigate their initial interactions with the health system.

Design
Grounded theory was used to address the study objectives. Data were obtained through in-depth semi-structured interviews.

Setting
Participants were recruited through two community health centres in a Sydney metropolitan area health service.

Subjects
The purposive sample consisted of eight males and twelve females between the ages of eighteen and twenty five (mean age was 21).

Main outcome measures
The research identified a basic social process, a core category or central phenomenon which had the characteristics of a maze through which the participants had to struggle to find a way. The process of 'finding a way' has four stages. These are (a) first sign in the early stages, often involving denial or fear, and self-medication with alcohol or other drugs; (b) recognition of the symptoms as a sign of mental illness; (c) understanding, discovering information about the illness; and (d) resolution, when care is successfully accessed. At each stage, barriers and/or facilitating factors either delay or speed progress.

Conclusions
The study offers insights into the experiences of a small group of individuals and hence has limitations; however this theoretical approach provides an understanding of what 'finding a way' means to this group of participants and how it influences their lives. It offers a framework for understanding some of the cultural and contextual factors that affect young people's pathways into mental health services and can inform interventions.

INTRODUCTION

Mental health is a major public health issue, particularly for young people. The last National Survey of Mental Health and Wellbeing, currently being updated, showed that the prevalence of mental health disorder among young people aged 18 to 24 years was 27% (AIHW 2007). Early intervention for this group is extremely important to alleviate the considerable personal and public burdens associated with neglecting mental illness. These burdens include increased suicide, drug and alcohol misuse and homelessness (Farmer et al 2003).

To assist young people with mental illness and to be able to intervene effectively, primary care health professionals such as general medical practitioners (GPs) and nurses need to be able to understand the experiences that young adult consumers go through. However previous studies have tended to focus more on what happens after consumers have come into contact with health professionals in the health care system (Sheppard and Benjamin-Coleman 2001; Carlton and Deane 2000; Rickwood 2000). This study therefore, was concerned with what happens to young people as they begin to experience symptoms; how they make sense of them; where they go for help; and what delays them or assists them in completing their ‘pathway’ to care.

The study had two aims. The first, which is reported here, was to use grounded theory to explore and develop a substantive theory to explain how young people experience the onset of mental illness and manage their initial interactions with the health care system. Previous research had suggested that this was a difficult, often protracted, time. Early commencement of psychiatric treatment is considered to assist recovery significantly, while delays result in higher direct and indirect treatment costs and subjective suffering (Sourander et al 2001). Emmerson et al (2006) have suggested that the mental health system might be better described as a maze or as a ‘non-system’, because it requires manoeuvring skills on the part of the individual to successfully enter treatment.

The second aim of the research, which has already been reported (Webster and Harrison 2008), was to use these findings to construct a pre-care model that can be used by nurses and other health care professionals to design appropriate interventions.

LITERATURE REVIEW

Qualitative research is comparatively rare in this area though growing in importance. The literature from Australia is limited and none uses the full grounded theory protocol. Several recent research studies from Canada and the UK reflect a growing interest in the use of qualitative research to understand the experiences of consumers with mental health problems as well as their perceptions of and interactions with health care services. A small number are reviewed below.

Sourander et al (2001) employed self-report evaluation of families and teachers in the community to evaluate psychopathology, help-seeking variables, and family factors in the use of mental health services. The study emphasised that a greater understanding of a families’ psychology and family disruptions was associated with increased service use. The authors concluded that the rating scale approach they used offers useful information but lacks the specificity that in-depth interview formats might provide.

Timlin-Scalera et al’s (2003) grounded theory study of a select group of young people (white males) explored help-seeking behaviours and aimed to understand the factors involved with the participants’ decision to seek help or not. What emerged were communal pressures to obtain wealth and be successful; high expectations that created a tremendous amount of stress for males and contributed to a gender-linked stigma about males’ help-seeking behaviours. The study has implications for health service providers to be more sensitive to this population’s needs and to explore potential barriers which prevent help seeking.

