

FEATURE ARTICLE

# Impact of patient confidentiality on carers of people who have a mental disorder

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**ABSTRACT:** This paper discusses how patient confidentiality issues impact on carers of people with mental disorders. Data obtained from interviews with 27 primary carers were analysed using the grounded theory method. Despite the emphasis that Australian mental health policy documents place on collaboration with carers, the findings of this Western Australian study showed that carers were expected to undertake the caring role with little support, education or understanding. The lack of collaboration with health professionals increased carers' level of distress and left them feeling frustrated and resentful. Carers have identified that patient confidentiality was one reason why health professionals were unwilling to collaborate with them. To ensure carers' continued commitment to caring, negotiation about patient confidentiality issues must occur at the onset of the caregiving process. Carers have the right to certain information in order to maintain their level of well-being and their personal safety. Moreover, in certain circumstances, patient confidentiality may need to be breached if the life of the ill family member or others is in danger. A greater carer involvement in and understanding of the ill family member's illness will facilitate better treatment outcomes in the community for the ill family member.

**KEY WORDS:** carers, education and support, health professionals, least restrictive environment, level of well-being, patient confidentiality.

## INTRODUCTION AND BACKGROUND

This paper discusses the impact of patient confidentiality on carers of people who have a mental disorder. The findings are part of a larger study that described the primary carer's experience of caring for a person with a mental disorder in the Western Australian community (Wynaden 2003). Numerous studies have examined the dimensions of the caregiving experience (Parker 1993; Peternelj-Taylor *et al.* 1993; Winefield *et al.* 1998) and researchers have consistently found that the experience impacts negatively on the physical and mental well-being

of carers (Domenici *et al.* 1993; Muhlbauer 2002). Caregiving is demanding and emotionally draining and has been frequently associated with depression (Chambers *et al.* 2001; Grad & Sainsbury 1963; Karp & Tanarugsachock 2000). It has also been demonstrated that the level of collaboration between carers and health professionals impacts on carers' levels of well-being, knowledge, and caregiving skills (Peternelj-Taylor & Hartley 1993). Health professionals remain reluctant to share information about the ill family member with carers. This reluctance appears to happen because health professionals are unable to differentiate between information that falls under the guise of patient confidentiality and information that can and should be shared with carers (Domenici & Griffin-Francell 1993).

The legal obligation for health professionals to maintain patient confidentiality has been debated since the 'Tarasoff case' in 1974 and 1976 (Tarasoff v Regents of

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the University of California 551 P2d 334, 1976). Although this case raised controversial precedents, from the ethical point of view one can argue that even though confidentiality is a 'prima facie' duty, absolute confidentiality can contribute to serious harm (Orb 1993). In practice, this case must be relied on with caution, as the principle has not been followed in almost half of presenting cases in the USA (Kerridge *et al.* 1998). Traditionally, patient confidentiality has meant that health professionals respect the right of their patients to privacy and, therefore, they do not disclose information without the patient's permission (Brody 1989; Ramsay *et al.* 2001). Confidentiality is central to the concept of respect for the patient's dignity. Patients share their experiences with health professionals, and disseminating that information to other people without consent is a breach of trust and, consequently, a violation of patient confidentiality. Patients must be assured that what they say will be kept confidential otherwise they may hold back important diagnostic information. While patient confidentiality is an important and relevant legal and ethical requirement, the management of patient confidentiality in clinical practice is a very complex issue.

Deinstitutionalization has resulted in people with mental disorders now being treated in the least restrictive environment and preferably in their home. However, many families are unprepared for the caregiving role that has suddenly been placed on them. Major mental disorders alter peoples' level of understanding, reasoning, and judgement. Therefore, issues such as informed consent become more problematic with these patients. While health professionals owe patients the protection of privacy, the law in Australia remains blurred about what information should and can be shared with carers (Wallace 1991). This lack of clarity places health professionals in difficult situations when using their discretionary judgement, and creates ethical dilemmas between the right to know and the right to tell when working with carers (Bell 1993; Orb 1993; Szmukler 1999).

