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The unmet support needs of family members caring for a suicidal person

Abstract

Background: The prevention of suicide is a key aim for health care authorities and society in general and family members have a principal role in caring for suicidal people. However, the support needs of these essential family carers are relatively unknown.

Aim: To explore the support needs of family members of suicidal people.

Method: Eighteen participants were interviewed using a short topic guide. Transcripts were analysed using thematic analysis and confirmed by discussion.

Findings: Family members of suicidal people have unmet needs (this was the main theme). Four sub-themes emerged: having practical support, respite and advice; feeling acknowledged and included; having someone to turn-to; and consistency of support.

Conclusions: Family members are perceived to have an important role in suicide prevention; however some carers experience a lack of support which impinges on their ability to undertake this role. Family members need to be included in care and require support from healthcare staff.

Declaration of Interest: There was no conflict of interest.

Key Words: Suicide, suicidal behaviour, mental health, carer support needs, family support needs.

Introduction

Suicidal behaviour is a multifaceted phenomenon that stems from personal, social, psychological and environmental issues and the World Health Organization have made the prevention of suicide an important global target (WHO, 2014). The term suicidal behaviour includes suicide ideation, self-harm and attempted suicide (Maris et al. 2000) and there is a strong connection between suicidal behaviour and future completed suicide (Owens et al. 2002; Tidemalm et al. 2008). Therefore the reduction of suicidal behaviour is fundamental in preventing future suicide.

Family members are often to the forefront of suicide prevention (Prabhu et al. 2010) and where appropriate, the involvement of a family member in the person's care is important (WHO, 2014). However, Daly (2005) and Byrne et al. (2008) reported that parents lack suitable support from health care authorities in terms of how they as carers should intervene. The suicidal behaviour of a family member and the possibility of future suicide impacts heavily on other family members and causes distress (Buus et al., 2014). Also, the Royal College of Psychiatrists (RCP) acknowledged that family carers have an important role to play in caring for a suicidal person (RCP, 2010) and have recommended good practice to improve information sharing between staff, carers and patients.

Family members may know the suicidal person best and hence are well placed to provide care and prevent future suicide. As their care setting is the family home, there is potential for them to feel isolated and unsupported by healthcare staff. Also,

providing voluntary care to adults with mental health issues is fraught with difficulties. For instance, there may be tensions between the need for client confidentiality and recognising the potential key role of the family carer in promoting a positive therapeutic outcome (McLaughlin et al 2014). Whilst the importance of the family environment is acknowledged, the emphasis is on the client and so the support needs of family carers remain largely hidden. There is little research about carers' needs and their experiences of the support received whilst caring for suicidal family members. This article addresses this gap in knowledge and explores the support needs of these voluntary family carers. It also follows on from an earlier paper that highlighted the nature of the burden on the whole family and the stigma and the sense of helplessness and guilt that accompanied the caring role in this context (McLaughlin et al. 2014).

Methods

Qualitative semi-structured interviews were held with participants who identified themselves as currently living with and caring for, or had lived with and cared for, a suicidal family member. Recruitment was undertaken through a media call following ethical approval. Ethical approval was gained from the host Research Ethical Committee of the University.

Procedure

Participants made initial contact with the lead researcher via a publicised telephone number. Then the study was explained. Once eligibility was determined an appointment was made for the research interview. Informed consent was obtained prior to and affirmed following completion of the interview. Participants were informed that they could withdraw from the study

at any time and were offered the opportunity to comment on the findings.

Pseudonyms were used to preserve anonymity. Interview locations were chosen by the participant and included the participant's home, the rooms of a voluntary counselling facility, or a university office.

Data Collection

Data was gathered by in-depth semi-structured interview. Questions focussed on the participant's experiences of discovering and living with a suicidal person.

Additional probes were used, when required, to explore the experiences of any support they received. (See Table 1).

Table 1

I would like to start by asking you to tell me about how you felt when you found out about _____'s suicidal behaviour.

Additional Prompts:

- *In what way did you and the family react?*
- *What type of support did you and other members of the family have available at that particular time?*
- *What were your experiences of Health Care support services at that time?*
- *What kind of support do you think would have been useful for _____?*
- *What kind of support do you think would be useful for families or partners of suicidal people?*

Data Analysis

Each interview was digitally recorded, transcribed verbatim and each transcription was analysed using Thematic Analysis as described by Newall & Burnard (2006). The Lead Researcher conducted the analysis and investigator triangulation was used to agree the emergent themes.