A grounded theory study by McCann and Clark (2003) looked into the role that nurses play in increasing clients’ willingness to access community mental health. Although it had a very small sample (2), its findings are supported by earlier studies promoting early intervention to care and treatment as being essential for recovery. The findings showed that health care professionals need to recognise the importance of the care-giver's relationship with the client and their intimate insight into the client's behaviour when assessing client risk. The study highlighted the importance of the nurses' role, the impact of workloads, levels of clinical competence and time management skills in clinical practice.

Stigma about mental illness remains high in the community and can affect the willingness of clients to access services. Addressing this issue, Pescosolido et al (2007) discussed a common perception linking people with certain forms of mental illness, particularly depression and psychosis, with potential violence and danger. This may occur because some people with mental illness are seen to be coerced into legally mandated treatment. The authors consider that the perceived link between dangerousness and coercion warrants further research, because this is one likely cause of stigma.

Much more research remains to be done from the perspective of the client in terms of their experiences of mental health services. For example, although there is increasing recognition of the existence of 'difficult' clients who present particular challenges to mental health, to date no research has been conducted into their perceptions of services and their experiences of nursing care (Breeze and Repper 2002).

METHODOLOGY

A grounded theory design was chosen for this retrospective study because the aim was to make sense of the situation without imposing pre-existing expectations. Grounded theory is an approach based on theory development. The researcher seeks to gather data to add to and enhance an existing body of information with the aim of explaining what is happening. A key aspect of grounded theory is the interrelationship between the collection, coding and analysis of data which is carried out concurrently.

PARTICIPANTS

The study involved the participation of 20 young people, eight males and 12 females, aged between 18 and 25 years, who were experiencing mental health problems for the first time. Criteria for inclusion were: first-time referral to a community mental health centre; ability to describe 'reality'; give written informed consent; articulate in English; and consent to tape-recorded interviews and follow-ups. The potential impact of being interviewed (eg that it may or may not trigger psychological distress) was explained.

Potential participants were given information about the study by health professionals who were aware of the inclusion criteria. Participants then contacted the researcher and signed a consent form. They were interviewed privately, either in their homes or at a community health centre. Debriefing was offered at each interview and the participants were supplied with a resources list.

ETHICS

The study was approved by the Human Research Ethics Committees of the University of Wollongong and the area health service from which the participants were drawn. Participants were given pseudonyms to ensure privacy when reporting the data.

DATA COLLECTION AND ANALYSIS

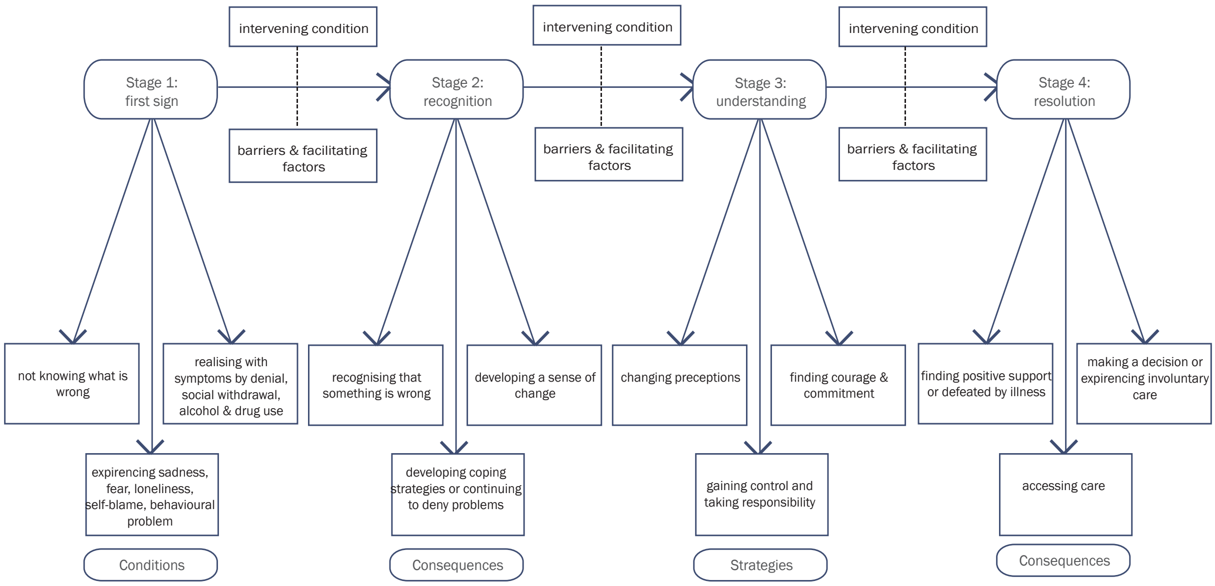
The open-ended questions allowed participants to talk about their experiences from their perspective. For example: what made you realise something was wrong; could you describe what the experience was like for you; etc. Consistent with the procedures of constant comparative analysis (Strauss and Corbin 1990; Glaser and Strauss 1967), the questions became more focused as the analysis continued and the findings emerged. This process continued until theoretical saturation was reached, which means that no new data were found that added to the analysis (Strauss and Corbin 1998). Theoretical saturation was evident after examining 16 transcripts. The remaining four confirmed and refined the analysis, but did not contribute new insights. The data were managed with the use of the computer software program NVivo (Richards 1999).

