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Needs and experiences of families after a sudden unexplained death in childhood: a qualitative study

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ABSTRACT

Background Sudden unexplained death in childhood (SUDC) is a rare and devastating experience for families. In the UK, multi-agency investigation by police, health and social care of sudden, unexpected child deaths is a statutory requirement aiming to identify full causes for deaths. Families should be allocated bereavement keyworkers for support throughout the investigative process which can take several months. Previous research has focused on multi-agency investigation of sudden infant deaths, with little known about parents' experiences for deaths of older children.

Methods Bereaved parents of children in the UK, aged 1 to 17 years who died from SUDC during 2018–2022, were recruited through SUDC-UK charity and their mailing list and word of mouth. Semi-structured interviews were conducted in 2023. Interview transcripts underwent thematic analysis.

Results Interviews were conducted with parents from 20 families across England, Scotland and Northern Ireland in 2023. Four key themes were identified: the importance of keyworkers, trauma-informed communication, proactivity from professionals and provision of medical screening for families. Keyworkers were valued by parents, but only 12/20 families had keyworkers allocated. Communication and language were important; families were often distressed by unexpected telephone calls particularly relating to post-mortem results. Parents felt they had to be proactive explaining about SUDC to professionals who lacked knowledge of the condition. Parents wanted medical screening to be proactively offered for their families.

Conclusions Every family must receive swift, proactive, knowledgeable communication from professionals, during and beyond the investigation into their child's sudden unexpected death. This will help them through the process and mitigate the impact of poor communication on their grief. While all parents expressed that they wanted to find out why their child died, they also identified key improvements to the consistency and effectiveness of the investigation process.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ The sudden unexpected loss of a child impacts bereaved parents, siblings, the wider family and community in multi-faceted ways, both short and long term.

⇒ Multi-agency working should lead to high-quality investigations helping bereaved families to gain answers about the death of their child. Previous research has focused only on infants, not older children.

WHAT THIS STUDY ADDS

⇒ This is the first study to qualitatively capture the experiences of the multi-agency investigation from bereaved parents whose child died from sudden unexplained death in childhood (SUDC).

⇒ A knowledgeable, accessible dedicated keyworker who coordinates communication about the multi-agency investigation process is important for families.

⇒ Compassionate, trauma-informed communication with families, with mechanisms such as method and timing being pre-agreed, is essential throughout the investigation process.

⇒ Families should be offered medical screening following sudden unexpected child death.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY: IMPLICATIONS

⇒ Keyworkers provide vital support to bereaved families following sudden child death; those from health backgrounds were particularly valued due to the combination of clinical knowledge and compassion. All child health professionals require knowledge of SUDC, so they are adequately equipped to understand the families' communication and support needs during the multi-agency investigation.

⇒ Every SUDC family should be offered prompt medical screening to help provide reassurance.

INTRODUCTION

Each year in England, there are about 250 sudden, unexpected deaths of children aged between 1 and 17 years[1]; most will have a cause of death identified following detailed investigations. A minority remain unexplained, these are referred to as sudden unexplained death in childhood (SUDC). This is defined as the sudden and unexpected death of a child aged 1–17 years that remains unexplained after a thorough case investigation, including review of the child's medical history, circumstances of death, a complete autopsy and ancillary testing.[2] There are around 30 SUDC annually among children aged 1 to 14 years in England

and Wales, with this remaining static despite overall falls in child mortality.[3] Sudden infant death syndrome (SIDS), is similar to SUDC in that deaths remain unexplained despite detailed investigation,[2] but unlike SIDS, there are no recognised risk factors or prevention strategies for SUDC.

