A qualitative analysis of psychosocial needs and support impacts in families affected by young sudden cardiac death (YSCD): The role of community and peer support

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ABSTRACT

Background: Young sudden cardiac death (YSCD), often occurring in previously healthy individuals, is a tragic event with devastating impact on affected families who are at heightened risk of posttraumatic stress and prolonged grief and may themselves be at risk of YSCD. Previous research suggests that surviving family members' psychosocial support needs are often unmet.

Purpose: This study sought to identify how YSCD-affected families experience dedicated community and peer support in light of their psychosocial support needs.

Methods: The study used a qualitative design, employing a thematic analysis of focus group and interview data. Three focus groups and five individual interviews were conducted with affected family members (N=19). The sample was drawn from a UK-based charity, Cardiac Risk in the Young (CRY). Audio-recordings of the focus groups and interviews were transcribed and subjected to thematic analysis.

Results: Three super-ordinate themes were identified: 1. YSCD community support as offering a place of safety, 2. YSCD community support as fostering sense-making, 3. YSCD community support as facilitating finding new meaning.

Conclusions: YSCD-affected families can benefit from access to dedicated community and peer support that offers a safe environment, provides affiliation, understanding and normalisation and enables sense-making and the rebuilding of a sense of self. Dedicated community support can facilitate meaningful re-engagement with life through helping prevent YSCD and through memorialisation and legacy-building to maintain a continuing bond with the deceased. Clinicians need to be aware of the need to incorporate available community and peer support into patient pathways.

Keywords: young sudden cardiac death; cardiac arrest; bereavement; peer support; unascertained death; sudden arrhythmic death syndrome

INTRODUCTION

Young sudden cardiac death (YSCD) is a devastating event for affected families, often occurring in healthy and active young people without prior symptoms.[1] The cause of the death is frequently uncertain or associated with genetic heart diseases, suggesting possible future risks for other relatives and thus imposing additional stresses on the surviving family.[2] YSCD-bereaved family members are at increased risk of anxiety and depression[3]; half experience post-traumatic stress and prolonged grief symptoms, with particularly high rates reported for mothers and those who witnessed the death.[4] Prolonged grief is furthermore associated with other health complications such as cancer and heart disease and carries an elevated risk for death by suicide.[5,6] Bereavement through sudden death has been linked with greater feelings of isolation [7], and parents' heightened support needs following the sudden loss of a child from any cause have been have been noted.[8] Although the significant psychosocial burden and unique challenges for YSCD-bereaved families have been observed[2], support provision for YSCD-affected families has been found wanting.[9] A cross-sectional survey investigating the support needs of Australian YSCD-bereaved families found that psychosocial needs – particularly the need to understand the cause of death – were most likely to be left unmet in comparison with medical, spiritual and financial needs.[10] While the authors identified broad categories of need, more detailed understanding of those needs and of what would be most helpful to families is required. Families may, for example, seek support from dedicated community organisations that offer medical and social (peer) support outside or alongside statutory service provisions. It would be of interest to ascertain how families engaging with such organisations experience this support and how it might meet or not meet their needs. The current study therefore aimed to identify YSCD-bereaved families' specific psychosocial needs and the impacts of targeted community and peer support provision.

METHODS

Design and sampling

The methodological approach was qualitative and exploratory. Participants were drawn from YSCD-affected families that had lost a member under the age of 35 and had accessed community (e.g. fundraising events, newsletters and social media groups) and peer support from a dedicated charity, Cardiac Risk in the Young (CRY), one of the largest European charities for families affected by YSCD.[11] It offers clinical support through expert pathology, cardiology and screening services to identify young people at risk. It funds research, engages in awareness-raising and has a dedicated peer-to-peer bereavement support programme. It also offers general community support through fundraising and other events, publications and social media networking. Other charities such as Compassionate Friends[12] and the Sudden Arrhythmia Death Syndromes (SADS) Foundation[13] also offer some relevant support. However, Compassionate Friends offers broader support to families bereaved due to any cause, and SADS is not aimed at young SCD specifically. Families accessing CRY as dedicated specialist support for YSCD bereavement thus constituted the target population. Recruitment aimed to secure a broad sample with members from each of the different stakeholder groups: 1. peer supporters who had provided telephone support for at least a year; 2. peer support users who had received telephone support, 3. bereaved families who had accessed the organisation's general community support but had not opted into the peer support. Those bereaved for less than 18 months were excluded.

