



Family and carer participation in mental health care: perspectives of consumers and carers in hospital and home care settings

R. LAKEMAN DipNsg, BN, BA Hons, PGDip (Psychotherapy)

Lecturer, School of Nursing, Dublin City University, Glasnevin, Dublin, Ireland, and Doctoral Candidate, James Cook University, Queensland, Australia

Correspondence:

R. Lakeman

School of Nursing

Dublin City University

Glasnevin

Dublin 9

Ireland

E-mail: richard.lakeman@dcu.ie

LAKEMAN R. (2008) *Journal of Psychiatric and Mental Health Nursing* 15, 203–211

Family and carer participation in mental health care: perspectives of consumers and carers in hospital and home care settings

It is widely accepted that family and carer participation in adult mental health care is desirable. However, rarely is service development informed by representative opinions of both carers and service users. This study took place in the context of a larger project to introduce and evaluate practice standards relating to family participation. The aim of this paper is to explore the perceptions of service users and carers to carer participation in adult mental health services. One hundred and twenty-nine service users and 86 family members recruited via hospital and community settings completed a survey which addressed obstacles to family participation, perceived benefits of participation and areas for improvement. Many service users and family were entirely satisfied with existing levels of family participation. Different needs for information, support and the nature of participation in mental health care are highlighted in acute hospital and community settings. Across settings, the provision of support and accessing services were identified as the most useful aspects of family participation. Meaningful carer and family participation in mental health care should proceed from respectful connection with carers and be informed by need which will vary depending on setting and circumstances.

Keywords: care givers, carers, participation, service evaluation, user involvement

Accepted for publication: 24 September 2007

Introduction

Mental health services have been required to involve consumers and carers in the planning, delivery and evaluation of mental health services for over a decade (Commonwealth of Australia 1997). Services have been challenged to find ways to facilitate meaningful participation with varying degrees of success but surveys continue to reveal that families, in particular, experience marginalization or exclusion from involvement (Mental Health Council of Australia and Carers Association of Australia 2000, Hodgson *et al.* 2002, Lammers & Happell 2004a). Mental health practitioners have been found to be sympathetic to the plight of carers and some express a desire to be more

inclusive (Sjöblom *et al.* 2005). However, it has been suggested that carers and service users can have different and sometimes conflicting agendas that may be difficult to balance (Goodwin & Happell 2006). Rarely have the viewpoints of carers and service users been systematically solicited and reported (Lammers & Happell 2004b).

How carer participation is translated into practice needs to be articulated (Cleary *et al.* 2006). In order to do so, an Australian district health service in partnership with community interest groups introduced explicit practice standards for family and carer participation (see Lakeman 2008). Lloyd & King (2003) suggest that one meaningful way to facilitate carer and consumer participation is to undertake regular surveys relating to

inpatient and community care to determine areas in which services can be improved. This paper reports on a survey of carers and service users in both hospital and community settings regarding their experiences and views of family/carers participation.

Method

This study was part of a larger project which involved the development, promotion and evaluation of practice standards relating to family/carers participation. The practice standards (which were adopted as local policy) required professionals to ask users of the mental health service whom they would like to be involved in their care and the extent of involvement. Two part-time project officers were appointed (one an experienced nurse/researcher and the other, a mother of local service users) for a 1-year period to promote the practice standards to service users, family and staff of the service, and to undertake evaluations relating to family/carers participation. Fuller details of the promotional activities, the standards themselves and details of the respondents are reported elsewhere (see Lakeman 2008).

The protocol was developed in consultation with a steering group consisting of representatives from carer and consumer organizations and senior clinicians in the health service. It included provision of informed consent by phone, and offering written information and adequate time to consider participation. The research was reviewed, approved and monitored by the local Health Research Ethics Committee, and supervision was provided by the clinical director of the health service. Approaching service users and family members directly to inquire about their experience of carer participation was construed to be an essential quality assurance activity. The researchers were not involved in the provision of direct care to any of the respondents at the time the research was conducted thus minimizing potential for coercion.

Instrument

Three open-ended questions relating to obstacles to family participation, how family participation helped and how family participation could have been improved were posed to participants. Questions were adjusted slightly for hospital or outpatient settings, i.e. people were asked to consider a current admission episode or the last 3 months of community care as appropriate.

