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Double deprivation: A phenomenological study into the experience of being a carer during a mental health crisis

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**Double deprivation: a phenomenological study into the experience of being a carer
during a mental health crisis**

Abstract

Aim. To explore carers' experience of caring during a mental health crisis.

Background. Community mental health care including crisis care relies increasingly on carers. The relationship between carers and professionals is at times fraught due to issues of what constitutes a crisis, confidentiality and a perception of lack of empathy. The caring inexperience can lead carers to feel isolated and neglected.

Design. A qualitative study with a phenomenological approach. Eight carers participated and were interviewed individually using a semi-structured approach.

Method. Analysis used the 'Interpretive Phenomenological Analysis' method including transcribing of interviews, initial noting, searching for connections and patterns across the transcripts and cases. The themes were checked with the participants for their views on the emerging themes. The data were collected from November 2011 - May 2012.

Findings. Carers experienced 'double deprivation' by not receiving support from professionals and protecting their social network from the trauma of the crisis. The caring in crisis invoked complex feelings of guilt and loyalty which made discussing aggression difficult. Caring was described as a terrifying experience not just because of the aggression but also because of the perception of abandonment by professionals.

Conclusion. The experience was an overwhelmingly negative one with a wish for acknowledgement of the crisis and support from mental health services. For most of the participants the caring during crisis was traumatic which left the carer feeling isolated and unsupported. The study should be used to help educate professionals on the complexities of caring during a crisis.

Keywords. Nursing, Mental health crisis, carers, abandonment, ineffective care, deprivation, support

Summary statement

Why this research is needed?

- **There are few studies into being a mental health carer in general and very little research into caring in a mental health crisis. This study aim to fill the gap.**
- **There is a move towards more community care which relies on carers supporting the person in crisis. Understanding the experience will help mental health services in proving better support to the carers.**

What are the key findings?

- **Carers experience ‘double deprivation’ of support from mental health services and their social network by feeling rejected by professionals and trying to protect their social network.**
- **The carers describe complex feelings of loyalty and guilt which makes discussing aggression difficult.**
- **The experience of a mental health crisis is traumatic and terrifying not just because of experience of aggression but also because of feelings of abandonment from professionals.**

How should the findings be used to influence policy/practice/research/education?

- **The findings should be used in educating professionals in the complexities of caring during a crisis.**
- **The study is aimed to fill the gap in research into mental health crisis and caring and as such should influence future research.**

Introduction

With an increased emphasis on providing mental health care in the community, carers are playing a big role in supporting the person with the mental health problem during a crisis.

The term carer used in this study relates to unpaid family and friends who support a person who has mental illness, often including when they are in crisis. Mental health crisis does not have a specific definition, but is generally accepted as being a combination of clinical symptoms of mental ill health, social problems and associated risks (Johnson *et al.* 2008, MIND 2012). It is a period of stress for both the person with a mental health problem and the people around them.

Taking on the role of a carer is complex and the support carers can give can be important in resolving a mental health crisis (Johnson *et al.* 2008). However, there has been little research into what caring entails at these points and how carers cope with the crisis. This study will attempt to fill the gap by exploring the experience of caring during a mental health crisis from the perspective of carers.

Background

When a person is in a mental health crisis there are several ways they can be supported. Some people receive support in the community from a combination of friends, family, general practitioners (GP) or mental health services. This is commonly referred to as their 'social network' (Johnson *et al.* 2008). This social network is essential in resolving the mental health crisis and without their involvement, the person with mental health problems may be admitted to hospital for treatment (Bowers *et al.* 2005).

The literature dealing with being a mental health carer is limited and primarily deals with caring in general (Wooff *et al.* 2003, Jeon *et al.* 2005). Research looking at carers and mental health crises is sparse although studies from more recent time have been published (Kaliefeh *et al.* 2009, Lyons *et al.* 2009).

Lyons *et al.* (2009) found the concept of crisis as being subjective where each person will describe and perceive a mental health crisis differently. When in crisis, service users and carers found it difficult to access support unless their situation was seen to be fitting the services criteria for crisis.