Patient and public involvement

Prior to designing the study, the first author attended events run by the charity and conducted interviews with supporters and support users to gain an initial understanding of the field and the ethical requirements of the study. Information gathered from stakeholders informed

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decisions on the study design, interview and focus group schedule development, and geographical locations and settings for data collection. A report of the findings was made available to the charity.

Table 1: Sample characteristics

Demographic category	Sub-category	Number of participants	Percentage of sample
Gender	Female	14	73.7%
	Male	5	26.3%
Age range	Under 30	0	0%
	30-39	1	5.3%
	40-49	0	0%
	50-59	4	21.0%
	60-69	13	68.4%
	70+	1	5.3%
Ethnicity	White British	18	94.7%
	White American	1	5.3%
Education	Graduate or post-graduate level	9	47.4%
	Diploma level	6	31.6%
	GCSE-level school certificates and no qualification	4	21.0%
Relationship to person who died	Mother	14	73.7%
	Father	4	21.0%
	Partner	1	5.3%
Gender of person who died (N=21)	Female	6	28.6%
	Male	15	71.4%
Years since death (N=21)	0-2	0	0%
	3-5	3	14.3%
	6-10	10	47.6%
	11-15	4	19.0%
	16-20	3	14.3%
	21+	1	4.8%
Years of involvement with the charity	0-2	1	5.3%
	3-5	3	15.8%
	6-10	10	52.6%
	11-15	5	26.3%
	16-20	2	10.5%
Role within the charity	Peer and community support users	5	26.3%
	Peer supporters	6	31.6%
	Community support only users	8	42.1%

Data collection

The investigation was approved by the University of Surrey's Research Ethics Committee (EC/2013/132/FAHS) and conforms with the principles outlined in the Declaration of Helsinki (Br Me J 1964;ii:177) (see Appendix A for data collection procedure). Nineteen people made up the final sample (see Table 1). The majority of participants were female (73.7%), White British (94.7%) and had diploma, graduate or postgraduate level qualifications (79%). Participants' age ranged from 30 to 71, with a mean age of 61.23 (SD=8.29); 18 (94.7%) stated their ethnicity as White British. In terms of their relationship with the deceased, there were 14 (73.7%) mothers, 4 (21%) fathers and 1 (5.3%) partner. In 15 cases (71.4%), the person who died was male and in 6 cases (28.6%) female (some had lost more than one person to YSCD). In 3 cases (14.3%) the loss had occurred 3-5 years previously. In 10 cases (47.6%) the loss occurred 6-10 years previously, in 8 cases (38.1%) 11 or more years had elapsed since the death.

Data collection consisted of three focus groups (one for each stakeholder group) and five individual interviews. The focus group participants were trained and experienced peer supporters (FG1; N=5), peer support users (FG2; N=4) and bereaved users of CRY who had accessed the charity's wider community support (FG3; N=5). The individual interviews involved 1 peer supporter, 1 peer support user and 3 community support users. Prior to the interview, people were given information on what would be involved and a consent form to sign. The interview schedules (available online) addressed three general topics: the support needs of YSCD-affected families, the features of community and peer support that participants found helpful, and the impact of such provision on participants' lives and wellbeing.

Data analysis

Interviews and focus groups were audio-recorded, transcribed and analysed using an inductive and semantic version of thematic analysis so as to stay as close to the participants' meanings as possible.[14,15] (For more on the data analysis procedure, see Appendix B). Data analysis was conducted by three researchers working closely together to ensure that themes were grounded in the data and that criteria for high-quality qualitative research were met.[16] None of the researchers had experienced YSCD personally, although all of them had experienced bereavement previously. This facilitated an empathic stance but also some distance from the specific phenomenon. Standards for Reporting Qualitative Research (SPQR)[17] were used in the preparation of this report.