Data collection

A researcher attended a 'community meeting' on the acute inpatient unit at least twice a week for 3 months and dis-

cussed the practice standards related to carer participation. Information was provided about the project and an information sheet was provided about the survey. Attendees were invited to seek out one of the researchers (who were located on the ward) if they wished to participate in the survey. Those who agreed to participate completed a consent form and completed the survey alone or with the project officer according to their wishes. Most opted to have the project officer complete the survey. Their responses were reduced to declarative statements and read back to the participant for validation.

Attempts were made to contact all people receiving case management services ($n = 230$) except when the case manager recommended against contact (in 18 cases). Attempts were made to contact approximately 100 people by phone (of these seven refused involvement). Letters were sent to 130 people who either requested this mode of contact or could not be contacted by phone. The letter included a personalized invitation, an information sheet, survey and postage-paid return envelope. In some instances in which people had no fixed abode or unstable accommodation, the case manager personally delivered a letter.

As well as completing the survey, service users were invited to nominate a carer or family member who was involved in their care to be invited to participate. Attempts were made to contact these respondents by the mode recommended by respondents, e.g. telephone or mail. An additional 26 carers were identified and contacted from the clinical notes relating to 100 consecutive admissions. All were invited to participate by either returning a survey or responding to questions via phone. In cases of telephone or assisted completion of questionnaires, a standardized schedule of questions was used and verbal consent for participation was recorded.

Data analysis

All responses were transcribed and imported into the NUD*IST software package, and analysed using a summative content analysis (Hsieh & Shannon 2005). According to Weber (1990, p. 70), 'content analysis procedures create quantitative indicators that assess the degree of attention or concern devoted to cultural units such as themes categories or issues'. Unlike strictly qualitative designs, this form of analysis is concerned about external validity (Downe-Wamboldt 1992). Every discrete unit of content was coded and accounted for under themes. Emergent themes were discussed with a supervisor and ambiguous themes recorded. This was seldom necessary as responses were typically short and unambiguous. The frequency of respondents who provided responses in accord with each theme

was quantified and therefore provides an indication of the strength of support for themes.

Respondents

In all, 41 consumer surveys and 53 carer surveys were obtained from the hospital group and 86 consumer and 33 carer surveys were obtained from the community group. Not all respondents answered every question. Consumer respondents were representative of local service users on age, living arrangement, gender and diagnosis. Overwhelmingly carer respondents identified as immediate family members of service users, e.g. mothers (49%), partner/spouse (17%), father (10%), sibling (9%), adult child (5%), grandparent (1%). Friends or some other relationship accounted for 8% of respondents. Hospital and community groups were similar except that partner/spouse relationships accounted for 21% of respondents in the hospital sample vs. 12% in the community sample.

Results

Obstacles to family involvement

Table 1 provides a summary of reported obstacles to family involvement. Relatively more people in the community sample stated there were no obstacles to family involvement. Indeed comments were often highly complimentary, e.g. 'Everyone has been fantastic'. Family participants in hospital provided more qualified comments, e.g. 'At first, I was not given an opportunity for involvement, but now things are going well in that regard'. Another stated, 'At the start it was difficult to engage with mental health workers. Once he was on an order, this improved'. Only service users in the hospital sample group ($n = 4$) stated that families did not want to be involved or that violence or conflict precluded involvement.

The tyranny of distance

Respondents in all groups acknowledged that distance posed an obstacle for involvement with family or friends living in other towns or states. Some parents were identified as having English as a second language, which created difficulties for monolingual staff communicating via telephone. Some service users stated that family in other towns may not know about their illness while others stated that family provided as much support as they could despite being far away.

Lack of family understanding

Service users in both hospital and community commented that lack of family understanding was an obstacle to family involvement. Several stated that their family did not understand their condition. Sometimes a lack of trust was also cited, e.g. 'My sister's children live with my parents so I have to leave when they come home'.

Poor communication

Groups had different perspectives on the nature of communication problems and how these posed obstacles to carer participation. A service user in hospital stated that there was 'a lack of contact' between staff and family, but paradoxically the mother stated there were no obstacles and rated collaboration highly. Another stated that their family '... was given too much leeway to provide their point of view and converse with doctors without allowing me to present my point of view. I felt like an anonymous third party during this conversation'. Poor communication was most often cited by family in the hospital group. One father commented near the end of his daughter's 13-day admission, 'At this stage there has been no involvement unless I have initiated it'. Another said 'We didn't know he was in there at first'. Some respondents reported not being contacted at all, despite the patient living with them or clear evidence of their being involved in the patient's care.