Many countries have detailed investigative processes or child death review (CDR) for sudden infant or child deaths. In England and Wales, there is mandatory multi-agency investigation by health, police and social care[4 5]; this includes deceased children being taken to hospital, paediatricians obtaining medical histories from parents, a review of circumstances of death with the police and a full post-mortem examination. The investigation concludes with a multi-agency case discussion (or CDR meeting) to agree the cause of death and any modifiable factors. All deaths are subject to further independent scrutiny at local child death overview panels (CDOP). Statutory CDR guidance for England requires that all bereaved families are allocated a keyworker who 'acts as a single point of contact for the bereaved family' throughout the investigative process.[6]

The sudden, unexpected death of a child is a devastating experience for families. Studies show that the grief and trauma experienced by bereaved parents are protracted and multi-faceted, involving a complex mix of emotional, physical, behavioural and social impacts.[7–9] Contact with professionals can have a significant impact on the family's ability to cope with the investigation process and can leave a permanent mark on their memory of the events.[10 11] Studies have discussed how the lack of compassion and empathy in communication, and ineffective discussions with parents about the events surrounding their child's death, impact their ability to 'survive the trauma', process it and grieve in a 'healthy way'.[10] Previous research on multi-agency investigation following sudden infant death found that parents valued the process for helping them understand why their infant might have died but could find the process intrusive and wanted more emotional support to be readily available.[12] There is limited research in this area after infancy, so this study sought to address this gap. The research question was 'what are the communication needs of bereaved families after sudden child death from professionals involved in the investigation?'.

This paper draws on interviews with parents from families affected by the sudden, unexpected and unexplained death of their child. It assesses how the frequency and quality of communication from professionals in the multi-agency response to the death impacted parents' experiences of the investigation and the grieving process and presents examples of good practice.

METHOD

Study design

We used qualitative methods. In-depth interviews with bereaved parents allowed parents the space to share their experiences of the investigation process and make recommendations for improvement. The research team comprises practitioners with experience of multi-agency investigations in the medical and police sectors (Authors 3 and 4); a bereaved SUDC parent and chief executive officer of the charity SUDC-UK which supports bereaved families (Author 2); and a bereaved SUDC parent and academic (Author 1). Given the importance of lived experience in designing ethical, impactful research[13] and valuing and responding to the stories of those that policies affect,[14 15] the team's holistic perspective of the investigation process is a key methodological strength.

Inclusion criteria, sampling and recruitment

Parents were recruited via SUDC-UK, a national charity which directly supports bereaved parents following the sudden unexplained loss of a child between the age of 1 and 17 years. Due to the sensitive nature of the interview content, this enabled a charity representative to be present during interviews for support if needed. As recommended by,[16] additional criteria included that the child's death needed to be between 1 and 5 years prior to the interview date (2018–2022) for effective recall of the events and to be at a distance from the immediate aftermath. Recruitment through the charity minimised the chance of inappropriate sampling occurring, as advertisement of the study only reached parents who met the criteria, and eligibility criteria was re-checked as part of informed consent.

Data collection methods

Interview questions were devised collectively, based on the team's individual experiences of the investigation, and several years of experience in supporting bereaved families. Question topics included the circumstances of their child's death, their experiences of communication from all agencies involved in the investigation across the investigation timeline and how communication quality and frequency affected their experiences of grief. Parents were given the option of conducting interviews alone or with their partners and/or with a support person present from SUDC-UK. Interviewees could choose to conduct interviews online using Microsoft Teams or in person in the parents' home. Interviews were conducted by Author 1 and lasted between 1 and 2 hours. Parents were provided with open questions as interview prompts. After an initial opening question asking about their child's life, the next question, '*do you feel comfortable telling me what happened on the day that (child) died*?' was often enough for parents to go into detail about the different stages of the investigation process and engagement with professionals. The interview schedule is available in the online supplemental appendix 1. Field notes were completed after the interview concluded.

Data analysis

Interviews were digitally recorded on Microsoft Teams and transcribed. Using NVivo, transcripts were thematically analysed[17] and coded inductively by Authors 1 and 2, and then, themes were agreed. Authors 2 and 4 then applied the themes to a random selection of transcripts to test the coding strategy, and a final set of themes was collectively agreed following a workshop discussion. We offered all parents registered with SUDC-UK the opportunity to hear a summary of the results following analysis in a closed online presentation, to enable them the chance to provide comments and to include their input into the dissemination plans before formal write up commenced.

Patient and public involvement

The study had extensive patient and public involvement as it was designed and led by bereaved parents.

