

An emotive subject: insights from social, voluntary and healthcare professionals into the feelings of family carers for people with mental health problems*

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Abstract

Caring for people with mental health problems can generate a whole range of positive and negative emotions, including fear, disbelief, guilt and chaos as well as a sense of purpose, pride and achievement. This paper explores the emotions of family carers from the perspectives of social, voluntary and healthcare professionals. Sixty-five participants were interviewed, the sample included directors, managers and senior staff from social, voluntary and healthcare organisations. Participants were encouraged to talk in detail about their understanding of the emotions of family carers. Findings highlight a rich understanding of the broad spectrum of carer emotions and the huge emotional adjustments that are often involved. Diagnosis was seen to be imbued with negative emotions, such as fear, anger and denial. However, feelings of hopelessness and desolation were often counterbalanced by feelings of hope, satisfaction and the emotional rewards of caring for a loved one. Participants noted a clear lack of emotional support for family carers, with accompanying feelings of marginalisation, particularly during transitions and especially involving young carers as well as ethnic minorities. By way of contrast, carer support groups were suggested by professionals to be a holistic, effective and economical way of meeting carers' emotional needs. This paper explores the challenge of family carer emotions from the perspective of managers and practitioners and draws out implications for research, policy and practice.

Keywords: emotions, family carers, mental health.

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Introduction

An emotive subject: the feelings of family carers

The project on which this paper was based was conducted throughout Wales, funded by the Big Lottery and run by Crossroads Caring for Carers, Wales. The drivers for the study came from the increasing role of family carers in supporting people with mental health problems and concern from the statutory and voluntary sectors in Wales and the United Kingdom that more effective and holistic care plans are necessary that take into account the increasing and important role of family carers.

Informal carers have increasingly become the work-horses of health and social care so their expertise and

knowledge is important. Clarke *et al.* (2006) suggest that individuals such as carers have been activated, empowered, 'responsibilised' but also abandoned. Many carers feel at a loss as to what to do in caring for someone with mental health problems, and lack vital information and necessary training to provide adequate support (Pinfold *et al.* 2004).

Seedhouse (2000) lays the foundations of a holistic approach by taking into account the basic emotional, ethical and human dimensions of care. People are not only physical beings but have complex mental and emotional lives. Caring for carers in mental health provides a prime example of the importance of engaging emotions. For example, the study of Taggart *et al.* (2000)

shows the success of professionals when they engage the emotions of families, helping people to 'feel human again'.

Family carers for people with mental health problems have until recently been neglected by empirical research, which has traditionally focused on the experiences of carers for elderly people, in particular, carers for elderly people with dementia. However, recent policy initiatives and legislation underpinning the assessment of carer need have not only emphasised the importance of addressing carers' needs *per se* (HM Government 1999, 2004, Tennakoon *et al.* 2000, Department of Health 2006), but have specifically highlighted the needs of family carers for people with mental health problems (Department of Health 1999). For example, Standard Six of the National Service Framework for Mental Health is *Caring About Carers*. The policy emphasis on supporting carers for people with mental health problems highlights the importance of understanding their experiences and emotions and developing interventions to meet their needs.

According to Arksey (2002, 2003), family carers for people with mental health problems go through a variety of often difficult and conflicting emotions, involving frustration, despair, isolation, tiredness, depression as well as happiness, satisfaction and relief when things are going well. Caring for people with mental health problems generates fear, disbelief, guilt and chaos, which are controlled through information, optimism, routine living and social expectation (James 1989).

In many cases, difficult and profoundly troubling feelings leave family carers with the frightening prospect that they are isolated and alone. Family carers of people with mental health problems suffer from significant emotions involving loss, grief, guilt, isolation and sorrow. Family carers can often feel guilty even about minor things, such as asking others (including family members, neighbours, friends or professionals) for help (Barnett & Parker 1998, Ashworth & Baker 2000, Arksey 2002, 2003).

Compared with carers from other groups, family carers of people with mental health issues are noted to be especially susceptible to feelings of stigma, and are very vulnerable and often marginalised. Family carers often avoid contact with friends, neighbours and professionals because they have deeply embedded feelings of embarrassment, fear, shame and fear of associative stigma (Carson & Manchershaw 1992, Byrne 2001, Arksey 2002, 2003, Ostman & Kjellin 2002, Magliano *et al.* 2005).

