Constructing a research based pre-care model to improve mental health interventions for young people

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ABSTRACT

Objective
This study had two aims. Firstly, to explore how young people experienced the onset of mental health problems and to investigate their initial interactions with the health system; and secondly, 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.

Design
Grounded theory method was used to develop a theory of young people's experience of the pathway to mental health care. 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 - Findings
The categories identified from analysis of the interviews were (a) first sign - often involved denial or fear in the early stages 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. Barriers and facilitating factors either delay or assist movement from one stage to the next. The ''maze to care'' model is suggested as a guide to action for health professionals. It can direct attention to broader social and systems interventions or, at the individual level, assist assessment.

Conclusions
The study offers insights into the experiences of a small group of individuals and hence has limitations however the development of a model which can be tested in practice demonstrates that grounded theory can be a useful research approach when used to develop frameworks for action in nursing and mental health care.

INTRODUCTION

Mental health is recognised as a major public health issue. Recently emphasis has been placed on programs focusing on early intervention such as suicide prevention training outside the mental health service system (Emmerson et al 2006; Owen and Burgess 2004). This is particularly important for young people. Neglecting the mental health needs of young people has high social and economic cost implications. Some of these costs, such as distress, are intangible, whereas others are only too easily measured - increased suicide, increased drug and alcohol misuse, homelessness, and interruption to psychological, educational and social development (Farmer et al 2003).

The last Australian National Survey of Mental Health and Wellbeing, currently being updated, showed that the prevalence of mental health disorder among those aged 18 to 24 years was 27% (AIHW 2007). It is particularly important therefore that primary care health professionals such as nurses are aware of the experiences of young people and especially of the barriers which prevent them accessing appropriate care in a timely way (Rickwood et al 2005).

This paper reports the findings of a grounded theory study which investigated the experiences of young people, from their perspective, as they attempted to make sense of what was happening to them. The intention was to focus on the pre-care environment and to construct from the findings a 'guide to action' model which could alert health professionals to the factors which impede or facilitate young people accessing care and which could also assist health professionals in assessing individuals and/or designing appropriate interventions.

Literature Review

A literature search was conducted through the data-bases Austhealth, Cinahl, Medline, and PsycINFO covering the years 1998-2008. Search strategies covered the following terms: mental disorders and young people (aged 15-25), pre-treatment, patients' acceptance of health care, health services accessibility, help seeking behaviour, young people's

journey through the health system, health care utilisation, self referral and mental health service utilisation. Literature was also covered pertaining to grounded theory and qualitative studies of consumers' experiences of mental disorders, accessing care, health care seeking behaviours, help seeking behaviours, commitment to treatment (psychiatric), health care utilisation, hospital admission, and mental health services.

There are many studies which look at help seeking behaviour (see Wilson et al 2005; Fallon and Bowles 2001). However as Rickwood et al (2005) point out, these studies tend to focus more on what happens after people have come into contact with health professionals in the health care system, that is, on diagnosis and treatment aspects. The studies focus more on quality and outcomes, with an increasing interest in clinical practice guidelines, benchmarking of services and development, and evaluation of models of practice (Wilson et al 2005). The present study was concerned with what happens to young people as they begin to experience symptoms of a mental disorder, how they make sense of their symptoms, where they go for help, and what delays them or assists them in finding help.

The help seeking pathway metaphor presents a picture of a visible, organised and defined route to providers who have the mandate to treat, care for and be responsible for the people seeking help, however pathways to effective care are often unclear and difficult to negotiate, especially for young people and their families (Pescosolido et al 1998). The study by Pescosolido et al showed that, in practice, the route is rarely simple. A young person may experience the distressing circumstances of an initial episode well outside the health care system. The symptoms may be unrecognised, or recognised by others from a wide range of backgrounds, such as friends, teachers, parents or police. Thus the symptoms and how they are dealt with are a challenge not only for the individual, but for the health care system as well.