Strauss and Corbin's (1990) method was used in the analysis process. Data were coded and each piece of data compared so that similarities and difference in phenomena were distinguished. This method was applied at three different levels of analysis (called open, axial, and selective coding) and resulted in increasing levels of interpretation and abstraction. Although the processes are separate coding procedures, the researcher moves back and forth between these procedures throughout the data analyses. Concepts are grouped into categories according to their characteristics or properties and relationships between categories are identified. The aim is to achieve a dense but parsimonious explanatory theory accounting for as much variation in the experiences of the participants as possible.

RIGOR

The criteria for rigor includes strict adherence to the method as well as validation of the results. This was done in two ways: through the participants to ensure accuracy; and with clinicians to ensure clinical application. To help ensure the credibility of data, eight of the twenty participants reviewed the exhaustive description of 'finding a way' to validate that it accurately captured the essence of their lived experience. Similarly, findings were presented to meetings of mental health professionals from the health service involved in the research and at conferences.

Figure 1: Four-stage process of 'finding a way' (format of model suggested by Beck 1993)



FINDINGS

The findings showed that young people experienced a basic social problem, a central phenomenon which had the characteristics of a maze through which the participants had to struggle to find a way. The process of 'finding a way' has four stages, shown in figure 1. At each stage, barriers and/or facilitating factors (intervening conditions), which are to be found in their social, personal and health-care environments, could delay or speed progress.

'Finding a way' indicates the life-changing process that the participants undergo in response to and as a result of the onset of mental health problems. Not all participants experienced each stage in the process, but all at some point experienced barriers which impeded their progress to care and factors which facilitated their movement from one step to the next. These could occur at any stage of the process depending on the life circumstances of the participants. Although these life circumstances are to some extent peculiar to the individual, there are common patterns and themes which allow development of interventions aimed at removing barriers and supporting facilitating factors.

Stage 1: First sign

The first stage was characterised by the participants not knowing what was wrong, and experiencing sadness, fear, loneliness and self-blame. They had to find a way through the first sign (causal conditions) of debilitating symptoms which they could not initially understand and which they dealt with poorly, by behaviour such as denial, social withdrawal, alcohol and other drug use.

The central idea is the period of time associated with a set of experiences that marked a change from the participants' previous way of dealing with life events and interacting with others. The feelings they experienced at the time were inchoate, but which were later identified by the participants in their accounts as the onset of their mental health problems.