The role and importance of carers is recognised as essential in social healthcare. However, research and anecdotal evidence suggests that the role is fraught and continues to lack meaningful support from professional services (Ridley *et al.* 2010). Some literature (Schneider *et al.* 2001, Oyebode 2003) suggests that professionals' views of the caring experience are mainly negative, which is not a full reflection of the caring role. It is further suggested that there is a lack of understanding from some professionals of the caring role which may result in a lack of empathy (Rapaport *et al.* 2006). Carers have identified that input from professionals is mainly focused on information gathering and for the primary benefit of the professionals (Johnson *et al.* 2008). Jones (2004) further argues that relatives of someone with a severe mental illness experience complex emotions of guilt and loss. When not involved by professionals, carers describe feelings of anxiety, depression, isolation, fear, anger and resentment towards the person with mental health problems (Wooff *et al.* 2003, Wynaden & Orb 2005, Gray *et al.* 2008).

There is little research focussed on carers of people with mental health problems. A few of the studies available address the dilemma of either extreme stress of home care versus the guilt and perceived inappropriateness of hospital care (Wooff *et al.* 2003, Jeon *et al.* 2005). In

a more recent a study, it was found that young carers' experiences of home treatment during an acute phase of a mental illness was stressful and distressing (Khalifeh *et al.* 2009). In contrast Hoult *et al.* (1983) found that the majority of carers preferred community treatment with carers experiencing less burden of care compared with those caring for people in hospital. Fulford & Farhall (2001) found that the preference of home care versus hospital care was influenced by the psychological coping mechanisms of the carers.

THE STUDY

Aims

The objective of the study was to explore the experience of caring for a relative or friend during a mental health crisis. As there is little literature available on mental health carers in general and mental health caring in crisis in particular exploring the experience is a first step in building up the body of literature on the subject.

Design

The study is a phenomenological study of carers using qualitative semi-structured interviews as the method to collect data (please see table 1 for interview questions in bold and prompts). Each interview was transcribed and analysed using the interpretative phenomenological analysis (IPA) method.

Participants

The inclusion criterion for the study was any person who had supported a relative or a friend with a functional mental illness such as psychosis, depression, personality disorder during a mental health crisis. Participants were recruited through carers' support groups provided by both local health providers and voluntary agencies. One participant was recruited via word of mouth or snowballing (Morse 1991). The sampling was purposive with the researcher

screening for a variety of experience and knowledge of caring during a crisis. The participants themselves defined what constituted a crisis reflecting the phenomenological method being one where the individual is an expert in their own experience. Nine carers were recruited and a total of eight participated, as one withdrew before the interview for personal reasons.

The participants' demographic details were not formally recorded although basic information was available from meeting with them. They were all females from a mix of ethnic backgrounds. The majority were mothers of the person with the mental illness, but also one daughter and one sister took part.

The participants were not asked about the diagnosis or whether the person with the mental health problem was under the care of mental health services. This approach reflected Lyons *et al.* (2009) study where it was found that professionals' understanding of a mental health crisis varied from that of the carers. Sampling carers using their own interpretation of a mental health crisis reflects the phenomenological ethos of the participants being the experts of their lived experience. As it transpired all participants' family members had at one time or another been in contact with mental health services during a crisis.

Data collection

The interviews were semi-structured with 10 questions used to guide and prompt the discussion (see Table 1). The research proposal and questions were adapted following consultation with a local university's carer and service user advisory group on research (Simpson *et al.* 2014). The participants were interviewed individually and recorded using a digital recorder. One participant was interviewed over the phone. The data were collected from November 2011 - May 2012.

Ethical considerations

The study was reviewed by a National Health Service (NHS) research ethics committee and received full approval (REC Ref: 11/LO/1101). Informed consent was obtained prior to the interviews and participants were reminded they could withdraw their consent at any time. As the participants were asked to describe experiences which potentially would be distressing each participant was made aware of this possibility before starting.