By way of contrast, there is a great amount of satisfaction and emotional reward in caring for a family member with mental health issues and sustaining a comfortable, loving and caring relationship. Seeing someone go through recovery, recuperate, learn to cope with difficulties such as hearing voices and start a life afresh in the community is arguably a major reward for

family carers and also for professionals (Arksey 2002, 2003, Pinfold *et al.* 2004, Chang & Horrocks 2006, Coleman & Smith 2007).

The challenging emotions that family carers go through remain relatively undocumented, which one might think might lead to social and professional misunderstandings and perhaps even societal ignorance. The ways in which professionals manage the difficult emotions presented by family carers also remains relatively unexplored. This paper goes some way to addressing this gap by focusing on the professional understanding of family carers' emotions and exploring the challenging emotions that professionals suggest are associated with caring for a family member with mental health problems.

Methods

Qualitative data were collected from a sample of staff in the statutory and independent sectors throughout Wales, all of whom had an explicit service delivery role involving carers and mental health. Sixty-five people were interviewed, which included senior social workers; managers and planners in statutory mental health services; senior managers in voluntary organisations; general practitioners; service developers in Local Health Boards; and management staff in mental health advocacy groups.

The staff were recruited by sending 300 letters of introduction to directors and senior staff in the agencies and organisations listed above, of which 65 people replied. Staff in these services and planning groups served city, town and rural areas throughout Wales.

The study was subject to ethical review by a Multi-Centre Research Ethics Committee and approval by the Association of Directors of Social Services. Participants were assured that great care would be taken to protect their identity and steps taken to ensure anonymity and confidentiality. Because the study involved emotions and discussion of topics of a sensitive nature, participants were told that they could halt interviews at any time and withdraw at any stage of the research.

Interviews were semi-structured in nature. Interviewees were asked to discuss caring for people with mental health problems from their own perspectives, work and management experience as well as to offer comment on strategic, planning, policy and practice issues. Interviewees were also asked to give examples of best practice as well as challenges to providing effective social and healthcare provision for family carers. Interviewees were invited to comment at length on the emotions of family carers and explore the service responses to these emotions.

The aim was to elicit key narratives on caring for carers in mental health that would contribute to identifying

the unmet needs of family carers and clarify examples of good practice. A vital aim of this research is to enable all participants to tell their stories of care in mental health, both good and bad, so that the findings not only contribute to knowledge and empirical understanding in the subject but also inform the service development of key organisations involved in providing care for carers in mental health.

An independent Project Reference Group (PRG) was convened in order to discuss the development of interview schedules, comment on initial findings, collaboratively identify key themes and main issues, and discuss gaps in the research. Members of the PRG included carers and service users, directors and managers of voluntary organisations, senior academics, and social and healthcare staff.

Management and analysis of data

The data were derived from transcribed tape-recordings and note-taking. Themes were identified by reading and re-reading the transcripts and notes and during debriefing sessions between the researchers. Using N6, a qualitative data analysis package, a content analysis of the responses to the key research questions concerning caring for carers in mental health was undertaken. In particular, latent content analysis (Field & Morse 1985) was used as the approach of choice since it permitted themes to be developed and refined in terms of 'the major thrust or intent' and 'significant meanings' inferred from the data. Confirmation of the validity, reliability and importance of the findings came from feedback from the PRG and focus groups.

Findings

This paper explores the challenging emotions of family carers of people with mental health problems from the perspectives of professionals. Topics illustrate professional understanding of aspects of carers' emotions and the severe challenges, including isolation, stigma, alienation, worries about diagnosis, and even notions of life and death, which family carers go through in their daily lives. Transitions in caring, particularly the end of the caring role, is a major gap in professional practice and research that needs to be filled.

The emotions of family carers

The spectrum of family carers' emotions

It was well understood by interviewees that family carers may go through complex and multifarious emotions associated with the unpredictability and uncertainty

of caring for a family member with mental health problems. Interviewees reported a spectrum of emotions involved in caring for a family member with mental health difficulties.

Challenging and sometimes negative emotions associated with family caring were mentioned more frequently than positive emotions.