Findings

Participants

Participants were aged between 25 - 78 years. At the time of the interview, 7 participants had experienced the death of a parent or sibling following several years of living with them, whilst they were exhibiting suicidal behaviour. A further 11 participants were currently living with someone who was exhibiting suicidal behaviour.

The 'Carers' unmet needs' was a core theme and encompassed their perceptions of the support they received or required in order to care for the suicidal person. Four sub-themes emerged: having practical support, respite and advice; feeling acknowledged and included; having someone to turn-to and consistency of support.

Having practical support, respite and advice:

The importance of being in contact with caring staff and having some practical support was mentioned by all participants. They felt that healthcare staff could have been more proactive in asking them about the type of practical help or support they needed.

For example, Anthony, whose son was suicidal, was critical of the lack of support and said: *"there's nothing there for us, do you understand, there's been nothing there over the years, as a carer there's nothing there for you ...but had there been at the start I reckon.....(pause) some sort of support for us....., we could have had a better life as a family."*

Conversely, Rebecca described the good support and advice her family received: *"she (CPN) was very good because she was practical and she gave us coping skills because sometimes you don't know how to cope and you feel helpless as well. As soon as we went to her with a practical problem she would have said 'right, here's how you deal with this and this will make it easier for you to deal with it in the future."*

However, Kevin felt that health-carers could be more proactive in offering help: *"someone to say I'll look after "Mary and Kevin" now and make sure they're ok and just call in and see things are ok, just ring them and see if things are ok, instead of us always having to do the running when you were distraught and lacking in sleep and at the end of your tether."*

Furthermore, Bernadette, felt that some respite care would be helpful: *"Someone to come and talk to him and stay with him to let me get a break..... it's 4 years from I had a break."*

Additionally, Maureen, whose eldest daughter was suicidal, said..... *"What the health service needs to do is focus on the family and maybe help with external activities for family. I was a mother trying to help her children and help a suicidal child as well. It was hard. Simple things like housework or shopping or even making the dinner are difficult.....(pause) It is difficult to plan things as you are always looking over your shoulder. Children in families need support too and they need a break. It really affects them and you have to do your best to protect them."*

Participants found it difficult to leave their suicidal family member at home alone. A common point among them was that any help that provided a few hours respite time for carers to do shopping, visit friends or simply relax would have been appreciated.

Feeling acknowledged and included:

Participants' overwhelming desire to be involved in the hospitalised care for their suicidal family member was very evident from the interviews. However, participants experienced exclusion when their family member turned 18 years of age. This happened suddenly and without explanation or preparation, which added to the stress of the situation. Participants were scathing of this. While healthcare staff were respecting the patient's right to confidentiality, participants argued their need to be included in order to provide care at home.

For example, Joseph said: *"when she turned 18, they were no longer interested in us as her parents and.....(pause) to be suddenly cut out of it and you think..... have we done something wrong and why aren't we being talked to and suddenly it's all*

about the young adult and they have to give consent for you to be involved in that process."

Gertrude said: "staff were nice to my sister but they were not helpful to me. I was not allowed to be given any information about her treatment. They said it was up to my sister to tell me. My sister didn't really want to be there, I was worried about her, I cared about her and so did her children and they wouldn't give us any help or information. There is no support for carers. We need to be able to ring up the services to find out how she is. The services tell you nothing. That is no good as we are expected to help. How can we help if we don't know and are kept in the dark? Services need to talk to family members about their relatives."

Anthony said: "The medical side of affairs will not, and I stress this point, will not discuss anything with us and I think that for people to be asked to look after somebody who is in this state of mind without telling them how they can actually help or when should they step in to help, is totally wrong."

Another father (Kevin), whose son killed himself, was adamant: "Nobody listened to us, and in fact, we were ignored a whole lot of times. We are part of the solution, not part of the problem and there has to be some kind of way whereby you need information, you need help and you need to be recognised as well too."

A daughter (Sharon), whose mother killed herself, commented: "Staff need to make an effort to approach people, even if it seems like a betrayal of a person's feelings. In my case keeping the secret did not help and only created problems for me."