Table 1

Summary of reported obstacles to family involvement with the frequency of respondents who mentioned the themes

Theme	Consumers – hospital	Family – hospital	Consumers – community	Family – community
Number who responded to this question	25	46	79	34
No obstacles	9 (36%)	18 (39%)	45 (57%)	21 (62%)
Family don't want to be involved/conflict	4			
The tyranny of distance	6	3	6	2
Lack of family understanding	3		12	
Poor communication	3	12	7	4
Waiting time	2	8		
Lack of or dissatisfaction with services		6	7	
Need for independence/personal choice			9	6
Concern for the well-being of family			4	
The person's condition/behaviour				4

Some people clearly wanted to be involved, e.g. 'None of the family really know what's going on about her illness. I'd like to take some of the burden'. However, a member who did initiate contact expressed frustration, e.g. 'I rang on numerous occasions regarding his changing mood/depression while under our care. They were not interested until they saw him go to the other extreme'.

Only one respondent cited confidentiality as a potential obstacle, e.g. 'I know staff won't discuss mum's health with me'. There were several examples provided of family not being provided with information despite the service user perceiving it as necessary, e.g. 'The hospital didn't tell them anything'. The consequences of this were profound for some, e.g. '... I feel the lack of information as to my condition passed on to my family, may have resulted in them forming premature conclusions and as a result [they] have totally abandoned me'.

Waiting time

Service users and family in the hospital group described waiting time in the emergency department or the process of admission frustrating. One respondent said it was 'long, intense and very stressful'.

Lack of or dissatisfaction with services

A small number of family respondents in the hospital sample expressed dissatisfaction with other aspects of the service, e.g. 'There are not enough case managers...'. Another family member stated that no one spoke to them at the hospital but when the person was allocated a case manager they then had someone to talk to. One respondent stated his brother had been discharged too early and another suggested that doctors '... had little direct observation of the patients and what they did' and consequently they believed the medical diagnosis was wrong. Others were suspicious of medical judgments, e.g. 'The individual nurses were extremely good. Our relations with them were excellent. The doctors were not so given to consulting with us and made some judgments that did not seem right'. Comments by community service users related to the inaccessibility of case managers or that they were not receiving the kind of services that they thought would be helpful, e.g. psychotherapy.

Need for independence/personal choice

Both service users and family in the community groups described a need for independence or a choice about the nature of involvement at that time. This did not mean that there was necessarily a rift with the family, e.g. 'My family was involved [in my care] years ago but not recently. I am still close to my family'. Another person said 'I have in the last three months moved out of a need for intensive care by

my family and the mental health professionals. I am doing well and am keeping good contact with family and mental health staff'. Others simply exercised a personal choice not to have their family involved in their treatment, e.g. 'My family is not involved because I didn't ever invite them'. Another stated that he shared information with his family, and not mental health staff.

Sometimes respondents gave accounts of when their personal choice about the nature of family involvement was not respected, e.g. 'The professionals were checking my story with my adolescent daughter. This added to the friction which started my bout of illness'. This respondent was accepting of her children being kept informed of her treatment but was unhappy about the veracity of her story being challenged in the eyes of her daughter, thus undermining her parental authority.

Six community family respondents acknowledged that they had limited involvement with mental health services because they did not perceive there was a need, and/or out of respect of their family member's autonomy, e.g. 'There has been no need for me to be directly involved at this point. I ask X how things are going and he tells me where he is at. I am under the impression from X that if I am concerned about anything I can contact mental health services without a problem'.

The well-being of family

Several community service user respondents reported that their family were elderly or disabled themselves and thus could not contribute to their care or treatment. Others said they were worried about their family or acknowledged that sometimes their behaviour was frustrating or concerning to their family.

The person's condition or behaviour

Four family respondents identified aspects of their family member's behaviour that caused conflict or alienated them from others, e.g. the person's temper, requests for money, aggression or lack of motivation were cited as obstacles to involvement.

How has family participation helped?