Although there is limited literature addressing the consumer's perspective, it does provide some useful insights involving the personal accounts of

consumers (Rose et al 2002) and insights into the impact of family and friends on an individual's personal interpretation of mental illness and their help seeking behaviours. More importantly, qualitative self report data seem useful for exploring the feelings and experiences of the younger age group. Research has shown that adolescents' social networks are important influences on their help seeking processes (Dean et al 2001). Dean et al found that most of adolescents' help seeking knowledge was gained by observing others, by word of mouth, and by help seeking carried out on their behalf.

Scholars suggest there are multiple contributors to mental health disorders and their outcomes in each individual. Steel et al (2006) contend that the pathways to initial care are highly individualised and vary from person to person and for different populations. Thus a 'life context' model is more complete in describing the stages of the illness in order to address the gaps between research and practice. There is diversity in the mental illness process and there are different help seeking pathways to initial care, each with different critical points and this could discourage health service providers from engaging in individualised interventions.

The literature search revealed that most of the available models are statistical 'risk predicting' models. It is rare in the mental health field to find a model of care that involves family members and consumers in accessing care and care planning (Furman and Jackson 2002). Models have been used to explain behaviours that signify mental health problems and to identify frameworks for effective management in an effort to minimise the ill health of individuals (Donovan et al 2006; Hall and Torres 2002). The analytical difficulty lies not only in ascertaining the incidence of risk among those who develop mental health problems, but also in determining the likely significance of the problem in the decision making processes of the individual accessing care. Social, emotional and adaptive difficulties are generally complex and the processes of interaction are complex and non-linear (Pescosolido et al 1998).

Although appropriate help seeking is considered protective, it has been reported consistently that few adolescents who experience distress, particularly suicidal thoughts, seek appropriate help (Wilson and Dean 2001). In this population, as suicidal ideation increases, willingness to seek help decreases, particularly help seeking from a source such as a mental health professional (Dean et al 2001; Calton and Dean 2000).

Evaluation studies of mental health care programs have suggested a number of barriers as key areas of intervention, including stigmatising attitudes toward mental illness (Wilson and Deane 2001); personal factors such as grief issues (Tennant 2002); social factors such as substance abuse (Cornelius et al 2001); cultural factors (Cauce et al 2002); as well as service issues such as service inefficiency and health service professionals' lack of mental health knowledge (Emmerson et al 2006). Despite the obvious potential of mental health care programs, there is little empirical evidence to suggest they offer effective protection against suicidal risk (Calton and Dean 2000).

METHODOLOGY

A grounded theory design was chosen for this 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 are 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 community mental health centres; able to describe 'reality' as well as give written informed consent; able to articulate in English; and able to 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. Each interview took between 30 to 60 minutes. All interviews were tape recorded with the permission of the participant and were transcribed verbatim. Debriefing was offered at each interview and the participants were supplied with a resources list. Additionally, participants were provided with a summary of the results of the research at a community meeting after the completion of the study.

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 on 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 that 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; Glaser 1978).

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. Concepts were grouped into categories according to their characteristics or properties and relationships between categories were identified. The aim was to achieve a dense but parsimonious explanatory theory accounting for as much variation in the young's people experiences as possible. The data were managed with the use of the computer software program NVivo (Richards 1999).

Rigor

In this study, the researcher has produced a theory building study which is rigorous, useful, relevant and current (Strauss and Corbin 1998). The criteria for rigor includes strict adherence to the method as well as validation of the results - through the participants for accuracy and with clinicians for 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. A written summary of the study and descriptions of the 'maze to care' (including the figure) were given to the participants to critique for accuracy and truthfulness. Inter-subjective agreement between the researcher and an independent judge (a nurse with experience in grounded theory analysis) was reached at each phase of data analysis.