Carers experience anger, frustration, guilt, shame – usually negative ones, I think. (Interviewee 35: Social Worker)

Having been a carer myself, we go through guilt, despair, happiness, worry, anxiety, grief, the whole range of emotions, it can all be applied. (Interviewee 60: Director of Voluntary Service)

Caring for people with mental health problems is largely conceived of by professionals as a negative experience, albeit with occasional rewards and carer satisfaction. Family carers were said by participants to go through many highly troubling feelings, including guilt, grief, helplessness, anger, sadness, despair, frustration, hatred, isolation, anxiety, disempowerment, worry, loneliness, shame, depression, desperation, denial, stress and believing that they have no future.

With reference to positive emotions, interviewees perceived that family carers also had rewarding feelings from their caring role, such as satisfaction and pleasure when 'things are going well', and they can see improvement in the person with mental health problems. According to professionals, there is a great deal of satisfaction in caring for a family member with mental health problems and sustaining a caring, comfortable and loving relationship. Seeing someone recuperate and maintain stable community tenure is arguably a major reward both for family carers and the professionals involved.

Carers were also reported to experience more than one emotion at a time, which could lead to emotional conflicts that could in turn lead to long-term feelings of insecurity and ambiguity towards the care-recipient.

The following extracts reflect the spectrum of emotions perceived to be involved in the role of family caring in mental health:

Carers experience every emotion going probably: guilt, frustration, anger, love, happiness; everything, all spectrums and more than one at each time. Things are very difficult and people should not feel guilty about needing a break and try to help people work through that. (Interviewee 62: Social Worker)

Carers experience everything from frustration, hating the person they are living with, to wanting to escape the situation. There's a conflict undoubtedly psychologically between the fact that you do care for the person that you are caring for but the frustration that you can't do anything for them. (Interviewee 17: Social Worker)

Feelings of guilt, psychosocial isolation and stigma

A common theme in the above extracts and in the entirety of the data set was feelings of guilt and isolation. According to interviewees, an accompanying feeling of guilt was pervasive when carers asked others, be they relatives, neighbours or professionals, for support, such as carer breaks. Several other studies have confirmed this conclusion, finding that family carers' relationships with mental health professionals engender feelings of guilt, especially when asking for assistance, and can also lead to feelings of stigma (Lefley 1987, 1996, Winefield & Burnett 1996, Wahl 1999, Pejler 2001).

Feelings of isolation were stated by participants to be a major problem. According to a respondent:

I imagine that it can be a very lonely job and a job where you feel entirely unsupported and very much on your own. I would think the sense of isolation that you must feel because, depending on how debilitated the person is that you're caring for, will also impinge on how much you can get out yourself and actually get away from that situation of being a carer and become a, if you like, a different human being, a human being that's not a carer. So I always think that loneliness and isolation will be quite major emotions in a carer's life. (Interviewee 42: Senior Social Worker)

Being a family carer limits the possibilities and opportunities that are available in society; it can result in a person being trapped and isolated in the narrow confines of the caring role. Research has highlighted that the impact of mental illness on carers can be felt across a broad spectrum of family life, including employment, income, education, leisure, children, family health, and relationships with extended family, friends and neighbours (Clausen & Yarrow 1955, Grad & Sainsbury 1968, McCausland 1987, Maurin & Boyd 1990, Magliano *et al.* 2005).

A common and recurring theme in the data was the psychosocial isolation of carers in rural or remote areas where a lack of supportive social networks, difficulties in providing and accessing comprehensive professional support, and poor transport combined to compound feelings of isolation and marginalisation. Feelings of embarrassment, stigma and fear of a small community's reactions to mental illness were touched on in many of the interviews. Combined together these feelings were reported as putting people off accessing services:

The stigma associated to mental health as well because you have the close-knit communities where people don't talk about it. I'm told there's greater stigma in rural communities and that causes access problems in that people don't want to be seen going to a service in their village. (Interviewee 22: Social Worker)

This also meant that carers remained a hidden and largely invisible population:

Because of their isolation they're not very visible in the community. (Interviewee 59: General Practitioner)

The process by which family members and carers are stigmatised by association with another stigmatised person has been termed as 'courtesy' (Goffman 1963) or 'associative' stigma (Mehta & Farina 1988, Sommer 1990, Phelan *et al.* 1998, Struening *et al.* 2001, Byrne 2001). In Carson & Manchershaw's (1992) study, family carers described avoiding contact with neighbours, friends and professionals through embarrassment, shame and fear of stigma. In addition, Ostman & Kjellin (2002) note that relatives who acted as carers had deep-seated feelings of inferiority to staff, which may be an explanation for low levels of cooperation between relatives and professionals as well as entailing problems with access to appropriate services. Several studies have found that carers' relationships with social care and mental health professionals engender feelings of guilt which can affect the severity of stigma (Lefley 1987, 1996, Winefield & Burnett 1996, Wahl 1999, Pejler 2001). One of the central issues, according to a participant, was associative stigma:

I think one of the biggest challenges is stigma. If you're a carer for a disabled child, if you're a carer for somebody with a learning disability, if you're a carer for someone with cancer, the instinctive reaction is 'Oh, you must be an angel, you're having to deal with that, poor thing', you know, it's a tragedy. With mental illness there's still the stigma of: 'Hold on, is it catching?'. It's the fault of the carers that the individual has a mental illness. (Interviewee 37: Mental Health Nurse)

According to Peternelj-Taylor & Hartley (1993), too many therapists, professionals and theories have blamed family carers in one way or another and have failed to view parents, spouses and siblings as people with rights and entitled to respect.

Coming to terms with the caring role

Coming to terms with the caring role in the family may be a difficult, protracted and painful process. Initially, many family members may not identify themselves as carers. After all, as Repper *et al.* (2006) ask, when do the responsibilities associated with being a parent, a spouse or a sibling end and the caring role begin? According to Peternelj-Taylor & Hartley (1993), feelings of helplessness can entrench feelings of social exclusion and marginalisation, resulting in family carers feeling isolated in their role and trapped in the family home. Pinfold *et al.* (2004) and Arksey (2002, 2003) suggest that carers coming to terms with being carers have clear needs of their own for information, support and help with coping with an unfamiliar range of problems. Health and social services should be aware of these needs,

especially family carers' emotional needs, as suggested in recent research and established policy legislation (Department of Health 1999, HM Government 1999, 2004, Tennakoon *et al.* 2000, Arksey 2002, 2003, Pinfold *et al.* 2004, Repper *et al.* 2006).

Interviewees report a huge emotional drain on family carers coming to terms with their difficult role. In addition, family carers are initially at a loss, sometimes in shock and are prone to ask irresolvable questions such as 'why has this happened?' and 'why me?'. Coming to terms with the caring role, according to a respondent, involves a steep and often unsupported learning curve that requires a huge emotional adjustment:

If you're talking about the parents of an 18-year-old who's developed a psychotic illness, it being the first episode, there's a huge learning curve for them. Again there's a huge emotional adjustment they need to make to their child who they had all these aspirations for who suddenly it looks like they'll have to change their views on what that person's able to achieve and learning to cope with the professional services. (Interviewee 13: Senior Social Worker)

According to professionals, changes in the care-recipient's behaviour and personality, either due to mental health problems or side-effects from medication, also affect carers and can lead to family carers feeling isolated and alienated even from their loved one for whom they care. According to a participant:

Sometimes it's not easy to care for somebody who is perhaps not the person who you married or the person that you've known for a long time because the illness, or whatever's happened to them, changes them. So they often feel guilty, they often feel, 'I wish I wasn't doing this'. (Interviewee 52: Mental Health Nurse Manager)

Another respondent summarised the issue:

It's hard to accept really, you know that's been my experience – it's hard to accept that the person that they love has changed, has got the onset of mental illness. (Interviewee 60: Director of Voluntary Service)

Another major issue for carers, according to professionals, is coming to terms with and understanding the meaning of diagnosis. Pejler (2001) found that diagnosis was never mentioned in the narratives of her research participants. The disease was never mentioned in terms of a diagnosis; rather, more anodyne terminology was used with expressions such as 'illness', 'disabled', 'something s/he has to take medicine for', indicating that the diagnosis was loaded with negative meaning. Odd behaviour of care-recipients was thought of as difficult to understand and shameful for family carers.

