Experiences of support from primary care and perceived needs of parents bereaved by suicide:

a qualitative study

INTRODUCTION

Annually, around 6000 suicides are recorded in the UK,1 and suicide prevention is a government priority.2-3 The economic cost of suicide is estimated to be £1.67 million per death; however, 70% of this cost is attributed to the impact on those bereaved by suicide,4 and it has been estimated that approximately 135 people are affected by each death,5 therefore suicide exposure and bereavement is widespread.2 Suicide bereavement is associated with a higher risk of a suicide attempt in those bereaved.6 Therefore, the provision of care for this vulnerable group (referred to as postvention) is a key component of suicide prevention strategies.5

Research has shown that parents bereaved by their son or daughter’s suicide are more likely to experience adverse physical and mental health outcomes,7 including increased risk of admission to psychiatric care.8 Mothers bereaved by suicide are especially at risk of dying in the same way.1,2,9,10 Outcomes are further complicated by relatives and friends of people who have died by suicide having higher levels of perceived stigma, shame, responsibility, and guilt than those bereaved by other causes of death.11,12 Feelings such as shame and stigma will likely influence help-seeking behaviour among this group,11,13 and their potential awareness of avenues of support. This may in turn negatively impact on health outcomes.13 For those who do seek help, some parents may disengage from services if they perceive health professionals have responded inappropriately.14 Therefore, there are a number of potential challenges when supporting people bereaved by suicide.

The national suicide prevention strategy for England15 highlights the need for effective and timely support for those bereaved by suicide. However, the most recent report on the strategy16 suggested progress in this area had not been wholly successful, with those bereaved by suicide reporting they had not always received the necessary help and support they needed. In recent years, there have been qualitative explorations of the support needs of those bereaved...
How this fits in

Parents bereaved by suicide are at risk of mental health problems and suicide. Understanding what parents’ support needs are and how they perceive the role of primary care may help inform how general practice can support these patients. This study offers an insight into the perspectives of parents bereaved by their son or daughter’s suicide and has implications for practice that may help improve the care of this vulnerable group.

by a relative’s suicide.17–19 These studies highlight the importance of services being informed by the experiences of suicide-bereaved people. However, parents are potentially one of the most traumatised groups of suicide-bereaved people, and there is less evidence available20–22 about how to support them in the UK.

The GP will often be an initial source of support for those bereaved by suicide, and GPs have previously been recognised as key in the provision of care to this group.18 In a review of the literature, the evidence base for GP services to inform their support of people bereaved by suicide was considered limited but GPs viewed bereavement care as an important part of their role.23 The review also found that there was a great deal of variability among GP services in terms of the protocols they had in place to support those bereaved by suicide: some had clear structures in place but others did not.23 In interviews with 13 GPs, they reported that they felt ill-equipped to deal with suicide and its effects on bereaved parents, although they did recognise the vulnerability of this group.24 It has been suggested that there is a need for further education and training for health professionals about the needs of those bereaved by suicide.10,13,24 This article offers an insight specifically into parents’ experiences of support and their perceived needs following the death of their son or daughter to try to provide a deeper understanding of how this group can be supported in primary care.

METHOD

Setting and participants

Biological mothers, fathers, and step-parents whose son or daughter had died by suicide were identified and recruited from the north of England and the Midlands. For inclusion in the study, the cause of death, as determined by the Coroner, was suicide, open, or a narrative verdict. Parents who had been bereaved less than 12 months were excluded from the study because it was believed that participation may be too distressing during the early stages following their bereavement. Parents who had been bereaved for more than 10 years were excluded to minimise recall bias.

Participants were recruited using a number of methods. Coroners contacted families directly to inform them of the study; posters/advertisements publicised the study in GP surgeries, pharmacies, and in a local newspaper; and suicide bereavement self-help groups informed their members. Depending on how potential participants became aware of the study, they either contacted the research team directly to express their interest in taking part (by email or phone) or consented to their contact details being passed to the researcher to make contact with them. The research team then provided further information about the study and what participation would entail to all potential participants via an information sheet. The researcher also offered to speak to all participants over the telephone to discuss the study. For participants who then confirmed they would like to take part, a convenient time and date to conduct the interview was agreed, and all participants provided informed, written consent to take part.

Interviews were conducted between 2012 and 2014, and the suicides had occurred between 2002 and 2012; parents had been bereaved for between 2 and 10 years.

