TO BE TREATED LIKE A PERSON: THE ROLE OF THE PSYCHIATRIC NURSE IN PROMOTING CONSUMER AND CARER PARTICIPATION IN MENTAL HEALTH SERVICE DELIVERY

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Abstract:

Collaboration with service users and carers is now considered an integral aspect of mental health service delivery. A review of the literature, however, suggests that this ideal is not always realised. This paper presents the results of a study undertaken to examine the perceptions of consumers, carers, psychiatric nurses and a group of key informants regarding the major barriers to the formation of a collaborative relationship. A joint venture between two Victorian rural mental health services and the Centre for Psychiatric Nursing Research and Practice at the University of Melbourne, the study utilised focus groups to assist participants to describe their experiences. In particular, the groups sought to examine aspects of nursing intervention which consumers and carers found to be helpful and those which were unhelpful or detrimental. The purpose of the investigation was to elicit information concerning barriers to nurses including consumers and carers in care planning and other decision making. Findings from the study indicate that the opinions of all stakeholder groups regarding such barriers were not entirely dissimilar. The ramifications of these findings for both the preparation of psychiatric nurses and the support of consumers and carers will be discussed.

Introduction

Since the early 1990s, Australian mental health policy has clearly articulated the messages that consumers of mental health services and their unpaid carers are major stakeholders in mental health service delivery and should be regarded as participants rather than purely as recipients (Commonwealth of Australia, 1992; Commonwealth of Australia, 1998; Commonwealth of Australia, 2003).

Determining the extent to which this goal has been successful implemented is impeded by the paucity of literature (Lammers & Happell, 2003). There is, however, a suggestion that the negative attitudes of mental health professionals pose a significant barrier (Caldwell & Jorm, 2001). Nurses constitute the majority of the professional mental health workforce (Australian Institute of Health and Welfare, 2004) and therefore pay a pivotal role in shaping the culture of an organisation.

Caldwell and Jorm (2001) suggest that nurses' views of the long-term prognosis for people with mental illness is more pessimistic than those of the general population, but more optimistic than the views of psychiatrists. How such views might impact on the willingness of nurses to involve consumers and carers as partners in the treatment process, might be assumed but cannot be clearly understood without further exploration. Furthermore, consumers and carers are seldom consulted regarding their experiences or their expert opinion, and indeed that they are seldom recognised as having any expertise at all (Lammers & Happell, 2004).

The aim of the current study was to examine the issue of consumer and carer participation in mental health care from the perspectives of psychiatric nurses, consumers of mental health services and their carers.

Method

A qualitative framework was utilised for the conduct of this study, in order to provide a more in-depth form of enquiry, capable of recording and exploring the meaning of the experience of the participants (Aranda & Street, 2001). The study utilised focus groups to assist the participants to describe their experience of collaborative care and treatment planning. In particular the groups focused on ways in which this form of collaboration had been most effective or helpful for the participants. Focus groups were selected as they enable access to larger numbers of participants and facilitate interaction among members of the group (Happell, 1996; Reed & Peyton, 1997; Webb & Kevern, 2001).

Focus groups have their origins in market research (Webb & Kevern, 2001). The literature describing focus groups is often restricted to guidelines on the process of running a group, rather than the analysis of ensuing data. Reed and Payton state that the literature also frequently assumes that group members do not know each other, which is not generally the case in nursing research, where nursing staff and other participants such as consumers are often very familiar with each other. This clearly changes the dynamics of the group. Indeed, it is precisely the interactions within the group that can be of great interest to the researcher, and can enrich the data. The focus groups were assembled according to the criteria identified by Krueger (1994). That is, they involved 4-10 persons, brought together in a series of groups, the members of which shared common characteristics. The objective of the groups was to provide data through group interactions, that was of a qualitative nature, and which would be generated in a focussed discussion.

Focus groups were conducted with psychiatric nurses, consumers of mental health services and carers. The majority of the focus groups were conducted in a neutral venue, that is, one that was not attached to or associated with clinical service delivery. The only exceptions to this were a group conducted in a mental health service staff room for nurse participants, where no other venue was accessible to the group, and a nurses group held in a general hospital meeting room, agreed to by consensus of the participants. Other venues used were selected for their convenient location, privacy, quiet, comfort, and the ability to support the requirements of the focus group, such as audio taping and refreshments.