Data analysis

Data from the interviews was analysed by the researcher using the Interpretative Phenomenological Analysis (IPA) approach. The data analysis followed the strategies of immersion in data through repeated reading of transcripts, initial noting, developing emerging themes, searching for connections across emergent themes and looking for patterns across cases (Smith *et al.* 2009). Each transcript was processed individually following those steps. Once all the transcripts had been analysed individually all the themes were compared to find commonalities which then made up the final themes for the study. All participants agreed to be contacted after the analysis to provide comments on the themes. Although, Smith *et al.* (2009) do not use participants in their process the approach fits with the cyclical analysis used in qualitative research (Schneider *et al.* 2003). The theme of 'reluctance to discuss aggression' emerged as a result of this member-checking process with the participants. The findings were discussed with second author as part of the analysis process.

Validity & reliability

The process of checking themes with the participants allowed clarification on whether the interpretative analysis was accurately reflecting carers' own experiences and is a recognised method of ensuring credibility of findings in qualitative research (Houghton *et al.* 2012).

During the analysis process the researcher kept a reflective journal to ensure objectivity and the analysis process is backed up by an audit trail. Regular presentation of emergent findings and discussion with an academic supervisor (second author) also supported this process. The number of participants helped to ensure the data were as rich as possible and is further strengthened by the different types of mental health crisis which the participant had experienced.

Findings

The analysis identified four themes with several subthemes. The following sections will explore each of these themes in detail. The relationship with mental health services and professionals was a prominent theme for all of the carers and will as such be described first.

The second theme concerns carers and their interaction with their social network. The following section will look at the third theme concerning complex emotions which carers experienced during a crisis. Then, through the analysis and checking with the participants another theme emerged which concerned the reluctance to discuss aggression. Each of the themes will be described and anonymous quotes from the carers will be used to illustrate the themes.

Before that, we outline how the carers in this study understood or defined a 'crisis'. All participants described the crisis and there were similarities in the descriptions. All the carers described a mix of changes to behaviour in the family member, increased evidence of distress and emerging symptoms of mental illness. Change to sleep patterns was mentioned by all as an indicator of a crisis:

‘My daughter was experiencing psychosis symptoms and it took a long while to be prescribed medication. When she was prescribed, she was non-compliant with it. So often she would not sleep for days. Now, I would consider that a crisis... the team didn’t’. [P 7]

An increase in distressed or disturbed behaviour was described, often with associated risk such as an increase in aggression or the person putting themselves or others in vulnerable situations.

‘My only alternative was to call the police because it was his dad and him actually come into physical blows. And weapons and god knows what. So I [thought] ‘you know what, this is getting out of hand. I can’t handle this’. [P5]

Theme 1: Mental health services’ response to the crisis

Sub-theme – mental health services ineffectual in dealing with crisis:

This theme was prominent in the majority of the interviews. Carers described how approaching mental health services to get help was an experience that left them feeling disrespected and unsupported. They described difficulties in making professionals from the mental health services understand and respond to the crisis.

‘My distress as a carer was twofold throughout all of that. . One was the feeling that I knew my son... I’ve been with him all his life. 20 years I have known him....very very well and whatever I was saying to people... the information... I was not being listened to or respected’. [P2]

The participants described professionals either discounting their reports of crisis or minimising the reports. This left the carers feeling their concerns were not taken seriously

and that the professionals did not do their job or were looking for reasons not to provide support.

‘On that day I phoned and [said] ‘she’s got to come’ [to hospital]. We managed to get her on the bus, which was incredibly difficult because of the voices and all the rest of it. And we were there and were seen for about 15 minutes. ‘Oh, she seems fine now’.

The fact that she’s made the bus journey, she is not in crisis anymore?’ [P7]

Additionally, the experience of mental health services’ response to a crisis was also one of services being slow in responding to crises at times resulting in the crisis having escalated to the extent that the person ended up in hospital. The perception of a slow response to the crisis made the participants feel the system was ineffectual in responding.

