



‘Who cares?’ An exploratory study of carer needs in adult mental health

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Abstract

Overall, health professionals have been slow to recognise the needs of families and carers, and have tended to marginalise their input in aiding consumer recovery. Despite the rhetoric of carer inclusion in mental health policy, the continued lack of systematic involvement of carers in mental health systems ensures that they remain outside the realm of core business in mental health treatment. Based on dialogues with 31 participants in a series of focus groups who are directly engaged in caring for an adult with a serious mental illness, this study reinforces the need for carer inclusion and legitimacy, and highlights necessary changes to service delivery that acknowledge carer isolation and secondary stigma. The importance of psychoeducation programs, consistency in case management roles, and better information about the interface with legal systems were seen as particularly critical.

Keywords

carers, caregiving, consumers, mental health services, psychoeducation, policy, qualitative

Introduction

Mental health workers are often confronted with a complexity of issues and a fragmented practice knowledge base for working with families of people with mental health problems (Walsh, 2000). The research upon which this article is based took place within a context of service restructuring where the needs of carers, and carer inclusiveness, were seen as critically important. There had been many changes over previous years in service delivery structures and processes within the service, and these were perceived by staff to have been quite difficult for consumers and their families. Service delivery in the adult mental health area includes specialist assessment

and provision of diagnostic and care coordination services to consumers aged between 18 and 65 years with a serious mental illness, and their families. Integral to carer interventions in this study was an ongoing family group psychoeducation program (developed by Bland, 1987) that promotes practice and research based carer support groups.

This study, developed by a small team of mental health workers from the disciplines of social work and nursing, was an essential part of the overall evaluative framework of family group interventions, albeit with a specified set of research questions. The primary aim and purpose of the study was to assist mental health clinicians, program administrators, and policy

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makers to better understand the experiences, concerns and needs of family carers during times of acute and post-discharge care. The rationale for the study was the hope that better understanding of needs and experiences of carers would assist the planning of carer support interventions and therefore have more positive implications for consumer outcomes.

Studies of carers of people with serious mental illness have been the subject of reasonably extensive research. In 2000, it was estimated that carers ‘...on average contribute up to 104 hours per week caring for a person with mental illness...’ (Mental Health Council of Australia [MHCA] & Carers Association of Australia [CAA], 2000, p. 4). It is well acknowledged that family carers want and expect ‘information and support, and good communication with services’ (Noble & Douglas, 2004, p. 289), and that there are differences in the needs of carers and consumers especially during acute episodes of mental illness (Goodwin & Happell, 2006; Lammers & Happell, 2004). Despite this acknowledgement, there is evidence that the pathways of care delivered by public mental health systems are often complex and confusing, and often fail to engage carers in the treatment process. As a result, carer distress is ‘intensified by structural barriers that [prevent] the fulfilment of family needs’ (Reid, Lloyd & de Groot, 2005, p. 11). Some of these barriers can be seen in conflicts that often exist between carers’ rights to information and consumer’s rights to confidentiality (Goodwin & Happell, 2006). As the journey of caring for a person with a mental illness can often stretch over significant periods of time, the reality is that carers must contend with crises and symptomatic behaviour of their loved ones, while simultaneously mustering the resiliency to continue with their own lives (Bland & Darlington, 1999; Hatfield, 1995; Levine & Ligenza, 2002; Solomon, 1996).

Overwhelmingly, research supports family and carer engagement with mental health services (Chambers, Ryan & Connor, 2001), promotes inclusion of carers in decision-making (Reid et al., 2005; Walker & Dewar, 2001), encourages information exchange and active partnerships in care (Lloyd & Carson, 2005; Rapaport, Bellringer, Pinfold & Huxley, 2006), and acknowledges the difficult and challenging

demands of the carer role and factors that contribute to carer burden (Cleary, Freeman, Hunt & Walter, 2006; van Wijngaarden, Schene & Koeter, 2004).