The importance of family involvement on the ill person's level of well-being is highlighted in numerous government reports and policy documents (*Health Department of Western Australia Policy Document on Consumer/Caregiver Participation* 1999; *Mental Health Promotion and Prevention National Action Plan* 1999). These documents place emphasis on the development of a 'partnerships in care' model that encourages health professionals, families, and the ill family member to collaborate with each other. However, while governments and policy makers encourage collaboration, in reality carers feel excluded from this process (Walker & Dewar 2001; Wynaden 2003). This occurs when health professionals

fail to recognize the active role that carers play in the ill family member's care (Morris & Thomas 2002). Moreover, patient confidentiality means that the routine non-disclosure of essential information further impacts on carers' level of well-being (Orb 1993). There is a growing community recognition that carers of people with mental disorders require adequate and specific information about the ill family member and that health professionals are a key source to provide this information (Ramsay *et al.* 2001; Szmukler 1999). Therefore, the purpose of this paper is to report the problems that carers experience on a regular basis as a result of patient confidentiality.

## METHOD

The grounded theory method was used in this study. Carers were recruited from carer groups, through advertisements in community newspapers, over local radio stations, and by referral. Data collection included the use of semi-structured interviews, using theoretical and purposeful sampling techniques. Field notes, memos, reflective journaling, and the review of relevant literature and reports were also included as data. All interviews were conducted between September 1999 and December 2000. Interviews ranged in length from 1 to 3 hours (1 hour 20 min mean time) and they were conducted in a private, mutually agreed-on location. Each interview began with the open-ended question 'Can you start by telling me about the person you care for'. As theoretical sampling techniques were implemented, the open-ended questions became more focused. Interviewing stopped when saturation occurred and no new information was provided (Sandelowski 1995).

All interviews were transcribed verbatim and NUD\*IST was used for data management (Richards & Richards 1997). Data analysis was based on the researcher's interpretation of Glaser and Strauss' (Glaser 1978; Glaser & Strauss 1967; Strauss 1987) original descriptions of conducting the grounded theory method, but the application also included aspects of both authors' divergent methods.

Credibility of the findings of the study was supported by participants' accounts of similar experiences and similarities in the existing scientific literature. Recurrent patterning of responses from carers also added to the trustworthiness of the findings. Transferability of the findings meant that the findings are applicable to carers in other geographical areas and enduring illnesses.

Ethical approval to conduct the study was obtained from a university human research ethics committee. All

carers were given an information sheet explaining the purpose of the study. They were assured of their confidentiality and gave informed consent. Confidentiality was maintained by replacing the carers' names with pseudonyms.

## RESULTS

A total of 27 carers (22 women and five men) participated in this study. In total, 11 carers were reinterviewed to clarify and expand on data obtained during their initial interview. The range of experience of caring was from 1 to 33 years with a mean of 8 years. The majority of carers were caring for a son or a daughter with disorders such as schizophrenia, depression, bipolar disorder, and obsessive-compulsive disorder. Some carers were caring for more than one ill family member (multiple-carer) or were child carers and they were now caring for an ageing parent or a sibling (child/adult carer).

A theme called 'being excluded because of patient confidentiality' emerged from the data.

### Being excluded because of patient confidentiality

Carers reported that patient confidentiality impacted on their caregiving role because health professionals had excluded them and they were reluctant to collaborate and to share information with them. Carers were particularly concerned that they were not provided with information about the family member's illness and about how they could be more effective as carers. One carer said,

You are supposed to be actively involved in the treatment, part of the treatment team but you stumble through and pick up the pieces because they [health professionals] don't involve you at all. (P9)

Participants explained that patient confidentiality impacted on their level of well-being because health professionals were unable to differentiate between information that could be shared with them and information that should remain confidential. When confusion occurred, the health professional usually opted to withhold all information about the ill family member from the carer. This is illustrated in the following excerpt: 'With patient confidentiality most of what is happening [problems and care of the family member] is hidden' (P3). The lack of collaboration impacted on carers' day-to-day caregiving experiences and left them with feelings of powerlessness: 'I couldn't find anybody [health professionals] who would listen to me' (P17); 'The community nurse hasn't really ever listened to me about how things are with Louise' (P5). When health professionals did not engage and col-

laborate, carers were left to 'flounder in the dark' (P9) not knowing whether the care they were giving to the ill family member was helpful or not. One carer said: 'This holy grail, this confidentiality thing. . . . I just wanted to feel that I was doing things along the same lines, things that were advisable or helpful. I just want some guidance' (P3). A multiple-carer provided further insight: 'I am concerned with confidentiality as unless I know the details [how to care for daughter] I am unable to deal with it [caring]' (P21).