Data analysis

The software chosen to support the analysis of the data was QSR NUD*IST Vivo 1.3, commonly referred to as NVivo. This software is used extensively in qualitative research, as it is capable of assisting the qualitative researcher to methodically order and work with the raw data generated from focus groups and interviews. The software assists in the identification of themes and supports the researcher in the development of categories and coding, and the exploration of emerging patterns in the data. Recordings of the focus groups were transcribed professionally, and were then reviewed by the researcher. Transcripts were uploaded to the NVivo programme before the process of data immersion commenced. Data immersion refers to the means by which the researcher becomes intensely familiar with the raw data. This is achieved by reading the transcripts several times, and beginning to identify emerging common themes in the data.

The identification of themes arising from the data was arrived at via the content analysis process described by Collaizi (1978). Using notes generated during the data immersion phase, the researcher began the formulation of a range of possible themes emerging from each group transcript (Van der Zalm & Bergum, 2000; van Manen, 1997; Rose, Beeby & Parker, 1995). The transcript was then coded, using the NVivo software, to enable comparison and further reflection on the concepts arising from the data.

Coding of the data enables the researcher to enter into a more analytical review of the information, by providing a way in which sets of data may be viewed in an interrelated fashion. Using the software, passages of transcript, paragraphs, phrases or single words may be highlighted, and assigned a code. The researcher utilised Visual Coding, which enabled specific themes to be identified by colour, and thence to be compared and grouped into related sets describing specific attributes, termed Nodes. Once this had been completed, codes were then reviewed and revised, using the software's Node browser facility, as new categories and data attributes arose. In order to provide a framework for the reporting of the findings from the data, the themes identified within each node were arranged in related groups. Findings from consumer, carer, nurse and key informant groups provided the researcher with theme groupings which had a number of commonalities, but themes also arose from the data which were unique to each group. The themes are described in Table I.

Table I

THEMES ARISING FROM FINDINGS	
Consumers: • **Respect** • **Encouragement** • **Systemic barriers** • **Collaboration**	**Nurses:** • **Respect** • **Encouragement** • **Systemic barriers** • **Conflicting agenda**
Carers: • **Respect** • **Encouragement** • **Systemic barriers** • **The carer as expert**	

Findings

Excerpts from the findings are provided here to illustrate the themes identified during the analysis of the data. The examples offered here demonstrate both the similarities and differences between stakeholder experiences of levels of participation, and their views of what may constitute barriers and facilitators to collaborative care planning. As there is insufficient space in this paper to show examples from all the themes, the following quotations are taken from those themes which were common to two or more groups.

Respect

Nurse participants in the study referred to the significance of respect in establishing a collaborative relationship:

> … you used all [your] skills to make sure you didn't lose that rapport and respect. You cut that common ground.

Where consumer participants spoke of respect, they identified it as a basic need, as in the following comment:

> I find when I'm totally out of control that I can't focus or can't think straight and the only way that I can come back in to control is to talk to somebody with sense that will sit there quietly and treat me with respect and talk me through it.

Some consumers, however, spoke of the dehumanising effects of lack of respect:

> [I want] to be treated like a person. I think it's very relevant because I don't very often get treated like a person; you get treated like you're a thing. You're just a means to an end.

The need for nurses to deal respectfully with all concerned was also important to carers:

> I think that's an issue, being able to interact with the patient and people and individuals with respect. [Responding] to them and not just as a number there in the room

Encouragement

Participants were unanimous in stating the value of encouragement in achieving good levels of participation. For nurses, this meant embedding encouragement into case management practices:

> I suppose I'm thinking in terms of the consumer-carer participation models that are around, I don't think that we are that active in terms of our involvement with carers, it tends to be more case specific with encouragement or an openness to have others involved rather than an insistence or [saying] this is the way we work.

And:

> It's really important for us to reach out to them too isn't it? That's part of that whole business of establishing rapport. It's important with the consumer, but it's also very important with the carers, with the family, and worthwhile developing.

Nurses who provide positive encouragement are held in high esteem by both consumers and carers, who stated respectively:

> When you're positive to people it's a great thing. They've [nurses] always said really good things to me and that really helps. And if it helps a person to stay alive and keep going that's the most beautiful, fantastic thing you can do.

And:

> I felt we were encouraged much more in the beginning, now it seems more of an acceptance of us. They [nurses] feel its part of their job to work with, rather than to encourage the carer.

Systemic barriers

Nurse participants described two main types of systemic barriers, these being heavy workloads and geographical distances, as in the following examples:

> You'd like to sit down and give people a lot of support but you just don't have the time. In the two days that you're on, if you've got five people and their families, and all those families have come in, you're really pressed for time to give a meaningful amount of time to them all, you just sort of find out the basics.

And:

> … you have to cop their [consumers and carers] frustrations that they're not able to access other services and they have to more or less come up country to be admitted to a hospital two hours away.