FINDINGS

The findings showed that the concept of a 'pathway to care', a term used frequently in the literature to refer to what happens once the consumer has accessed care, is a misnomer when applied to what happens at the outset. The term suggests a smooth transition to care along a defined and known route, but the participants did not experience such a pathway. Some of the participants used the metaphor of a maze in their accounts and this more accurately reflects the experience of all.
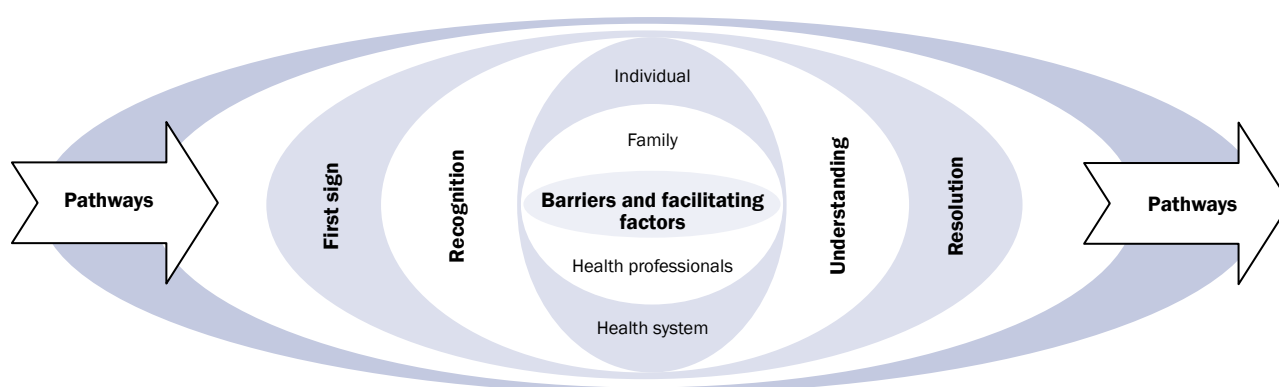
'Finding a way' through this 'maze to care' is the core category which emerged from the participants' accounts. It involved the active accomplishment of a number of complex and interconnected tasks. The participants had to learn about their illness and

about themselves, deal with changes in personal relationships, and seek suitable professional help in an often hostile social environment. These are all difficult propositions for young people experiencing mental health problems.

The participants attempted to cope with this problem of finding a way to care through a four-stage process. The stages which emerged from the data were (a) **first sign** in the early stages of the illness, often involving denial or fear, self medication with alcohol or other drugs, and characterised by not knowing; (b) **recognition** of the symptoms as a sign of mental illness, indicating that help was needed; (c) **understanding** by discovering information about the illness and its impact on self and others; and (d) **resolution**, when appropriate care is successfully accessed (figure 1).

Figure 1: The 'maze to care' model

The journey to resolution may be short-circuited for some at earlier stages through involuntary commitment after a particular incident or exacerbation of the illness. These participants were less likely to enter the stage of understanding in their pathway to care. Finding a way for them required the active interventions of others. At each stage, barriers and facilitating factors are the phenomena which either delay or assist movement from one stage to the next. They are found in the personal, social and health care environments.

The 'maze to care' model
The 'maze to care' model (see figure 1), which is based on the findings briefly outlined above, has two dimensions. The horizontal dimension represents the time taken by young people from the onset of symptoms, through the stages, to the successful accessing of care. The vertical dimension represents barriers and facilitating factors which impede or assist progress through the process. These may be encountered at any stage and are therefore placed in the centre of the model. They can be seen as guides to possible interventions which may speed up the process of accessing care for young people with mental illness.

The complexity of young people's experiences with mental illness is indicated in the model by the oval lines and concentric circles that surround and delineate the different stages, rather than arrows that would imply a more unproblematic progression than actually occurs. As presented, the model directs the focus to broader social and systems interventions which would enhance the capacity of young people and their families to recognise the symptoms of mental illness and to access appropriate and timely support. It also illustrates that failure to access effective care is not the result of personal or social factors alone, but may be compounded by shortcomings in the health care system. Although the model can be used as a guide with individuals, careful assessment is required to understand which of the variety of possible factors are influencing

each individual's personal journey. In this research, the participants identified a number of factors that speeded or impeded their progress.

Given that most participants had difficulty recognising initially they were experiencing symptoms of mental illness, their progress to recognition, understanding and resolution was influenced by their immediate family and peer environments and by the general community environment in which they were embedded. Ideas about 'normal' adolescent behaviour, unhelpful family dynamics, the desire not to seem different, and the stigma attached to mental illness, meant that the onset of symptoms and what they might mean was a time of fear and isolation for some of the participants.

