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The experience and support needs of adult family members who face a sudden adult death: a systematic review study.

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The experience and support needs of adult family members who face a sudden adult death: A systematic review study

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Implications for practice and/or theory and/or policy

- **Further research:** while there is developed understanding of support needs and services for those family members who experience an expected death (cancer) or the death of a child under 16, there is lack of understanding of the particular experience and needs of those family members for whom the death of an adult relative was sudden, and implications for service delivery and professional support.
- **Educational needs:** responders who attend at the time of a sudden death of an adult family member, or in the short term afterwards should understand the important part they play in enabling the bereaved close family members to cope with the immediate situation and the resulting grief, bereavement and healing processes.
- **Development of services and information that is widely and easily accessible:** public information development and dissemination is required for adults who have experienced the sudden death of an adult family member to enable access to information about professional, evidence based, and skilled services and support.

Abstract

This systematic review explored the experiences of adults with support from professional service providers when facing the sudden death of an adult family member.

The reviewers used Joanna Briggs Institute methods, tools and software. Database searches were carried out in ASSIA, CINAHL, MEDLINE, PsychArticles. These were supplemented with searches of e-thesis databases, and specialist law sites. Studies were identified for inclusion if they were qualitative, in English and published between 1990 and December 2021.

Across the 19 papers included, the review found family members received support at the time of a sudden death from a range of sources. However, there were differences in timing and content and for some relatives, barriers to access and many unmet needs. Experiences of support from professionals varied and some had more positive outcomes than others. A relationship between the family member and the professional which was perceived as supportive led to benefits for processing grief.

While informal support and information is essential, anticipation of needs and appropriate responses require regulated professionals and organisations who encounter the bereaved to be visible, accessible, skilled and able to respond. It is recommended this is formalised in standards or protocols for support in relation to sudden death situations.

Introduction

The sudden death of a family member is a traumatic event and is usually something which takes time for the family and individual members to adapt to emotionally and practically. Sudden deaths may arise from natural or unnatural causes, including trauma, self-harm or violence perpetrated by others. As well as the unfamiliarity of sudden death itself, relatives may encounter and interact with a range of professionals, including health and social care staff, police, and those whose responsibility is to investigate the death (Kristensen *et al*, 2012). Relatives may be unfamiliar with some professional roles and the processes and procedures that need to be carried out by, for example, paramedics, police liaison officers, coroner, and criminal justice services (NHS, 2018; Stephen *et al*, 2015).

It is known that bereavement adversely affects the mortality of surviving individuals and specifically creates higher risk of death for those bereaved suddenly (Boyle, 2011; Shah, 2013). Bereavement after sudden death has a varied range of characteristics depending on the nature of the death. Survivors may exhibit inability to process the reality of the loss, frustration at the authoritative processes restricting the ability to view the body, the effects of witnessing the death, and for some the distress of having no body to grieve (Kristensen *et al*, 2012).

Sudden death is ill-defined and open to a range of perceptions. Sudden death may be defined as unanticipated and therefore unexpected, with no time for preparation or saying goodbye, consequent shock for relatives, feelings of unreality, guilt and needing to apportion blame. Although causes of sudden death may be diverse, relatives' experiences of its effects are united in these kinds of commonalities (Worden, 2009). Further, definitions of sudden death are mostly related to the time period from the onset of symptoms as in a death by natural causes. For example, the World Health Organization (2016) states less than 24 hours from onset, though for deaths by unnatural causes the occurrence of a fatal episode would define the death as sudden.

In terms of support for close relatives and friends post-suicide, Pitman *et al* (2017) identified a quarter of those bereaved receive no informal or formal support and linked this to failed suicide prevention

strategy implementation in the UK. This is of concern when it is known that those bereaved by suicide are more likely to also take their own lives (Scottish Government, 2018). However, the study was limited by non-response from young males in the population sampled, those who are most adversely affected by suicide in the UK. Every Life Matters (Scottish Government, 2018) reiterates the provision of support and referral pathways for those bereaved by suicide as a priority to reduce suicide rates.

Prolonged grief disorder (PGD) may affect 10–20% of the population of people bereaved through natural causes (Prigerson, 2004), but when the death is sudden the risk may be increased (Boelen & Boelen, 2017). Certain bereavement challenges which may be common in suddenly bereaved individuals may also give rise to prolonged grieving, for example, struggling to accept the loss and guilt related to the death (Trevino *et al*, 2018). In addition, sudden death may mean greater incidence of drug or alcohol dependency, symptoms of post-traumatic stress disorder (PTSD) or suicidal ideation in survivors (Kristensen *et al*, 2012). However, violent loss may be a greater predictor of these outcomes than suddenness (Currier *et al*, 2006). Where there has been a suicide there may also be challenges to a healthy bereavement and a more protracted grieving trajectory. Post-suicide loss, individuals with signs of complicated grief are more likely to have had a pre-loss history of mental ill-health, suicide ideation and symptoms PTSD. This may be down to families in which suicide has occurred being more likely to have an ongoing burden of mental and psychological stresses (Tal *et al*, 2017).

Professionals in immediate attendance at the time of the death, or in the short term after the loss, have a crucial role in caring for the bereaved. Compassionate, effective response is critical to allow the bereaved to cope with the immediate situation and the resulting grief, bereavement, and healing processes (Norton, 2017). They can also lay the foundation for the difficult journey of mourning and healing that must follow. Indeed, evidence in Scotland of financial costs for healthcare providers related to bereavement (Stephen *et al*, 2014) strengthens the case for improving support and, in cases of sudden loss, support at the time of the death seems appropriate and necessary.

The current systematic review aimed to explore the experiences of adult family members with care received from professional service providers when they face a sudden death of an adult family member which occurred in the clinical or community setting as well as to identify support needs, met and unmet.

Methods

The review was carried out using Joanna Briggs Institute methods, tools and software (Aromataris & Munn, 2020). A search for existing reviews in the topic area revealed none which looked specifically at sudden death and bereavement, when the person who died and the bereaved are all adults. In the wider context, this review included interactions with services such as the coroner, police, mortuary and pathology, and the criminal justice system. The focus on identifying support in these areas provided a novel and interesting perspective.