Mental Health Services need to contact family and children and involve them and inform them."

Participants were emphatic that they should be involved in the care of their suicidal family member. Their frustration and anger on being excluded was very evident.

Having someone to turn-to:

Each participant described how caring for a suicidal person impacted heavily on their wellbeing and were adamant that they needed support themselves. However, this support was not readily forthcoming. Evident among all participants was their own need to talk to others about their own feelings.

For instance, Martina, whose sister tried several times to kill herself, said: *"Families need a place to talk and acknowledge the impact that it has on the family. The offer to speak to someone would have been appreciated. It has had a devastating effect on my family."*

Anita, whose brother killed himself, stated: *"I had no contact with the Health Care services and was not offered any help or support by them. I was invisible to them and so were my parents and my sister. We were all invisible to them."*

Also, Denise, a young wife whose partner was suicidal found it difficult to approach staff: *"his psychiatrist occasionally asked me into his office just to get information about how (name) was doing but never really asked about me, so it was purelyyou know focussed on my partner and I never felt really that there was any*

opportunity for me to speak about me. I wanted them to talk to me but I couldn't just talk to them.....(pause) I wanted them to know that I needed help too but I got none and I felt let down and lonely."

Sharon (whose mother killed herself) added: *"It was very strange for me as a child with no understanding. I didn't know what to do..... and I got no help or support. They knew that I was there but I didn't seem to matter to them."*

Kevin (whose son killed himself) was adamant: *"There was nobody to turn-to, you can write that in capital letters THERE WAS NOBODY TO TURN-TO. We were the carers that needed care and if we had got that, maybe we could have cared for (name) better."*

Anthony said: *"the mental health people, you know the mental health part of the people, they don't seem to understand how the ordinary people, the father and mother feels. If they do, I would love to tell them it doesn't come across, it definitely does not come across."*

It is evident that the behaviour of the suicidal family member impacted on participants' mental health and participants would have appreciated if healthcare staff had ask them how they were coping. Such a gesture would have shown that staff were aware of the emotional difficulties faced by carers. Participants were not seeking therapy for themselves but wanted an empathetic healthcare professional to provide emotional support and who would have some understanding of their needs. However, participants

commented that while their suicidal family member was being cared for, healthcare staff did not recognize that carers also needed emotional support.

Consistency of support:

Each participant described the input of different healthcare staff. The examples suggest that healthcare staff could do more in terms of inter-professional cooperation. The input by the Police was highly commended and similarly with community based agencies. However, participants felt that healthcare staff seemed to work independently of each other. Also, participants felt that continuity of care by the involvement of the same staff member would be more appropriate.

Rebecca commented: *"we were lucky to have a good psychiatric team, there was continuity of care, the same consultant that looked after him in the community, (also) looked after him in the hospital."*

However, Kevin's experience was very different: *"There are different people..... agencies had information but as far as we could gather, they had never pulled them together and if they had co-ordinated and pulled them together, they would have seen a devastating picture of (name), because they only saw wee bits."*

Furthermore, Anthony was extremely adamant: *"there was no continuity.... He doesn't have an actual social worker anymore. It's any Tom, Dick and Harry to see a person like him. (Name) said he's fed up with repeating everything, there's different ones coming all the time.... he needs somebody who he trusts and can understand....."*

Having to deal with different staff is frustrating for both participants and their suicidal family member. Participants' responses suggest that there must be trust and understanding between patients and staff members and that this can only come about if there is consistency in the team members providing care.

Discussion

It is evident that family carers have a number of emotionally distressing issues to contend with and findings here magnify those in our earlier report in McLaughlin et al. (2014). Also, our findings echo the issues raised in the 'Good Practice Checklist' (RCP, 2010). For example, participants stated that healthcare staff, citing confidentiality, excluded them (participants) from the hospitalised care of the suicidal person and this was particularly acute where the suicidal person reached adulthood. Also, similar to Daly (2005) and Byrne et al. (2008), we found a lack of appropriate support from healthcare staff for volunteer family carers.