‘The team was very scared to act quickly and said ‘oh we will have a meeting on such and such a day to look at what is happening’’ [P1]

The delayed response to carers’ concerns caused frustration especially to the ones who had experienced a crisis before. This was further complicated by the feelings of having let down the person with mental health problems as the slow response would contribute to the need for admission. This issue will be discussed further in theme 3.

Two of the participants talked about support from professionals during a crisis which had been helpful. The main points were around the professionals taking concerns seriously and knowing and understanding the person.

‘And it was the social worker that I called. The social worker came to the house and to see... to talk to him. And while he was at the house the crisis team people came. So I must say the social worker calmed him down. Get him talking to him and the crisis team came. And then through that they were able to get him to the hospital’. [P4]

The participant above described getting practical help to calm her son down as particularly helpful. This sentiment was described in reverse in other interviews where carers required help in dealing with aggressive outbursts. The majority of the participants who needed support in dealing with aggressive behaviour were advised to call the police.

For many of the carers involving the police was a last resort; they described how they would prefer mental health professionals to help de-escalate the situation. Another participant described a professional offering to protect her from any resentment from her son about admission by saying it was her [the professional's] decision to call the police for help. The carer felt the suggestion was helpful as the professional understood agreeing to admission would be difficult for her.

It is worth noting that all of the carers wanted intervention before the crisis escalated to require police involvement. More importantly they wanted support to prevent the crisis deteriorating until the person needed hospital admission. The feelings associated with the crisis escalating into either needing help from the police or the person with a mental health crisis being admitted to hospital will be explored further in the theme 3.

Sub-theme - Feeling abandoned by MH services

In the first theme there was an underlying sub-theme of feeling abandoned by mental health services. The carers described feeling they had to deal with the crisis alone as they could not rely on the mental health services to support them.

The participants who described the abandonment all described the feeling in context of being let down by mental health services. For some not being able to rely on mental health services in the crisis meant the coping was so much more difficult and also meant they would dread any future crisis.

‘Their [the professionals’] words... they thought ‘he was an angry young man who needed to be taught a lesson’. That was the first thing they said to me in the nursing station... which was traumatic for me to hear. Because I suddenly thought where is the professional support for him and me and the understanding?’ [P2]

For others the sense of their concerns not being taken seriously meant they felt abandoned by the professional services. The carers described feeling overwhelmed and outside of their comfort zone having to deal with the crisis.

‘When she was suicidal, the psychiatrist, I wanted her to go into the teen unit, said; ‘just watch her around the clock’. I’m a single parent, no family to support me. So how was I supposed to stay awake and watch her...’[P7]

Theme 2: protecting the social network from the mental health crisis

Although most of the carers had a social network to support them during the crisis few felt that the network was able to cope with the crisis as well as they did either because of lack of resources, knowledge or coping skills. This view was further complicated by some of the participants wanting to protect members of their network from becoming traumatised in the way they had been by the crisis.

‘They [siblings] are trying their best to help him but it got so much so that for everyone... It is too stressful. They have got their own life. They can only help for a certain amount’. [P4]

For others the social network also posed a conflict in how and what care the person was given. Often it was a question of having different views on how to approach the person in crisis. The conflict was a source of stress. The following quote demonstrates this difficulty:

‘My husband... it was getting a bit too much for him. He did try his best but when it got too much he just would sign the papers to take him to hospital’. [P4]

The importance of involving the social network as a way of resolving a mental health crisis is seen as an integral part of crisis resolution (Johnson *et al.* 2008). However, the carers described experiences of not being able to get or use support from the social network. This was mainly because they did not want to burden others with the stress of the crisis.

‘My other son is working and was very busy. . So it was very difficult and he would have wanted to know... no I couldn’t really involve him.... to come and rescue him’.

[P1]

Another carer described not wanting to talk to members of their social network about the crisis as she felt it would stigmatise the person in future interactions with the network. There was an overall description by all the carers of feeling alone in dealing with the crisis. As such, not getting support from their social network and mental health services can be described as double deprivation of support.

