

"How much more can we lose?": carer and family perspectives on living with a person with depression

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Although carers and families of people with mental disorders are a crucial part of health and community support systems, their experiences are rarely explored systematically. Reviews of the quality of general healthcare now place emphasis on the collection of patient experiences.¹ In the mental healthcare setting, internationally,² and in Australia,³⁻⁵ such processes are being expanded to capture information from carers and families.

The experiences of carers and families of people with mental disorders are particularly salient. Adverse interactions between people with mental disorders and their intimate partners or other family members predict poor health outcomes, and this is particularly true in the case of depressive disorders.⁶⁻⁹ By contrast, a supportive, intimate or family environment predicts better outcomes.^{6,8} However, the quality of such an environment may change progressively in response to illness-related factors, which include the chronicity of illness and its impact on social, economic and interpersonal functioning, as well as other adverse interactions with healthcare, social welfare services, and the employment and insurance industries.¹⁰ Other studies have identified the problems associated with caring for people with depression,¹¹⁻¹⁴ including constraints on work, finances, social and leisure activities, marital relationships and intimacy, together with detrimental effects on the mental and emotional wellbeing of carers.

As part of the review of the second phase (1998–2003) of Australia's National Mental Health Strategy,¹⁵ information, both quantitative and qualitative, about the quality of primary care and specialist mental health services was collected from health professionals, people with mental disorders, carers and family members.¹⁶ The review uncovered feelings of frustration with the lack of implementation of key aspects of the proposed national mental health reforms.¹⁶ Previously, we have reported on the broader social and healthcare system experiences of people with depression.¹⁰ Both these processes suggested that there was a need to explore further the specific nature of the grievances expressed by carers and families of people with depression.

METHODS

Participants and questions

Between February 2002 and July 2002, focus groups were conducted in six Australian capital cities with people who directly

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ABSTRACT

Objective: To explore the experiences of carers and families of people with depression.

Design and setting: Structured focus groups conducted in six Australian capital cities between February 2002 and July 2002. Thematic analyses were conducted using the QSR NUD*IST software package for qualitative data.

Participants: Thirty-seven carers or family members.

Results: Thematic analyses highlighted five key themes. Most notably, the carer's role is made more difficult by the lack of community awareness about depression, and, in some instances, an unwillingness of other family and friends to provide ongoing support. Carers experience a resulting sense of isolation, often exacerbated by adverse experiences with healthcare providers. Carers and family members are frequently excluded when key decisions are made, and report that emergency services are relatively unresponsive to their concerns. By contrast, community support organisations usually provided a sense of inclusion and common purpose.

Conclusions: The experiences of carers and families of people with depression highlight the urgent need for more extensive community education about the illness and more productive collaboration within the healthcare system.

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cared for, or were partners of or in the same family as, a person with a diagnosis of unipolar depression. Participants were recruited through prior written contact with *beyondblue: the national depression initiative*, contact with the *beyondblue* website (www.beyondblue.org.au), and/or participation in other current Australian consumer or carer organisations for people with mental disorders (ie, Association of Relatives and Friends of the Emotionally and Mentally Ill, and Carers Australia). Each focus group involved two sessions, with the same participants invited to attend each session. All 12 focus group sessions consisted of five to eight participants, and lasted about 2 hours. Participants were paid a nominal fee for their time and travel expenses.

The sessions were conducted by one of two experienced facilitators (N J H or B G McN) and followed a structured format whereby six stem questions were asked and then discussed openly within the group (Box 1).

Analyses

Responses from each session were collated from transcripts of audio recordings and subjected to thematic analyses using the QSR NUD*IST software package for analysing qualitative data (QSR N6).¹⁷ To be considered a key theme, the subject matter was required to

- have spontaneously and consistently arisen across all focus groups and interviews; and
- reflect the experiences of at least a third of all participants.

1 The six stem questions asked during each focus group

- What did you first recognise that wasn't quite right with the person with depression?
- What did this mean to you?
- How did this impact on your relationship?
- How did you come to seek help for the person with depression?
- What was the impact of the illness on other members of the family?
- As a carer, what do you need from the healthcare system and the wider society?

Univariate data analyses were conducted with the Statistical Package for the Social Sciences.¹⁸

Ethical approval

Institutional ethics committee approval was obtained from the University of New South Wales Committee on Experimental Procedures Involving Human Subjects.