RESULTS

The thematic analysis of the data produced three themes, each consisting of two sub-themes (see Table 2). In what follows, key findings are described, illustrated by data excerpts. The following abbreviations have been used to indicate which focus group or individual interview the data stem from:

FG1 = Focus Group 1 (peer supporters)

FG2 = Focus Group 2 (peer and community support users)

FG3 = Focus Group 3 (community support users)

II1 = Individual Interview 1 (Community support user)

II2 = Individual Interview 2 (Community support user)

II3 = Individual Interview 3 (Community support user)

II4 = Individual Interview 4 (Peer and community support user)

II5 = Individual Interview 5 (Peer supporter)

Table 2: Themes and sub-themes

	Themes and sub-themes		Example quotes from participants
1.	**YSCD community support as offering a place of safety**		'it's the one place… it's the one group of people you can go with and can feel safe' (II1)
	1.1	A safe haven in the aftermath of YSCD	'it was just a complete lifeline' (FG2)
	1.2	Shared experience of YSCD	'it's the connection with somebody that's had exactly that happen to them' (FG1)
2.	**YSCD community support as fostering sense-making**		'there is actually an organisation out there that actually can explain to us what on earth has happened' (II2)
	2.1	Making sense of young sudden cardiac death	'somebody to talk to who could help you make some kind of sense of what had happened' (FG3)
	2.2	Understanding YSCD-related grief	'they need to know that they are not going mad, you know' (FG1)
3.	**YSCD community support as facilitating finding new meaning**		'when we got involved, then we felt he had not died in vain.' (FG3)
	3.1	Finding a new 'cause' through helping to prevent YSCD	'I think it's positive [ ] trying to raise money to, you know, help the charity so that they can stop it happening to other people' (II4)
	3.2	Finding meaning after YSCD through honouring the deceased	'you're all doing it together, and that is good, things like that [ ], bringing in money but also, it's a sort of a memorial to the person you've lost.' (II5)

Theme 1: YSCD community support as offering a place of safety

This theme describes YSCD-bereaved family members' need for support that provides a sense of safety and comfort, particularly in the early days following the death. Participants

often described feeling desperate or afraid of going mad, and they referred to community

support as helpful if it conferred safety.

Sub-theme 1.1: A safe haven in the aftermath of YSCD

This sub-theme is mostly connected with the perception of YSCD community support as

rescuing the bereaved at the time of greatest distress in their life:

> It was like an anchor in the storm. I was going to capsize, I was going to drown, and
>
> it was that profound, that I knew she was there. (FG2)

> It was certainly quite a saviour, I think, to be able to speak to somebody who had had
>
> the same thing happened and yeah… could empathise. (II4)

Participants stressed the importance of the availability and reliability of support that can be

accessed when needed:

> And the fact that there's an organisation there that you could turn to, should you so
>
> wish to, for support, is a great comfort. (FG3)

This sense of safety also needs to be conveyed through appropriate and sensitive

communication:

> …where no one asks the wrong questions, where no one says "How many children [do
>
> you have]?" The first question people ask is "Who did you lose? Tell me about your
>
> story." (FG2)

Similarly, not feeling under pressure to share one's story contributes to feeling safe:

> Just being with people who you know you don't have to explain anything to. (II1)

Participants emphasised the devastating change to their sense of self following this traumatic loss and the importance of this being understood:

> It's like being stripped and being put into a place where you're totally … you don't speak the language any more. And that person on the phone knows who you are and you can speak to them. (FG2)

In the light of having been 'stripped' of their former identity, being recognised as someone in the specific YSCD bereavement context was perceived as important. One support user said that this felt like "going home, somewhere there's a home for you, where you know who you are" (FG2). This points to the connection between being recognised, understood and known in this specific loss and feeling safe. These may be key ingredients for restoring a trauma-shaken sense of self.

Sub-theme 1.2: Shared experience of YSCD

The sub-theme of 'safe haven' or 'home' closely aligns with a sense of belonging based on shared experience. Having experienced the uniqueness of YSCD-bereavement, participants across the data set expressed the importance of a sense of affiliation and community:

It's the sort of realisation that you're not… you know, you're not alone in it, that, you

know, there are other people out there. (FG3)

Receiving support from trained peers was often described as enabling such belonging.

