'It's like getting a group hug and you can cry there and be yourself and they understand'. Family members' experiences of using a suicide bereavement peer support group

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Abstract: Suicide bereavement support groups are a valuable source of help for people coping with a suicide and it is important to understand how they are beneficial, as well as ways in which they may be unhelpful or even detrimental. A constructivist grounded theory approach was implemented and 17 family members bereaved by suicide were interviewed, along with seven participants in a focus group. The findings highlighted the difficulties for participants to adjust to the suicide, which motivated them to meet others in a peer suicide bereavement group who had shared a similar experience. This helped them to normalise their grief experiences and share ways of coping with the death. Some participants encountered practical challenges of accessing groups, found other ways of coping or described their needs as unmet. It is recommended that health services proactively provide bereaved families with timely and ongoing information on support available, including peer support groups, to minimise negative health outcomes.

Keywords: suicide, grief, bereavement, peer support, postvention

Introduction

Suicide prevention and reduction are among the priorities in the Five Year Forward View for Mental Health Implementation Plan (NHS England, 2016). Extensive evidence also highlights the detrimental impact on people affected by the suicide of a significant other, especially first-degree relatives, and the distinctiveness of a suicide bereavement compared with other types of bereavement (Andriessen, 2009; Sanford, Cerel, McGann, & Maple, 2016; Wilson & Marshall, 2010). People bereaved by suicide can experience an increased risk of mental health problems such as depression, anxiety, and post-traumatic stress disorder, suicide and suicidal ideation (Andriessen & Krysinska, 2011; Samaritans, 2016; Young et al., 2012). In order to provide more effective support for those bereaved by suicide, it is important to understand how they make sense of the suicide, what impact a suicide has on them, and to identify ways in which they can be supported.

Most often, a suicide is experienced as a sudden traumatic unnatural death that strongly motivates family members to make sense of the death by searching for

answers (Lindqvist, Johansson, & Karlsson, 2008). The task of making sense of the suicide is likely to be more difficult when the suicide is unexpected and may be easier, at least at a rational rather than emotional level, if the deceased had a severe mental illness, had expressed suicide ideation or had made previous attempts (Maple, Plummer, Edwards, & Minichiello, 2007). Clearly, a known mental illness and prior involvement with mental health services will take many forms, and these will affect how the bereaved person makes sense of the suicide and its impact on them and other family members. For example, health services and clinicians who were treating the deceased can be blamed by the families for failing to prevent the suicide (Spillane et al., 2017), which may dissuade the bereaved person from seeking help for themselves (Feigelman & Feigelman, 2008). Also, the extent of involvement and openness by clinicians regarding their relative's care, due to patient confidentiality, can have a profound impact on how they make sense of or accept the death (Care Quality Commission, 2016).

Most people bereaved by suicide do not access any type of support from health services or other interventions, struggle to find help and therefore develop their own ways of coping with their loss (Cerel, Padgett, Conwell, & Reed Jr, 2009). They often draw upon family or social support networks (Wilson & Marshall, 2010), and a minority access postvention, which Andriessen (2006) defines very broadly as activities that aid recovery post-suicide. Postvention is also a term that describes interventions provided to those bereaved by suicide, including medication, counselling and peer support groups (Jordan, 2008), so we use the term in that way in this paper. Arguably generic postvention can be ineffective, or even harmful, if it fails to consider the distinctiveness of the experiences of those bereaved by suicide (Andriessen & Krysinska, 2011; Hall, 2014). For instance, Wilson and Marshall (2010) investigated the self-reported support needs and experiences of people bereaved by suicide and found they were dissatisfied with clinicians who lacked knowledge or appropriate training in suicide bereavement. Participants said they would have preferred peer support groups, but were not given information on such groups by health services.