I guess when I started to have weird thoughts, like … it came on very quickly, but it only lasted a week or so, like a fit of rage (Laura)

Participants described a variety of symptoms, ranging from paranoia to auditory and visual hallucinations, delusions, anxiety and depression. Denial was a fairly common response to the emergence of symptoms for many of the participants as Rickwood et al have reported (2005). Other people might notice the symptoms and realise that the young person needed help before the person themself. Some of the young people cast around for other reasons to explain away what they were experiencing. While this may be characterised as denial, it can also mean a lack of information or knowledge about mental illness. Denial is the greatest barrier and is expressed as repudiation of having the symptoms and the need for intervention. Denial can occur at any point of the illness and can be used as a way of coping. Many participants identified denial as a defence when the symptoms emerged.

I had some idea what was wrong with me, but I didn't want to hear about that. It was real upsetting to me. I didn't want to know (Nat).

The way participants handled the causal condition depended on their social context, the extent to which their feelings and changed behaviours were recognised and dealt with by their families and, to a lesser extent, their friends. Their actions had a number of consequences for them, mostly unintended. They experienced feelings of isolation, loss, confusion, low self-esteem, depression and other unpleasant outcomes such as relationship break-ups. Many explained that, at times, as a result of their symptoms, they felt that life was not worth living and contemplated death as an alternative, to end their living nightmare; five participants did attempt suicide, some more than once.

Stage 2: Recognition

The dawn of recognition (the consequences of the causal conditions) is characterised by the individual developing a sense of change as a result of the illness which has altered themselves and their personal relationships. The participants began to develop coping strategies while continuing to experience the distressing emotions and symptoms associated with their illness. They could no longer deny that something was wrong, but although this knowledge could be experienced as devastating, at the same time it could lead to personal growth and the discovery of resilience.

The recognition that something was wrong occurred through an awareness either of the increasing intensity of their symptoms, or of their increased difficulty in coping with life. For example, participants deliberately avoided situations they would have previously enjoyed, worried what others would think of them. They felt out of touch with reality and knew it. As a result of this recognition, the timing of which depended on social, personal and familial contexts, participants began to develop a sense of change. Some with supportive social contexts and with personal insight into their problems developed a sense of resilience; they began to seek out information and tried to come to terms with their symptoms in various ways. For others, recognition of 'something is wrong' brought increased loneliness and loss of self-confidence and they tried to persist with their earlier strategies of denial and self-medication with alcohol and other drugs. For these participants, the consequences were, in many respects, a continuation of their previous experiences, including altered personal relationships, especially with partners. They were less likely to attempt to seek out help at this stage than were the participants whose sense of change included actions (such as seeking information) which allowed them to develop more effective coping strategies.

The sense of loss and grief the participants experienced when they began to realise something was wrong was intensified when they recognised that what they had was a mental disorder. They described becoming painfully aware of the chronic trajectory of their illness.

I've lost my hope and dream of having a family and a career. I mourn about long term-loss, a future loss. With this, the mentally ill person ..., that mourning never really quits (Mary).

However growth in personal attitudes and individual coping strategies are also elements of this recognition phase. These are often dependent on an empathic family and on peer support. Because of the fear surrounding mental illness, people in its early stages need to trust and to receive reassurance from their families, and from their peers.

The only way I would go anywhere was if my mother took me, since my mother was the only person I trusted. If she suggested something, I would say OK (John).

Enlightenment could come from an unlikely source.

I saw the movie of Russel Crowe ... he played the person with a mental health problem ... I had suspected for a long time that something was wrong with me (Nat).

Stage 3: Understanding

Understanding is characterised by strategies for action: gaining control and taking responsibility. Many participants found courage and commitment during this stage, and learned acceptance.

Understanding was characterised by the participants changing their perceptions of their illness as a result of connecting with others, choosing to accept help and trusting they would understand. These participants wanted to gain control of their lives by seeking out the right support and professional help, not always successfully, but they found the courage and commitment to keep going. The minority who failed to develop effective coping strategies and who continued to experience devastating symptoms and self-destructive behaviours were more likely not to enter this stage in their progress to care. They did not experience the causal conditions which led to understanding. On their own, they could not take control.