Theme 3: Feelings associated with the crisis

The feelings which the carers described when recounting their experience of a mental health crisis was one of trauma and stress. Although being a carer is a mix of positive and negative experiences the feelings described associated with the crisis were only negative.

‘If your child is in a crisis you can guarantee that the carers have been in a terrible crisis for the previous three days or however long it built up. And while that is going on you are having your own internal crisis because you can’t believe what is

happening and it's so distressing. And you want so desperately to do something but there is nothing you can do'. [P7]

Talking about the experience of crisis was emotional for all of the participants. Words like 'terrified', 'scared', 'petrified', 'frightening' and 'freaked out' were used to describe caring during a crisis. Sometimes these words were used in the context of verbal or physical aggression. Other times it was in the context of the responsibility the carer felt for the person being supported.

'She has never physically attacked me. She has only ever mentioned that she will have my throat slit. Or she will burn the house down. Or she has wished me dead under the wheels of a bus. Things like that. She can be very very nasty...' [P6]

The carers described a fear of being alone in caring during the crisis. Carers who had previous experience of mental health crises described the fear due to previous experience of having felt let down by mental health services. Some would describe an anticipation of not getting support in a future crisis which would in turn have an impact on their recovery from the trauma of the current crisis.

Other carers would describe the experience of fear from the aggression from the person in crisis. The following quote describes how trying to get away from the person due to their aggression was distressing.

'Sometimes you got to be hiding from him. If he hasn't taken his medication or he has taken a drink he ought not to have taken with the medication it affects him so badly that you could end up running away from your own child as well'. [P4]

The extent of the feelings associated with the crisis and in particular feelings of fear were possibly played down out of a sense of loyalty towards the person in crisis. The carers described loyalty mixed with fears of being let down which made coping with the crisis more difficult. This was compounded by an overall belief that the carers would in the end be left to pick up the pieces.

‘I knew if they saw him in that condition they would not have had the kind of confidence that I had that slowly slowly I can get him back. They would have felt as their duty [that] they needed to take him and institutionalise him. That would have made the situation a billion times worse for me because I would have to deal with the person they return back. Who I would have... as far as he is concerned, betrayed him’.

[P3]

When hospital care was seen as an undesirable option it left the carers feeling guilt for not having prevented the crisis from escalating. Many of the carers described a sense of guilt for not being able to prevent the person going into a crisis. The feelings were often linked to their role as a mother. Although not all the participants were mothers it can be argued they all took on a parenting role when providing care. The guilt was often downplayed and when carers talked about the guilt it would trigger them becoming distressed.

‘I’m in my late 50’s and it is not what I expected to be happening to me at this point in my life. And I suffer huge guilt because as the mum of course it is all my fault. I know it isn’t but anyway....’ [P2]

Theme 4: reluctance to discuss aggression

Although most carers had experienced verbal or physical aggression during a mental health crisis the issue of aggression did not at first translate into a specific theme. The descriptions were generally subsumed into other themes and formed part of the descriptive language.

During the reflective process of the analysis a picture emerged of the carers minimising the experiences they had had with aggression. When discussing the initial analysis with the carers, it was proposed to the carers that acknowledging the aggression may be a betrayal of the loyalty which carers feel towards the person. The carers confirmed that was the case.

One carer described how she would often not talk about the aggression or other difficult behaviours out of a sense of loyalty. As she knew it was not permanent behaviour she did not want the person to be judged or treated differently in future interactions with people. By not talking about the aggression she was trying to avoid the person she cared for being stigmatised.

One participant described how experiencing incidents of aggression as a child by the person she cares for influenced how she responded when caring for him as an adult. Other carers described how past crises influenced how future crises were dealt with and how they felt about it. This is demonstrated by the following quote:

‘I called MIND [mental health charity] to try and get advice ... but I tried not to call social services because I feared they would over react. And recalling back what happened with him when pulling that butcher knife I didn’t want to have the professionals ... then he[the person in crisis] over reacts and he is then institutionalised’. [P3]

This carer did not discuss the aggression with professionals because she was worried the care which the person in crisis would get would be detrimental to him. As such she would carry a

sense of responsibility for potential dangerous behaviour out of a sense of loyalty and not wanting to let him down.