Ethical considerations

Ethics approval was granted by the University of Central Lancashire, reference BAHSS201024. Participants were recruited based on fully informed consent and told they could stop the interview or withdraw within an agreed time limit. All identifying information has been removed, including geographical references and names of all agencies such as NHS trusts. Every attempt was made to provide a supportive interview environment by allowing participants to choose venue, format (digital or in person) and if they wanted an accompanying representative. The interviewer having lived experience was cited by several participants as a reason for their willing participation.

We were guided in methods and reflexivity in analysis by the consolidated criteria for reporting qualitative research.[18]

RESULTS

Parents from 20 families were recruited and interviewed (England, n=18; Scotland, n=1, Northern Ireland, n=1). Parents were not asked to disclose postcodes, but discussions during interviews demonstrated that narratives were captured across a range of socio-economic backgrounds. Most chose to conduct the interview alone (n=15; all biological mothers), some chose to do so with their partners (n=4; all biological mothers and fathers) and one (biological mother) chose to have a SUDC-UK representative present with her. Data were obtained about the circumstances of the child's death and medical history deemed relevant by parents (table 1).

In all interviews, parents gave detailed accounts of their engagement with professionals. The nature and frequency of these interactions had significant impacts on their experience of the investigation and their ongoing grief and trauma. While there was key learning identified for individual organisations within the multi-agency response, this paper will summarise four overarching interconnected themes relevant to all agencies.

Importance of keyworkers

Guidance for the child death review process in England states that a keyworker should be appointed who 'acts as a single point of contact for the bereaved family' to provide information about the investigation and signpost them to appropriate support. 12 families said they had a keyworker (n=10 families based in England; n=1 Scotland; n=1 Northern Ireland), and the agency providing this role varied (table 2). Eight families from England stated they had no keyworker.

Table 1 Circumstances of child's death and important history

Age of child (in years)	1–3	13
	4–6	2
	6–8	0
	8–10	1
	11+	4
Year of death	**2018–2019**	2
	2020–2021	14
	2022–2023	4
Death witnessed or unwitnessed* *unwitnessed referring to the death of child **occurring during sleep in a cot or bed**	**Witnessed**	7
	Unwitnessed	13

Families who were not allocated a keyworker spoke about how this led to feeling '*passed around*' from one agency to another. This increased pressure on them to '*chase*' for information, exacerbating feelings of abandonment. In contrast, families with a keyworker (table 3) felt they had more tailored support for their needs (quote 3.1), which helped them cope with the emotional and administrative burdens.

Parents talked about the value of the keyworker relaying information about the progress of the investigation from the various agencies involved (quote 3.2). This was essential for setting expectations and gathering wishes and feedback from families about key touchpoints, such as receiving the post-mortem results.

Parents who reported regular and prolonged engagement, throughout and beyond the conclusion of the investigation, noted the importance of the consistent emotional support provided (quote 3.3).

However, some families reported issues with the capability and capacity of the keyworker to support them (table 4). For example, one family was given a senior police officer, and this was a barrier for the parent in feeling able to contact her (quote 4.1). Other parents highlighted concerns that the keyworker was not knowledgeable enough or equipped to express the family's views effectively on their behalf (quote 4.2). There were also issues noted with their keyworker's lack of consistent communication, unfulfilled promises and that there was no exit strategy once their role with the family concluded (quote 4.3).

Trauma-informed communication

Communication frequency, style and delivery were discussed by all parents as hugely impactful (table 5). Several parents reported being left for prolonged periods

Table 2 Keyworker details

Keyworker provided	Nine NHS (SUDC nurse, child death nurse, bereavement nurse) One coroner's officer One police One social worker	Keyworker not provided	8

SUDC, sudden unexpected death in childhood.

without updates about the investigation, which caused significant distress (quote 5.1). When communication did occur, updates described as '*out of the blue*' were highlighted as poor practice (quote 5.2).

A key touchpoint was the delivery of the post-mortem results. Several families spoke of the unexpected delivery of the report and the impact this had. A planned delivery of the report with trained medical professional there to explain its contents was considered best practice, as this provided the opportunity to ask questions about their child's care and to have terminology or next steps explained. Communication techniques that were pre-agreed with families (ie, with a chosen mechanism or time) were also praised.