Being excluded from what was happening increased carers' feelings of isolation:

Michael [son] is 24 years old. If he says they [health professionals] are not to tell me anything I don't get to know anything. At the moment the nurse is very good. . . . He visits Michael and I phone him from time to time. He says, 'he is as well as can be expected but there is nothing I can do. My hands are tied' [regarding issues of confidentiality]. (P17)

When they were excluded carers found it very difficult to manage day-to-day problems associated with the caregiving role:

Confidentiality is a problem. . . . For example, I can't get information for Aaron [son]. It doesn't matter how involved I am in his care. It is frustrating. I have got him on one hand saying 'can't you do it [ring the doctor]' or him saying, 'I am not going to go [for an appointment], so you will have to cancel it'. On the other hand they [health professionals] say, 'Aaron has got to do it'. They say, 'we [carers] can't be involved in this, we [health professionals] can't tell you anything, and we can't tell you why'. Then Aaron is saying, 'just ask the doctor' and the doctor is saying, 'I can't tell you'. So you end up between the two. (P9)

As a result of being excluded, carers were slow to learn how to care and, therefore, the ill family member's chances of recovery were not optimized. Carers reported that health professionals also practised exclusionary behaviour during periods when the ill family member was hospitalized. This was a time when carers were under additional stress and a time when a collaborative relationship would have been beneficial to their well-being:

When June [daughter] is in hospital the doctors don't like to talk to us [carer and husband]. They say, 'confidentiality is a big thing'. When June was first in hospital it was fine. But now unless she agrees, unless she can be there in the interview, and unless this and that we don't find out anything. We keep arguing that it is wrong. We have to watch out for her so why shouldn't we find out about things. We just think it is wrong to have that level of confidentiality. (P16)

On occasions carers reported that health professionals' behaviours were so exclusionary that they were not even informed when the ill family member was discharged from hospital. This led to increased family stress, as one carer explained:

Peter was discharged from \*[hospital] and caught a plane to Sydney [a 4-hour flight from the west to the east coast of Australia]. He was 21 years old. Nobody told me [that son was being discharged and going to Sydney]. . . . I got a phone call from my sister [who lived in Sydney] and she said, 'guess who I have got here'. I said, 'I have no idea'. She said, 'Peter is here'. He had arrived at her place with a new computer, a new TV [television] and a guitar. He had no money to pay any board. He also had no Medicare card [health care card]. He was still quite psychotic. She had four children and Peter to deal with. (P11, multiple-carer)

Unlike health professionals, carers were able to distinguish between the information that should remain private between the health professional and the ill family member and the information that could and should be shared with them:

I respect Michael's privacy he is an adult. He doesn't want me to know everything and I don't want to know everything. . . . I would be happy if he didn't need me to prop him up. I would love him to do all of this himself. . . . I don't want to know everything that Michael discusses with Patrick [nurse]. I want him to have people he can talk to. It is not healthy for him just to have me and for me just to have him. I just want to know how to manage things better. (P17)

When carers requested information, it was to facilitate a better understanding of the family member's illness and treatment interventions, and strategies that could be used to optimize the family member's recovery:

. . . We really want to know what are the signs to look out for, which we probably know already. We want to know which ones to really look out for rather than ones that are silly to watch out for. We want to know where we really ought to go [how to help their daughter] and that sort of thing. (P16)

Carers also reported that exclusionary behaviours compromised their relationship with the ill family member. For example, while communication between the health professional and the ill family member was not shared with the carer, communication between the carer and the health professional was often relayed back to the ill family member. This caused additional resentment and interpersonal difficulties between the ill family member and the carer. One carer explained:

This one-way process of patient confidentiality impacts not only on our ability to care but also on our relationship with our ill family member. (P3)

Carers indicated that exclusionary behaviour on occasions placed them 'at risk' from their ill family member. The following excerpt from a carer showed that she had a poor level of knowledge and understanding about her son's schizophrenia. She had been a carer for 4 years and her son was regularly paranoid and very suspicious. It was apparent that she had not been provided with information and education about her son's disorder and could be 'at risk' when her son was unwell:

I have read as much as I can on it [schizophrenia]. I don't fully understand it. I know it is a chemical imbalance in the brain. I know that his symptoms they are never able to complete anything. Is that right? I hope one day he is going to get better. (P17)

Another carer spoke of how she was consumed by the caregiving experience because health professionals' exclusionary behaviours made her feel she was an intrusion in her daughter's life:

They [health professionals] are very arrogant people who would not talk to me without Robyn [daughter] being present. This cancelled out everything [makes it difficult to talk when daughter is there]. They treated me like a huge intrusion in Robyn's life. . . . It was mainly the doctors. They were dealing with Robyn and they didn't want to deal with anyone else. It makes it very difficult [for the carer]. (P12)