Table 2 provides a summary of the themes relating to how family participation has helped. Of the 173 responses to this question, 23 (13%) simply reiterated that family participation was helpful, e.g. a service user responded '[it] helped make me well again'. Two community family respondents stated that they did 'everything for' their family member.

Twenty-nine responses (16%) mostly from service users commented that family participation wasn't helpful and

Table 2

Summary of reported ways that family has helped in care and treatment with the frequency of respondents who mentioned the themes

Theme	Consumers – hospital	Family – hospital	Consumers – community	Family – community
Number who responded to this question	24	42	77	30
Family participation did not help	5	5	19	
The provision of support	11	15	37	16
Facilitating/accessing care	4	12	11	11
Working as a team				4

some were critical of their families and the level of support they received. A number of reasons for non-involvement were cited:

1. Family were not involved in their life, e.g. 'My son came [to this town] but did not come to see me'.
2. Family were perceived to 'not care' about or 'understand' them, e.g. 'It hasn't helped as my family don't want to know about it, especially my mum'.
3. Family were perceived as a hindrance, e.g. 'They were meddlesome. I have improved when I was in control'.

Several people said they relied on health professionals in the absence of family. One person said that nothing helped when on medication and another said that he was happy 'doing his own thing'. Some family respondents from the hospital sample were ambivalent about whether or not their calls or contact helped, e.g. 'I wasn't able to help much as we are separated so I stood back a little. I still see him regularly and try to help'.

The provision of support

The dominant theme across groups was the provision of practical, material and emotional support that family provided. People's responses appeared as much about involvement in people's lives as about mental health care. An inpatient service user said that family helped '... by caring, looking after my animals doing my housework. Just being there'. One respondent summed up material support as 'Mum brings me cool stuff'. People spoke of the value of family 'being there', providing 'stability' 'enduring the storm', e.g. 'I am a severe bipolar and my episode was particularly severe to start with. However, my husband ... "weathered the storm" and made daily visits; always bringing some tasty tit bits such as biscuits, grapes and cherries'. People also spoke of valuing a non-judgmental and encouraging attitude that their family had learned to adopt or the 'understanding' and 'care' of particular family members that they found helpful.

Hospital family responses emphasized the helpfulness of 'presence' and 'belonging'. Some respondents pointed out that they would 'always be there' for their family member and that it helped for people to know that. One summed up that 'A bit of care and attention from family goes a long way psychologically' and others observed that the con-

sumer appeared 'better' or 'cheered up' after a visit. People also described practical and material assistance such as looking after children or bringing children to the consumer when their family member was unwell. One person said that they changed their working hours so that they could be with their relative in hospital. Other activities included bringing clothing or lending money. Some people cited educative support, i.e. attempting to reinforce medical advice or assisting the person to trust the healthcare team. One respondent cautioned, 'If the family is involved, the consumer is sent home more quickly ... sometimes too quickly'.

Service users in the community (57%) sample described combinations of different kinds of support that family provided. People repeatedly stated that it was 'reassuring' to know that one 'belongs' or has access to 'empathetic' or 'understanding people', e.g. 'In the last three months my family has continued to be a good emotional support for me. I can now speak freely about the symptoms of the illness ...'. Another stated '... Without them [family] I would be worse. When deeply depressed you need family and good friends. They bring you self-esteem'. The simple act of talking appeared to be valued highly, e.g. 'Schizophrenics need someone to talk to – especially our families'. A consequence of emotional support was the facilitation of hope, e.g. 'Their involvement gives you hope that everything will be all right some day'. Examples of practical or material support included help with keeping the house clean, shopping, child care, visiting and going on outings. One person stated 'He [father] pays all the bills and does all the shopping because I have lost the comprehension to do it'.

The majority of community family described practical support and alluded to the emotional support they also provided, e.g. 'I take this person to my home every Wednesday and Sunday. I encourage him to phone his family who live down south. I often take him [to the community centre] if his case manager is unable to. We do grocery shopping together on pension day which he says is a big help'. Others described simply 'being there for them' or '... showing them they are loved'. People described encouraging their family members in various ways, e.g. to exercise, maintain a healthy diet, maintain a social life, establish or maintain a routine, take medication, solve problems and manage

Table 3

Summary of responses to question of how family/carer participation could be improved with the frequency of respondents who mentioned the themes

Theme	Consumers – hospital	Family – hospital	Consumers – community	Family – community
Number who responded to this question	20	43	70	32
Improve sharing of information	3	11	8	1
Increase/improve access to family	2	2	8	
Improve family functioning	3	1	9	2
Improve adherence/access to treatment	1	2	1	6
Improve services generally	1	6		9

health. Practical assistance towards these ends was also provided such as accompanying the person to appointments, having them around for dinner, going on walks, sharing holidays, assisting with correspondence and paying bills. One respondent stated 'He would have no housing and be on the street without our involvement . . . '.