RESULTS**Participants**

Twelve focus group sessions (37 participants; mean attendance, 6; range, 5–8) were held in six Australian capital cities — Adelaide (5/37), Brisbane (7/37), Canberra (5/37), Melbourne (8/37), Perth (7/37) and Sydney (5/37). Participants' ages ranged from 23 to 65 years, and there were similar numbers of women and men (22/37 v 15/37; $\chi^2 = 1.32$; $P > 0.05$). "Carers" included parents (19/37), partners/spouses (15/37) and siblings (3/37).

Themes

Qualitative analyses of the transcripts revealed five key themes. These are expanded in Box 2 (page S8).

DISCUSSION

Carers and families of people with depression face a broad range of everyday difficulties that are exacerbated by the nature of the illness, feelings of social isolation and a severe lack of understanding, empathy and support, not only from the wider community but also from healthcare providers. People participating in this style of enquiry are likely to have extensive and often adverse experiences to report. In that sense, they are not likely to be representative of carers of people with less severe, less persistent or less disabling forms of illness. However, the experiences reported here are consistent with other previously published research highlighting a lack of community understanding about depression,^{19,20} and the frustration experienced by those who need to access mental health services.¹⁶

Our study extends previous research by highlighting the specific experiences and needs of carers and families. Often depression is viewed as a rather trivial or transient disorder both by members of the general public and healthcare providers.^{10,20} The experiences reported here are consistent with other reports that, at least for some carers, there is a significant and unrelenting burden,¹² and that this burden ultimately contributes to the strain on relationships¹¹ and may jeopardise the mental and physical well-being of the carer.¹⁴ The lack of respect for or engagement of carers

within the healthcare system was also indicated, and is consistent with experiences reported both overseas¹¹ and in Australia.¹⁶ Finally, this work is consistent with studies examining the impact of carers of people with other mental illness, including schizophrenia and psychotic disorders,¹¹ eating disorders,²¹ generalised anxiety disorder,²² and obsessive-compulsive disorder.²²⁻²⁴

In addition to supporting widespread quantitative research, our study's qualitative methodology allows a more detailed exploration of carer experiences, providing insight and understanding into the nature and extent of the burden for carers of people with depression. It assists our efforts to develop more appropriate measures of the impacts on carers for use in larger-scale and longitudinal quantitative studies. Accurate portrayal of the personal experiences of both consumers and carers affected by depression highlights the need to increase awareness and understanding, as well as reduce stigma, and, in doing so, foster a more literate, empathic and supportive community.¹⁶

The qualitative approach reveals how experiences with healthcare services may further exacerbate the burden of care, as too often current practices frustrate and isolate carers. Excluding carers from providing or receiving important information, particularly in crisis situations, is likely to lead to adverse outcomes. The legitimate roles of carers and families within our healthcare systems require formal recognition and promotion. Furthermore, future undergraduate and postgraduate medical education needs to emphasise skills that foster collaborative partnerships between people with depressive illness, their carers and healthcare providers.

The current research reveals that community agencies are often the sole avenue of support for carers. For carers and families of people with depression, such agencies are not as well established as those for people with schizophrenia or dementia. In response to this perceived lack of national coordination, *beyondblue* has established a new national association, *blueVoices*, which promotes the interests of people with depression and their carers and families.²⁵ Other national agencies, such as the Mental Health Council of Australia,²⁶ with its new National Consumer and Carer Forum (NCCF),²⁷ and SANE Australia,²⁸ also play key roles.

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COMPETING INTERESTS

None identified.

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2 Themes from focus groups for carers, family members or partners of people with a diagnosis of depression

Theme 1: Direct impacts of depression on carers

The impact of living with and/or caring for someone with depression is intense and persistent. Carers report they are often unprepared for the profound and broad impact that the illness has on their family, work and social life. In particular, carers described their continual concerns over safety. This was likened to “living on the edge of [my] seat” and never being able to be “off duty”. Carers received little reprieve from their caring role. This was further compounded by a lack of faith in the capacity of the healthcare system to respond to crisis calls. Over time, the intensity of the interaction and the lack of reprieve were felt to have adverse effects on the health and wellbeing of the carer.

- *There is constant emotional tension . . . everyday I wake up and think — “What is going to happen today, what will they be like?”*
- *You come home from work, you get changed and you’re on. It’s like working double shifts.*
- *You have to be ever-vigilant . . . everyday there is a potential crisis.*
- *When a dog goes to sleep, it always has one ear up — that’s what it’s like to care for someone with depression.*
- *You live each day feeling like you’re walking on eggshells.*
- *We’re on call 24 hours a day . . . we have our phone by our bed all the time. Everywhere we go we have a phone with us.*
- *I couldn’t stand his suffering . . . I was getting severely depressed myself.*
- *You can only keep propping the other person up for so long, then you feel deflated and exhausted . . . and then you start to feel down.*

Theme 2: Impacts of depression on intimate relationships

Carers described intense feelings of sadness and loss when the depressive illness persisted. Often, the focus of this sadness was the loss of intimacy with the person with depression. This was further compounded by the side effects of medication. The adverse impacts of depression on interpersonal functioning, coupled with the sense of isolation that accompanied the caring role, often increased the potential for more permanent breaks in marital, family or personal relationships.