Finally, several carers reported that they were excluded except during times of crisis. However, even then the carer was not provided with enough information to fully understand what was happening to the family member as one carer explained:

My wife's psychologist wasn't interested in seeing me. . . . She rang me once to let me know that Rose [wife] was feeling suicidal and told me to keep an eye on her. It really scared me. (P7)

## DISCUSSION

To provide quality mental health care and to sustain carers' commitment to ongoing caregiving, patient confidentiality issues in relation to carers requires review. While health professionals have a requirement to maintain confidentiality (Fitch 1994), in reality this application is not a clear-cut issue. Confusion exists concerning what constitutes confidential information and what information should and can be freely shared with carers (Marshall &

Solomon 2000). The confusion around patient confidentiality is not accordant with the 'partnership in care' model promoted by governments under community mental health care policies (Australian Health Ministers 1992; 1998). Therefore, health professionals require education on the application of patient confidentiality to clinical practice. The findings of this study support Szmukler's (1999) claim that: 'In this era of community care we expect much from informal carers but this has not been balanced yet by mapping out our duties towards them' (p. 337).

Collaboration between health professionals, carers, and consumers can be a rewarding experience for all parties if an ethically sensitive approach to family engagement is negotiated at the outset of treatment. This approach involves spelling out, through the process of informed consent from the patient perspective, the basic steps on which the family involvement can proceed when caring for the ill family member (Szmukler 1999). Agreements regarding what information can and can't be shared with carers should be negotiated at this time. When working with carers, health professionals need to reframe the carer's relationship to one of not only being a family member but also to one of being a carer. Patient confidentiality needs to be negotiated with the family as they contribute so much to the care of the ill family member and as such should be viewed as a 'unit of treatment' (Szmukler 1999). Carers should be given certain information that they need to know, particularly information to ensure their safety and their ongoing commitment to caregiving.

The development of procedural definitions and guidelines related to patient confidentiality in relation to carers is needed at a national and service level. Carers in this study struggled to obtain adequate information about the ill family member in the face of misunderstanding regarding legal restrictions and management policies. It can be argued that a breakdown in collaboration occurred because many health professionals lack understanding of the ethical principles that guide professional practice. Carers have the right to be informed and there are different levels of information that must be discussed with carers and the ill family member to allow them to make decisions regarding what information can and should be shared (Downie & Calman 1994). Health-care professionals, carers, and consumers need to negotiate how patient confidentiality will work in each relationship (Kerridge *et al.* 1998). Moreover, there are cases where confidentiality may need to be breached if the life of the patient or others is in danger.

To understand the mental health system and the treatment the family member is receiving requires much per-

sonal effort on the part of carers (Marshall & Solomon 2000), and Rose *et al.* (2004) found that the system impeded and obstructed the delivery of family support. Among the barriers identified were issues related to patient confidentiality. Marshall and Solomon (2000) claimed that carers need to know, at a minimum, the ill person's diagnosis, the nature of the illness, and the medication prescribed for the affected family member and its side effects (Parker 1993). As patient consent is needed to release information, family members expected health providers to initiate this release process and to work collaboratively with them in caring for the ill family member (Marshall & Solomon 2000). For example, carers are frequently the first to recognize warning signs and symptoms when the affected family member is relapsing (Bogart & Solomon 1999). However, misunderstanding about patient confidentiality prevents carers from being given or allowed to share information that is helpful to this process.

While current treatment guidelines recommend family involvement in all aspects of the treatment process, patient confidentiality issues frequently inhibit this involvement on any ongoing basis. The lack of collaboration and involvement occurs even when research suggests that when carers are provided with sufficient information about their relative's illness, the affected family member's relapse rate and number of readmissions to hospital decrease (Bogart & Solomon 1999). According to Bogart and Solomon, 'without ongoing contact with providers, families may observe signs of relapse but have no means to share this information with providers' (Bogart & Solomon 1999; p. 1323). Effective collaborative practices can provide carers with information that allow them to be more effective carers to the ill family member.

## CONCLUSION

Patient confidentiality issues impacted on carers' levels of well-being throughout the caregiving experience. Carers' exclusion from involvement in the ill family member's care meant that they were left to 'flounder in the dark', and reported that at times they were placed 'at risk'. Carers reported that they had little support from health professionals in managing difficult day-to-day caregiving experience. Collaboration although espoused in policy documents on community mental health care, in reality, is not always practised at the clinical level. Review and negotiation of patient confidentiality issues is required to ensure carers continual support to the ill family members, thus allowing the further expansion of community mental health.

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