Data collection

Given the sensitivity and personal nature of the topic, individual interviews were considered the most appropriate method of data collection. One researcher conducted all interviews; she is an experienced qualitative suicide bereavement researcher who was personally bereaved by suicide and therefore was aware of the vulnerabilities of those participating and the sensitivities required to conduct such interviews. The research team were, however, mindful of study bias; the researcher’s bereavement was disclosed to participants for transparency and two study team members independently read the interview transcripts. The research team met on a regular basis to review the interview process.

Interviews were semi-structured [see Supplementary Box 1 for details]. This format was not only chosen to guide topic coverage in the interview but also to allow a natural conversational style that would put participants at ease and enable them to share as much or as little as they wanted.
No time limit was imposed on the interview so that it could be guided by participants and all were allowed to come to a natural conclusion. Interviews were conducted at participants’ homes and aimed to identify parents’ experiences and perceived needs following the death. The topic guide included questions that prompted exploration of their reactions to the death; the way in which they felt health professionals had responded to them; what they deemed helpful or unhelpful; and how they thought they could be better supported in the future.

At the end of the interview, the interviewer debriefed participants and ensured that they had contact details of national and local suicide bereavement support services, as well as the researchers’ contact details.

Interviews continued until data saturation occurred, that is, no new data were emerging.26

Analysis
Interviews were audio-recorded with consent and transcribed verbatim by an external transcription service. Data analysis was conducted by an independent researcher who was not involved in the design or conduct of the study but all transcripts were also read by two members of the study team. Data were analysed using thematic analysis and constant comparison methods.27,28 This involved the researcher qualitatively coding the transcripts as they were read, adding any notes, observations, and labels to the data. Emerging codes and categories were then constantly compared and cross-referenced between transcripts (by moving back and forward between transcripts and comparing and contrasting incidences and noting occurrences) as the analysis progressed. Interpretations of the data were discussed between the researchers to agree the broader themes.

The ‘one sheet of paper’ method was then used to describe and summarise each theme. This method ensures that all perspectives, including any variances, are taken into account during analysis.

RESULTS
Twenty-three interviews were conducted with a total of 29 parents (six interviews were conducted jointly with parents who were married to each other or cohabiting) between 2012 and 2014. Findings reflect the narratives associated with 23 deaths: 17 sons and 6 daughters, aged between 16 and 40. The most common method of suicide was hanging (n = 17), followed by overdose (n = 4), carbon monoxide poisoning (n = 1), and jumping (n = 1).

Of the 23 interviews, 13 were with mothers, four were with fathers and six were joint interviews. Of the joint interviews, three were with the mother and father of the deceased; two were with the father and stepmother; and one was with the mother and stepfather. Participants were aged between 46 and 70 years. Interviews lasted for up to 4 hours and averaged 1 hour and 45 minutes.

Most participants reported some form of contact with their general practice with a view to accessing support following the suicide of their son or daughter; seven participants had not sought support from their GP service in relation to the suicide. This article explored the parents’ experiences of contact with their GP following the suicide, as well as their wider experiences and support needs. Three themes were identified in the data: the importance of not feeling alone; perceived barriers to accessing support; and the need for signposting for additional support. Data extracts will be given to illustrate the themes.

The importance of not feeling alone
Parents discussed the nature of the death and the stigma surrounding it. The importance of not feeling alone in the grief was highlighted, with parents often talking about the helpfulness of talking to someone who had experienced suicide bereavement themselves. Conversely, talking about the death with those not bereaved by suicide was considered difficult. One mother spoke about her experience of talking to others about her son’s death:

‘You’re trying to pre-empt somebody’s reaction and you’re trying to think about how they’re gonna feel. Err, and I think eventually you do. I don’t think there’s as far as I can see, there’s no magic wand to make, to make that, erm, bearable for either, for either party. And I think you
probably, from my experience, you just end up, you, you go with it for a while and you try and deal with it, and then you end up with ... you just withdraw more and a bit more and a bit more over the months, erm, so that you’re not ... you’re not making those kind of contacts and you’re not ... you almost feel, I almost felt like I was kind of inflicting myself on to people. ‘[Mother [M], interview [I]6]

A number of parents echoed similar sentiments of not wanting to upset others by talking about the death:

‘They get this look of horror on their face and they’d be embarrassed.’ (M, I12)

One way in which parents believed that they could access support without worrying about people’s reactions or fear of judgement was via suicide bereavement self-help group meetings. These were accessed in person, arranged by local charity organisations, and by using online forums. As one mother described, the group helped her realise she was not alone:

‘I went initially because you sort of want validation that you are OK, you are not a bad parent, it’s not what you’ve done. So I went to this group and you look at all these people who have been bereaved to the same thing — some of them are parents, some of them are partners, some of them are siblings — and you just sort of half think to yourself well these all look like decent people, it’s happened ...’ (M, I12)