Database searches were carried out in ASSIA, CINAHL, MEDLINE, PILOTS, PsychArticles, Web of Science, Google Scholar, Mednar, Social Care Online and Social Science Research Network. These were supplemented with searches of e-thesis databases (eg OpenDoar, EthOS), and specialist law sites (eg Westlaw). An initial scoping of two databases (CINAHL, MEDLINE) identified a substantial body of evidence ranging back to the early 1990s. Therefore, studies were identified for inclusion if they were written in English and published between 1990 to end of 2021.

Inclusion criteria applied were: studies including adult participants aged 18 or above; relationships to the deceased (also aged 18 or above) included spouse or partner including civil or same sex relationship; parent; child; brother or sister; grandparent or grandchild; niece or nephew; step-parent; half-brother or half-sister; partner of over six months; uncle; aunt, and cousin; short-, medium- and long-term support needs, and qualitative methodologies (phenomenology, ethnography, grounded theory, action research, feminist research).

Studies eliminated were those which focused on: health,

social care or any other professionals' perspectives in relation to relatives' needs following sudden death; implementation studies; studies testing effectiveness or evaluation of bereavement interventions, and studies relating to donation of organs or tissue.

The following search strategy was developed and used across databases, with adaptation where necessary to fit with the specific requirements of databases:

1. Sudden death or unexpected death or accidental death or traumatic death or violent death or military death or suicide or homicide or murder
2. Family member* or relative* or spouse* or parent*
3. Bereave* or mourn* or grie* or grieve*
4. Need
5. Experience
6. Support
7. Adult*
8. Hospital* or emergency department* or communit* or out-of-hospital
9. Procurator fiscal* or coroner*
10. Forensic*
11. Post-mortem
12. Criminal justice
13. Qualitative

Methodological quality was assessed independently by two reviewers using the JBI critical appraisal tool for qualitative studies (Aromataris & Munn, 2017). This allowed scrutiny of studies focusing on 10 key areas which are summarised in Box 1 and depicted in Table 2 in the results section.

Box 1. JBI Critical appraisal checklist (summarised)

1. Congruence between philosophical perspective and methodology
2. Congruity between methodology and research question
3. Congruity between methodology and methods
4. Congruity between methodology and data analysis
5. Congruity between methodology and interpretation of results
6. Researchers' position culturally and theoretically
7. Influence of researcher on research
8. Representation of the participant voice
9. Ethical aspects discussed and approvals stated
10. Flow of conclusions from the data analysis and interpretation

Responses applied to each quality criteria were 'yes', 'no' or 'unclear'. Differences of opinion between reviewers were discussed, study content reviewed, and agreement reached. A third party, though identified, was not required. Across the included studies a percentage score was calculated based on the number of 'yes' responses to provide indication of the strength of the research reviewed. Data extraction was also carried out through systematic application of the JBI tool designed for the purpose.

Synthesis of findings developed through a process of assembling findings as extracted from papers (level 1), categorising findings based on similar meanings (level 2), and the production of a single set of findings synthesised in defined themes (level 3). Findings were identified in the themes and content of themes as presented by authors of papers and were extracted as short pieces of data. These were identified through repeated reading of study results sections. Based on similarity of content of extracted findings, categories of similar meaning were amalgamated. Categories were agreed through consensus between both reviewers, and this led to development and agreement of the synthesised findings of this review presented below as four themes (Munn *et al*, 2014). Credibility of findings in a JBI review is established by assessing each individual finding depending on the congruency of the study authors' interpretation with the supporting data included in the paper (Munn *et al*, 2014). When drawing findings from included papers, an accompanying judgement was made related to the credibility of the finding. Each level 1 finding was given a ranking of unequivocal, equivocal, or unsupported to determine the level of credibility related to representation of participants' voice. To additionally gain understanding of the overall credibility and dependability of synthesised findings at level 3, the ConQual scoring system was applied (Munn *et al*, 2014). Five critical appraisal criteria in the JBI tool, related to congruity through philosophical perspective, methodology and methods, and data extraction and interpretation were used to assess dependability, while the assigned status of the individual findings as unequivocal, credible (equivocal) and unsupported (U, C, US) are used to define credibility. Synthesised findings were then ranked as either high, moderate, low or very low in terms of confidence in quality. Each synthesised finding was allocated a ConQual ranking which was agreed

through consensus between the two reviewers (Aveyard *et al*, 2021).

Results

Search results and study selection

In total 2,008 studies were identified through searching of the databases. The titles and abstracts were screened by both authors, and 113 were identified as eligible. Following removal of duplicate studies, 80 were retrieved in full text format. These were read in detail and inclusion and exclusion criteria applied, and following this process 35 studies were critically appraised, at which stage a further 16 were found to be poor quality and eliminated. A total of 19 studies were found to be eligible for the review and of sufficient quality for inclusion, and the process was recorded in a PRISMA flow chart (Page *et al*, 2021) (Figure 1).

Description of included articles

Papers analysed originated from authors working in Canada (Gall *et al*, 2014; Harrington & Sprowl, 2011), Republic of Ireland (Begley & Quayle, 2007), the UK (Chapple & Zeibland, 2010; Biddle, 2003), New Zealand (Fielden, 2003), Australia (McKinnon & Chonody, 2014; Mowell, 2007; Ratnarajah *et al*, 2014; Rodger *et al*, 2006; Peters *et al*, 2016a, Peters *et al*, 2016b), the USA (Sharpe *et al*, 2012; Sharpe, 2008; van Dongen, 1991; van Dongen, 1990; Mayer *et al*, 2013); Sweden (Pettersen *et al*, 2015) and Tanzania (Outwater *et al*, 2012). Table 1 provides additional information for each included study. Table 2 provides results of the appraisal process. Across studies the participant voice is well represented, and this links well to the conclusions drawn by the authors. Less well addressed are the philosophical perspective, the researchers' perspective on the topic of interest, and their relationship to participants. However, most studies are congruent through methodology, methods, and interpretations. It should be noted there was limited breaking down of relationships of participants to the deceased or any analysis of experiences of needs of specific groups of family members. However, Pettersen *et al* (2015) explored sibling experiences.