Participants spoke of the need to talk to someone who had experienced the same kind of loss:

It's such…an isolating trauma that you go through, because, you know it's the

connection with somebody that's had exactly that happen to them. (FG1)

The need for the supporter to have had a similar experience was stressed throughout the

dataset:

'It's actually very important to have somebody who's been through a semi-identical

experience because then they understand you and you understand them' (II1)

Knowing that the peer supporter had experienced a similar loss created a sense of safety with

them. As one peer supporter said:

Once they know that – it's almost like then, it's like… "Oh, it is the same," and then

they feel safe. (FG1)

This highlights the interrelationship between shared experience and feeling safe,

counteracting the sense of isolation in YSCD bereavement. Support provision that conveys

this sense of safety and belonging can create a new community for the bereft – even a new

family:

In a word, the first word that comes to mind is "family" because it's the one place …

it's the one group of people you can go with and can feel safe. (II2)

Theme 2: YSCD community support as fostering sense-making

The second theme centres on the psychosocial need for making sense of unexpected YSCD

and developing understanding of the unique impacts of YSCD loss on the surviving family.

The complex sense-making processes that such a loss entails require YSCD-sensitive support

provisions.

Sub-theme 2.1: Making sense of young sudden cardiac death

The difficulty of making sense of a death as unexpected as YSCD and how services and

agencies can be helpful in finding an explanation were apparent across the data set. In one

focus group, when being asked what YSCD-affected families wanted from services, a

participant said:

Answers really I think – a few answers we wanted, didn't we really? (FG3)

While any death of a young person may be difficult to make sense of, the lack of a clear or

obvious cause of death was frequently mentioned by participants when characterising their

uniquely difficult situation. Such sense-making could be as simple as being given a medical

explanation:

I think clear medical explanations are very important. I don't know whether the

bereavement counsellors can give those clear medical explanations because, actually,

they need to come from … probably from cardiologists, who may not have the time or

the… possibly always the empathy to do it. (II1)

The above quotation demonstrates the need for different types of support to be integrated, as

counsellors and peer supporters may lack medical knowledge while medical staff may

sometimes lack sensitivity and empathy. Getting an explanation and having answers is,

however, not the same as seeing a reason for this devastating loss:

For me, as in personally, I…I have…if I can see a reason for something, it's easier, but

I could see no reason whatsoever for [daughter's name] dying. (II2)

The struggle with sense-making following YSCD is thus connected to a wider crisis of

meaning for the person. It links the need for medical information with people's psychological

need to make sense of the loss in order to be able to cope with it.

Sub-theme 2.2: Understanding YSCD-related grief

Sense-making in the aftermath of YSCD loss also includes developing an understanding of

how such a sudden and untimely death impacts those affected by it. Learning about and

understanding the nature of one's grief may be part of the journey through it. Having access

to a YSCD-dedicated organisation meant that the affected families' grief can be met with

expert understanding:

People couldn't understand except [organisation] could. [Organisation] understood the

depth of the grief and the sorrow that people who'd lost a child so suddenly, and it's

just dismissed as Sudden Adult Death syndrome – doesn't tell you why, what sort of

medical condition there was, and so you're just left. But [organisation] understood.

(FG3)

In addition, having contact with someone with a shared experience helped participants understand their turmoil as a normal response to this devastating event:

And they tell you they had the same, you can then say, "Oh okay, it's because of the experience, it's not that I'm having these thoughts or whatever, it's not me, that I'm having a psychotic breakdown." (FG2)

This normalising impact of peer-to-peer support was also connected with gaining hope for the future:

Seeing the supporters who have been through it, they take up life again, you know. You don't want to get over the loss of a child – that's the last thing you want to do. But obviously, you do want to be able to function in life again. (II5)

It seemed important that YSCD-bereaved parents also learned from their peer supporters that, despite the shared experience, grief is an individual process:

It's not that you're telling them what to do but they need to know something about you so that they can…clutch at something and … "OK, so I can…can I get through this?" "Yes, you can, but you'll do it your way." (FG1)

These excerpts demonstrate that developing an understanding of YSCD-related grief as normal, understandable and survivable can prepare the way for coping and moving forward.