Carers need to know the appropriate information that will enable them to deliver care at home (RCP, 2006). However, the rigid enforcement of confidentiality when the suicidal person attains 18 years of age is a particular obstacle between healthcare staff and family carers. The difficulties that this specific issue creates for carers should not be underestimated. The Royal College of Psychiatrists (2010) make it very clear that confidentiality issues between patients, healthcare staff, and carers need to be addressed as early as possible in the care programme. Carers were unwavering in this problematic area and were unequivocal in stating that healthcare staff require a realistic and pragmatic approach to solving this problem

and help family carers to provide care in the home setting. Our findings suggest that the guidelines within the good practice checklist (RCP, 2010) may not be adhered to.

The World Health Organization makes it clear that the prevention of future suicide requires collaboration and co-operation between healthcare staff and relevant non-health care personnel including family members (WHO, 2014). Healthcare staff should be proactive in encouraging carers as an integral part of a supportive team. They need to accept that family carers are part of the solution, are very much in the front line of suicide prevention and are a resource that very much wants to be involved in the care of the suicidal person. Our findings strongly suggest that excluding carers from important decision making discussions is very frustrating and demoralising for family carers. There is thus a need for healthcare staff to negotiate with the patient and the carers to establish the level of carer involvement in each case.

The sub-themes suggest how healthcare staff can better help family carers to provide care at home. For instance, carers wanted healthcare staff to 'check in' with them to see how they and their suicidal family member were doing. Indeed, this need is supported by the WHO (2014) suggestion that follow-up by healthcare staff such as telephone calls and brief in-person visits are effective in reducing suicide. Follow-up care would help reduce the carer's feeling of isolation and provide them with much needed psychological support. Also, carers want to be involved in the hospitalised care of their suicidal family member. However, there may be issues that the suicidal person will request to

be kept confidential. These issues need not lead to the exclusion of family carers as partners in care. The Royal College of Psychiatrists (RCP, 2010) acknowledge that sharing of information about patients with family carers can be difficult, but they emphasise that it is often crucial to the ongoing wellbeing of both patients and carers. Carers should be given sufficient information, in a way they can readily understand, to help them provide care efficiently in the home setting. Therefore, it is imperative that healthcare staff and patients negotiate the advantages of sharing relevant information with family carers.

Furthermore, carers need information and practical advice about what to do in crisis situations. In the community, the assigned healthcare professional, such as the Community Psychiatric Nurse, would be the most appropriate resource and an important link between the patient, family carers, community services and hospital. Two instances of good practice were identified in this current study. First, the assigned Community Psychiatric Nurse visited the patient in hospital to ascertain progress and maintain their relationship. Second, the same psychiatrist was responsible for the patient in both community and hospital. Other participants said that healthcare staff changed all too often and that this created anxiety and uncertainty in the suicidal person. Continuity of care and the inclusion of the family carer as part of a supportive team could benefit the patient; reduce tension between staff and carers; provide a better picture of the patient's care needs and possible interventions would be better focused.

Suicidal behaviour creates a heavy burden on carers and other family members (McLaughlin et al. 2014) and our earlier paper demonstrated that carers wanted the

opportunity to talk to staff but found it difficult to ask healthcare staff for this help. While some participants had close friends whom they could confide in, others had none. The feeling of loneliness and isolation felt by carers echoes the findings reported by Daly (2005) and Byrne et al. (2008). However, healthcare staff are in a prime position to offer carers emotional and practical support (RCP, 2010). It is the assertion of our findings that providing carers with such support will help them cope better in the home setting.

Limitations of the Study

This is a small sample study and findings cannot be generalised to the larger population. The findings suggest the need for additional research.

Conclusion

It is worrying that concerns expressed by the Royal College of Psychiatrists (2006) are still evident today. Family carers make it very clear that they want to be involved in caring for the suicidal person but they require help and support to do so.

Perversely, they are obstructed from involvement when the suicidal person attains 18 years of age. The 'Good Practice Checklist' (RCP, 2010) advocates that healthcare staff should engage with carers in addressing difficulties surrounding confidentiality and other emotional or practical issues. Engaging with carers can reduce tension between them and healthcare professionals and has potential to improve the caring environment for the carer and the suicidal person's benefit. By being more proactive in helping carers to meet their practical and emotional needs, healthcare staff might help voluntary carers to be better able to care for the suicidal

person in the home setting. In doing so, such proactive intervention by healthcare staff may help to reduce the incidence of future suicide.

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