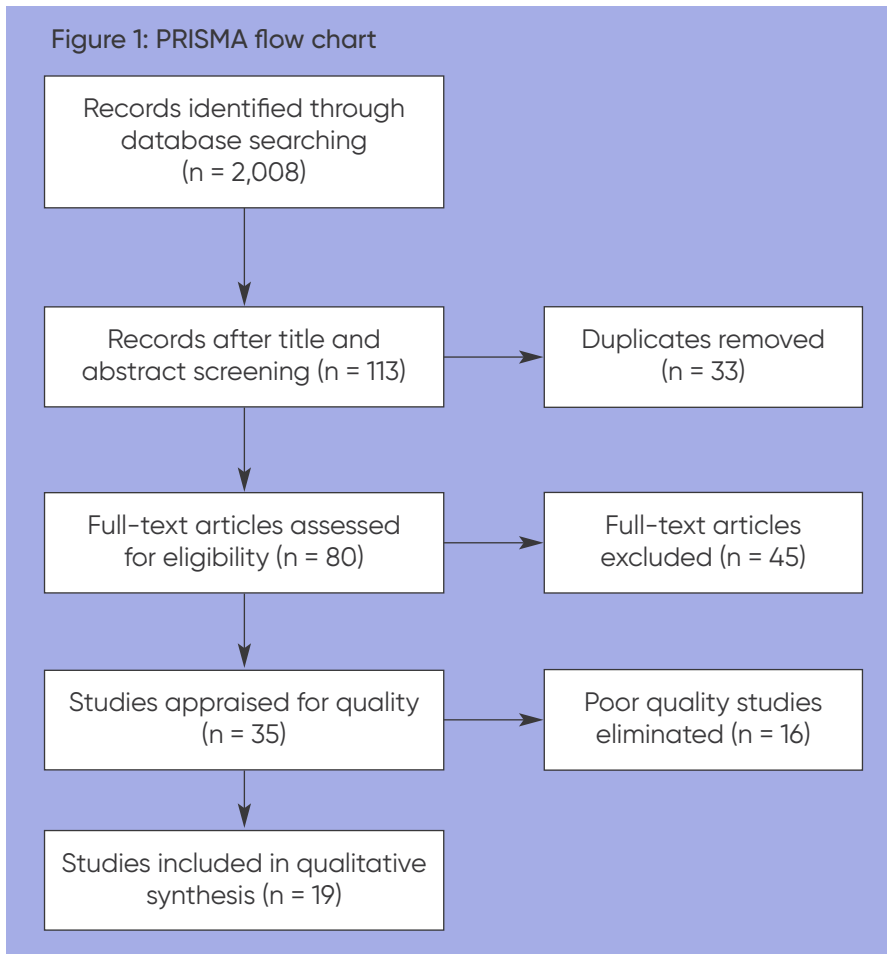


Table 1. Overview of included studies

| Study | Methodology/ methods | Participants | Phenomena of interest | Conclusions |
|-------------------------------|---|---|--|---|
| Begley M & Quayle E, 2007. | In-depth face-to-face interviews. | Eight suicide bereaved individuals (adults): 3 males, 5 females; age range 27–72. | Bereavement experience of adults bereaved by suicide. | Suicide bereavement is different from the more usual forms of bereavement. Support groups focusing on suicide bereavement appear to be helpful. |
| Biddle L, 2003. | In-depth interviews face-to-face or by phone. | 16 participants (1 male); 6 parents; 7 spouses (1 ex); 2 child; 1 sibling relationship. | Bereaved people's experiences of the suicide inquest. | Overwhelmingly negative perceptions of the coroner inquest. Some examples of positive experience when the coroner showed sympathy and the inquest was informal in nature. Recommendations for relative support during inquests. |
| Chapple A & Ziebland S, 2010. | Narrative and semi-structured interview. | Suicide bereaved individuals. | Influence of the internet on experiences of suicide bereavement. | People who are bereaved access support through the internet. Often not from professionals as they do not have a diagnosis. From others who have been through the same experience. |

| Study | Methodology/ methods | Participants | Phenomena of interest | Conclusions |
|--|---|---|--|--|
| Fielden JM, 2003. | In-depth interviews and researcher journal entries. | Five parents and 1 sister of young people who had completed suicide. | Journey after deceased has completed suicide and the transformation that happens. | Service provision and support was not mentioned following death. There was a focus on family involvement and support before death and during the deceased's treatment by services. |
| Gall TL, Henneberry J, Eyre M, 2014. | Semi-structured interviews. | 11 suicide bereaved individuals and 4 mental health workers. | Needs of individuals bereaved by suicide. | Six best practice recommendations were created for health professionals supporting bereaved. |
| Harrington C & Sprowl B, 2011. | Semi-structured interviews and researcher field notes. | 16 participants – family members of deceased. | The influence of viewing the body of the deceased on the bereavement process. | Caring attitude of the professional towards the family and towards the deceased when handling the body was significant in relation to facilitating the bereavement process. |
| Mayer DM, Rosenfeld AG, Gilbert K, 2013. | Taped and semi-structured interviews with families and individual bereaved relatives. | Seven families comprising 17 individual family members. | Family bereavement experiences after sudden cardiac death. | Professional knowledge and follow-up to provide support was a focus. |
| McKinnon JM, Chonody J, 2014. | In-depth interviews. | 14 people bereaved by suicide. | Formal support used by people bereaved by suicide. | Professionals showed compassion, including police. |
| Mowll J, 2007. | Interview and questionnaire. | 25 participants, some of whom viewed the body and some who did not. | Experience of viewing deceased after a sudden death. | Professionals described as sensitive in relation to interactions with relatives when assisting with viewing the deceased. |
| Outwater AH, Tarimo EAM, Miller JE, Campbell JC, 2012. | Interviews using open ended prompts. | The study population consisted of 31 informants who had experienced an adult homicide death by assault or through mob violence. | Meanings of care by bereaved relatives of homicide victims in Dar es Salaam. | Focus on nurses as professional supporters. Competent nursing care at the mortuary eases the burden of grief. |
| Peters K, Cunningham C, Murphy G, Jackson D, 2016. | Face-to-face in-depth interviews, open ended questions. | Seven women, 2 men. Bereaved 2–10 years earlier. 5 lost a spouse, 4 a son, one an uncle. | Experiences of a family member's suicide, and of encounters with services and the general community after the suicide. | Identifies the contrast between services and related support policies provided for those bereaved by suicide. |