Families and significant others can play a pivotal role in the long-term treatment and support of an individual with serious mental illness. They are often involved in long-term care, whether the person returns home post-discharge from a hospital admission, lives on his or her own, or resides in a more supervised setting. Provision of timely information, the sharing of information between all interested parties, clarification of roles and responsibilities, and development of a genuinely participatory and responsive culture have been seen as critical (Walker & Dewar, 2001). Significantly, academic literature and government policy, especially the *National Mental Health Plan 2003-2008* (Australian Health Ministers, 2003), *National Action Plan on Mental Health 2006-2011* (Council of Australian Governments, 2006) and the Queensland Government (2003) *Carer Recognition Policy*, accept the establishment of consumer/carer involvement processes at all levels, both individual and organisational, as well as the development of a consumer-focused service. Goodwin & Happell (2006) have rightly pointed out that consumer and carer needs and issues are incorrectly treated synonymously by policy makers. While in the past, government mental health policy documents have tended to discuss consumers and carers as though their needs and desires are essentially similar, more recent policy statements have given dedicated separate space to issues confronting carers; for example, the *National Mental Health Policy 2008* (Australian Health Ministers, 2009). The policy clearly states that ‘the crucial role of carers in prevention, early intervention, treatment and recovery will be acknowledged and respected and provided with appropriate support to enable them to fulfil their role’ (Section 2.7).

The current research project recognises this commitment by focusing exclusively on the experiences of carers. In doing so, it has partially replicated the *Carers of People with Mental Illness Project* (MHCA & CAA, 2000). This national study was largely based on the use of focus groups (composed of carers and mental

health service providers/stakeholders respectively) to identify priority actions to better support and recognise the role of carers of people with mental illness. In designing this local study of carer needs, the mental health practitioners involved agreed that the focus group methodology employed in the national study would also be the most appropriate method of discussing issues and concerns with carers from the participating service.

Methodology

Five qualitative focus groups were conducted to ask: *'What are the experiences and support needs of carers/families that provide care to people with a serious mental illness receiving services from the adult mental health service?'* For the purposes of this study, the term 'carer' applies to a person of any age who, without being paid, cares for another person who needs ongoing support because of a long-term medical condition, a mental illness, a disability, frailty or the need for palliative care. A carer may or may not be a family member and may or may not live with the person (Queensland Government, 2003). All carers in this study were required to be 18 years or over. 'Serious mental illness' includes long-term illnesses such as schizophrenia, schizoaffective disorder, bipolar illness, severe depression, and borderline personality disorder (Levine & Ligenza, 2002).

Participants

Participants for the focus groups were recruited by disseminating information about the study to all staff of the adult mental health service, external organisations that provided support to consumers and their carers, and through Consumer Advisory Groups and posters displayed in the psychiatric inpatient units. Further information about the study was distributed to eligible persons on request who were one of the following: a spouse, sibling, partner, adult child, grandparent, parent or significant other of the person being provided the mental health service. Carers from previous psychoeducation groups were also invited to attend. Participants needed to have been involved with the service at some time in the past 12 months so that their experiences of service delivery and programs were relatively recent. Focus groups were conducted after

ethical clearance had been obtained from the relevant Health Service District Ethics Committee.

Thirty one carers participated in the focus groups. Their demographic information is shown in Table 1. Between them, participants supported 24 consumers, whose demographic information is shown in Table 2. As was the case in the national study, the demographic data show that older aged carers (primarily female) tend to care for younger single males with diagnoses of schizophrenia living in the same home.

Table 1. Demographic characteristics of carers (n = 31)

| Carer demographics | n | % |
|---------------------------------|----|------|
| Sex | | |
| Male | 12 | 38.7 |
| Female | 19 | 61.3 |
| Age | | |
| Over 55 years | 21 | 67.7 |
| Under 55 years | 10 | 32.3 |
| Marital status | | |
| Married/in partnership | 21 | 67.7 |
| Divorced/separated/single | 10 | 32.3 |
| Relationship to consumer | | |
| Mother | 16 | 51.6 |
| Father | 9 | 29.0 |
| Partner | 3 | 9.7 |
| Sibling | 3 | 9.7 |
| Living arrangements | | |
| Living with consumer | 25 | 80.6 |
| Not living with consumer | 6 | 19.4 |

Table 2. Demographic characteristics of consumers (n = 24)

| Consumer demographics | n | % |
|--|----|------|
| Sex | | |
| Male | 18 | 75.0 |
| Female | 6 | 25.0 |
| Age | | |
| Over 25 years | 15 | 62.5 |
| Under 25 years | 9 | 37.5 |
| Marital status | | |
| Married/in partnership | 3 | 12.5 |
| Single | 21 | 87.5 |
| Diagnosis | | |
| Schizophrenia | 23 | 95.8 |
| Depression | 1 | 4.2 |
| Co-existing issues (carer report) | | |
| Illicit drugs | 7 | 29.2 |
| Alcohol | 8 | 33.3 |