A father relayed a similar experience:

‘I realised after talking to him, that a lot of the things that I’ve felt, or was feeling, and stuff, it wasn’t abnormal and stuff like that, he’d just been through exactly the same.’ (Father [F], I17)

Attendance at such groups also provided parents with a light at the end of the tunnel, helping them to feel they could get through the grief:

‘... and I listened to her, and I’m so glad I did. Because she gave us hope. She’d survived it.’ (M, I16)

The importance of such groups as a way to support those bereaved by suicide was highlighted by the actions of one mother who, as her nearest support group was over an hour’s drive away, set up a group locally to support others in her area. Another parent also emphasised the importance of accessing support from people with the shared experience of suicide bereavement:

‘But I only stumbled across them on the internet, when I was feeling quite desperate with not having anybody to talk to, and nowhere to turn, and nobody who’d been in this situation who understands ... what would life have been like had I not found him?’ (F, I17)

Perceived barriers to accessing support

Most parents wanted contact to be initiated by their general practice. Most believed that the simple act of acknowledging the death and ‘extending the hand’ of support was enough to let parents know support was available:

‘I think they should be given the opportunity to make the first move, so put the feelers out; “Would you like to come? ... it’s not compulsory, but the offer’s there” sort of thing.’ (F, I3)

A few of the parents suggested that if general practices initiated contact it could encourage those who needed support to access it, who might not otherwise have done so. One mother believed that fathers, in particular, might benefit from contact for this reason. For one of the few parents whose general practice had initiated contact to arrange an appointment, she recognised she would not have sought the help she had needed otherwise:

‘I were glad that he’d actually made the first move, because I ... I wouldn’t have gone down to the doctor and said, “oh I’m having real problems here, you know, you’re going to have to ... please help me”. I were ... I were glad that he actually said, you know, invited me to go down and see him.’ (M, I4)

One mother reported a very positive experience with her practice overall but believed that the offer of a home visit would have been helpful:

‘Hmm, it would be nicer because, as I say, I were in a state, and I felt ... not only did I feel embarrassed but people ask you, and then you try to tell them and you can’t tell them, and then you get upset, and then ...’ (M, I22)

Another mother commented:

‘I’ve sat in waiting room fighting back tears, you know, and it’s not the best place to be in (upset) is it?’ (M, I22)
A number of other parents concurred, feeling that a home visit would have been welcomed and would have improved their experience of support. Other parents also perceived additional physical barriers in accessing general practice support.

One mother, discussing the triage process at her local practice, said:

’I can’t just ring up anyone and say “Can I speak, can I see me GP?” You’ve got to get through the receptionist first, so she wants a basic overview of why you want to speak to him. Then, then a, then a GP will ring you back... they decide whether or not you should go there now. So if you are feeling depressed, you don’t want to go through them barriers, so I must admit that probably, if I could have just rung up, rang my GP and said ‘Can I see the GP please?’ and then go up and speak to him face to face [I would have].’ (M, I12)

The triage process was not the participants’ only practical concern. A couple of the fathers interviewed also commented about the length of time available for a consultation with a GP. One father, when asked if he could talk to his doctor about the death, said:

’Er, no, I can’t, but that ... that the reason I can’t is because ... I’m, I’m, I’m mindful of the time that doctors ... have to see patients, because they make them usually about, er, 5 minutes apart, or 10 minutes apart. If I had longer I feel I could talk to my GP.’ (F, I7)

When seeking help from professionals, fear regarding the reaction to suicide was also evident.

A mother who sought support through counselling stressed the importance of professionals not being daunted by suicide bereavement, saying: ‘I couldn’t just talk to anybody about it.’ When reflecting on her experience of counselling, she said:

’They kind of made you feel as if what you were feeling was normal and [she] just listened and wasn’t afraid of anything I said or, you know, so she was good.’ (M, I11)

The need for signposting for additional support

Most parents identified the need to source information following the death, particularly to understand more about suicide; however, many parents felt overwhelmed and in need of signposting to appropriate and acceptable resources and support:

‘You’re wanting answers, you want to know why, and you’re wanting some help or some advice yourself, but you’re not getting any of that, and you don’t know where to go for it.’ (M, I15)

Many parents suggested that general practice may be best placed to provide this but identified that they did not always have this information.