Discussion

In this phenomenological study, carers of people with a mental illness were able to discuss their experiences of living through and dealing with mental health crises. The relationship with mental health services was by far the most prominent theme. What this study adds to other research is that even when services acknowledge there is a crisis, the response to it is seen by the carers in this study as ineffectual. The discrepancy between parties in recognising a crisis and the experience of an ineffective response left the carers feeling abandoned. The carers who described a positive experience during a crisis was one where mental health services responded quickly and took over dealing with their son's aggression. Although this was seen as a helpful intervention the caring was overall perceived as negative as the response was after a period of having attempted to get help and did not prevent the person being admitted. The sub themes of ineffectual mental health services and abandonment have implications on the services providing support. The slow response to carers' concerns during a crisis meant the carers felt they were not taken seriously. Combined with the fear of being abandoned during the crisis carers are likely to go through immense feelings of stress.

High levels of stress and illness are frequently reported in studies of carers (Cormac & Tihanyi 2006, Oyeboode 2003) and higher levels of family stress are related to relapse in the person with mental illness (Fadden 1998). Family interventions to support carers and families should be considered as there is some evidence that those that receive family interventions report high levels of satisfaction with the intervention, reductions in stress levels and carer burden in the families, enhanced communication skills and a positive sense of empowerment (Campbell 2004). Alternatively, shorter focused support in line with carers' specific requests

for help may be more welcome and effective Mairs and Bradshaw (2005). The carers in this study wanted support with specific issues such as agitation and managing behaviour.

This study also showed carers feeling rejected by mental health services and trying to protect their wider family and social network from the trauma of the crisis. Previous research (Rapaport *et al.* 2006) described a lack of empathy from professionals which although not clearly defined as a theme here is evident in this study from some of the reports around feeling rejected. The complex interplay of rejection and protection is likely to lead to double deprivation of support for the carers. The carer is not getting support from professionals and they protect their social network from the extent of the crisis.

The feelings of trauma following a mental health crisis were palpable during the interview. The words describing the crisis such as terrified and petrified emphasises the high levels of stress which the carers felt during a crisis. This finding is similar to the work of Kalifeh *et al.* (2009) who also found that young carers felt overwhelmed by the crisis. However, this study differs in that the carers wanted to support the person in crisis at home rather than hospital but did not feel helped mainly by mental health services to do so. This study also differs from previous work (Schneider *et al.* 2001, Oyeboode 2003) which talks about caring being both a positive and negative experience for the carers. The carers predominantly described caring in a crisis as being only negative albeit two carers experienced mental health services dealing with aggression as helpful.

The stress of caring in a crisis mixed with a sense of loyalty and guilt makes the experience particularly difficult and complex for carers. It can be argued that acknowledging the aggression may be for some a betrayal of the loyalty which the carer feels. The sense of loyalty was further complicated by the sense of parental protection which all the carers described. As such, the interplay of fearful emotions because of aggression and loyalty is

important not only in understanding the caring experience but also for the professionals to be able to make an accurate assessment of the needs of the family in crisis. Mental health staff need to engage with sensitivity and skill in such a complex, fraught family dynamic.

All participants became distressed during the interview and described the cathartic experience of being able to tell their story. Providing carers with information, feedback and an opportunity to talk following crisis incidents may be another way of supporting carers in a crisis.