Insensitive language choice, or professional jargon, was highlighted as being distressing and inappropriate for bereaved parents, especially when it concerned reference to their child, or the home (quote 5.3).

Table 3 Keyworker good practice

3.1 Tailored support for family's needs	*In the run up to the inquest, (keyworker) did the best because of how pregnant I was – she was mindful of us having the funeral sooner rather than later. She was pushing behind the scenes that all that process needs to happen*. (Parent 14) *Just knowing what those trigger points will potentially be. and even with your job, she will say 'so how are you finding it back at work?* (Parent 20)
3.2 Relaying information about the progress of the investigation	*Good practice was having a nurse. She came really quickly the day after and she had a very good manner, she was very compassionate, she told us as much as she could, told us what would be happening*. (Parent 3) *She came to our house 3–4 times, and she gave us all the time in the world, she never rushed me, went through all his medical notes, gave me so much time and that also meant we could feedback our complaints*. (Parent 12)
3.3 Consistent emotional support provided	*We've had almost like a grief guide through all of this. The thought of what it would have been to navigate this without her*. (Parent 14) *From the minute we lost him it seemed like she was there and helped us through that journey. 3 years on I feel like I can pick the phone up to her today if I'm really struggling with anything*. (Parent 1)

Table 4 Issues raised about keyworker

4.1 Inappropriate keyworker job role	*I don't want to disturb her for follow-up questions (…) Because even now, like I tried to ring the other day just to find out when the inquest is happening. She hasn't got back to me, but I don't want to nag and be a nuisance either. It's nothing important for her*. (Parent 8)
4.2 Lack of knowledge or power to represent family	*She was very friendly and helpful but I'm not sure how good she was in the CDOP process in expressing what we wanted… I just think either her hands were tied, or she didn't have the tools or training to be able to ask questions that needed to be asked. (Parent 3)*
4.3 Lack of consistency and unfulfilled promises	*Yeah, I got told that would happen and I messaged (NAME) on (date) asking what happened on the child death review.* *She has never text me back (…) from the bereavement nurse's perspective she was great at first and then she just disappeared*. (Parent 13) *She was nice, but I feel like I had to follow-up a lot of times. Like when she'd say I'll ring you back, I'll give you a few days and I'll ring you back and then I'd get no call and then I'd be ringing and ringing.* (Parent 19). *And we felt like that you don't matter anymore, that love and attention and dialogue has gone away. You're on to the next one*. (Parent 5)

Professionals showing '*humanity*' and empathy, assisting them with the transition from parenting their child alive to parenting them while they are no longer alive, was noted as important for bereaved families in coping with the trauma (quote 5.4). Any attempts to empower families in decision-making or allowing them to conduct '*normal*' acts of parenting were spoken about with gratitude (quote 5.5).

Proactivity

Those who had to do considerable amounts of self-advocacy, seeking or giving information, or trying to access bereavement or medical support (table 6), spoke about their lack of '*energy*' to do so because of the grief and trauma (quote 6.1). Parents also noted their concern with the different levels of privilege and access needed for this level of self-advocacy and that they worried about those families who did not have the same literacy, social capital and/or financial privilege to seek mechanisms of support, such as private counselling and medical reassurance screenings, or to challenge ineffective care. Some spoke of the additional layers of abandonment or exclusion felt during the process because of specific vulnerabilities and/or different backgrounds or circumstances of their child's death (quote 6.2).

Table 5 Trauma-informed communication

5.1 Lack of communication	*We just felt abandoned. It's the only way I could say it. We just felt left like we had very good care on the day, like the police - I can't fault the police on the day. I can't fault the ambulance on the day and the people at the hospital, they were all great. And then we were just sent home and that was it. And nothing, you know, that's how I felt*. (Parent 18)
5.2 Unexpected updates for example, postmortem results	*It's very, very different if you've requested that information, you can open it when you are ready. You have to be in a headspace and a safe space to be able to look at medical notes, terms. You can't be looking at it when you are doing your kids' dinner. That was dreadfu*l. (Parent 12)
5.3 Insensitive or inappropriate language	*Would you like it (child's brain) back or would you like us to dispose of it ourselves?' Dispose of it like he's a piece of rubbish.* (Parent 4) *They kept using the word scene, and I'm like this isn't a scene, it's my house, my home, where I've raised my family*. (Parent 13)
5.4 Empathetic language and behaviour	*Even on the way there (to hospital) like you know cause I was holding (child) but he was asking me lots of questions about her and where she went to school and what she liked*. (Parent 16)
5.5 Attempts to empower parents and retain parent roles	*I said 'I know this is a bit strange, but can I change his nappy? Can I clean him up?'. She said yeah and they went and got a nappy and she said, 'we need to keep the nappy but of course you can'. And they were just, they were really good, and they didn't rush us*. (Parent 15)