Theme 3: YSCD community support as facilitating finding new meaning

The third theme captures how participants saw YSCD-related community support as opening up ways of engagement that could be meaningful in connection with their loved ones' death and providing them with an ongoing connection with the deceased.

3.1 Finding a new 'cause' through helping to prevent YSCD

Some participants described how engaging in YSCD-related fundraising activities provided them with a different kind of support:

> I think it's the fact that you feel so helpless and you've got to do something, and fundraising was the big thing with us. (FG3)

Involvement in this 'cause' was sometimes likened to therapy, "a way of working through your bereavement" (II1):

> He [husband] finds the fundraising is his therapy. (FG3)

The therapeutic aspect of the bereaved person's active involvement seemed to be linked with doing something meaningful in light of YSCD. Even if nothing can be done about the death of one's own loved one, helping prevent future YSCD in others was experienced as meaningful:

I've had this hideous disaster but actually I've got to make something of it. I mean, just something has got to change now and it's that real drive to make some change happen. (II1)

Sub-theme 3.2: Finding meaning after YSCD through honouring the deceased

Participants talked about their engagement in fundraising not only as providing them with a new purpose but also as meaningful in connection with their deceased loved one. One participant described a fundraising walk as "a sort of memorial to the person that you've lost" (II5). The importance of the personal connection to the loved one was also emphasised in the following data extract:

I couldn't see the point in the fundraising at first because I just thought "I'm not bothered. It won't bring back [son's name] so why should I bother?" But then I just thought "[Son's name] would have hated me to say that because he was such a caring person." So you go to that other level where you think, "No, this is for him, because he would have wanted us to do that." (FG3)

This engagement goes beyond doing something about the specific cause of the death. What is described as meaningful here is the deeper link with who the deceased was as a person. Another participant described their involvement as doing something "that she would have been proud of as well" (FG3). This suggests honouring the relationship with the deceased, something that participants experienced as providing emotional and moral support on a long-term basis, addressing the ongoing psychosocial needs of this population. As one person put it:

"You want to keep in touch with [organisation] because that is part of your life which is going to go on, in a way, because you can't just put it behind you" (FG2)

Thus, enabling meaningful engagement through fundraising and honouring the continued connection with the deceased can be important aspects of YSCD-related community support.

DISCUSSION

The present study constitutes the first interview-based study of the psychosocial support needs of YSCD-affected families and the role that dedicated community and peer support can play in meeting those needs.

Firstly, our results are broadly in line with general observations about the devastating impact of the sudden loss of a child and resulting support needs.[8] As regards the specific challenges of YSCD, our results concur with the recent needs analysis by McDonald et al.[10] which identified needs for instrumental support in the form of a safe place to turn to and emotional support through affiliation and informational input. This is reflected in Theme 1 (YSCD community support as offering a place of safety). Our study extends previous findings by drawing on the actual voices of affected families. Participants spoke about "drowning" or "capsizing", conveying the enormity of their ordeal, thus highlighting the significance of highly empathic and sensitive support ("an anchor in the storm"; "safe haven"), particularly in the acute phases following YSCD. Psychological reactions have been found to be more intense in early grief,[18] and interventions for those with very severe early distress are called for, particularly as this is a vulnerable group with a potentially complicated or prolonged grief trajectory if left unsupported.[19] Participants' use of analogies such as "drowning" and then finding a "safe haven" could be seen as pointing to

their need for a 'holding environment' in early grief, something that seems especially important after a sudden or violent death.[20]

Secondly, our study draws attention to the significance of meaning-making as an overarching psychosocial need in the aftermath of YSCD. This is reflected in Theme 2 (YSCD community support as fostering sense-making). McDonald et al.[10] observed that the need for medical information and for understanding the cause of the death constituted the most significant need in families and was mostly unmet. Our study showed that making sense of the death was not only about medical explanations but about meaning-making at a broader level, reflecting definitions of sense-making and meaning-making in the literature on trauma and bereavement.[21] An expansive understanding of what sense-making entails links with research on the significance of meaning as a mediator for complicated or prolonged grief.[22] This may partially answer concerns expressed by Christiaans[23], who drew attention to the lack of *understanding* of the cause of death in surviving relatives even in the face of an established cause, which undermined uptake of genetic counselling by some family members. For family members in our study, meaning-making included understanding the impact of the death on their sense of self and their place in the world. This suggests that affected families may require supporters to have full awareness of the extent of this devastation if they are to communicate normalisation, i.e. that this grief reaction is normal in the light of the nature of the loss, and to facilitate meaning-making and coping.