One father described his GP as very approachable, but that he had difficulties providing information:

’Because he only had that number, I think he was clutching at straws a bit... so he was a bit lost.’ (F, I3)

Another parent felt that her GP seemed anxious and uncertain how to respond to her. Unable to provide any information there and then, the GP said she would get back to her:

’... anyway, I went to the doctor and I said at the time, “I need to talk to somebody” ... And, it was all panic, “oh I don’t know who... oh I don’t know... I’ll have to go and see another doctor”, and then she went away. She was only young this doctor, and she came back and she said, “oh he’s just looking for somebody for you to whatshername, blah, blah, blah, oh, er, we’ve got your phone number, all right, we’ll phone you up when we find somebody.”’ (M, I21)

The mother explained that a counsellor contacted her directly a few days later following a referral from the GP. However, the mother, wanting other parents to have access to information straight away, reported that she later took leaflets from a suicide bereavement charity to the practice to enable them to provide this for other patients in the same situation.

The lack of knowledge about suicide bereavement by some general practice staff meant that some parents felt helpless and uncertain where to seek support, and emphasised the importance of the role of primary care:

‘You need your support of your GP, if you can’t talk to your GP who can you talk to?’ (M, I10)

One parent cited a very positive experience with her practice, including the provision of ample time in the appointment and that the GP contacted services directly:

‘He actually went straight out of office and got a telephone number and actually phoned them there and then for me.’ (M, I4)
Parents not only often recognised the various difficulties faced by primary care in providing support but also spoke about the impact of professionals not knowing where to direct them:

‘Because of the situation, it’s, there’s all sorts of different parameters, the social stigma, there’s professionals not knowing themselves how to cope with it, what sort of infrastructure to put in place. You’ve got a guy sat there thinking ... essentially crying for help, falling apart, and nobody knows where to send you.’ (F, I3)

Most parents felt their GPs were approachable and tried to provide support but that they would have benefited from more awareness of suicide bereavement and relevant support services.

**DISCUSSION**

**Summary**

This study reports the views of parents bereaved by suicide, about the support they received from their general practice. Three themes were identified from the data: the importance of not feeling alone; perceived barriers to accessing support; and the need for signposting for additional support. Most of the participants reported some contact with their practice following their child’s suicide. Participants welcomed contact being initiated by the practice and they considered it would encourage people to access support. Participants reported that a home visit would be particularly valuable, citing barriers to consulting including practice triage processes, sitting in the waiting room while upset, and the time-limited consultation.

Parents did suggest, however, that they had found their GP approachable. Parents often cited the need to seek and access information about suicide and suicide bereavement. They considered the practice an important source of support and means of accessing relevant information and other support, following the death. However, there were a number of difficulties noted, with some parents recalling that their GP had lacked knowledge of the resources available to provide information directly and had limited knowledge about where to signpost them. Although some parents highlighted positive examples of practice and support, others emphasised the desperation and helplessness they felt when their GP was unsure how to respond to them.

In discussions about accessing support and support needs, a number of parents discussed shame and stigma attached to suicide and suicide bereavement. This was evident when discussing their fear of other people’s reactions to the death and not wanting to ‘upset’ other people when talking about it. This fear extended to professionals and they talked about the relief of not being judged when accessing support. To help them not feel alone with the death, some parents considered accessing support groups helpful, either in person or online. The shared experience of suicide bereavement was discussed, referencing the helpfulness of normalising their experiences of grief and providing hope of getting through it. This therefore improved the feelings of isolation many parents felt as a consequence of stigma and shame.

**Strengths and limitations**

This study provides an insight into the perspectives of parents bereaved by suicide and is strengthened by the multiple methods used to recruit participants. Although most parents in the study had accessed support in some way following their child’s suicide, an advantage of this study is that it also captured the perspectives of those who had not sought help, often a limitation of suicide bereavement research. However, recruiting people bereaved by suicide to research has been noted as difficult, and it is possible that the perspectives of those willing to be interviewed may be different from those who do not volunteer. Parents in this study were interviewed if their deceased offspring were aged 16–40 years, which was an extension to the original parameters of 18–35 as a consequence of recruitment to the study being challenging. Nevertheless, the participants who took part were open and shared in-depth accounts of their experiences, evidenced by the length of their interviews.

The author who conducted the interviews has personally been bereaved by suicide; this experience likely facilitated engagement in the interviews, fostering rapport and trust between the interviewer and participants; however, the research team were also mindful about the potential bias this may have introduced. Therefore, to ensure transparency, the researcher’s bereavement was disclosed to participants before the interviews. In addition, two study members also had oversight of the process, reading transcripts to review the process on a regular basis at team meetings.