Limitations

Although the participants were from a mix of ethnic backgrounds a wider sample group may have provided different experiences. All participants spoke English (though not all as first language). The study only looked at carers' experiences and did not look at the professionals' perspective. Future research into mental health crisis and carers may benefit from trying to understand the barriers between carers and professionals and what impact it has on support. In this study carers described their experience as predominantly negative although one person had a positive response to crisis. At the time of the study they were all receiving support from carers support groups which may reflect their negative experience of a crisis. Recruiting participants from groups who are not as linked in with support services or from more socially excluded groups may provide different experiences of caring during a mental health crisis. A further limitation is the size of sample which means the findings will need further research to be fully generalizable.

Conclusions

The carers in this study described double deprivation of support from their social network and mental health staff. This was caused by a mix of wanting to protect their family and wider social network from the trauma of the crisis, the social network not tolerating or understanding the person in crisis and an experience of rejection by mental health professionals. Strong feelings of guilt and loss was associated with caring in crisis and made more complex by the protective parenting role which the majority of the participants had (or adopted). This complex emotional experience made discussion of aggression during crisis more difficult as carers had concerns the person with the mental health problem would be judged by mental health professionals and the wider social network.

References

- Bowers, L., Simpson, A., Alexander, J. Hackney, D., Nijman, H., Grange, A. & Warren, J. (2005) The Nature and Purpose of Acute Psychiatric Wards: The Tompkins Acute Ward Study. *Journal of Mental Health*, 14(6), 625-635.
- Campbell, A (2004) How was it for you? Families' experiences of receiving Behavioural Family Therapy. *Journal of Psychiatric and Mental Health Nursing*, 11, 261-267.
- Cormac, I. & Tihanyi, P. (2006) Meeting the mental and physical healthcare needs of carers. *Advances in Psychiatric Treatment*, 12, 162-172.
- Fadden, G. (1998) Family intervention in psychosis. *Journal of Mental Health*, 7, 2, 115-122.
- Fulford M & Farhall J (2001) 'Hospital versus home care for the acutely mentally ill? Preferences of caregivers who have experienced both forms of service', *Australian and New Zealand Journal of Psychiatry*, Oct, 35(5), pp 619-625.
- Gray B, Robinson C, Seddon D & Roberts A (2008) "Confidentiality Smokescreen' and carers for people with mental health problems: the perspective of professionals', *Health and Social Care in the Community*, July, Vol 16, Nr 14, pp378-387.
- Houghton C, Caser D, Shaw D & Murphy (2013) Rigour in qualitative case study research in *Nurse Researcher*, 20, 4, pp 12-17.
- Hoult J, Reynolds I, Charbonneau-Powis M, Weekes P & Briggs J (1983) 'Psychiatric hospital versus community treatment: the results of a randomised controlled trial', *Australian and New Zealand Journal of Psychiatry*, 17, pp 160-167.
- Jeon YH, Brodaty H, Chesterson J (2005) 'Respite care for caregivers and people with severe mental illness', *Journal of advanced nursing*, Vol 49 (3), pp 297-306.
- Johnson S, Needle Jm Bindman P & Thornicroft G (Eds) (2008) *Crisis resolution and Home Treatment in Mental Health*, Cambridge, Cambridge University Press.
- Jones D (2004) 'Family and serious mental illness: working with loss and ambivalence', *British Journal of Social Work*, Oct, Vol 34, Issue 7, pp961-979.
- Khalifeh, H; Murgatroyd, C; Freeman, M; Johnson, S & Killaspy, H (2009) 'Home Treatment as an alternative to hospital admission for mothers in a mental health crisis: a qualitative study', *Psychiatric Services*, May, Vol 60, Issue 5, pp634-639.
- Lyons, C, Hopley, P & Horrocks, J (2009) 'Mental health crisis and respite services: service user and carer aspirations' *Journal of Psychiatry and Mental Health Nursing*, vol 16, pp 424-433.
- Mairs, H. & Bradshaw, T. (2005) Implementing family intervention following training: what can the matter be? *Journal of Psychiatric and Mental Health Nursing*, 12, 488-494.

MIND (2012) *What is a mental health crisis*, [online],
[http://www.mind.org.uk/help/medical and alternative care/crisis services](http://www.mind.org.uk/help/medical_and_alternative_care/crisis_services) , [accessed 2/9/2012]

Morse J (ed) (1991) *Qualitative nursing research: a contemporary dialogue*, California, Sage Publication.