Procedure

The focus groups were conducted over a 12-month period, and each two hour session was facilitated by two members of the research team. Where possible, the facilitators were not known to the group participants, in order to minimise biased responses that may relate to a previous favourable or unfavourable experience with the facilitators. Participant consent was obtained on audio-tape at the focus groups, and some demographic data about the carer and about the person for whom they were caring was also obtained. The participants were allocated to groups ranging from six to eight participants. All participants were asked the same six questions, as shown in Box 1.

One benefit of focus group methodology for research of this nature is that the small group format promoted a safe environment where carers could speak about their experiences with others in similar situations. In discussing their contact with mental health services and experiences of caregiving, carers were able to reflect on the stories of others, which encouraged a depth of discussion that resulted in rich data. Participants were given the opportunity to discuss a topic that may in other circumstances be sensitive because of stigma, marginalisation, or lack of opportunity.

| Box 1. Questions asked in focus groups | |
|--|---|
| 1. | Describe what it is like for you being a carer of a person with a mental illness. When you first became a carer, what difficulties did you experience? |
| 2. | Describe the responsibilities that you have as a carer. What are the things you need to know and what skills do you need? |
| 3. | Describe your knowledge of the services provided to carers in this District. What do you know about the services that are available to the person you are caring for? |
| 4. | Have you had experiences of mental health services elsewhere and what were your experiences of these services? |
| 5. | What do you feel you need by way of support from mental health services? What do you feel that you need from other services outside mental health? |
| 6. | If you could specify one thing that would make a positive difference to your life as a carer, what would this be? |

Limitations of this study included a relatively small sample size, a lack of participants from culturally and linguistically diverse backgrounds, and a predominance of parental caregivers. As this was a small practitioner-based research project, carers were not involved in the conduct or design of the study, although there is scope for this in future projects. As a targeted study on carer needs, however, analysis of the data did yield some valuable findings.

Data analysis

Data analysis was conducted thematically, and the research team was collaboratively involved in the coding of transcripts in accordance with the research questions asked in the focus groups. The primary themes were explored under three main headings: (1) experiences of carers in relation to (a) their role as carers, and (b) the mental health system; (2) identified needs of carers in relation to (a) knowledge and support, and (b) mental health systems; and (3) strategies or factors that would improve the experience of caregiving.

Findings: The carer journey in context

Participants in the focus groups spoke readily about what it was like for them being in the primary carer role. Carers talked about periods of acute stress preceding relief when the family member was assessed, treated and admitted to hospital; and about frustration, fear, confusion, grief, loss, sadness, love, anger, respect, exhaustion, hopelessness and hope. Examples ranged from negative comments, such as:

‘There is nothing positive about being a carer,’

‘We spent years treading on eggshells,’ and

‘When I did try to get help, it was like hitting a brick wall,’

through to the optimism expressed when a case manager was assigned:

‘It is the greatest thing that has ever happened.’

The context of caregiving, then, is characterised by diverse experiences and responses, within a journey that starts often well before the time of initial assessment and moves through a number of phases. The following sections examine themes through these phases.

Initial assessment and treatment

When a person first shows signs of mental illness, carers typically experience a period of distress and confusion leading up to the first period of formal assessment and, often, subsequent admission to an acute care unit. Carers enter unfamiliar territory where initial contact with mental health services is commonly experienced as traumatic. This is a time when high levels of support and clear explanations are required. Carers identified three key elements of this first phase. These were anxiety associated with time delays in assessment; lack of inclusion in major decisions; and lack of knowledge about important legal issues. Complicating an already difficult period, carers sometimes dealt with resistant and often frightening behaviour, including threats of suicide and self-harm, or the complications of alcohol or other drugs, while waiting for assessment. One comment about this assessment waiting time was:

'That first day was horrendous waiting for him [son] to be assessed at the Emergency as it was so slow. We were living on edge for seven days to be assessed.'

Additionally, in times of crisis, carers felt that high levels of stress impeded the ability to fully process all the information provided. Several suggested that written information about the basics of mental health services would be useful to take away and read later. As one carer stated,

'When you are in shock, you don't retain the information... with the information pack you could go home and read it later on.'