Peer support groups are popular for the bereaved in general, yet little research has been conducted on the experiences of these groups for those bereaved by suicide (Cerel et al., 2009). According to Hardy, Hallett, and Chaplin (2019), peer support generally involves a group of people who share a similar experience or condition, who learn from each other and seek or offer support. Underpinning peer support groups are self-help, mutual support, mentoring, recovery and open dialogue (Hardy et al., 2019). Pietilä (2002) found these factors are important in a peer suicide bereavement support group and helped the participants to cope with and make sense of the suicide and their bereavement experiences. Participants were able

to see their own experiences from a different perspective, found acceptance in the group, received affirmation of the normality of their experiences and felt comfortable sharing their feelings without the judgement of others. Peer support groups vary in their format and structure, reflecting the local and cultural context of the host organisation's values and beliefs (Hardy et al., 2019). Feigelman & Feigelman (2011a) suggest effective groups are run by peer workers who are good listeners, alert to the group dynamics, able to prevent potential conflict, and possess leadership skills.

Despite these benefits and the popularity of peer support groups, they may not be suitable for some people bereaved by suicide. Feigelman & Feigelman, (2011a; 2011b) identified how some may find support groups unhelpful or disengage because of the fluctuating changes in the group dynamics such as dealing with cliques in the group, individuals dominating the discussions and new attendees experiencing difficulties integrating into pre-existing groups. Some families may feel distressed from hearing others' stories or feel re-traumatised (Cerel et al., 2009), thereby increasing the intensity of their grief and leading to their disengagement (Feigelman & Feigelman, 2011a). Moreover, most support groups meet monthly so immediate or more intensive support is not available (Grad, Clark, Dyregrov, & Andriessen, 2004). Few studies have looked at how suicide bereavement groups help people to make sense of the suicide, and how they benefit from the peer support of those with similar lived experiences. Further in-depth qualitative research is required that takes account of the personal and social context and the diversity in individual's experiences.

This paper describes part of a larger grounded theory study in which the experiences of family members who accessed a Survivors of Bereavement by Suicide (SOBS) support group were explored. SOBS is a UK charity that provides volunteer-led peer support for adults bereaved by suicide, including locality-based support groups and a national helpline (www.uksobs.org). This study focused on understanding the impact of suicide on families of people who were in receipt of mental health services in order to understand how this prior involvement influences how the bereaved person makes sense of the suicide, its impact on them and their willingness to seek support for themselves. This is also important in order to provide more appropriate support for the bereaved person, and so that mental health services can learn lessons about the implications of the extent of involvement of family members in the support and treatment of a person with a mental health problem.

Methodological approach

It is acknowledged that situational and personal factors greatly influence how people bereaved by suicide make sense of the death as they reconstruct their social worlds (Neimeyer, Baldwin, & Gillies, 2006). Parkes (2010) also highlights the diversity in the bereaved's experiences and that

'normal' grief can only be understood in a social context. Consistent with this view, this study employed a social constructivist theoretical framework (O'Connor, Netting, & Thomas, 2008), which offered a greater understanding of how families reconstructed their social worlds from before to after the suicide and its impact on them. Constructivist grounded theory (CGT) (Charmaz, 2014) aims to develop a theory or an explanation on how an individual internalises and actively constructs meaning through their social relationships and interactions with others. Data gathered from semi-structured in-depth interviews and a focus group was comparatively analysed. This process is useful when exploring emergent insights during the research in developing the theory (Charmaz, 2014), and in checking the appropriateness of the findings (Cho & Trent, 2006).

Sampling strategy and recruitment

The inclusion criteria for participants were: adults aged 18 years or over who had lost a family member (including extended family member) through suicide (or apparent suicide), and the deceased had been in receipt of mental health services within the last 12 months before their death. For the larger study, two participants were recruited via an NHS Trust Patient Safety Team and 22 participants were recruited via one SOBS group. Two SOBS helpline workers were recruited using the same inclusion criteria for the participants, with the addition that they had worked on the service for at least two years to ensure they had received the necessary training and experience. This paper describes the analysis of the SOBS group members and helpline workers only.

The SOBS group attendees visited from a number of different localities, served by different mental health service providers. Initially, convenience sampling was used to recruit those who met the criteria and who volunteered to be interviewed. Following early coding, the need for more diversity was identified so a purposive approach was used to include participants in terms of the kinship and nature of the relationship with the deceased, age, gender and the length of time since the suicide. To facilitate recruitment, the main researcher (FA) visited a monthly SOBS group for one year to speak with the attendees, share the study literature and answer questions. This enabled FA to gain the trust of attendees, and the identification of participants who would be willing to share their experiences.