Facilitating/accessing care

Two of the hospital consumer group explicitly expressed gratitude to family members for intervening at a time of crisis, e.g. 'Without my mother's help . . . I believe that I would have probably been successful in taking my life'. Two others spoke of the value of planning for crisis, e.g. 'Both my family and I have agreed the best way to keep up my relationship is to be in hospital if unwell'.

Five of the hospital family respondents described recognizing the warning signs that the person was becoming unwell and acting to have the person seen by a health professional who arranged admission to hospital, e.g. 'Because I saw he was ill, I had him admitted and he has now been treated and appointments made for him'. Two people said that they were always the one who initiated contact with health services on their relative's behalf, e.g. 'X relies on me to be the one who makes the initial contact because she has lost her initiative. My point of view has always been valued by staff'. People also suggested that the personal knowledge and relationship that they had with the person could help prevent hospitalization, e.g. 'Mum's illness depends on a balance of family and professional involvement. There are patterns and we watch her for signs. A tiny intervention will prevent a hospital stay'. Several respondents pointed out that having a partnership between health professionals and family, and sharing background information was helpful to everybody, e.g. 'Having family aware of plans helps create a unified and cohesive treatment plan which the client is happy with'.

Eleven people in the community consumer sample described assistance by family with managing aspects of the illness or treatment as helpful. More often people said that family understood their illness, what caused them stress and were available to talk, a thing through which was

helpful in preventing relapse. Two people described family seeking professional advice or contacting a doctor when they were ill. One person acknowledged that family assisted with having an oversight function in relation to their care, e.g. 'Family participation has been used because we don't necessarily agree with the psychiatric unit . . . '.

Community family spoke of their capacity to respond to or interact with their family member in positive ways to enhance their wellness, e.g. 'I think I calm mum down a lot. When she is calm I can help her see things differently so that she can manage her illness'. Sometimes having an oversight or monitoring approach was described, e.g. ' . . . I am guided by X's comments. If he has a concern I ask him how it will be resolved. In the majority of case he has the right approach'. This oversight was to ensure quick intervention in the case of illness, e.g. ' . . . to act quickly in case of sickness, e.g. bronchitis recently . . . In our case there are many more disabilities than mental illness . . . '. Another said 'We have been able to tell workers about his symptoms when he has been too ill to do so . . . '.

Working as a team

Four community carers described working as a team with mental health professionals and consumers to mutual benefit, e.g. 'We have got things down pat . . . X the nurse . . . Y the doctor . . . We work as a team . . . I have my own mental health problems and together we support each other.' Others suggested that regarding all parties as a team reduced stress (for all), reduced the potential for 'divided loyalties', and increased service responsiveness.

How could family/carer participation be improved?

The majority of responses to this question reiterated that family participation could not be improved, did not need to be or circumstances did not allow for greater participation. A summary of themes directly related to how participation could be improved is outlined in Table 3.

Improve sharing of information

Some respondents in all groups recommended improvements in information sharing. Hospital consumer respon-

dents recommended providing information about progress and literature about illness to families. Family groups were more pointed about desiring specific information about treatment and discharge arrangements and wanting to be listened to. Five from the hospital family group recommended more information for families particularly when it is their first experience of hospitalization. Some wanted more direct lines of communication with physicians. One community family member who had recently been informed that she was welcome to accompany her mother to appointments said, 'Families should be informed that they are welcome to see the psychiatrist. I could make sure mum would be helped to move forward and that I understood the medications'.

Increasing/improving access to family

The hospital sample recommended extended visiting times and less restrictive access to phones on the acute unit. Eight of the community consumer sample commented that they wished that their family or friends would visit more often or be more involved in their lives.