In addition, carers also strongly identified the need to be listened to and included in the treatment process from this initial point of contact with the mental health service. Whilst some carers had positive experiences at this stage, many felt excluded and alienated from the diagnostic and treatment process. The following comment summarised the need for inclusion in the early assessment stages:

'You know what is normal for this person. You know what is abnormal. You are the people who know that and what you say should be taken seriously. This should be included as part of the initial assessment.'

An issue raised as one of critical importance was that of the legal considerations involved in decisions around the need for hospitalisation in an acute phase of a mental illness. Carers

expressed frustration with lack of inclusion in these decisions, particularly when this involved admission to an inpatient mental health unit; as one carer said:

'She (daughter) was made involuntary without us even knowing.'

Carers were most interested in information pertaining to their rights as carers as well as the Justice Examination Order (JEO) process. One carer commented:

'It took us a fortnight to find out about [JEOs]. We took out a JEO but were terrified for our lives.'

Carers were particularly interested in learning more about the role of the police and the role of mental health services in the JEO process. Responsibilities of all involved in this legal process were not often clear, and overwhelmingly, carers felt this stage of their journey may have been somewhat less traumatic if this information had been more accessible during the initial crisis period. Importantly, carers also felt there was a need for a prompt mental health service response and help, particularly when their family member was threatening suicide. Here again, a 'crisis' information pack was identified as extremely important. Carers recommended the need for an 'Early Psychosis Team' for early intervention – a team which has since been incorporated into the district mental health service. These experiences highlight the need for carers to be treated as legitimate sources of knowledge in the assessment phase.

Carer experiences of mental health service delivery

As carers move beyond the initial period of crisis and into a more ongoing relationship with mental health services, they begin to engage in therapeutic alliances with a range of service providers. Participants provided extensive views about their experiences of mental health service provision across hospital and community settings. As expected, there were significant differences in how mental health services managed responsiveness to carer needs, but common themes emerged: (1) the role of the case manager (seen as crucial by carers); (2) the importance of continuity of care; and (3) the perceived differences between intensive support services and other treatment services.

A case manager or care coordinator is the focal point for provision of a holistic approach to assessment and care. Experiences of the case management model ranged from very poor to very satisfactory, and one carer emphatically stated:

'The case manager to me is critical... without the case manager the whole bloody system falls over.'

Carers spoke about the need to know (throughout the course of treatment) the designated case manager, their role and responsibilities, and the need to have clear communication with this worker. There were concerns about the frequent changes of both case managers and doctors, with carers feeling that case managers, in particular, needed to remain a stable and consistent figure in treatment. It was felt that the timing and frequency of interventions was important and that case managers should be appointed early in treatment and have lower caseloads to enable them to deal with complex issues. Carer access to case managers and doctors was reported to be difficult for some carers who worked full-time, leading to a recommendation for more flexibility with regard to contact.

A significant and notable finding was that carers whose family member was receiving care through a part of the service that specialised in mobile, intensive support and rehabilitation, reported significantly higher levels of satisfaction than those involved with continuing care teams. These findings signal that carer experiences are affected by structures within health systems, including staff continuity and retention, and different innovations in service delivery (such as mobile intensive support and rehabilitation). It is important that mental health services acknowledge the impact of these issues on carers, and ensure that they are included in evaluations of service models. This need for inclusion and legitimacy highlights another important theme: communication as an ongoing part of the relationship between carers, consumers and mental health professionals.

Communication and knowledge: the road to legitimacy

Communication and the need for information and knowledge essentially covered three areas: (1) lack of clarity around issues of confidentiality and privacy; (2) quality of

communication in relation to treatment options and service delivery; and (3) communication of knowledge about discharge planning processes, mental illness, symptoms, medications, treatments and legal issues (commonly the area known as 'psychoeducation').

'Confidentiality' was largely experienced as a mechanism which excluded carers and their role in the treatment process. Carers cited difficulties around the release of information to them at critical points, such as admission, discharge, case management allocation, and clinic case reviews. The legislation regulating privacy and confidentiality was seen to frequently confuse both professionals and families and thus contribute to a lack of clarity both about information sharing and the role of carers in treatment planning. While carers did acknowledge that their family members have a right to privacy, they drew the line on confidentiality when this impacted upon information that they felt they had a need to know. As one carer stated:

'The 'craziness' is that you know that a person is not being treated because of confidentiality, which is really inhumane....'