The interviews with SOBS participants included core questions based on: life before the suicide, the suicide, and life after suicide. During the analysis, it became clear that participants sought support from others who shared a similar lived experience rather than or in addition to accessing support from health professionals. Therefore, SOBS helpline workers were interviewed to explore their motivations for becoming a volunteer for the helpline,

what they gained from supporting helpline users, and what service users asked for. A focus group of seven participants then explored how participants felt their experiences related to the tentative findings, and suggestions for any further additions or omissions which informed the development of the final theory.

Data analysis

Following guidance from Charmaz (2014), the analysis began with open coding of the transcribed data line by line at an abstract level to capture the participants' views, meanings or actions. These codes were then synthesised into focused codes that encapsulated the tentative categories at an analytic level. Throughout the analysis, memos were continually written and sorted into categories to develop a tentative conceptual model on the impact of suicide. After interviewing 17 participants (including two participants from the Trust), the findings were shared with seven focus group participants and led to amendments. However, as no new insights emerged, theoretical saturation occurred and no further data was collected.

Approvals

The study was approved by an NHS Research Ethics Committee (REC reference number: 14/YH/0015). Approvals were also provided by the participating NHS Trust and the SOBS charity.

Findings

Of the 22 SOBS participants, 16 were females and six were males. Twelve were parents of the deceased, two were siblings, three were husbands, two were wives, two were extended family members and one participant had lost a parent. The 19 deceased were all white, aged between 27 to 60 years old and 12 were males. At the point of data collection, most participants had experienced the suicide at least three years previously, although times varied from three months to 19 years. Participants' ages ranged from 23 to 67 years old and, on average, began accessing SOBS four months after the suicide. During the one year the main researcher FA visited SOBS, approximately one-third of the participants regularly attended, whereas the majority of participants visited intermittently or only once.

The conceptual model developed in the study highlights how participants reconstructed their social realities from before to after the suicide (Ali, 2019). The findings described in this paper relate to the final element of the model – the 'impact on life after suicide', which includes the themes of 'personal ways of coping' and 'dealing with the grief'. This provides insights into the experiences, benefits and difficulties involved in attending a suicide bereavement group demonstrated in the following themes.

Distinctiveness of the suicide

Nearly all the participants felt the suicide was distinctive compared with other types of death they had experienced:

> *'They've left you with no goodbyes, no reason as to why they've done it, you're not able to say goodbye. When a person is terminally ill and you can bring closure and you can say what you want to say to your loved one. You're deprived of that, it's taken away from you.' (Husband)*

All participants reported that they had not received any information or support from the mental health services who were treating the deceased, so they had to find their own sources of support. A strong motivation for participants to access SOBS was to make sense of the suicide by meeting others bereaved by suicide. Participants ruminated on their past experiences with the deceased or became intensely preoccupied with the death, which negatively affected their mental wellbeing. They experienced emotions such as rejection, abandonment, shame, guilt and responsibility for the death that intensified their difficulties of coping with their loss. The mental health of the deceased added another level of complexity by raising conflict on the rationality or irrationality of the suicide, and resulted in a strong need for answers as to why the suicide occurred. Therefore, participants wanted to talk to others to gain some insights into why their loved one may have died or how they coped and dealt with the death. Participants also perceived stigma from others, which was not the case from other types of bereavement.

These experiences culminated in self-isolation for certain participants, further negatively impacting their mental health. Some participants lacked family and social support or wanted to avoid distressing and burdening others, so SOBS was considered a safer space that protected them from the judgement of others. Moreover, participants felt others in their social support networks or community had limited knowledge of suicide bereavement or were unresponsive to their needs.

Experiences of SOBS and other bereavement support groups

Three participants had also accessed generic peer bereavement support groups and the shared sense of loss was the common factor regardless of the cause of death and the kinship relationship.