'I knew there was something wrong, but I couldn't put my finger on it. I was pretty ignorant about the whole thing. My parents thought I was being difficult' (John).

McGraw et al (2008) has pointed out that families influence beliefs and values about mental illness. Again, this could be a positive or negative factor for the participants.

'In our family … just like everything else, you just cope, that's how I've learned to live with it, it's always been that way' (Jess).

'My family believed in churches, not doctors … and I thought I was just nuts, and I didn't think there was anything you could do about it' (Joe).

Other negative impacts included experiences of sexual abuse, the use of alcohol and illicit drugs, and traumatic life events such as relationship breakdown and death within the family or peer group. McGraw et al (2008) has argued that separation from parents following divorce may increase adolescent vulnerability. At the same time, for many participants the ability to communicate their distress effectively was compromised by their illness and by their fear of acknowledging it. However where symptoms were recognised for what they were by supportive family or friends, the process of persuading the young person that something was wrong and that they needed help, could begin.

'My friend tricked me into the car and took me to the hospital … things got ugly and I was committed. I was having a good time [in a manic phase], I thought' (Joss).

'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).

Some participants also had more resilience than others and were able to more actively seek care; to find out what was wrong with them; and to see a future for them. Of course, the type of mental illness they experienced affected these behaviours.

This is only my first breakdown…I hope to have full recovery from it' (Peter).

'I've learned to live with it, this is me' (Jane).

The perspectives of the participants and their families may differ with regard to understanding symptoms and accessing care strategies. Strategies may be independent or linked in a variety of ways and related to the degree of understanding or misunderstanding of mental illness and health care. For example, three participants reported they enjoyed having the symptoms and that seeking help deprived them of this enjoyment. Such misunderstanding constitutes a problem, resulting in postponing access to initial care and creating a barrier to health care. Similar phenomena were reported by Williams and Healey (2001) and Pescosolido and Boyer (1999). In other words, there is no clear and direct relationship between the young person with a mental illness, understanding of symptoms and accessing care. As the 'maze to care' model suggests, a variety of mediating factors is involved in a complex process of interpretation.

The 'maze to care' model might be used to optimise assessment, education and management in this group of young people and when assessing and designing services for young people who are experiencing a mental health problem for the first time. It also acknowledges why the perceptions and experiences of young people underpin their decision for help seeking.

Health care factors

The health care system can appear complex and decidedly user unfriendly to the outsider. It involves a range of practitioners, agencies and institutions which operate more or less independently. Donovan et al (2006) suggested that some professionals are reluctant to refer their clients to the psychiatric system as they do not perceive it as preventive or effective in nature. Delay in contacting services until a crisis arises is particularly common, at times leading to emergency admission.

Service quality is experienced as variable, with the skilful professionalism of some contrasting with lack of care and attention by others. Using this complex health care system made the participants anxious and at times they were unable to manage themselves.

'My mother had to navigate the system for me. She is my gateway' (John).

This underlines the importance of supportive family and the problems in accessing care which can arise when support is not available.

'I kept going back and phoning my mum to say something was wrong, but she wouldn't believe me…[later] I rang her again to say my thoughts were jumbled …and I was scared. She told me to go to the hospital, but I couldn't get myself there' (Cath).

The health system is a human web, a community of people whose job it is to help those in distress. Participants recognised that some did this to great effect, but they were also very clear in their identification of professionals who were unhelpful, hurtful or ineffectual. Many participants saw their general practitioners (GPs) as having a key role in the initial pathway to care. Most of them had visited a GP as a first port of call, but found that the encounter did not lead to action or an adequate response; further delays still occurred, extending the access process.

'There was a major turning point and a change in my life when I saw this GP, [… saw a few of them in 2 years], she told me I'd got depression and it can be treated, she actually put a label on me … I felt

relief that I'm not just being lazy and felt drained all the time. It was a relief. I felt like it was something I could live with' (Jane).

Another point made by the participants was that health care professionals tended to lack specialist mental health expertise. Such individuals could minimise or downplay the significance of the problem or fail to carry out proper follow-up and referral, as Garralda (2001) also reported.