As expected, carer experiences varied widely in relation to quality of communication with mental health professionals. Some carers reported very positive experiences in their communication with particular doctors and case managers:

'Dr X was brilliant.'

Others had quite negative experiences:

'We had to push to be heard in hospital, both from me and her mother.'

Overall, however, carers expressed a greater degree of dissatisfaction and frustration than approval with the level of communication provided by the mental health services with which they had interacted over time. It was felt that the issue of confidentiality, together with a general disregard and lack of appreciation of the needs and knowledge of carers in relation to their loved one, hindered the treatment process. Consequently, the 'system' was seen by many to be non-conducive to achieving optimal outcomes.

Carers also discussed their perception of the discharge planning process. Again, there were

experiences ranging from total exclusion to appropriate inclusion. Non-inclusion or limited involvement in discharge planning and the crucial transition from hospital to community was a common theme for carers, the majority of whom resided with their family member. One carer related a story about how she was disengaged from discharge planning discussions only to find that her son was to be discharged to her care at a time when she had arranged to be out of the city visiting a friend. This situation caused a great deal of trauma for all concerned, and could have been avoided had communication been more open. Carers also consider involvement and communication about issues that affect their lives to be one of basic respect - they too have lives that need to be accommodated outside of their caregiver responsibilities and they appreciate acknowledgement of this. Some carers did not make complaints about the care and treatment provided by the mental health service for fear that this would compromise the care of their family member.

Psychoeducation has been defined as 'interventions in which the family is offered coping strategies or specific ways of dealing with the challenges of mental illness' (Mottaghipour & Bickerton, 2005, p. 5). Carers clearly identified the need for carer education and support services, including being kept informed of diagnosis, symptoms, medications (particularly side-effects) and treatments. This was seen as most crucial, but not limited to, the time of first contact with the mental health service, and most useful if presented in such a way that complex diagnostic terminology and use of mental health 'jargon' did not impede information provision. As one carer pleaded:

'...plain language please.'

Another carer stated:

'We had talks with the doctor and the case manager at the hospital, but it's really... they do everything for him and not for us... we don't know anything.'

The feedback from carers who had participated in past and more recent versions of the mental health service's six week Family Support and Education Program (Bland, 1987) was particularly positive in terms of information provision and support. Carers noted:

'The knowledge about the family support program was truly excellent and we probably didn't have hardly any knowledge at all until then. That was absolutely excellent,' and *'the family education program made people feel that they were not alone.'*

The initial and evolving complexity of illness issues led carers to identify the acquisition of negotiation, problem solving and counselling skills as essential to their knowledge base.

Information relating to mental health systems and structures was also perceived by carers to be extremely important and lack of knowledge about the mental health system made advocacy on behalf of family members very difficult. This was seen to be particularly important where issues of suicide were involved. Thus, involvement in psychoeducation groups was seen as a valuable way of connecting with others about similar experiences and sharing knowledge gained through personal journeys.

Travelling together: the ongoing family impact

All participants, without exception, reported that living with mental illness impacted significantly on the entire family and dramatically altered their lives. These changes were largely about increased emotional and practical responsibility. Emotional responsibilities included trying to keep the family intact, constant monitoring of the mental state of the family member, and provision of supportive interventions. Practical responsibility involved monitoring of finances, medication compliance, provision of food and shelter, assistance with transport, and accompaniment to mental health service visits and Mental Health Tribunal reviews. Comments included:

'We have all of our son's responsibilities – personal safety, hygiene, financial management....'

'You are sort of everything for a certain period of time.'

Of particular concern was the way that carers described their experiences of looking after family members with a serious mental illness, comparing their family life, for example, to:

'[being in] a war zone for five years,'

'living in a nightmare,'

'[being] terrified for our lives.'

Another said that it was

'like living with a time bomb waiting to go off,'

and yet another described experiences such as,

'having the odd knife waved around'

and receiving threats like,

'I'll blow up your bloody car.'

The sense of fear during times that family members were unwell, psychotic or failing to take medication was often overwhelming for carers. Drug-induced aggression and violence was particularly frightening. As one carer said:

'Our son has a drug problem and people use him... his friends use his home to organise drugs.'