| | | | | |
|--|--|---|---|--|
| Pettersen R, Omerov P, Steineck G, Dyregrov A, Titelman D, Dyregrov K, Nyberg U, 2015. | In-depth open interviews. | 18 suicide bereaved siblings (13 women). | Professional support experiences of suicide bereaved. | Experiences of the deceased having difficulties with health services prior to the death. The bereaved seek help which facilitates empathic dialogue, and the quest for explanations. Preference for outreach from health services. Bereaved may benefit from understanding current research and thinking on suicide. |
| Ratnarajah D, Maple M, Minichiello V, 2014. | Narrative interviews. | 18 suicide bereaved parents, spouses, partners, children, siblings. | Experiences of loss for suicide bereaved family members in the context of familial relationships. | Narratives of loss for families bereaved by suicide are informed by complex experiences and resulting needs. |
| Rodger ML, Sherwood P, O'Conner M, Leslie G, 2006. | Individual interview. | 10 women, 5 men whose partner had died suddenly and unexpectedly. | Grief following sudden death and its impact on men and women partners. | The partner needs support in the places where the death occurs (eg hospitals), and there needs to be outreach from the hospital. Nurses work schedules should include time for bereavement care. Sharing information and particularly, informing the GP is important. |
| Sharpe TL, Joe S, Taylor KC, 2012. | Focus group and individual semi structured interviews. | 12 surviving immediate family members (3 women, 9 men). | The lived experience of being an African American suicide or homicide bereaved relative. | Counselling or psychiatric input, group or individual, was helpful for some but challenging for others to 'open up'; lack of trust. Most participants endorsed survivor support groups. Education, information and training on grief and bereavement was needed. |
| Sharpe TL, 2008. | Semi-structured interview, by phone or face to face, with field notes. | Five relatives (3 women, 2 men) bereaved by homicide, African American descent. | Experiences of African Americans coping with the homicide loss of a family member. | Social support very important, but supplemented by formal support to find meaning in the murder; empathy with survivor, their background and situation is important. |
| van Dongen CJ, 1991. | In-depth individual interviews. | 25 women, 10 men. | The nature of post-suicide bereavement. | The family physician is seen as the key person to initiate support. Roles for other health and social care professionals are not acknowledged. |
| van Dongen CJ, 1990. | In-depth interviews, 90 mins, audio taped, field notes. | 35 relatives of persons who had died by suicide, snow-ball sampling. | Life experience of survivors of suicide 3-9 months after the death. | Survivors need information and a place to ask questions about their relative's death, some used programmes for survivors. Participants had contact with a range of services since the death. Participants wanted health professionals to make the approach. Survivors expect professionals to be knowledgeable of suicide and its effects. |

Table 2. Results of the critical appraisal

| Citation | JBI appraisal criteria | | | | | | | | | |
|---|------------------------|----|----|----|----|----|----|-----|----|-----|
| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| Begley M, Quayle E, 2007 | U | Y | Y | Y | Y | Y | U | Y | Y | Y |
| Biddle L, 2003 | U | Y | Y | Y | Y | Y | N | Y | Y | Y |
| Chapple A, Ziebland S, 2011 | Y | Y | Y | Y | Y | N | N | Y | Y | Y |
| Fielden JM, 2003 | Y | Y | Y | Y | Y | N | N | Y | Y | Y |
| Gall TL, Henneberry J, Eyre M, 2014 | Y | Y | Y | Y | Y | N | N | Y | Y | Y |
| Harrington C, Sprowl B, 2011 | Y | Y | Y | Y | Y | N | N | Y | N | Y |
| Mayer DM, Rosenfeld AG, Gilbert K, 2013 | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y |
| McKinnon JM, Chonody J, 2014 | Y | Y | Y | Y | Y | N | N | Y | U | Y |
| Mowll J, 2007 | N | N | Y | Y | Y | Y | N | Y | U | Y |
| Outwater AH, Tarimo EAM, Miller JE, Campbell JC, 2012 | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y |
| Peters K, Cunningham C, Murphy G, Jackson D, 2016 (a) | U | Y | Y | Y | Y | N | N | Y | Y | Y |
| Peters K, Cunningham C, Murphy G, Jackson D, 2016 (b) | U | Y | Y | Y | Y | U | N | Y | Y | Y |
| Pettersen R, Omerov P, Steineck G, Dyregrov A, Titelman D, Dyregrov K, Nyberg U, 2015 | U | U | U | U | U | N | N | Y | Y | Y |
| Ratnarajah D, Maple M, Minichiello V, 2014 | Y | Y | Y | Y | Y | N | N | Y | Y | Y |
| Sharpe TL, 2008 | U | Y | Y | Y | Y | Y | N | Y | Y | Y |
| Sharpe TL, Joe S, Taylor KC, 2012 | U | Y | Y | Y | Y | Y | Y | Y | Y | Y |
| van Dongen CJ, 1990 | U | Y | Y | Y | N | Y | Y | Y | N | Y |
| van Dongen C, 1991 | U | U | Y | Y | Y | N | N | Y | N | Y |
| % 'yes' responses | 47 | 84 | 95 | 95 | 89 | 47 | 26 | 100 | 74 | 100 |

Meta-synthesis of textual data generated four synthesised themes (level 3). These were derived from 206 pieces of extracted data (findings) from across the 19 papers (level 1) that were subsequently aggregated into 12 categories (level 2). In the ConQual analysis (Munn *et al.*, 2014) for dependability each synthesised finding was downgraded by one level, from high to moderate,

group found to consistently offer support to suddenly bereaved individuals. At the immediate time of the death the research identified those first on the scene as potential sources of support for relatives. However, engagement with families was variable and, for example, McKinnon & Conody (2014) found in their interview study with relatives of people who had completed suicide, first