Diagnosis was also perceived by professionals to be imbued with challenging emotions such as fear, guilt, anger, grieving and denial:

We've got a young man who's just had a diagnosis and just had his first episode of a psychotic illness. I think his carers, his parents as it happens, actually, despite the fact that we've given them a lot of information, are actually still in denial. It's very much, I think, a bit like a grieving process in some ways. I think the denial is there for quite a long time and that can be just as much with service users as with carers. And it sort of gradually changes, I think, over time. (Interviewee 9: Mental Health Nurse)

Notions of life and death

At a more extreme and worrying level, several of the respondents mentioned that the caring role may affect family carers' attitudes towards life and death. The severe burden of caring was reported by professionals to be so emotionally draining that it led to family carers resenting their role and the person that they supported. Carers saw little improvement in the care-recipient, so felt that their efforts were wasted. One professional recalled such a troubling case:

He was saying that a number of times he thought he would like to kill his wife. He said: 'I knew I wouldn't, but I was thinking it because my life was over'. He was a man in his late fifties and I think we've got to try and avoid this – We've got to try and take the strain off before people get to this point. And then they have this awful guilt about feeling that about someone they love. (Interviewee 6: Social Worker)

Ostman & Kjellin (2002) found that the burdens of family caring seriously affected thoughts about life and death. Isolation, hopelessness and feeling that life was over led to despair. This is a startling and worrying finding.

Worries and fears about the end of the caring role

Although the majority of family carers want to continue in their role for as long as they can, there comes a point when for many it is not in either their best interests, or those of the cared-for individual. Maintaining the care-recipient in the community and keeping them out of institutional settings is of pivotal importance to family carers and often underpins their motivation to provide support and care. In circumstances where this is no longer possible, the potential guilt is enormous. Reaching the decision to place a loved one in an institutional setting is therefore extremely difficult, problematic and engenders considerable emotional turmoil. This is exacerbated by the fact that most admissions to care are made at a time of crisis, usually following an acute episode of ill-health.

As summarised by the two professional respondents in the extracts cited below, the end of the caring role is perceived to involve feelings particularly of worry,

guilt, depression and the grieving process of letting go of the caring role:

Carers are constantly worried as to the person they're looking after and how they're going to be able to carry on looking after them. Because carers, I would stress, have made it quite clear to me that they're very worried that they won't actually, obviously, be around forever and who is going to look after their loved one when they're no longer around to do so? (Interviewee 35: Social Worker)

It promotes more guilt, but a whole range of feelings and also, of course, at the end, when their caring role may end for whatever reason. (Interviewee 7: Director of Mental Health Services)

According to Nolan *et al.* (1996), the end of the caring role involves a process of letting go of caring, moving on and reclaiming a new life. In the present study and confirmed in Nolan *et al.*'s research, with scant few exceptions carers received minimal assistance at this difficult period and generally thought they were left to 'sink or swim'. Many family carers are left with a legacy of guilt and continued stress (Nolan *et al.* 1996).

Lack of emotional support vs. carer support groups

Emotional support in the statutory and voluntary sectors was said by professionals to be very basic. There were limited resources and long waiting lists for more specialised interventions such as counselling and cognitive behavioural therapy. This lack of any concerted emotional support led to feelings of being trapped in the caring role as well as anger at not getting answers and appropriate emotional reassurance:

So there's a very grave problem and terrible isolation because it's difficult to talk to anybody else. I'm afraid carers get little information and support. There's a strong sense of being trapped. There's anger that nobody's providing any support. (Interviewee 49: Social Worker)

This lack of emotional support with accompanying feelings of marginalisation was perceived by professionals to be compounded by family carers' feeling that they were often not consulted or involved by services, particularly statutory health and social care services. This led to frustration:

Family carers do get very down, they get very frustrated by the lack of being involved. It's frustration and anger sometimes at not getting answers. (Interviewee 3: Mental Health Nurse Manager)

Professionals reported that a troubling consequence of not getting answers or being involved by health and social care services was depression and feelings of desolation:

From my personal experience, family carers get very tired and can become quite low, really. And you sometimes think

whether there is anybody out there who is able to help you through some of the difficult times. (Interviewee 60: Director of Voluntary Service)

Twigg & Atkin (1994) also found that services were often lacking or in short supply and were frequently ad hoc and ill-equipped. Although social work staff are willing and want to help, according to Kuipers *et al.* (1989) as well as more recently Repper *et al.* (2006), professionals in many settings say they lack the time, resources and expertise to work in depth with carers and relatives about their emotional issues.

A further difficulty is that even when services are available, attempts to recruit families to appropriate psychological and emotional interventions during remission or periods of stable community tenure are linked with difficulties in engagement. The indications are that in these circumstances, only about half of carers are likely to take up offers of emotional and psychological support. Once the situation of the care-recipient has stabilised, many families may be unwilling to rock or upset the status quo, preferring to keep their distance from services so as to maintain a sense of normality (Sellwood *et al.* 2001).