Improve family functioning

Improving family functioning and communication within the family was a dominant and important theme for service users. This theme subsumed increasing family understanding of the client and mental illness. Service users recommended family therapy or counselling, 'teaching parenting skills', improving communication within the family, families owning responsibility for problems and treating members with respect. Family members recommended group family therapy.

Improve adherence/access to treatment

One consumer in each group stated that if they had taken medication it would have helped. Family respondents recommended accessing services earlier. Other comments related to increasing the amount of contact between service users and case managers or therapists, e.g. '. . . He told me he feels very much alone. He would like to talk to a therapist. I have heard other people with mental illness saying the same thing'.

Improve services generally

Lastly, many comments related to improving services generally. It was not always apparent how this might improve family participation but it did illustrate the general concern for the well-being of service users. Comments related to people's specific experiences and problems encountered with the health service. Some family members recommended consistent application of rules as they had received conflicted advice about visiting on the acute unit. Others

recommended greater continuity of case managers, reducing waiting time in the emergency department and increasing consultation times with doctors.

Discussion

The demographic and diagnostic criteria of service users from inpatient and community settings (reported in detail in Lakeman 2008) suggest that service users who participated were representative of those who used mental health services in this district. Hospitalized consumers tended to participate close to discharge date. Given that service users nominated particular family members for invitation to participate (and some choose not to nominate anyone), it is uncertain whether family/carers who participate are representative or 'typical'. Those service users who chose not to participate and family members who did not have the opportunity to participate might well have different perceptions regarding participation. Cleary *et al.* (2006) point out that service users and carers are not homogeneous groups and often have different perceptions from each other and mental health practitioners. This survey does, however, present a cross-section of opinions about how family participation might be of assistance in hospital and community provision of mental health care.

The researchers were both involved in promoting standards relating to family participation and thereby encouraging positive family participation. In many instances they were also known and trusted by respondents. This may have influenced people's responses, although there appeared to be no obvious differences in tone and content of surveys that were completed anonymously. There was also no evidence at the time or in subsequent feedback that completing the survey was at all distressing.

Family and service users perceived the needs in relation to acute care and community care somewhat differently. Östman *et al.* (2005) found that being a close relative and living together with a severely mentally ill person in an acute situation influence the experience of burden and participation quite independently from the person's diagnosis. Hospital service users and carer respondents in this survey acknowledged a greater need for families to share their perceptions of the crisis situation, be involved in treatment and discharge planning, have explanations of treatment and negotiate personal support. Both service users and family members from the community sample acknowledged that the need for formal involvement in care planning was less important when the person was well. As people recover the need to re-establish or maintain independence, ordinary familial relationships and a degree of respectful vigilance, to protect the consumer or to promote health were emphasized.

A common thread across all respondents was the need for basic respectful engagement and ready access to advice and help if needed. This is consistent with Mottaghypour & Bickerton's (2005) observation that connection with families is the foundation for all further interactions or interventions. This initial connection often occurs during acute crisis when carers and service users might be experiencing the most distress and disruption, and are challenged to make sense of and navigate mental health services as well as illness. Some nurses in a study by Goodwin & Happell (2006) were concerned that service users and carers might have unrealistic expectations of what practitioners could provide. In this survey the expectations of participation and recommendations for improving care were modest and commenced from a desire for good treatment and respectful communication.

Many service users expressed a view that their family did not understand them or their illness and made recommendations around improving family functioning as a way of enhancing family participation. A small number of service users alluded to dissatisfaction with the way problems were perceived to be theirs or misattributed to them by family members and health professionals. Indeed, many of the problems that people bring with them during acute crisis are shared issues or challenges but are construed differently depending on the person's position. Some service users and carers clearly viewed problems as arising between them (Becvar & Becvar 2000) not just within family members and recommended family therapy as a way of tackling difficulties. This is somewhat at odds with Hatfield & Lefley's (1987, p. 5) assertion in relation to families of people with schizophrenia that 'These families do not need treatment. They need education, advice and support'. This survey suggests that at times people may need both or at least treatment in the sense of facilitating communication between family members.

The needs of families and carers defy simplistic classification and prescription. For example, the needs of families who struggle to maintain some equilibrium and to provide support to a young person grappling with psychosis and addicted to amphetamines are somewhat different to the married couple whose relationship has become stagnant, communication absent and one or both severely depressed. To some extent, there is a tension between the need to treat mental illness and assisting in addressing the problems of living that people present with, arise from or are compounded by mental illness. Many respondents spoke of a lack of or deficiencies in the nature of services. For the most part they were not alluding to a lack of medical treatment but a plethora of other issues for which emotional, material and practical support might be more useful but that is not always forthcoming from mental health services.