> *'I found SOBS and the Compassionate Friends support people who've lost a child in any way. Sharing helps quite a lot with your grief, because you can talk about it and they can talk about theirs and you swap bits of information and feelings.' (Mother)*

The importance of having a diverse range of peer support groups for the bereaved was exemplified by Christine. After the death of her husband to a terminal illness she visited a support group at the hospice and realised that '*the only people my age had lost parents* […] *at that time that wasn't really what I needed*'. Subsequently, she accessed online peer bereavement support groups which she found effective. However, after her son's suicide three months previously, she wanted '*to meet other people that have lost sons, and the people that have lost partners so I'll be able to compare notes with them*'. Although the suicide was distinctive, the collective sense of loss was the unifying factor in the group attendees' experiences.

SOBS helped participants gain a greater understanding of their own and others' experiences through the process of sharing and hearing others' stories. This helped many participants to put their experience into perspective as shown by one participant, '*I think I'm in a bad situation, but then I listen to other people then I think "you're in a worse situation". It does open your eyes to others*'.

The difficulties of making sense of the suicide was highlighted and all the participants ruminated on what they could have done differently to prevent the suicide. However, listening to how other attendees had tried different approaches helped some to find resolution that they could not have prevented the death. Over time, regular long-term members of SOBS learned to accept that they could not take responsibility for the death and this reduced some of the guilt they felt.

Participants reported their suicide bereavement did not follow a similar pattern to other bereavements and challenged the assumptive norms of grief and coping. Talking to other attendees at SOBS enabled them to empathise with each other and receive confirmation that every individual's grief was unique.

> *'I say at SOBS you can laugh about things, where in a group away from SOBS … I suppose if you're in a group of people, say the hospital or something like that with professionals, if you laughed they'd all look at you like that, what's wrong with this person are they having a nervous breakdown?* […] *but sometimes the laugh is a relief because you know somebody's understanding what you're talking about.'*

There was a need to find others of the same gender and who had the same kinship relationship with the deceased. Very few males attended SOBS and Peter shared his experiences with another member regarding their wives' suicides: '*I know why he's feeling like that and it's something between us two that we can talk about that the other group can't*'.

The rolling nature of the group was advantageous for new members who continually joined and contributed to the

diversity of the group and changing dynamics. Longer-term regulars helped others, became role models and provided hope for new attendees rather than seeking support themselves. Victoria emphasised, '*the value of the group is that you can see other people are further down the road of coping and it gives you the hope that you can cope too*'.

The findings identified the process of transitioning from life before the suicide to life after the suicide as they reconstructed a different social world. Christine stated, '*The way your life was, is altered so you have to start doing something else and get a new type of normal*'. Participants described a changed sense of self and identity and defined themselves as 'survivors' – '*because we are "survivors or bereavement" not "victims " as such*.' The reconceptualisation of 'survivor' was empowering for many participants because it challenged the negative societal connotations of the bereaved. Taking control and ownership of this label reflected personal positive growth at an individual level, but also contributed to constructing a collective identity as participants developed a sense of belonging and developed new friendships. The group took part in shared activities such as lighting candles in memory of the loved ones at Christmas, which became a ritual outside of the group for a few participants. Group members also shared their diverse ways of coping with the suicide, for instance two participants disclosed visiting mediums after hearing a few members' experiences, although neither believed in the afterlife.

All the participants disclosed how they benefited from attending SOBS although the group format of SOBS left a few participants feeling uncomfortable. Speaking in public was problematic for some although the group leaders made it clear that attendees could share as much or as little information as they wanted. One helpline worker confirmed that '*I've had people who've phoned me that say I couldn't come to a group and talk in a room full of strangers*'. This explains why the helpline is helpful for some as this service is anonymous, immediately accessible at times of crises and practical. Helpline workers were trained volunteers and bereaved by suicide themselves, so were able to share their personal experiences, offer advice and inform callers of available support.

A minority of participants felt unable to empathise with the majority of those attending SOBS, because of a different kinship relationship with the deceased. A few participants suggested that separate suicide bereavement support groups reflecting specific kinships would be useful. Another difficulty for a few participants was finding others in the group who had had an estranged or distant relationship with the deceased, because their grief experiences felt different compared with the majority of the group who had a closer relationship with the deceased.