The impact of the illness is significant on individuals' lives during this time. It may be that fear and loss of control escalate to the point where seeking help, or being made to accept help, is the only option. For some, this means that through personal growth and the development of more effective coping strategies, they become receptive to sources of information and assistance.

I started to think, oh God help me; I've got to change my life, somehow. Look where I am now, you know (Catie).

Committing involves a sense of obligation to engage on a course of treatment to alleviate symptoms. By this stage, many of the participants were well on their way to accessing effective care, beginning the search once they had recognised they had a mental illness. They could make judgements about whether their present care was appropriate or not and they continued to be determined to find what worked for them.

I just was determined that I was going to be the one that recovered ... the therapy cost me heaps, but I was getting nowhere (George).

George likened the committing part of the process to learning to live with any chronic illness; it requires commitment to treatment, but also acceptance.

I just try to get some acceptance that this is how I have to live my life (George).

Courage is defined as the participants' strength in this process of understanding the illness. It was having courage that motivated the participants to seek help, and finally to successfully access care.

I think I have had this illness for some time now, and I have been utterly destitute many times … I've managed to survive, but since I had the courage to walk into the community health centre … my life changed for the better (Joe).

Stage 4: Resolution

Resolution is the consequences of the strategies, both intended and unintended, which is the final stage in the process. For some this meant they were able to find supportive care as a result of their determined attempts, while others experienced the trauma of involuntary commitment. Resolution is the final stage, when all the participants accessed appropriate care. Some, as a result of their decision-making and help seeking, were able to find positive support and appropriate treatment. Others were defeated by the symptoms of their condition and experienced the trauma of involuntary commitment to care.

Among this group of participants, the length of time from first sign to resolution varied from two weeks to 12 years, depending on the individual and the contributing factors in their lives. Some had had contact with two or more health professionals, mainly general medical practitioners (GPs), for extended periods without effective resolution.

I knew from when I was little, 10 years old that I can't cope with pressure well. I panic instead of trying to work through things and my depression is intertwined with anorexia and bulimia. I was not formally diagnosed. I saw GPs and a few psychologists through the years, but they never mentioned that I have depression. I have only experienced since last year or so. ….. I have an abusive father so it's just coming through now. I went to community health because I couldn't work any more … they said I have depression (Catie).

An issue raised by participants was the impact of their initial experience of the hospitalisation process, especially if it included aspects such as police involvement, a seclusion room and an emergency ward. McGorry et al (1991) have argued that the experience of scheduling which is traumatic and coercive can deter people from seeking help in the future. Police were involved with five of the participants; a quarter of the group. Coercive services, such as involuntary hospitalisation, reinforced feelings of powerlessness, as indicated by the use of the word 'drag':

The most frightening thing is not knowing what's going on and to find myself being dragged to the unit in the police van (Cath).

The fifth major category: called 'barriers and facilitators' to care, refers to the processes and factors which the participants identified in their accounts as accelerating or impeding their progress to care. These were often recounted by the participants in terms of particular incidents that prevented or allowed them to achieve a goal or purpose.

Facilitating factors also allow movement from one stage of the process to care to the next. To some extent, both barriers and facilitating factors are peculiar to the individual and depend on their unique circumstances. This is demonstrated, for example, by the wide variation in the length of time it took participants to progress from first sign to resolution, however there were common experiences and common responses which allowed patterns to become apparent. This is important since, to be useful, the theory must indicate when and what type of intervention would be appropriate. Barriers to care need to be identified and, as far as possible, removed or attenuated; facilitating factors should be assisted and strengthened. For example, family dynamics often influenced the extent to which parents made decisions for their children, or allowed them to make their own. This could delay or expedite help seeking.

My dad is the decision-maker at home. I don't mind listening to friends, but ultimately Dad has to okay it (Mark).