Thirdly, our study highlights the need for peer support following YSCD. This is reflected across themes 1 and 2. The value of peer support has been reported for bereavement in general.[24] A recent investigation into the utility of bereaved people's social networks found peer support to be particularly helpful.[25] This was linked with a number of benefits for the

bereaved including the provision of emotional and informational support as well as instilling a sense of communality and belonging.[26] The latter quality is particularly critical in unique or rare bereavement circumstances[27] such as YSCD bereavement. Our study adds to these findings by giving nuanced insight into the actual experience of receiving support from trained supporters and how this may function as a psychosocial conduit for processing grief and 'relearning the world'.[28]

Fourthly, our analysis highlights that effective community support for YSCD-affected families is more than 'support *in* the community' but 'support *through* a community', as relevant community structures themselves are experienced as healing. This is particularly reflected in Theme 3 (YSCD community support as facilitating finding new meaning). Participants spoke about re-engaging with life through joint fundraising, helping prevent future YSCD, and engaging in legacy projects that honoured the deceased and helped maintain *continuing bonds* with their loved ones.[29] This also points to the ongoing support needs of YSCD-bereaved parents, often many years after the death.

Specific recommendations for practice are given in Table 3. These include providing families with a safe and understanding environment in the immediate aftermath of the death. Medical explanations should be provided sensitively, including, if possible, relevant resources developed by patient representative organisations. It should be noted that clinical pathways often focus on the immediate needs of the patient within the context of determining risk due to a diagnosis of a condition. In the case of YSCD, an additional step should be integrated into the patient pathway whereby, at the conclusion of the clinical appointment, families are made aware of patient representative groups that can offer additional and ongoing support. This should involve informational and emotional support and would ideally include access to

families with prior experience of YSCD. It should be ensured that patients are aware of any such available resources when they leave the clinical appointment.

Table 3: Recommendations for practice

Psychosocial needs	Recommendations
Need for a safe environment	Providing access to YSCD-sensitive psychosocial support in the aftermath of this extremely traumatic event; family members may be in a highly vulnerable state and require a dedicated environment that conveys safety and understanding.
Need to make sense of the death	Giving medical explanations for the death and communicating these sensitively and empathically, if possible including relevant resources as developed by patient representative organisations. Showing awareness that these are important but need to combine with other support to enable sense-making at a broader level.
Need for affiliation and normalisation	Providing contact with or referring to trained supporters who have lost a loved one through YSCD (peer support), as they can convey understanding, affiliation, validation and normalisation i.e. communicating that their grief reaction is normal in the light of this tragic event, as well as give hope and model survival.
Need to find new meaning and maintain a continuing bond with the deceased	Facilitating access to a broader YSCD-relevant enduring social network (community support) that can be accessed on an ongoing basis and which offer opportunities for meaningful 'legacy work' such as helping prevent YSCD and for commemorating and honouring deceased loved ones, enabling the development and maintenance of continuing bonds with the deceased as part of this community.

Limitations

The present study is based on a sample drawn from an YSCD-specific UK charity, Cardiac Risk in the Young (CRY). Participants were already engaged with the organisation and may have been motivated to emphasise the benefits of this involvement. However, previous research with non-involved samples stressed people's expressed need for community support, and our study provides evidence for what YSCD-affected families perceive as effective support. Psychosocial support needs and impacts relating to provision outside YSCD-dedicated settings were not our focus. Future qualitative research could explore YSCD-affected families' psychosocial support needs and experiences relating to informal support networks, or other formal provisions such as workplace assistance or religious community support. Another limitation of the research is that while the entire database of the support organisation had been contacted, only some chose to contact the researchers, and out of those who wanted to participate, not all were able to. However, the recruitment of a broad sample across the three stakeholder groups means that the themes are likely to be common in this population.