Carers also understood the difficulties arising from staff shortages in services, particularly when this resulted in remaining staff becoming stressed by increased caseloads. In addition, the level of resources such as vehicles was mentioned. Carers saw this under-resourcing as a source of frustration:

> … the area mental health [services]…are so short staffed…you ring them daily, hourly when you're in a crisis situation … and they say we're coming out to see you on Friday, and this might be Monday. Then Friday comes and they've been stuck, they've got no car, they've got some excuse. Every single minute of that day that you're with your loved ones when they're unwell, they're the only help you've got and they're not there.

While consumers appreciated that nurses carried heavy case loads, they were more concerned with continuity of care and issues regarding the availability of follow up in the community:

> I think there's an extension of care needed too, and that is not just in hospital when you're in a crisis. It's an ongoing care need when you're out in the community again and you need to touch base every so often just to keep you going. It's no good having care while you're in hospital and then being discharged, and overnight you're on your own.

Conflicting agendas

Discussion of conflicting agendas occurred in the nurse participants groups. Nurses raised the issue of needing to make decisions based on responding to the needs of the consumer, to whom they believed they owed primary responsibility. Role conflict arose for nurses when the needs of the carer and consumer were unable to be met without some degree of compromise. This placed demands upon nurses to be flexible in order maintain the collaborative relationship:

> I guess the other thing is there's a lot of competing needs and you've got to keep in mind that you're there primarily to support the client and sometimes when there's conflicting needs to try and identify what those needs are and to try and communicate that back to both the client and the carer. As those needs change therefore your relationship both with the client and the carer can change.

And:

> You're adding another person in there and I think you've got to keep focus on what you're there for. I've been in some situations where perhaps the carers' needs and consumers' needs are two separate things and I think that's where it becomes really tricky for clinicians… (In) responding to the needs of the carer you may not be responding to the needs of the consumer, so needing to think about that, and sometimes needing to separate that.

While carers did not in general make detailed reference to conflict of interest during group discussions, there were some individual comments. One carer described the confusion arising from information provided separately to him and to the consumer:

> He [the nurse] spoke to my son separately, then he spoke to me on his way out the door, and I went back and spoke to my son about the matter again and we have a totally different opinion each of us on exactly what's going on.

Discussion

As can be seen from these brief excerpts from the findings, consumers and carers identified respect and encouragement from nurses as essential in enabling them to collaborate in care planning. Indeed, encouragement was described as having considerable therapeutic value for consumers. Adopting a positive approach is a fundamental component of the therapeutic relationship (Barker, 1999; Dunwell & Hanson, 1998; Horsfall & Stuhlmiller, 2001; Jackson & Stevenson, 2000; O'Brien, 1999). A respectful attitude was cited by all participants as constituting an integral part of the development of a truly collaborative relationship.

Many of the nurse participants demonstrated empathy with the plight of carers in coming to terms with the experience of mental illness for their loved one. Furthermore, some described a genuine desire to be more responsive to their expressed needs. However, they articulated the problems encountered when seeking to involve carers, and specifically referred to the fact that the consumer is the person to whom they owe a primary duty of care. Consequently, the rights of carers to information and involvement may be viewed by nurses as secondary to those of the consumer. The findings from the current study suggest that barriers to participation may be constituted by more than simply unwillingness to encourage participation, but may reflect, in part, the fact that nurses can be the "meat in the sandwich" in trying to address the sometimes conflicting needs of consumers and their carers.

Systemically, nurses, consumers and carers all identified that heavy workloads and the distances that nurses must travel to provide services in rural areas both constituted barriers to active and effective collaboration and participation. Crisis oriented service provision was also cited as an impediment to collaboration.

In order to address these issues, it is suggested that further education and training for nurses in the provision of family centred services would enhance both consumer and carer participation. The findings demonstrate that a focus of this training should be not only upon the one-way provision of information and psychoeducation, but more upon the instillation of hope. Consumers and carers, in their turn, would benefit from additional education and support in achieving effective participation. This would ideally be provided by consumers and carers themselves, under the auspice of their respective peak bodies.

Finally, the complexities of rural psychiatric nursing practice should be borne in mind when addressing case load and resourcing issues. It is hoped that rural services and nurses in leadership positions in rural settings would continue to advocate for a rural approach to service delivery that is not wholly directed from a metropolitan point of view.

Conclusion

It can be seen from the findings that all parties are agreed regarding the importance of maintaining respectful, encouraging attitudes. They also jointly acknowledge the potential barriers to collaboration imposed by systemic issues. From the perspective of the consumer participants, discussion of the importance of respect and encouragement represents more useful language than is presented in a discussion of attitudes per se. The findings of this study provide a platform for the provision of further education for clinicians in family centred practice, and the conduct of further research into consumer and carer participation in mental health care.

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