These fears were balanced against awareness that the illness was the problem, and that as long as the illness could be managed, there was greater chance of behaviour returning to a manageable level. One of the difficulties expressed was the ability to distinguish between effects and symptoms of mental illness, and behavioural and personality issues. These experiences often led to feelings of alienation from the ill family member, grief and sadness for the loss of a 'normal life', intense feelings of self-blame, and conflict within the family. As consumers were often lacking in motivation due to their illness, consequences were identified by carers including reduction in employment opportunities, neglect of self-care and changes in social relationships. One carer stated:

'My son's only friends are those with a mental illness and those he met on the ward.'

This isolation, frequently symptomatic of illness, was seen to have a 'rebound' effect for many carers. The secondary stigma of mental illness, together with the family member's growing dependence upon them, led many carers to identify carer isolation as another significant problem. Unfortunately, experiences of this stigma ranged from the general public to family/friends and even some health professionals. One family (whose son suffers from schizophrenia) was deeply disturbed by a doctor's comments in the earlier stages of treatment that their son's illness,

'might have been because he came from a toxic family.'

In fact, one common misconception experienced was that parents were to blame for their son or daughter's condition. Walsh (2000), in discussing the history of family advocacy

movements in mental health, highlighted the distressing effects of this stigmatisation and how this often resulted in professionals treating families with 'critical condescension' (p. 194).

Carers noted that knowledge of mental illness in the community remained very poor and that they were subsequently limited in who they could speak to comfortably (and with acceptance) of their experiences. Some carers reported struggling with

'...how to tell people about the illness.'

Overall, experience of a well-informed community that both recognised and understood mental illness was sadly, but not surprisingly, lacking. Carers subsequently identified the need to raise community awareness and public health education in order to help address this issue. Specifically, suggestions were made with regard to increasing mental health education for general practitioners and for children through the education system.

The survival pack: a solution for the future

As the needs of their family member progressed from the acute phase of diagnosis, assessment, and treatment, and into the recovery phase, the needs of carers also evolved. Carers identified access to rehabilitation and structured activities (for their family member) as extremely important, both in terms of potentially positive outcomes for their family member and as a source of great support and reassurance for themselves. Essentially, carers needed to know that all that could be done was being done. Community-based mental health support groups became very important as a bridge between the family and the outside world.

The enormity of the carer role meant that many carers reported a need for greater access to respite care for their family member. This was seen to be particularly important at times when physical and emotional exhaustion threatened to become overwhelming for carers. One carer states:

'We have nothing like that [respite]'

and talked about times when they were simply worn down. Another said:

'One of the hardest things as a mother is... constantly reminding her of things like washing her hair, having a bath....'

| Box 2. Personal coping strategies identified by carers | |
|--|---|
| <ul style="list-style-type: none"> • Attempt to remain as calm as possible in stressful and difficult situations • Maintain a positive attitude • Attempt to hide own distress from ill family member • Maintain strength and perseverance • Maintain a sense of humour • Maintain a healthy balance between your own needs and that of your family member | <ul style="list-style-type: none"> • Be non-judgemental • Have realistic expectations • Have trust in your own abilities/knowledge • Be assertive with service providers where necessary • Have patience • Remember that carer self-care is important – access support (professional or non-professional) for self if necessary |

As well as periodic respite, a number of carers expressed great concern about the future of their family member’s welfare when they themselves no longer have the physical, emotional and financial capacity to provide care. Carers spoke about the need for reassurance and strongly felt that support and guidance in planning for their family member’s future needed to be provided as part of an overall care program:

‘We need to know that there is going to be a program in place for the future when we are going to be pushing up the daisies.’

In addition to these concerns, carers also talked about a number of personal coping strategies that they hoped would potentially improve the experience of caregiving and be helpful to other carers (see Box 2). Carers also clearly articulated the need for ongoing research. As one carer says, *‘I want answers... like research answers.’*

The importance of this request cannot be underestimated because ultimately, the knowledge of ongoing research equates to ongoing hope.

Discussion

This qualitative study sought to explore the experiences and needs of carers of persons with serious mental illness who had been engaged with an adult mental health service. The data indicate that the current approach to carer-focused service delivery in the mental health service is largely determined by the experience, skills, and focus of individual clinicians rather than a formalised or standardised approach to service delivery and systematic inclusion of carers in service provision and ongoing treatment. This is despite the fact that the *National Mental Health Plan 2003-2008*

(Australian Health Ministers, 2003) recommends that mental health services be more responsive to the needs of carers, and actively develop 'carer plans' and improve information sharing (p. 23).