Other challenges included the unavailability of local support groups, the geographical distance of the nearest venues, and the difficulties of committing to the date and times of the monthly meetings. Many participants found their needs were also being met outside the group, for example by drawing on their family and social support networks, continued use of postvention, adopting new hobbies, reading on grief and bereavement or using coping strategies they developed after the death of significant others.

Other types of postvention

A third of the participants had been or were still in receipt of other forms of postvention, which was predominately counselling, although three had accessed cognitive behavioural therapy. A minority of participants had been taking prescribed medication for more than one year. Five participants had received longer-term counselling for up to a year, which was provided by bereavement charities, paid by their employer or the participant. However, generally counselling sessions provided by the NHS lasted between six to eight sessions. An important finding was how a few participants described the complementary nature of using both SOBS and counselling at the same time. SOBS was monthly, involving a group of people, whereas counselling was weekly, with one-to-one intensive support. Crucially, the quality of the relationship between the treating clinician and participants contributed to the perceived effectiveness and satisfaction of the services, consistent with extensive research into the importance of the therapy relationship in psychotherapy and counselling (Norcross & Lambert, 2018). Counselling was beneficial if participants developed a good rapport and understanding with the counsellor who they viewed as an 'expert', objective and unbiased. Acceptance of their experiences as 'normal' was particularly important if participants felt their grief did not conform to stereotypical societal assumptions. They could share their personal experiences in a private and safe setting with a counsellor without the fear of upsetting others or feeling judged. Any unresolved feelings or insights that emerged in the counselling sessions were then discussed by participants in SOBS or vice versa. Moreover, one participant who struggled with coping visited her general practitioner (GP) and found him helpful because '*he'd lost his own daughter, yeah, not through suicide […] he was very easy to talk to*'. In this case, the shared sense of loss with a professional was the common factor that enabled empathy, compassion and understanding of participants' experiences and helped them to receive individual support.

Some participants reported finding interventions and support from professionals ineffective and their dissatisfaction with some clinicians led to non-compliance and disengagement with services. Clinicians who lacked understanding of suicide bereavement or how to address the individual needs of participants were unable to

appropriately treat or support them. Moreover, a few participants felt that GPs focused on prescribing medication to address the physical symptoms of their grief rather than referring them into talking therapies. Most participants felt short-term counselling did not meet their expectations; one participant said, '*she* (the counsellor) *could have interacted with me but did she do it, no! Two sessions and that was it, waste of time, it was more upsetting actually than anything*'. Short-term counselling was insufficient to deal with the complexity of the suicide, so participants sought longer-term interventions. Additional barriers of postvention included the long waiting times for services such as counselling, which caused frustration for those who required immediate support.

Discussion

Few previous studies have examined how those bereaved by suicide cope and the benefits they derive from support groups and other forms of postvention (Cerel et al., 2009), so this study helps in part to fill these gaps. Participants described how the suicide was distinct from other bereavements and the subsequent need for particular types of support to help them cope with their loss, which had not been the case for other types of death they had encountered (Groos & Shakespeare-Finch, 2013). UK government guidelines clearly state that local NHS health services should provide people bereaved by suicide with timely information on support, including bereavement services, to minimise negative health outcomes (Department of Health, 2017). However, none of the participants reported receiving any information or support from the mental health services who were treating the deceased. It is possible that this is not representative of the wider population of people bereaved by suicide, but it is a serious concern that is consistently raised and requires urgent action by health services (CQC, 2016). A strong argument is made by participants in this study for services to proactively engage with family members immediately after the suicide and Pitman et al. (2018) propose that people bereaved by suicide should receive ongoing information on support based on their fluctuating needs that may change over time. This study also highlights the importance of offering a range of services, so people bereaved by suicide can choose to access different services at different times to meet their needs.