Table 3. Quality analysis of findings (ConQual)

| Synthesised theme | No of studies | Dependability | Credibility | Comments | ConQual |
|---|---------------|--|--------------------|---|----------|
| Support for suddenly bereaved individuals comes from a range of sources, and for some there are barriers to access. | 14 | Moderate (scored 4 or 5/5 for the 5 criteria in 6 studies, 2 or 3/5 in 7 studies, 0 or 1 in 1 study) | Downgraded 1 level | Synthesised theme includes mix of 24 unequivocal and 24 credible findings | Moderate |
| Support needs of suddenly bereaved people, met and unmet. | 15 | Moderate (scored 4 or 5/5 for the 5 criteria in 7 studies, 2 or 3/5 in 7 studies, 0 or 1 in 1 study) | Downgraded 1 level | Synthesised theme includes mix of 23 unequivocal and 34 credible findings | Moderate |
| Suddenly bereaved relatives experience positive and negative outcomes of support. | 11 | Moderate (scored 4 or 5/5 for the 5 criteria in 5 studies, 2 or 3/5 in 5 studies, 0 or 1 in 1 study) | Downgraded 1 level | Synthesised theme includes mix of 14 unequivocal and 15 credible findings | Moderate |
| Supportive relationships between suddenly bereaved people and professional carers are beneficial. | 15 | Moderate (scored 4 or 5/5 for the 5 criteria in 8 studies, 2 or 3/5 in 6 studies, 0 or 1 in 1 study) | Downgraded 1 level | Synthesised theme includes mix of 31 unequivocal and 14 credible findings | Moderate |

as no studies recorded a ‘yes’ response for all five key critical appraisal criteria. Analysis of credibility found a mix of unequivocal (clear supporting quotation) and credible (implied within text) findings for each synthesised finding. This demoted the strength of the synthesised themes from high to an overall quality rating of moderate (Table 3).

Theme 1: Support comes from a range of sources, but there are access barriers for some

Across studies a wide range of sources of support were identified, with no one place or professional

responders including paramedics could be insensitive and lack compassion or respect.

‘They said, “don’t hurry, nothing to do here.” I shall always remember that, at the top of his voice. . . . I thought good God. It was really bad . . . none of them spoke to him [husband].’ (p237)

Conversely, in the same study families reported positive experiences of support at the scene:

‘The police were fantastic. They were incredible, very understanding and very supportive. No pressure.’ (p237)

Police family liaison officers were identified as being particularly supportive for relatives bereaved by suicide (McKinnon & Chodony, 2014; Ratnarajah *et al*, 2014). However, Rodger *et al* (2006) who studied bereaved partners from a range of causes, identified difficulties for relatives when inexperienced police officers delivered bad news, a role which was believed by participants to be challenging for professionals in terms of providing immediate support. Taking a sensitive approach and not leaving the bereaved person alone in the aftermath of suicide death is further appreciated by relatives, as is the professional offering to let others in the family know (Peters *et al*, 2016b).

Suddenly-bereaved people may also engage with support groups, and some find benefit from being with others who had experienced a similar tragedy, for example, a family member's suicide (McKinnon & Chonody, 2014; Peters *et al* 2016b):

'So you might be talking to someone and you can actually feel as well as understand what is happening for them. You know, I think that having a peer person like that is essential.'
(McKinnon & Chodony, 2014: p239)

However, it was unclear whether there was any professional facilitation of the peer support groups participants described. Other participants in the same study sought support from counsellors, psychologists, and local doctors to help them identify coping strategies. The general practitioner being particularly helpful for some bereaved relatives.

'...our general practitioner has counselled us. I personally found his chat much more realistic and helpful than other counselling.'
(McKinnon & Chodony, 2014, p240)

However, the opposite experience was also reported:

'...she wasn't even very ...very compassionate actually ...was quite a clinical approach...'
(McKinnon & Chodony, 2014, p240).

Petersen *et al* (2015) in their study of siblings bereaved by suicide identified a range of services providing support, including a psychologist, psychiatrist, school nurses, counsellors, hospital managers and physicians. Additionally, van Dongen (1990) found marital counselling was an

option taken up by participants taking part in a phenomenological study of experiences of bereavement by suicide, as well as suicide support groups.

Relatives bereaved by suicide often described finding support online rather than looking for support from health or social care professionals. In Chapple & Ziebland's (2011) study, relatives felt that by going online and taking part in support groups, they were helping others while being helped themselves. Some find this kind of peer support more beneficial than formal professional services, and though not the focus of this review, it should be acknowledged that this kind of contemporary approach to support seems accessible and used by many as a source of bereavement support.

Participants in Peters *et al*'s (2016b) study of helpful and unhelpful interactions post suicide bereavement were clear that those also bereaved by suicide provided the most meaningful support. Begley and Quayle (2007) also found support in groups of people who have had the same experience to be the most beneficial. Those bereaved by suicide felt less vulnerable in the peer group support situation where experiences were shared.

Suicide bereavement groups or individual counselling for those bereaved by suicide were identified as useful for relatives where unique emotional reactions could be discussed (Gall *et al*, 2014; Peters *et al* 2016b). The timing of accessing this kind of service may be an important consideration for relatives and services, and the relative quoted below demonstrated his long-term need and the value of a trusting relationship between the bereaved person and the counsellor.

'I didn't want someone to be overwhelmed by what was going to come out of me, and I know he (counsellor) could handle it and that was the only time I spoke to anyone (20 years after son's suicide).'

 (Gall *et al*, 2014, p432)

Identifying services and making contact was often challenging for relatives and a range of reasons was revealed in the papers reviewed. McKinnon & Chonody (2014) found relatives bereaved by suicide could be emotionally drained and lack the will to actively seek support.

‘You don’t have the energy when you’re needing the help the most, you don’t have the energy to seek it out.’ (p243)

For the suicide bereaved, a particular barrier to accessing services post bereavement may be related to perceptions of the deceased person’s interactions with services when they were alive (Fielden, 2003; Pettersen *et al* 2015). A poor relationship between the professionals, the deceased and the family fostered distrust in services and a reluctance to make contact. Peters *et al* (2016a) identified that relatives often felt that they were held responsible for the suicide of their loved one. Responses from both external agencies and family members contributed to these feelings and compounded the distress of the bereaved and prevented them from receiving support:

‘[My wife] worried about it, she said, oh people think – I think she thinks it could be me; I could have pushed him.’ (p254)

The existence of the stigma attached to suicide, highlighted in the attitudes demonstrated, continued as a strong theme in Peters *et al* (2016a) and was mirrored by Biddle (2003):

‘Nobody prepared me for, God! The humiliation. I mean it was almost as if, well, I felt like I was put on trial. I didn’t realise until I got there I would have to stand in a witness box ... as if you’ve done something wrong.’ (p1036)

Sources of support are varied and there is no clear place for those suddenly bereaved to seek support. This is challenging for relatives to negotiate, particularly when professionals may in fact be unprepared to provide even basic information, reassurance, and signposting.