Furthermore, several parents felt they had to educate professionals about SUDC themselves or that their child's death was being considered the same as SIDS, and thus, they were being signposted to services that did not fit their needs or none at all. This was seen as a significant disadvantage to them seeking peer support and advice for decision-making, especially for families with no keyworker.

Relatedly, a number of families reported frustration with medical professionals being '*very dismissive*' or undermining their knowledge of their child's history and the circumstances of their death, particularly concerning febrile seizures. Out of 20 families, 10 of the children had one or more febrile seizures in their history or experienced their first event when they died. Febrile seizures are associated with SUDC, 30% of children dying from SUDC have had febrile seizures compared with 3% of all children, although the relationship is not clear.[19] One parent stated the consultant reporting the post-mortem results "*wouldn't even consider talking about febrile seizures and its connection to sudden unexplained death*".

Table 6 Lack of proactivity

6.1 Dismay at the lack of proactive engagement from professionals	*It should be flagged up automatically 'this is a family who are going through grief - they need the extra support'. It shouldn't be 'come and find your support' because you might not be in a place to go and get it*. (Parent 8) *I cannot believe after a child dies there is no pathway, what you're given with a newborn vs a mother who has gone through hell to check she is standing on her feet like there's nothing*. (Parent 12)
6.2 Intersectional barriers to self-advocacy	*I grew up incredibly poor and I'm brown, so I know there's not a lot of help for us (…) there was part of me that knew I needed to go out and help myself and help my family because I know that very quickly you can be uncared for, and I felt uncared for*. (Parent 16)

Several parents reported the relief felt when agencies proactively communicated with them about key aspects to the investigation, checked in on their well-being or gave them useful information without prompt or request (table 7). They highlighted proactive steps taken by professionals that were welcomed as good practice (quotes 7.1–7.5):

Medical screening and further investigation

Lack of referral for medical screening for parents and surviving children was noted as a key factor in increasing distress and anxiety (table 8) (quote 8.1). Eight families were not offered any screening; seven requested screening themselves as they were not offered this, either via the NHS or charities such as the British Heart Foundation; and five were proactively offered screening. All 15 families who were not offered screening, or who had to seek this themselves, stated that they would have wanted this to be offered without them having to request it. Families who were offered prompt exploratory health checks (such as an ECG and echocardiogram) or tailored care packages, such as additional appointments in pregnancy and open access to children's ward for surviving siblings, spoke highly of this for '*alleviating stress*'.

Of significant importance to all families was maximising the chances of obtaining answers for their child's death. A key aspect discussed by most parents was the need for clear, empathetic, knowledgeable explanation of the implication of the '*huge decision*' about tissue samples taken during post-mortem examination, such as the possibility for taking part in research or family genetic testing (quote 8.2).

DISCUSSION

The findings from this study demonstrate that the frequency and quality of communication from professionals is intimately connected to the families' experiences