The importance of the peer support group was apparent, which offered participants an opportunity to disclose their innermost feelings to others without the fear of upsetting significant others or feeling judged (Hardy et al., 2019; Keyes et al., 2016). The sharing of diverse coping strategies, stories, information, and learning from each other's experiences helped them make sense of the death and normalise their own experiences. Over time, this support may increase their resilience and help their recovery process (Feigelman & Feigelman, 2011a & 2011b). Furthermore,

the study highlighted the importance of a collective sense of identity as also reported by Groos and Shakespeare-Finch (2013), and included seeing themselves as 'survivors' which was empowering and gave them a sense of belonging. Participants also hoped their involvement in the research would help others by improving the understanding of the impact of a suicide, and to raise their concerns with health services about how to support those bereaved by suicide.

The study also identified reasons for disengagement from SOBS. Some participants found their kinship and nature of the relationship with the deceased were not reflective of the majority of attendees which reduced the sense of commonality, as also reported by Groos and Shakespeare-Finch (2013). Support groups can increase negative health outcomes in those bereaved by suicide according to Pietilä (2002), and although this was not reported in the current study, many participants reported experiencing distress at group sessions. Hearing others' stories or sharing their experiences was upsetting, leading to possible re-traumatisation and a barrier for individuals attending peer support groups (Cerel et al., 2009).

A recurring theme in this study, and consistent in previous studies, was that postvention did not meet the needs of a minority of participants (Sanford et al., 2016; Wilson & Marshall, 2010), which supports calls for health services to implement more tailor-made interventions for those bereaved by suicide (Hall, 2014; Jordan, Feigelman, McMenamy, & Mitchell, 2011). For example, although a minority of participants had received counselling, only longer-term counselling was found to be effective. Although the participants lived in areas served by different health service providers, it is possible access to longer-term counselling is better elsewhere. For example, Sanford et al. (2016) cites that two-thirds of people bereaved by suicide in the US sought individual therapy to cope with their loss. The study also highlighted the value of combining formal postvention with peer suicide bereavement support and a third of the participants used both counselling and SOBS, also highlighted by Feigelman & Feigelman (2011b).

An inevitable limitation of this study was the sampling and recruitment strategy. UK-wide statistics show suicide in young white males is disproportionately higher compared with females (Samaritans, 2016), as reflected in this study. This explains why most participants were white British females or parents who had predominately lost male relatives. Although the sample is a limitation (Sanford et al., 2016), this study still managed to capture some diversity and variability of participants based on their personal and situational context, and illuminated how these factors shape participants' experiences. We recognise that, as most people bereaved by suicide in the wider population do not attend peer support groups, recruiting participants from support groups excludes the majority of those bereaved by

suicide (Cerel et al., 2009; Jordan & McMenamy, 2004). It is important that researchers explore ways of accessing these other individuals, to understand how they cope without support groups or other forms of postvention. It is also acknowledged that in this study the people who had died by suicide had all been involved with mental health services at some point in the year before their death, and most participants expressed frustrations and negative experiences of mental health services. It is possible that this may have acted as a barrier to accessing postvention from these services, and increased their likelihood of accessing a peer support group such as SOBS. Maple, Cerel, Sanford, Pearce, and Jordan (2016) point out that the retrospective nature of qualitative studies may be considered a limitation. It is acknowledged that the self-reported recollections of participants can change over time, especially if their experiences had been traumatic, such as suicide. However, this study captured diversity in the length of times from the suicide to data collection, which could have impacted on participants' recollection of events and the tentative findings from the interviews were shared in the focus group, thereby providing a check on the appropriateness of the findings.

Conclusion and recommendations

This study reiterates the need for tailor-made interventions for people bereaved by suicide, a range of options to choose from and more acknowledgement of the valuable work of bereavement peer support groups. Moreover, there should be more flexibility in the timing and duration of postvention so they can be more tailored to the requirements of the individual and recognition given to the parallel use of different types of postvention, which may be more suitable for participants who require intensive support.

It is recommended that researchers, clinicians and commissioners should actively engage with people bereaved by suicide in order to understand their experiences, identify their needs and minimise negative health outcomes. The involvement of those bereaved by suicide and clinicians in the co-production of research and co-designing of future services will be more conducive to implementing tailor-made interventions appropriate to their needs. This was strongly advocated by participants in this study who suggested that health services should work collaboratively with suicide bereavement peer support groups to understand their work and listen to members' experiences. ■

Acknowledgments

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