- *This is not the person I married 4 years ago . . . he is just a shadow of who he was, and that is sad.*
- *One of the hardest things to do . . . is to step back from being a carer and resume being what you were before this thing happened.*
- *She is so withdrawn and standoffish . . . she doesn’t like to be touched or for me to be close — and that is really hard.*
- *Our love life used to be really good. She used to enjoy making love, she used to have orgasms . . . on medication it’s all gone . . . she feels nothing. So we don’t make love.*
- *You sacrifice so much, unwillingly, but nonetheless you do, to facilitate your life . . . but apparently I’m falling down in these areas. It’s very difficult in a relationship sense.*

Theme 3: Lack of broader social support

The difficulties of the caring role were often exacerbated by a sense of lack of support from other family and friends. That is, the illness experience not only isolated the person with depression but also their carer or close family. This social isolation is further compounded by a lack of awareness among other social contacts in the broader community. Such lack of awareness was often accompanied by active avoidance of both the consumer and their carer or close family.

- *I lost a lot of friends. It actually took all my time away from my life just trying to keep her entertained, trying to keep her active.*
- *She didn’t want to go out, so we didn’t go out. We’d knock back invitations . . . then they stopped coming, so we stayed home.*

- *I don’t know whether it was because they were actually genetically related and maybe they thought they were going to catch it or something. But [the family] . . . would back off and you wouldn’t hear from them. It hurt . . . it really hurt.*
- *They didn’t come near me because they didn’t know what to say.*
- *They’re judgemental and you wish you hadn’t said anything.*

Theme 4: Lack of respect or engagement by healthcare providers

Surprisingly, experiences with healthcare providers were often reported to compound the social difficulties faced by carers and families. The most frustrating issues were those pertaining to lack of access to care (particularly during acute exacerbations of illness) and lack of engagement of carers and families in critical assessment procedures and management decisions. Healthcare providers often justified this behaviour on the basis of the restrictions imposed by privacy legislation. Carers feel that this approach diminishes their role, rendering them unimportant and insignificant.

In response to this sense of unnecessary exclusion, carers increasingly insist on the need to be actively engaged in the treatment process. Indeed, in instances where the carer was consulted, this was perceived to be beneficial for the person with the illness, the carer and the healthcare provider. Carers indicate that ideally they and the person with the illness should be consulted independently as well as together. This is seen to greatly assist the carer with respect to management issues, yet allow the person with the illness to have privacy. When carers are also consumers of mental health services themselves, these issues are even more pronounced.

- *Consult the carer! I know there are privacy problems and that sort of thing; well, just too bad. You’re going to have to sort it out because you’re running on about a tenth of the information you should have.*
- *We didn’t know, we weren’t told. It’s almost as if we are irrelevant and a nuisance.*
- *We’re part of the team . . . don’t ignore me — I’m the one she comes home to.*
- *It’s great. We now [that I’m included] talk about issues and that’s fantastic. Not the personal therapy issues, but the management issues. And I’m really glad I persevered with that because I was getting a bit peeved.*
- *Our son was in community treatment . . . and we knew for 10 days that something was wrong. We were asking for help. The day before he died [suicide] they came out to see him but he walked off . . . and they just stood there and let him walk off.*
- *If there’s one thing that I think has impacted on me as a carer [it] is the fact that in a crisis . . . we’ve literally [at times] got nowhere to go. As an absolute last resort I call the crisis team, but they’re hopeless. I think it’s appalling that we have all this government funding going into supposedly supporting people. We talk about early intervention; well, what a joke, we can’t even get end-of-line crisis intervention.*

Theme 5: Importance of support groups/agencies

By contrast with the perceived lack of support from other family and friends and the healthcare system, carers stressed the crucial role of other support networks. In particular, carers highlighted the vital importance of designated mental health support groups for gaining information, sharing experiences, gaining helpful strategies, and reducing the social isolation.

- *I needed the help as a carer, not anything to do with my husband. It was just that I needed somewhere to go to for support for me.*
- *It’s been so beneficial to me being involved in carers groups . . . just hearing everybody’s story, and realising . . . hang on — I’m not the only one going through this.*

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