The priority carer needs identified in this study are largely consistent with those of similar studies in this area, including the *Carers of People with Mental Illness Project* (MHCA & CAA, 2000) which this study in part sought to replicate. Both studies identified the need for carers to be able to access respite and support services, the need for provision of information, and engagement of carers in treatment decisions. In terms of mental health service delivery specifically, the national study indicated that carers consistently reported ‘...negative experiences in their engagement with mental health professional service delivery... [with carers reporting] ...that they are excluded or the recognition of their role is minimised in professional service delivery functions regarding consumer assessment, care/treatment planning and implementation and case review’ (2000, p. 25).’ While the present study also found quality of communication to be problematic at times, it did find that consistency of case management approaches could lead to a more positive experience.

As discussed in the introduction, non-inclusion of carers has been identified by many empirical studies of mental health service delivery as a significant oversight by mental health professionals, and often detrimental to recovery and ongoing treatment of consumers (Chambers et al., 2001; Goodwin & Happell, 2006; Hodgson, King & Leggatt, 2002; Reid et al., 2005). Consequently, the *Carers of People with Mental Illness Project* (MHCA & CAA, 2000) consistently identified enormous delays in

information provision, chance identification of symptoms in family members (e.g., from television rather than from formal health services), and receipt of knowledge from professional sources ‘...in a form unintelligible to a lay person’ (p. 17). The project did acknowledge that there are ‘excellent’ examples of carer practice education in the Australian mental health community. Similarly, our study found that whilst not all carers had accessed available psychoeducation, those who had participated in the Family Support and Education Program rated it as ‘excellent’ and expressed high levels of satisfaction with the program’s efficacy. This finding is different from the Hodgson et al. (2002) study that found experiences of psychoeducation to be unsatisfactory.

Implications for mental health practice and policy

The following strategies have been collated from the carer discussions to provide a way forward for mental health services (and policy makers) who aspire to sensitivity to carer inclusivity.

- Policy documents should ensure distinct and separate participation standards for carers and consumers, and carers should continue to be involved in establishment of these standards.
- Mechanisms should be introduced to formalise and standardise carer inclusion and participation in mental health service delivery (not withstanding confidentiality legislation) across the service. This process should include the review and implementation of carer-focused psychoeducation programs through dedicated 'Carer Support Coordinator' positions.
- A comprehensive, standardised family caregiver assessment tool should be developed. This assessment process would inform the mental health service of the individual needs of carers and the supports required for caregivers to sustain their role. Areas of assessment should include psychiatric history and symptomatology of the ill family member, nature and extent of carer support, carer support systems, carer knowledge (of illness, mental health system and legal considerations), carer coping

strategies, socioeconomic issues, cultural issues, and any other areas of particular concern to carers.

- Generalist case management loads should be decreased, and/or more mobile intensive support teams developed. This would enable case managers and the service as a whole to achieve a stronger rehabilitative focus.
- Strategies and programs must be in place for when family members are no longer able to provide the care their loved one needs. This is a significant and complex issue requiring support and coordination of relevant service agencies at a national level. These agencies should include, but not be restricted to, mental health services, aged care services, home and community care services, housing services, and disability services. It is recommended that funding of special projects to identify and address issues and challenges in this area be seen as a priority.
- The availability of respite care must be increased. If carers do not receive the support they need and deserve, they can no longer provide the care their family member requires. Given that carers currently provide services valued at a substantial amount in economic terms, the cost of carers withdrawing their care is likely to be far more costly than the provision of appropriate carer-focused support services.
- Research into the causes, treatment and potential cures for mental illness must continue to be supported, as well as research into the needs of carers from diverse backgrounds and geographic locations.

Conclusion

This study has validated and verified concerns previously raised in empirical research and literature, and has highlighted several areas that can be translated into strategies for action in mental health service delivery. The findings therefore add weight to the arguments for a more concerted effort to be made in continuing to strengthen processes and systems to legitimate carer inclusion and involvement in treatment and recovery. Attention to carer needs is critical if the support base of the mental health system is to be maintained.

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