Conclusions

YSCD-affected families can benefit from having access to YSCD-sensitive peer and community support. Whilst YSCD trauma and the associated experiences of loss are often characterized by their uniqueness and isolating consequences, the concept of recovery seems to be anchored in social relationships. What is particularly important is the rebuilding of a sense of belonging through a community that can provide an anchor and a home to affected families, enabling meaning-making and the maintenance of continuing bonds with the loved ones who are no longer physically present. This paper highlights the need to incorporate

patient representative groups and peer-to-peer support into patient pathways. Clinicians need

to be aware that this is an essential part of patient care.

IMPLICATIONS FOR PRACTICE

- Provide safety through YSCD-sensitive support

- Communicate medical explanations sensitively

- Allow for sense-making of death through ongoing support

- Refer to peer supporters for normalisation of grief

- Facilitate involvement in an enduring YSCD-specific network

CONFLICT OF INTEREST
The authors declare no conflicts of interest.

AUTHORS' CONTRIBUTIONS
LT, AC and ES designed the study. ES organised the data collection and set up the study. ES and AC collected the data. EC, LT and AC analysed the data. ES wrote the first draft. All authors commented on and amended the draft.

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Appendix A – Data collection procedure

The investigation was approved by the University of Surrey's Research Ethics Committee (EC/2013/132/FAHS) and conforms with the principles outlined in the Declaration of Helsinki (Br Me J 1964;ii:177). The organisation emailed their database of circa 2,500 registered families, inviting them to participate in the research. Eighty two people contacted the research team who ascertained whether they met inclusion criteria and were interested in participating in a focus group or an individual interview. Five did not respond further; 14 did not meet inclusion criteria; 4 declined to participate; 33 were unable to participate in a focus group due to time and geographical constraints; 7 expressed a preference for individual interviews but could not be accommodated due to practical constraints. Nineteen people made up the final sample (see Table 1).

Data collection consisted of three focus groups (one for each stakeholder group) and five individual interviews. The focus group participants were trained and experienced peer supporters (Focus Group (FG)1; N=5), peer support users (FG2; N=4) and bereaved users of CRY who had accessed the charity's wider community support (FG3; N=5). An average of 5 participants per group was recruited to allow a range of views to be expressed while keeping numbers small enough to ensure a sense of safety in the group. The individual interviews involved 1 peer supporter, 1 peer support user and 3 community support users. Prior to the interview, people were given information on what would be involved and a consent form to sign.

Appendix B – Data analysis

The analysis was carried out in accordance with Braun & Clarke's (2006) 6-phase procedure: 1. Familiarising yourself with your data, 2. Generating initial codes. 3. Searching for themes. 4. Reviewing themes. 5. Defining and naming themes. 6. Producing the report. The first author conducted steps 1 to 3. Steps 4 and 5 were conducted jointly with the other authors, who considered the initial set of emergent themes in relation to the raw data (involving a reiteration of steps 1 and 3). Step 6 was started by the first author and completed in conjunction with the other two authors.

To ensure quality, this study was guided by the criteria for excellence in qualitative work identified by Tracy (2010). These included the worthiness of the topic, resonance, the significant contribution of the work, and rich rigor.' (Tracy, S. J. (2010). Qualitative quality: Eight 'Big Tent' criteria for excellent qualitative research. Qualitative Inquiry, 16, 837–851. doi: 10.1177/1077800410383121). Worthiness of the topic was achieved per rationale in the Introduction, pointing to the severity of the distress and risk of mental health problems in families affected by young sudden cardiac death. Resonance was achieved by interviewing affected families across the three stakeholder groups engaged in peer and community support following young sudden cardiac death. The significance of the contribution of this work is shown in the Discussion as pointing to the first study of its kind, with clear implications for practice. Rigor was achieved by following the six steps of thematic analysis closely, through repeated readings of the transcripts (step 1), close line-by-line coding (step 2) and repeated reviewing of codes prior to clustering codes and searching for themes (steps 2 and 3), with constant checking between codes and raw data, candidate themes and coded data among all

three researchers to develop and refine the themes (steps 4 and 5) plus grounding in data

segments to demonstrate the credibility of the analysis in the report (step 6).