Some families have difficulty differentiating between the early symptoms of mental illness and 'normal but difficult' behaviour which they expect from young people. In addition, young people may be made fearful by their initial experience of the illness especially when positive support from family and friends is not available. They and their families tend to fear the stigma which still accompanies a diagnosis of mental illness.

There is a shame attached to this condition … All of a sudden it goes bang … [and] you're stuck with it for the rest of your life (Catie).

Another barrier is presented by some health professionals themselves, which can result in ineffectual treatment. While this in part relates to the unstable profile of the early symptoms of the illness, participants reported a number of other issues such as limited assessments and failure to elicit key information. This may relate both to their inability to describe their own symptoms in concrete terms and to the lack of flexibility and persistence shown by health professionals during the assessment process. This can result in a failure to detect a mental health problem or a substance abuse disorder. Many consumers became disillusioned and did not return to the health care system, or returned under more dire circumstance, such as involuntary care.

An important facilitating factor was the positive support of family, friends, professionals and health-care facilities. The participants saw this as critical because positive support helped them to recognise and deal with the effect of the illness. Some participants suggested that seeking help from any source was primarily a matter of trust.

I told them [parents] that I had these attacks, and didn't know what to do … Mum said I should go home. They try to help me (Chris).

Information was not always gained through direct personal contact however, but could come to light through other means, such as websites. School-based interventions may be seen as threatening for young people who have a desire for conformity and acceptance by their peers.

Personal stories help, like the ones you get off the internet (Joe).

You'd feel a bit wimpy going to tell your mates and saying I've got this problem … they'd probably laugh at you (Fred).

CONCLUSION

This paper is based on the findings of a grounded theory research study investigating how young people experienced the onset of mental health problems and their interactions with the health care system. The study offers insights into the experiences of a small group of individuals and hence has limitations, but this theoretical approach provides an understanding of what 'finding a way' means to this group of participants and how it influences their lives. It offers a framework for understanding some of the cultural and contextual factors that affect young people's pathways into mental health services. Research such as this can inform the practice of primary health care professionals such as nurses, potentially increasing the effectiveness of interventions.

'Finding a way' indicates the life-changing process that the participants underwent in response to and as a result of the onset of mental health problems. Not all participants experienced each stage in the process, but all at some point experienced barriers that impeded their progress to care and factors that facilitated their movement from one step to the next. These could occur at any stage of the process, depending on the participants' life circumstances.

Mental health care is complex. For this reason, accessing care needs to be flexible and innovative for each individual. This research shows that the concept of a 'pathway to care', a term used frequently in the literature to refer either to what happens once the consumer has accessed care or to the developmental pathway of the illness itself, is a misnomer when applied to what happens at the outset. The term suggests a simple transition to care along a defined and known route; however the participants in this study did not experience such a pathway. The maze metaphor used by some of the participants more accurately reflected the experience of all.

'Finding a way' (see figure 1) through this maze to care, the core category and basic social process which emerged from the participants' accounts, involves the active accomplishment of a number of complex and interconnected tasks. The participants had to learn about their illness and about themselves; deal with changes in personal relationships; and seek out suitable professional help in an often hostile social environment. These are all difficult propositions for young people experiencing mental health problems.

This research indicates that the pathway to care must be thought of as a multifaceted journey, commenced in ignorance and confusion. If young people are able to call on personal resilience, trust, family support, and helpful and knowledgeable health professionals, the journey is likely to be completed successfully and they are able to find a way through the stages to care. While some factors assist young people through the process, others can impede and these are found at all stages and can occur simultaneously. Stigma is still a significant issue.

Consistent with previous research into delays in accessing care (Steel et al 2006; Webster and Harrison 2004; Pescosolido and Boyer 1999), it is suggested that substantial barriers to accessing care remain and that young people's social networks are important influences on help-seeking processes. This study's significance to nursing practice rests in the fact that it presents the young person's perspective and provides insight into the complexity of the 'pathway to care' and some of the experiences of young people in accessing mental health services.

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