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Research report

Identifying depression in a family member: The carers' experience

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Abstract

Background: Current research activity has not focused adequately upon the experience of caring for a person with depression. This study aimed to explore the carer's experience of living with a person with clinical depression. Specific focus was given to the detection and recognition of the disorder.

Methods: A series of focus groups and in-depth interviews was conducted with carers living with a person with clinical depression in rural and metropolitan Australia. Participants were recruited via support agencies and local advertising of the research.

Results: Signs and symptoms of depression were recognised by carers, generally in hindsight. Barriers to early detection were identified by carers and these were likely to contribute to the psychological reaction of carers and to the eventual diagnosis of the care recipient.

Limitations: The study would be strengthened by a greater diversity of relationships between the carer and the care recipient.

Conclusions: This research has important implications for clinical practice and health policy, which must evolve to facilitate early detection and intervention, and to address the experience and needs of carers.

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Keywords: *Beyondblue*; Depression; Carer; Caregiver; Burden; Strain

1. Introduction

A carer is defined as “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” (Disability Services Queensland, 2003). Furthermore, Carers' Taskforce Australia (1996) notes that carers often make sacrifices spanning numerous domains, such as work, freedom, financial security, social lives, and friends, to keep the person for whom they care out of medical institutions. In this article, the term ‘carer’ refers to a person who lives with and provides emotional support to a family member with clinically diagnosed depression, and may or may not be in receipt of an income supplement for this role.

Research in relation to caring for a person with depression has been limited. One study found that the

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spouses of depressed patients experienced restrictions in social and leisure activities, a decrease in family income, and strain on marital relationships as a result of their carer role (Fadden et al., 1987). While this study focused on middle-aged spousal carers, others have focused on elderly persons with depression and/or have compared caring for an older adult with depression versus dementia or Alzheimer's disease. Important inferences can be drawn from the research conducted in this area. For example, similar levels of burden have been reported by carers of people with depression and dementia (Scazufoa et al., 2002; Yeatman et al., 1993). Furthermore, living with a person with depression can affect the mental health of carers, with a number of studies reporting that caring for a person with depression can be a risk factor for the carer developing depression themselves (Scazufoa et al., 2002; Jacob et al., 1987; Coyne, 1976).

Several studies have identified the specific aspects of caring for a person with depression which contribute to the burden experienced by their carers. For example, changes in the patient's behaviour and mood, general apathy, lack of interest in usual activities and interactions with others, the patient's constant rumination and worrying, sleep disturbance, irritability, withdrawal, and inadequacies with health care services have been identified as contributing to the burden experienced in caring for a person with depression (Jacob et al., 1987; Fadden et al., 1987; Highet et al., 2004).

Since caring for a person with depressive symptoms has been demonstrated to be a significant strain, carers' needs must be recognised and carers must be supported in their role. This is important for the wellbeing of both the carers and the care recipients. For example, family members' levels of expressed emotion have been positively correlated with duration of depressive symptoms, thus exacerbating the burden of the illness on both those experiencing it and their carers/family members also (e.g., Rosenvinge et al., 1998; Hooley et al., 1986). Furthermore, greater support, such as respite and support groups, can alleviate the burden of caring (Baillie et al., 1988), and several studies have emphasised the need to support carers as a result of the associated strain experienced (e.g., Yun-Hee, 2003; Jacob et al., 1987).

As noted above, the strain experienced by carers and family members of persons with depression highlights multifaceted sources and manifestations of care-

giver burden. The current paper furthers the research in the area by providing an in-depth qualitative analysis of the carers' experience of the onset and progression of a depressive illness in a family member.

2. Methodology

Twelve 2-h focus group sessions (37 participants; mean attendance, six; range, five to eight) were conducted with primary carers of people with clinically diagnosed depression across six capital cities Australia in 2001–2002 (age range, 23–65 years). There was a similar proportion of men (22/37) and women (15/37), and carers consisted of partners ($n=15/37$), parents ($n=19/37$), and siblings ($n=3/37$) of people with depression. As the focus groups were conducted within metropolitan regions of Australia, four additional in-depth interviews were conducted with male ($n=2$) and female ($n=2$) carers living in rural localities and were partners ($n=2$) or parents ($n=2$) of people with depression. The final sample ($N=41$) was recruited by advertisements in related newsletters, through support groups, local newspapers, and radio, together with liaison with local mental health professionals. In order to qualify for the research, carers were required to live with, and be the primary carer of, a friend or family member with diagnosed clinical depression.

Six open-ended questions were asked consistently across the groups and interviews.

Box 1

1. What did you first recognise was not quite right in your partner/the person you care for with depression?
2. What did this mean to you as a carer?
3. How did this impact on your relationship?
4. How did you seek help/or did you leave it up to them/not believe it was going to happen?
5. What was the impact on other members of the family?
6. As a carer, what do you need from the healthcare system and wider society?

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