At the time of interview, parents had been bereaved for between 2 and 10 years. The variation of length of time since the death may have biased their reflections of support
received; however, this time frame is in line with the parameters of previous research with those bereaved by suicide.18,19 Although the interviews were conducted between 2012 and 2014, the implications of the work are still applicable given the recent calls for improved provision in this area.3

Comparison with existing literature

Although this study did not explore the differences between groups of people bereaved by suicide, based on previous research that has been conducted with suicide-bereaved people more generally,18,19 the findings suggest that parents’ support needs are not dissimilar. General practice is an important source of care for many people who are bereaved by suicide,30,32 and the findings of this study would certainly support that. Previous work has recommended that those bereaved by suicide need the help and support of their general practice,3,10,36 and parents in this study also emphasised this; however, the parents in this study did perceive some barriers to accessing this support. This is in line with previous work published by some of the co-authors of this article,24 who found that, although GPs were aware of the vulnerability of parents bereaved by suicide, they felt uncertain and often unprepared in how to respond to them.

Awareness of potential barriers, and exploring how these can be overcome, may increase the likelihood of engaging this group. This could be particularly important to engage bereaved men, given the known help-seeking differences between men and women.3,36

Previous work has found that stigma was particularly evident among those bereaved by suicide.1,15 There was evidence in this study of feelings of shame and stigma among parents and that this in turn impacted on help-seeking behaviour. Parents in this study found group support structures especially helpful. This was talked about with reference to it being easier to talk to people who had experienced suicide bereavement and not being alone with the grief. This is supported by previous work with suicide-bereaved relatives,18,37 and it has been suggested that suicide-bereavement groups may offer important opportunities for individuals to seek support.21 The views of parents in this study add further weight to this suggestion. However, although support groups are widely used, there have been calls for research to establish their efficacy.1,38

In addition, it has been suggested that those who have psychiatric or psychological issues may be better supported through services such as psychotherapy.29

Implications for practice

The NHS recently stated its commitment to provide post-crisis support for families bereaved by suicide via a 24-hour helpline.40 This demonstrates the importance and timeliness of this article. Given the number of people affected by suicide, those working in general practice are likely to come into contact with those who are bereaved. This study showed, from the experience of parents, that GPs were often considered approachable but were also deemed uncertain in their approach. It is imperative that awareness of suicide bereavement and knowledge of how to support this group is more standardised. Although it is envisaged that primary care will remain an important source of support, being able to direct patients bereaved by suicide to the support helpline will provide a practical way of helping patients access a specialist postvention service. Being able to engage this group will also help reduce the stigma and shame attached to suicide bereavement, and thus reduce the risk of adverse outcomes.

The study authors emphasise the suggestion made by previous work that there is a need for a coordinated provision of postvention services by the NHS and the third sector, as well as for ensuring that GPs feel confident and educated to advise bereaved people where to access further support.21 Having clear protocols at a local level is an important part of this.

The National Institute for Health and Care Excellence (NICE) guidance supports the need for postvention support for people bereaved by suicide, stressing that services need to maximise the opportunity to offer postvention support at the initial point of contact with the service. Ideally, as highlighted by NICE,3 local data gathering would be helpful to identify those in need of support and to enable a proactive approach. NICE suggests local data gathering could include information regarding method, location, timing, and details of individual and local circumstances. They suggest this could be captured from a range of sources including routinely collected data sources such as Public Health England’s public health profiles, the local ombudsman, and Coroner’s service. Such intelligence may enable GPs to initiate contact with the bereaved, something which was appreciated by the parents in this study and that has been previously noted as welcomed by individuals bereaved by suicide.29 A need for a proactive
approach has previously been argued, and may help reduce negative health outcomes; however, it is acknowledged that the time and resources for such data gathering could be burdensome.

Box 1 summarises recommendations for general practice for those bereaved by suicide.

A simple but achievable improvement would be practice staff being aware of, and having formal links with, local services, to which they can direct bereaved people to access support. However, it is important to note that judging the trustworthiness of third-sector services may be perceived as difficult by those in primary care and, given the often transient nature of such services because of short-term commissioning, links need updating regularly. Signposting and awareness are key components of Health Education England’s competency framework, and NICE’s draft quality standard on suicide prevention. In particular, given that participants found the shared experience of suicide bereavement important when accessing support, knowledge of such groups may be helpful. Arguably, there is no easy practical solution to accessing this information on a local level. Nevertheless, at the very least, having literature available about various national support services would empower participants to access further information themselves. If they do not already, general practices could provide reputable information leaflets and booklets about support that patients can access, such as Public Health England’s Help is at Hand resource and details of the national helpline.

As The NHS Long Term Plan comes into action, and suicide bereavement services in each region develop, there may be more support for general practice to provide further support to those bereaved by suicide.
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