'You expected me to raise my hand and walk across the playground to see a counsellor, that I had these bad thoughts …what do you think [would happen] when I returned to the class' (Mark).

This statement highlighted how young people could minimise or downplay the significance of the problem.

Removing an important health system barrier

System barriers, such as those briefly referred to above, confronted many of the participants in this study, but one of the most important was the difficulty participants experiencing mental health and substance misuse problems had in accessing an appropriate service. Evidence given to an enquiry into the care of the mentally ill in the community (Wilson et al 2005) regarding the high prevalence of substance abuse in persons with mental disorders highlighted a pronounced lack of communication between mental health and drug and alcohol services. As a result and it was apparent in this study, young people with drug and alcohol problems tend to 'fall through the gaps' in the health care system. It has been suggested that mental health services are unwilling to treat people with concomitant drug and alcohol problems due to their addiction, and conversely, detoxification centres and other health organisations dealing with substance abuse are unable or unwilling to treat people with signs of mental health problems.

Different philosophies and approaches underpin treatment in drug and alcohol services (New South Wales Health Department 2004). Whereas mental health workers generally adhere to an assertive follow-up model, drug and alcohol workers put greater reliance on self motivation in helping clients abstain

from substance use as a primary goal. This dichotomy can create difficulties and delays in treatment, particularly if young people with substance use disorder have unstable mental health symptoms and poor cognition and judgment in accessing appropriate services themselves. All too often they are refused access to many services because they do not meet strict entry criteria.

The barriers to combined mental health and drug and alcohol treatment are seen in terms of organisations that have become more specialised and exclusive when these services were once part of an integrated service framework. Primary care providers have stated that they need to access a greater level of skill and knowledge (New South Wales Health Department 2004), expertise and prompt back-up referrals. In contrast, despite shortages or perhaps because of them, clinicians in remote areas tend to be more accustomed to and accepting of the need to provide comprehensive and inclusive health care.

CONCLUSION

One of the intentions of this research was to construct a model which was simple but which reflected the experiences and perceptions of the participants as they moved through the pathway to care. Existing models tend to focus on the post-care environment and are oriented toward the perspective of the health professional, or they are behaviour change models used to predict behavioural choices. The use of a model to explain the context within which utilisation occurs - the role of the environment, life experience factors, and provider related factors - has been largely neglected.

The help seeking pathway metaphor conjures up a picture of a visible, organised and defined route to providers who have the mandate to treat, care for and be responsible for people with mental health problems, but pathways to effective care are often unclear and difficult to negotiate, especially for young people and their families, as Pescosolido et al (1998) have previously demonstrated. In this study, the pathway and the model are called the 'maze to care' because, although it ends with the consumer

entering the system and receiving treatment, it involves many complexities along the way, including abortive attempts to access care from various health professionals and others.

Ideally, adolescents and young adults live in supportive family environments where the symptoms of mental illness are quickly picked up and dealt with appropriately; where friends stayed loyal; and the health service is always responsive to their needs. The reality for many in this study was quite different. Families may mistake the early signs of mental illness for 'normal' behaviour because they expect people of this age to be moody or difficult, but consider that eventually they would come through it. As a result, and because the young people themselves often do not realise they need help, nothing is done until symptoms worsen and cannot be ignored. Lack of knowledge about the symptoms of mental illness remains widespread in the general community, of which the participants and their families are a part.

Undoubtedly, and the literature supports this, young people whose family or friends realise that help is required, achieve access to care more quickly than their less supported counterparts. However alcohol and other drug use can complicate matters, as can sexual and other abuse within the family. Even where families are generally supportive, they may fear a diagnosis of mental illness, perhaps because of previous experience within the family or, more generally, because of stigma. The young people themselves may express these views. Even when a problem is identified as serious, knowing what to do and how to obtain help may constitute significant barriers (Emmerson et al 2004).

The 'maze to care' model is based on the findings of a grounded theory research study investigating young people's experiences in accessing care. The study offers insights into the experiences of a small group of individuals and hence has limitations, but the development of a model which can be tested in practice demonstrates that grounded theory can be a useful research approach when used to develop frameworks for action in nursing and mental health care.

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