Table 7 Types of proactive support appreciated by families

7.1 Offering to contact schools/work/key people for families to inform them of the death or other investigation details	*I couldn't have made that phone call to his school. And I don't think they'd have understood me if I'd even tried to do it. So yeah*. (Parent 2)
7.2 Providing ideas for funerals; contacting directors and giving a list of choices to families	*I didn't want to admit that there'd have to be a funeral or anything else. And she rang round the local funeral directors for me. And said you know 'these three sound really nice, there's no charge for a child's funeral', which, like, who knows? 'And they're expecting your phone calls'. So that was helpful that she kind of sorted that bit out*. (Parent 5)
7.3 Providing timely updates of investigation process without families having to "chase", and supporting their understanding of the information	*So they were really mindful of that, talked about it in advance, said what they were gonna do and with the post mortem they said somebody can come up to you. (Parent 15)*
7.4 Organising support; offering to contact medical departments or charities on families' behalf, tailored to their needs	*All of them in some way, particularly the bereavement nurse, and SUDIC nurse helped me with other peripheral things to do with the situation. So, for example, I at one point really wanted to see an obstetrician instead of a midwife, and both of them just sorted it out for me within that week*. (Parent 1)
7.5 Other generic helpful supportive behaviours which demonstrated advocacy	*I felt really supported as soon as I walked in. The lady on reception would clock my eyes and just go 'sit down' so that I didn't have to come up to the window. I knew that everybody had been waiting there for ages, but I was always the first person in as soon as I sat down*. (Parent 10) *On the Friday night, we were like, obviously distraught and everything. But we just kind of left the hospital, but (name) noticed that we hadn't read (child's name) a bedtime story. So she did*. (Parent 20)

of the investigation and bereavement process.[11] Some families are receiving a disproportionately lower-level standard of support from professionals, with the consequences, such as feelings of abandonment, also being exacerbated by intersectional vulnerabilities. While there are some similarities with studies examining other types of unexpected death in childhood, including families' need for patience and sensitivity from professionals,[10 20 21] the findings show that the death being unexplained also requires additional considerations in communication and practice to help families cope. These include proactive and swift arrangement of medical screening for living family members and professionals avoiding dismissive attitudes about the child's medical history that parents deem important.

Table 8 Lack of screening and information about their implications

8.1 Impact of lack of reassurance medical screenings	*I just needed to know that we were okay, and I couldn't move on at all from the fear. The trauma just stayed all that time*. (Parent 3)
8.2 Lack of knowledgeable, timely advice about sample retention and genetic testing	*When we spoke to the coroner and you're given that form that you tick, whether they keep the samples or they don't and she said to him, 'it's usual for people to tick the box to destroy the samples'. So he was like OK, so he ticked the boxes to destroy the samples*. (Parent 18) *I think it's a really wrong time to ask that and there was still time before his funeral. I think what they should have done was say these are going to be the options and we'll give you another call in a few days and let you think about it and then we will come to a decision together and that would have given me time then to for example talk to (charity) about what they recommend*. (Parent 6)

Aligning with studies centring on the importance of streamlined, regular and consistent communication pathways for families experiencing trauma,[21 22] we found that having a dedicated keyworker was essential for managing the complex, distressing investigation process and administrative burdens grieving families face. However, there were gaps in the appointment of this role (8/20 families received no keyworker) and the service offered. This situation may be improving, a recent survey of paediatric intensive care units reported that 17/21 units appointed keyworkers to support families.[23] Keyworkers are to act as the conduit for information from the different agencies about the child death review process but also provide a 'voice' for families, especially when they cannot have a physical presence, such as at CDOP.[24–26] Specialist CDR and bereavement nurses were regarded more highly by families than other types of keyworker due to their specialist knowledge, empathetic approach and generally more consistent presence. However, several families still felt that their ability to provide a 'voice' for them was limited. Keyworkers should establish pre-agreed methods of communication, act as a 'regular and reliable' guide and support for the investigation process and delivery of results,[25] but also establish how best to represent the families' voices. This includes key touchpoints, such as at the hospital (eg, facilitating time with the child) or child death review meetings, but also throughout the several months between the child's death and conclusion of all investigations.

Several studies highlight the importance of professionals maintaining regular, trauma-informed and family-centred communication with bereaved families after the death of a child.[11 12 26 27] However, most families in our study recounted examples of poor practice across all agencies, whereby clinical, cold or accusatory language was used, or unexpected contact occurred with updates that caused significant distress. At a time when families are 'just managing', a thoughtless word or phrase can be catastrophic.[28 29] Our findings showed that few families had explanations of the post-mortem results with health professionals or a follow-up meeting to share the results of the final review. Many parents reported distress at receiving results from post-mortem examinations directly from coroners' staff, often by telephone and with little warning. This is contrary to national multi-agency guidelines, which recommend that the cause of death is given to parents by a healthcare professional.[4] Coroners have the legal responsibility to ensure that bereaved families receive post-mortem results in a timely manner; some coroners delegate this to paediatricians or specialist CDR nurses. Our study provides further evidence that having a keyworker streamlining the delivery of information about the investigation from agencies reduces the likelihood of unexpected, inappropriate communication that does not meet the family's needs. Tailoring communication to any potential vulnerabilities is also essential, noting how different family backgrounds may require specific avenues of support or advocacy responsibilities from the keyworker.