Theme 2: Support for suddenly bereaved people varied in relation to timing and content and needs may have remained unmet

The importance of receiving concrete and timely information was clearly emphasised in a range of studies, with those suddenly bereaved frequently describing their need for answers to questions about the death itself, how it occurred and what relatives should expect will happen in the short and long term.

‘The only thing that remains is whether he had taken any kind of drugs to, you know, to put him to sleep. Like an anti-anxiety, a Clonazepam or something like that but I never did find out the answer to that...’ (Harrington & Sprowl, 2011, p74)

In particular, relatives need information and time to be able to process thoughts about why the death occurred. Information from a professional person can facilitate the understanding and reassurance needed (Mayer, 2013).

‘The doctor who did the autopsy, to be able to explain it, umm, so that I understood why the heart failed, umm, like Kim said to understand that it was painless, it was quick [because] there is that feeling of: Oh I should have done something. But no, there was nothing [anyone could have done]. I mean this was 30 seconds and over with’ (Mayer *et al*, 2013)

Relatives were affected in a range of ways after their loss, including sadness, sleep disturbances, poor concentration, anger and self-blame and health professionals were often consulted. An example of this is evident in the work of van Dongen (1990), who explored the experiences of family members post suicide, most of whom saw a healthcare professional for physical concerns after the death (p227).

There are examples in the literature where participants’ initial response is to withdraw from social contact:

‘There’s also a tendency to want to isolate. I didn’t do that. I pushed myself not to do that.’ (Gall *et al*, 2014)

If information was immediately given on how to access professional support, the bereaved did not necessarily use the information provided for a variety of reasons such as being emotionally drained or having too many other things to organise and carry out. Participants strongly stated that a professional, preferably a family physician, should contact the family during the first few days after the death. It was described by one participant in van Dongen’s (1991) study as the ‘caring’ and ‘appropriate’ thing to do (p379). Participants in most of the studies reviewed described their need for healthcare professionals to take the initiative and contact them to see how they were and to offer support. It was a source of concern that this does not appear to happen routinely.

Theme 3: When suddenly bereaved relatives were supported by professionals there were positive and negative outcomes

Experiences of support from professionals are disparate across included studies. However, there is evidence of both positive and negative outcomes for bereaved relatives where there were service contacts. Getting answers to questions and reassurance was found to be important by Mayer *et al* (2013) who studied relatives after the deceased had died from a sudden cardiac event. In contrast, coroner services are an area where the evidence reviewed suggests support for relatives is lacking. Delays and poor communication were frustrating for relatives across some studies in the review.

'It's been months now, I keep thinking they must be keeping something awful from me. The coroner hasn't been contacting me at all. Even when I ring he doesn't get back to me.'
(Biddle, 2003)

For relatives, being called as witnesses was also a distressing experience they were unprepared for and felt unsupported.

'It just added to my experience of guilt is what it did. You know like, "Oh God! I am this bad mother, I hadn't seen my daughter" ...I felt I was being judged as a mother that day. I have to admit I felt more guilt after the inquest than I did possibly even when she died.'
(Biddle, 2003, p1073)

In contrast, a respondent in the same study described the coroner as helpful and sympathetic towards her while she gave evidence explaining that he conveyed an awareness of how distressing it may be for her and was anxious to minimise the discomfort. Five respondents also gained some level of enlightenment from the inquest, though only one obtained a sufficient explanation for why the suicide had occurred (Biddle, 2003). Additionally, participants bereaved by suicide in Peters *et al* (2016b) study recounted positive experiences of support from coroner services in South Australia and a compassionate approach.

Harrington & Sprowl (2011) studied family members experiences of viewing the deceased's body and identified caring and honest expressions of kindness enabling participants to recall interactions as positive. However, unkind interactions evoked a negative impact on

bereavement experiences, though some interactions seen as negative may have been meant to protect the individual:

'If it were my son I would not view him.' (p79)

However, it could be questioned whether this would be ethical or an expression of professional power. Mowl (2009) reported that when relatives saw the body it often allowed them to accept the reality of the death, and to say 'goodbye'. This was particularly beneficial when relatives had not been present at the time.

Written materials provided to relatives in the form of leaflets designed to help people to understand their bereavement were generally viewed negatively and considered outdated and irrelevant (McKinnon & Chonody 2014). In addition, peer support groups were also not the answer for some:

'I needed to do more than just talk around in circles...I needed to know there were strategies you could use, there were ways of healing.' (McKinnon & Chonody 2014, p238)

The lack of a professional facilitator was identified as problematic by some, while other participants valued the comfort provided by peers, giving them hope and understanding.

Ratnarajah *et al* (2014) also identified participants finding benefits from being listened to and developing trusting relationships with others in support groups, while some, particularly younger bereaved people, did not feel they belonged in the group (p53). Rodger *et al* (2006) further indicates long-term impact of poor support when relatives 'feel information about the death was held back by the professional, and this may lead to resentment which does not fade over time' (p123). This is mirrored in Peters *et al* (2016a), whose participants described medical care as in some cases 'hopeless' (p254), and an example was provided of a relative who was passed onto a colleague of the GP for bereavement support.

In the Tanzanian context (Outwater *et al*, 2012), nurses were seen as the main carers for suddenly bereaved people. However, nurses were judged on whether their verbal and non-verbal communications were caring or not.

'Many have compassion....nurses can heal...if you arrive they care for you as a nurse, as if you were their own child. But sometimes

others cause despair. They have words to embarrass people...' (p402)

In Sharpe (2008) the importance of culturally skilled care and understanding is evident. For example, for many African-American families due to the nature of the death, the fear of being further stigmatised prohibits them from seeking the support of professionals.

'African-Americans do not use therapy enough; we have a whole stigma about therapy.' (p209)

Sharpe *et al* (2012) further identify that counselling or psychiatric input at group or individual levels was helpful for some survivors but challenging for others to 'open up'. Due to the possible lack of trust with formal support most participants endorsed support groups. Sharp *et al* (2012) call for education, information and training in bereavement care.

In relation to suicide loss, Pettersen *et al* (2015) identified three main themes related to satisfaction with support from health professionals: grief related support; empathic encounters; and psychosocial benefits. In contrast, there were four main factors provoking negative emotions: lengthy access; insufficient care; non-empathic encounter; and perceived professional incompetence. Professional interventions participants considered as helpful included suggesting ways of coping with guilt feelings or concentration difficulties and information about depression and possible causes of suicide.