Oyebode J (2003) 'Assessment of carers' psychological needs', *Advances in psychiatric Treatment*, Vol 9, pp45-53.

Rapaport J, Bellringer S, Pinfold V & Huxley P (2006) 'Carers and confidentiality in mental health care: considering the role of the carer's assessment: a study of service users', carers' and practitioners' views', *Health and Social Care in the Community*, July, Vol 14, Nr 4, pp357-365.

Ridley J, Hunter S & Rosengard A (2010) 'Partners in care?: Views and experiences of carers from a cohort study of the early implementation of Mental Health (Care and Treatment) (Scotland) Act 2003', *Health and Social Care in the Community*, Vol 18, Nr 5, pp474-482.

Schneider J, Carpenter J, Wooff D, Brandon T & McNiven F (2001) 'Carers and community mental health services', *Social Psychiatry and Psychiatry*, Vol 36, Nr 12, pp604-607.

Simpson, A., Barlow, S., Cox, L., Jones, J. & SUGAR. (2014) Adding SUGAR: Collaborating with service users and carers in mental health nursing research. *Journal of Psychosocial Nursing and Health Services*, 52, 1: 22-30.

Smith J, Larkin M & Flowers P (2009) *Interpretative Phenomenological Analysis: theory, method and research*, London, Sage Publications

Wooff D, Schneider J, Carpenter J & Brandon T (2003) 'Correlates of stress in carers', *Journal of Mental Health*, Vol 12, Nr 1, pp29-40.

Wynaden D & Orb A (2005) 'Impact of patient confidentiality on carers of people who have mental disorder', *International Journal of Mental Health Nursing*, Sep, 14(30), pp166-171.

Table 1. Interview framework

1.	Please think of a time your [relative/friend]. went through a mental health crisis. Did the person stay at home or go to hospital?
2.	For the following questions please think about what happened while they were at home.
3.	What did you do to help them? Did you visit, shop for, talk to them, look after their children, pets, give them medication etc.?
4.	What was it like for you caring? Please talk about how it affected you?
5.	What support (if any) did you get in helping your [relative/friend].... stay at home? Did family/ friends support you? Did you get time off work?
6.	Who provided the support? Was that the right person or would you have liked someone else to help?
7.	What did you think about the support you were given? Was anything in particular helpful or not? What would have helped you during the crisis?
8.	How helpful to the person you supported did you think the support was you gave them? Would you want to do anything different in the future?
9.	If you could plan the ideal care during a crisis what would it be? Is help from professionals important? What type of help would you like i.e. practical, advice or emotional.
10.	Is there anything that hasn't been covered you think is important in relation to support for carers?

Table 2: Summary of discussion

What is known from previous research on mental health caring
<p>Carers and professionals often have different perspectives on what constitutes a crisis</p> <p>There may be a lack of understanding from professionals of the experience of carers which can lead to a lack of empathy</p> <p>The caring role can be fraught and lack meaningful involvement from the professionals</p> <p>Carers experience complex emotions of guilt and loss</p> <p>When carers are not involved by professionals it can evoke feelings of resentment, isolation, fear and anger towards the person in a mental health crisis.</p>
What this paper adds to understanding of mental health crisis
<p>Carers experience 'double deprivation' as by not getting support from professionals and protecting their social network from the crisis means they do not get support for themselves</p> <p>Caring during a mental health crisis was for the participants in this study a negative experience. This finding is different from caring in general which is described as a mix of positive and negative experiences.</p> <p>Complex emotions of loyalty and fear of stigmatisation makes acknowledging and talking about aggression difficult</p>
Implications for practice

How mental health services respond to the carer during a crisis will have an impact on their wellbeing.

Carers may withhold information on aggression out of sense of loyalty which has an impact on risk assessment

Offering debriefing for carers post crisis may be a way for the carer to process the trauma