In line with other research concerning parent experiences of sudden unexpected and unexplained death in childhood, our data highlighted the ways that investigations disempower parents[30] and that when professionals hand this power back, even in a small way, this is appreciated in the short- and long-term period after the child has died.[31 32] Parents reiterated other studies' findings regarding the importance of spending quality time with their child,[3 21 24 33] and in being given a voice in the CDR process,[24 25] or in providing feedback on their child's care.[33] We add that allowing them to retain as much control over their parental identity mitigates some of the distress and bewilderment at the sudden and unexplained nature of the death.[20]

Several parents reported feeling dismissed regarding their child's febrile seizure history, having acquired a greater knowledge of the scientific literature than their doctors. Listening to bereaved parents and acknowledging their concerns are important for parents, enabling trusted relationships between them and the professionals investigating their child's unexpected, unexplained death. Many parents expressed feelings of frustration at having to educate professionals about sudden unexplained death in childhood, adding to their isolation and exhaustion from self-advocacy. It is essential that all child health professionals are aware of SUDC, so that bereaved families do not have the burden of explaining about SUDC, as this understandably leads to a loss of confidence in professionals and increases families' sense of isolation.

Parents in this study directly highlighted their gratitude to the authors that their experiences and child's stories were included. However, as the sample was obtained directly through SUDC-UK, we were reliant on registered cohorts. Future research into sudden unexpected child death should incorporate more diverse experiences of families, across ethnic and religious groups, to assess cultural sensitivities and explore barriers to effective support such as socio-economic, physical or other vulnerabilities. As some of the interviews were done during the COVID-19 pandemic, it is also important to note that some of the delays in communication may have been impacted by uncontrollable factors related to this—although prior studies would suggest these are recurring themes. In line with,[34] we suggest that regular audits of the review process should be conducted to ensure families' needs are being met.

Finally, in line with other studies, our findings showed that, for families experiencing the sudden unexplained and unexpected death of a child, both the need for answers for their child's death and fears surrounding the health and well-being of living siblings feature strongly in their experience of the investigation.[24 35 36] Parents who received proactive, early referrals for cardiac, metabolic or general health screening with the general practitioner, or support plans being put in place for subsequent births of other siblings, spoke positively about the reassurance this gave. However, reiterating findings from,[8] many expressed frustrations at the extent to which these needs were unmet or had to be fought for, and there were inconsistencies across health services as to what screening was offered. Similarly, few families were offered genetic testing. The investigation of unexplained child deaths should improve as since April 2023 whole genome sequencing is routinely available following any unexplained infant or child death in England, looking for known cardiac, neurological and metabolic genes associated with sudden death.[37] In addition, a national inherited cardiac conditions pathway has recently been commissioned providing specialist assessment and screening to all families after the sudden unexplained death of anyone aged over 1 year. These enhanced investigations and screening, when combined with high-quality support from healthcare professionals knowledgeable about SUDC, and compassionate care from bereavement keyworkers should lead to world leading care for families at a time when they feel their world has ended.

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Contributors The study was designed by all authors. EC collected the data and conducted the interviews and wrote the draft findings. EC and JH conducted

primary data analysis, and NS and JG completed an independent review of analytical themes to agree the final codebook. EC with JG wrote the first draft of the manuscript, and all other authors commented and amended final manuscript for publication. EC is guarantor.

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Patient and public involvement Patients and/or the public were involved in the design, conduct, reporting or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was approved by University of Central Lancashire ref (BAHSS201024). Participants gave informed consent to participate in the study before taking part.

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Data availability statement No data are available. Due to the ethical requirement of the study, data cannot be shared with other researchers.

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