Theme 4: Supportive relationships between suddenly bereaved people and professionals are beneficial

Positive experiences for relatives are more likely when there are supportive relationships between relatives and professionals. A coroner described by a relative in Harrington & Sprowl's (2011) study, cared in a way that put the relative at the centre with profound effect on how the service was perceived.

'He (the coroner) acknowledged me as a person right away – that I lost someone. I wasn't a job. I was a person. And that kindness, it still makes me tear up to this day. It's the kindness you remember.'
(Harrington & Sprowl, 2011, p73)

In some cases, the best and most appropriate source of support is with professionals with whom there is already a relationship. For example, the GP for the relative interviewed in McKinnon & Chonody's (2014) study of relatives' experiences post suicide: 'our general practitioner has counselled us. I personally found his chat much more realistic, and helpful than other counselling' (p240).

Across studies, the ability to initiate a conversation with a bereaved relative and give them time, space and attention to speak and be listened to is a key theme. In the work of van Dongen (1990) looking at the experiences of family members (n=35) post suicide, 54% saw a healthcare professional for physical concerns after the death. However, only 7% indicated that the suicide was discussed during the healthcare visit (van Dongen 1990 p227). Moreover, survivors stressed the importance of the family physician being knowledgeable about suicide and grief and being comfortable and willing to discuss these topics (van Dongen, 1991, p380).

A key aspect of support is identified as the ability to develop a supportive relationship with a counsellor or psychiatrist, and quick turnover of staff was found by Mayer *et al* (2013) to challenge this process. The clinical approach to bereavement support may be seen by relatives to be unhelpful, though this may depend on the practitioner (Mayer *et al*, 2013). However, in the context of homicide in Tanzania, the nursing role was seen as the most appropriate for 'caring for the body and the relatives of the deceased.' This role included 'stabilising and strengthening the family' (Outwater *et al*, 2012, p402).

Discussion

This review has demonstrated the existence of supportive care for family members experiencing sudden bereavement as well as times when care and a sensitive approach was lacking. Across the studies it was also evident participants were offering solutions to improve interactions with service providers. In this discussion areas of concern will be highlighted first, and examples of a supportive approach discussed thereafter.

Areas of weakness were when the professional support for suddenly bereaved relatives after the death of an adult family member lacks

organisation, is at times inconsistent and largely unplanned (McKinnon & Chonody, 2014). Immediate care can be insensitive and unskilled, indicating a lack of understanding on the part of the responders about the emotional requirement for their response to be values based, and family centred (McKinnon & Chonody, 2014; Rodger *et al*, 2006). This negative impact continues longer-term post death when the ability of family members to seek support is compounded by perceptions that immediate contact with professional response services was insensitive and at times unresponsive to need (McKinnon & Chonody, 2014). Norton (2017) states that the previous experience and confidence level of the attending professional can influence their performance and the resulting experience for the family. It is necessary for supporting staff to develop bereavement care skills in their roles across all settings where care after sudden death is required by family members. By the very nature of the event, sudden death is more likely to occur outside the hospital setting. Identifying opportunities to provide sensitive and appropriate support in the immediate aftermath of the death should be within the competence of all healthcare professionals. Often post-death support for family members affected by sudden death may be provided by a range of organisations, but it often requires the bereaved to action this (McKinnon & Chonody, 2014).

Following sudden death, the current study found bereaved family members have unanswered questions and study participants expressed their desire for support services to approach them in the time after a loss. From this review it is apparent there is a need for those bereaved suddenly to have accurate information as far as possible, about how and why the death occurred. For healthcare professionals to freely offer this kind of information in a sensitive and values-based way would be highly appreciated by relatives. Support given in this way would have only small impact for services in terms of time and finance. Cowdry and Stirling (2020), in their literature review on sudden death of people with epilepsy, emphasise the importance of timely support for the family members that is available and open-ended and easily accessible, without the family members having to search and repeat their experiences to several people or organisations. More recently there has been an example of a professional-led bereavement service, when the death has been from Covid-19, which family

members found supportive and numbers of complaints to services were reduced (Grimes *et al*, 2020). With bereavement being shown to have an economic cost in terms of healthcare contact (Stephen *et al*, 2014), then it becomes incumbent on healthcare providers to be developing processes for contacting relatives after a loss, including the sudden loss of adult family members, with staff who can provide evidence based, skilled and supportive care. It is necessary for professional staff to develop bereavement care skills in their roles across healthcare settings, including in statutory and non-statutory community settings. This provides a basis from which support for suddenly bereaved individuals becomes part of a range of roles, for example, general practitioners, district nurses, coroner, counselling services, and a range of voluntary sector organisations not necessarily set up to work with bereaved individuals specifically.

Peer support using social media and more informally within the local community, though not the focus for this review, may be a helpful and responsive source of support for family members (Aoun *et al*, 2018). Internationally a lack of formal care for the bereaved is supplemented by a range of voluntary sector organisations providing bereavement support in the short and longer term, some being generic for bereavement, for example Cruse Bereavement Support, with others specific to the nature of the death or the situation of the bereaved, for example People Experiencing Trauma and Loss (PETAL) and Widowed and Young (WAY). This reflects a public health approach to bereavement care using community groups already known to the bereaved relative (Bellamy *et al*, 2014). However, the availability and efficacy of these organisations to support bereaved people may not be clear in the immediate aftermath of the death, and it may only be after some time when relatives recognise they are struggling to cope with feelings, or to adapt practically (Schut and Stroebe, 2011).

While the literature reviewed did not address the full scope of situations or professional involvement with bereaved relatives in the context of sudden death, there was some focus on coroner services. In many situations of sudden death, contact for families with coroner services is inevitable and interactions can affect families in a range of ways including feeling judged, being made to feel guilty, and generally feeling unprepared for an inquest. However, the coroner service was often able to provide information about the death, and this was

viewed as positive (Harrington & Sprowl, 2011). Professionals and relatives in coroner settings also play out the dilemma of whether to view the deceased's body. Relatives who see the body often benefit, and when the professional discourages viewing, they may be seen as misusing their power, even though this is well meant (Mowll, 2009). Current guidance encourages a sensitive approach from professionals when discussing whether to see the deceased's body (Ministry of Justice, 2020). Additionally, recent research on mortuary practice in Hong Kong has found positive impacts on relatives when a 'life-affirming' strategy was adopted in the service. Improving the mortuary environment, providing facilities for farewell ceremonies, and developing the skills and knowledge of staff in relation to bereavement and support for relatives were aspects of this approach (Lau *et al*, 2023).