Conclusions

Service users and carers emphasized and valued fairly unremarkable but essential ways that family and carers provided support. Support activities were not construed separately from participation in mental health care. Indeed, any demarcation between mental health care and other care makes little sense to family and carers whose responsibilities and relationships persist regardless of whether or not someone is involved with mental health services. For this reason mental health services need to support family and carers as the natural source of support for service users. Families, carers and service users have different but related informational and support needs, which vary depending on their familiarity with the mental health service, the acuity of problems, the presence of crisis, and the context in which care takes place.

Acknowledgments

This project was made possible by sponsorship from Queensland Health, the energy and enthusiasm of steering group members over the life of the project and the participants who generously shared their experiences. The steering group included the following people: Dr John Allan, Peter Edwards-Davis, Jill Edwards-Davis, Barbara Dennis, Andy Frogatt, Desley Gray, Phillipa Harris, Walter Humphreys, Graham Smalley, Lyn Tyson, Marilyn Voss and Kate Young. Members represented the Townsville Mental Health Service, the Townsville Consumer Advisory Group, Carers Queensland, The Migrant Resource Centre, the Mental Illness Fellowship of North Queensland, The Association of Relatives & Friends of the Mentally Ill and the Department of Premiers.

References

- Becvar D.S. & Becvar R.J. (2000) *Family Therapy: A Systemic Integration*. Allyn and Bacon, Boston, MA.
- Cleary M., Freeman A. & Walter G. (2006) Carer participation in mental health service delivery. *International Journal of Mental Health Nursing* 15, 189–194.
- Commonwealth of Australia (1997) *National Mental Health Standards*. Australian Government Printer, Canberra, ACT.
- Downe-Wamboldt B. (1992) Content analysis: method, applications, and issues. *Health Care for Women International* 13, 313–321.
- Goodwin V. & Happell B. (2006) Conflicting agendas between consumers and carers: the perspectives of carers and nurses. *International Journal of Mental Health Nursing* 15, 135–143.
- Hatfield A.B. & Lefley H.P., eds (1987) *Families of the Mentally Ill*. The Guilford Press, New York.
- Hodgson O., King R. & Leggatt M. (2002) Carers of mentally ill people in Queensland: their perceived relationships with pro-

- fessional mental health service providers: report on a survey. *Australian E-Journal for the Advancement of Mental Health* 1, 1–15.
- Hsieh H. & Shannon S. (2005) Three approaches to qualitative content analysis. *Qualitative Health Research* 15, 1277–1288.
- Lakeman R. (2008) Practice standards to improve the quality of family and carer participation in adult mental health care: an overview and evaluation. *International Journal of Mental Health Nursing* (in press).
- Lammers J. & Happell B. (2004a) Mental health reforms and their impact on consumer and carer participation: a perspective from Victoria, Australia. *Issues in Mental Health Nursing* 25, 261–276.
- Lammers J. & Happell B. (2004b) Research involving mental health consumers and carers: a reference group approach. *International Journal of Mental Health Nursing* 13, 262–266.
- Lloyd C. & King R. (2003) Consumer and carer participation in mental health services. *Australasian Psychiatry* 11, 180–184.
- Mental Health Council of Australia and Carers Association of Australia (2000) *Carers of People with Mental Illness – Final Report*. Commonwealth Department of Health and Aged Care, Canberra, ACT.
- Mottaghypour Y. & Bickerton A. (2005) The Pyramid of Family Care: a framework for family involvement with adult mental health services. *Australian E-Journal for the Advancement of Mental Health* 4, 1–8.
- Östman M., Wallsten T. & Kjellin L. (2005) Family burden and relatives' participation in psychiatric care: are the patient's diagnosis and the relation to the patient of importance? *International Journal of Social Psychiatry* 51, 291–301.
- Sjöblom L., Pejler A. & Asplund K. (2005) Nurses' view of the family in psychiatric care. *Journal of Clinical Nursing* 14, 562–569.
- Weber R.P. (1990) *Basic Content Analysis*. Sage, Newbury Park, CA.