In summary, professionals suggested that social and healthcare service responses to family carers' emotions were neither comprehensive, holistic nor specialised. The voluntary sector was reported to be more successful in tackling carers' emotional needs than the statutory sector but was still limited in scope and specialisation. Emotional support was very basic and only included such things as carer support groups, face-to-face work with voluntary workers and befriending with peers.

By way of contrast, the majority of professionals (60 of the 65) said that carer support groups were an economical, holistic and effective way of meeting the emotional needs of carers. Professionals suggested that group work can take several forms: family-led self-help groups, carers' circles, family groups run by professionals and mutual support groups. Each of these programme types has been shown in the research literature to decrease isolation and stigma and has been suggested to assist carers acquire knowledge, information, new skills and a sense of mastery over their personal situation (Nolan *et al.* 1996, Sellwood *et al.* 2001, Ostman & Kjellin 2002, Pinfold *et al.* 2004).

Through sharing life experiences and befriending other carers and professionals, individual family members are noted by professionals in this study to be able to express their feelings, gain new ideas about managing mental illness and report on their coping strategies. Family carers experience the validation and support of other carers in similar situations.

Other research has highlighted that moving-on groups and groups dealing with grieving carers are

especially important as they address gaps in carers' emotional needs (Nolan *et al.* 1996, Sellwood *et al.* 2001, Ostman & Kjellin 2002, Pinfold *et al.* 2004).

Conclusion

The emotions that family carers of people with mental health problems go through remain relatively unexplored. This paper has gone some way to redress this by exploring the professional understanding of family carers' emotions and the challenging feelings that professionals say are associated with caring for a family member with mental health problems. The majority of professionals perceived caring for a family member with mental health problems as deeply challenging and emphasised highly negative emotions associated with the caring role. Rewards and satisfaction, both for carers and the professionals involved, were downplayed and given less emphasis when compared to negative emotions.

Family carers for people with mental health problems are reported by professionals to go through complex, multifarious and ambivalent emotions including feelings of guilt, psychosocial isolation and stigma, as well as satisfaction and relief when things are going well. The key challenge for professionals therefore is to minimise negative emotions and maximise positive emotions through emotionally supportive and therapeutic interventions such as carer groups.

Caring in the family is often a thankless task and can even affect notions of life and death. Professionals say that many carers report that they see little improvement in their loved ones, meaning that feelings of hopelessness, loss, desolation and despair are often part and parcel of the caring role. Transitions in the caring role, particularly the end of the caring role, is a major gap in research and practice.

More research is needed on carers' emotions and successful practices and interventions, such as carer groups, that meet carers' emotional needs. The emotions of young carers and ethnic minorities, who are hidden and socially excluded groups, need to be brought more fully into focus and researched in a multidisciplinary way. Certainly, there is growing interest in marginalised groups such as young carers and ethnic minorities (Repper *et al.* 2006, Gray *et al.* 2007). Further study is necessary to evaluate the impact of carers' emotions as well as the success of interventions such as carer groups, with different groups of carers and at different phases of mental illness (Birchwood *et al.* 1992).

The implications of carers' emotions also need to be addressed by policy and practice. For example, there needs to be more weight and focus on family carers' emotional needs by social workers, for instance, as part of carer assessments (Repper *et al.* 2006).

Emotions and the emotional needs of groups such as carers for people with mental health problems are often implicit and tacit in policy legislation; therefore, this needs further elaboration by policy-makers, carers, service users and professionals working together in order to be codified, taken account of and their place acknowledged in professional training and education (Smith 1992, 1999, 2005, Smith & Gray 2001).

One major flaw of the current research was that it did not elicit the voices and experiences of family carers themselves. The next step will be to engage with family carers of people with mental health problems, touching upon their experiences, opinions of services, rights, needs and not least their emotions. Carers need to be seen, heard, valued and researched in their own right.

Finally, although negative emotions are given more emphasis by participants in this study, an interesting avenue of further research would be to explore the positive emotions of family carers, and interventions that sustain and build upon these positive carer experiences, to contribute to best social and healthcare practice and in order to be positive and inclusive (Arksey 2002, 2003, Pinfold *et al.* 2004).

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