The Ministry of Justice (2020) guidelines, publicly available in England and Wales, show enhancement of support for the bereaved in coroner services, particularly in relation to coroner inquests (Ministry of Justice, 2020). This outlines the responsibilities of coroner services to support the bereaved and identifies what family members can expect from the coroner's office. Voluntary sector support is also available through such organisations as The Coroners' Courts Support Service (www.coronerscourtsupportservice.org.uk). Overall, being open and providing opportunities for people to be together and share their experiences is usually positive. In a UK study Gregory (2014) supports these findings and highlighted that while coroners identified that they were not experts in bereavement in the main, they were aware of the fragility of bereavement for family member survivors and considerate of communication skills, shielding and protecting the family members as well as giving time. The study showed that coroners developed commendable insight when responding to the needs of the bereaved and were aware of how they could significantly impact on bereaved families' wellbeing and ability to continue after the inquest (Gregory, 2014). Again, this supports the call for staff to develop bereavement care skills in their roles across all settings where care after sudden death is required for family members.

The professional role in supporting relatives after a sudden death is seen as important and is most beneficial when there is a personal relationship between the bereaved person and the supporter.

On some occasions this may be the person's GP, though there is also scope for developing an established role for nurses in supporting those bereaved suddenly. In an intensive care context where sudden death is likely, Walker and Deacon (2016) advocate a person-centred approach to the bereaved with participating nurses expressing willingness to respond to relatives' needs, provide information and enable viewing of the body. However, nurses in their study admitted to avoiding the situation and being inadequately prepared to provide support. Across the papers reviewed it was not possible to identify trends in relation to cultural aspects of bereavement care. However, Sharpe (2008) and Sharpe *et al* (2012) focused on an African-American population and made reference to lack of trust, stigma and prejudice. Negative attitudes impacting on accessing health and social care services are pervasive and persistent and impact on experiences of those suddenly bereaved. Though not a focus of the review it is acknowledged poor cultural competence and lack of resource may influence the availability and development of services. The work of Finch, Wilson and Bibby (2023) identifies urgency to develop the relationship between service providers and under-represented groups. Appropriate professional development for healthcare staff appears to be a priority for improving support around sudden loss in a range of settings.

Importantly, the bereaved need the opportunity to meet with the same person and not have to retell their story over again. An open relationship where there is space to give attention to the bereaved, and to listen to their experiences and needs is vital. However, Aoun *et al* (2017), reporting their study of bereavement care in palliative care services, identified that professional support for every bereaved relative was neither beneficial nor affordable, and advocate a whole community approach. Referral pathways were recommended, though it was recognised that for those suddenly bereaved this kind of continuity was not always possible. For health professionals who are in contact with people who have suffered a sudden loss of a family member or friend, taking an enquiring approach like that recommended by the NHS initiative Making Every Contact Count (MECC) (Public Health England, 2016) could be one way of enabling supportive conversations and signposting to other services. This provides a structured way of encouraging people, including health and social care professionals, to hold

informal conversations with people creating the opportunity to signpost support. Though bereavement is not currently an aspect of MECC, it may be a small thing which can be added to improve interactions in a way that is acknowledging the loss and providing options for ongoing support. This kind of approach is supported in the Bereavement Charter for Children and Adults in Scotland (Scottish Care, 2020) which sees bereavement support as a human right and emphasises the need to develop a culture of care and support across society. This validates the position and the ongoing development of professionals as compassionate individuals who can create space to talk about death and bereavement and support bereaved families. However, in the immediate aftermath of a sudden death outside a formal care setting, when research included in this review indicates there is need, the opportunity for interactions with health professionals may be more limited. Other services, like the coroner, the undertaker or the first responder, may be best positioned to support and signpost. This study suggests inconsistent provision and quality of caring interactions, which could reflect the assumption that because bereavement is a natural process people will adapt and cope.

Strengths and limitations of the review

The review was limited by not exploring grey literature on the topic, which may have uncovered information about a wide range of situations, services and settings in which bereavement care is provided for those suddenly bereaved. However, looking for research related to relatives' experiences of support was the main aim of the study, and it is unclear whether grey literature would reveal this level of understanding. Use of JBI methods and processes provided a comprehensive structure for the review and enabled the detail within the papers included to be identified and analysed considering the whole body of literature reviewed. The process is well developed and has a key place in healthcare research in current times. The ConQual process for grading study quality (Munn *et al*, 2014) is continuously undergoing development, though it is perhaps fair to say that in this study the process lacked the sensitivity necessary to grade studies with sufficient clarity to enable useful conclusions to be drawn. It did reveal one study which was of poor quality and reduced the credibility of the

review, so this on its own was useful to identify and eliminate.

Conclusion and recommendations for practice and for further research

This systematic review revealed experiences of suddenly bereaved relatives of receiving support from professionals in the immediate aftermath of a loss, as well as in the days, weeks and months afterwards. There were examples of good practice which was reassuring and supportive for relatives, and examples where support was difficult to identify and access. The review indicates that people respond well to support offered spontaneously which is empathetic and shows willingness to engage with individuals when they have been bereaved with no preparation for such an event. This kind of support when it is widely practiced, offered and accessible to the bereaved is a key factor in promoting healing and a healthier grief and bereavement experience. Developing person and family centred skills and engaging confidently with those suddenly bereaved is the role of individual practitioners and organisations who encounter bereavement in its many forms. Opportunities to develop through collaborative education should be available, and practitioners should develop professionally through embracing experiences to interact on this level with people in their care. Overall, public information about professional, evidence based and skilled services and support for suddenly bereaved people should be visible and accessible when not offered spontaneously at the time of the death. This study has demonstrated that while informal support and information is essential for relatives, anticipation of needs and appropriate responses require regulated professionals and organisations who encounter the bereaved to be visible, accessible, skilled and able to respond. It is recommended this is formalised in standards or protocols for support in relation to sudden death situations.

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