The experiences and support needs of adult family members who face a sudden adult death: a qualitative systematic review protocol

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Review question/objective

The objective of this systematic review is to explore the experiences of adult family members with care received from service providers when they face a sudden adult death occurring in the clinical or community setting as well as to identify their support needs. More specifically the review questions are as follows:

1. How do adult family members experience the care received from service providers following a sudden adult death occurring in the clinical or community setting?

2. Based on the experiences of adult family members of service provision following a sudden adult death occurring in the clinical or community setting, what are their met and unmet support needs?

Background

The sudden death of a relative is usually a distressing event for any individual, their family and wider social network. Whether arising from natural or any other accidental or non-accidental causes, for example, mechanical trauma, self-harm or harm caused by others, there will be emotional and practical consequences. Additionally, sudden death means the involvement of services and professionals with which families may have varying levels of familiarity and which they may find challenging to negotiate, for example, coroner services, procurator fiscal services in Scotland, police liaison officers, pathologists, mortuary staff, health care professionals and representatives of the criminal justice system.¹ The focus of the proposed systematic review is on support for adult relatives (aged 18 years and over) within relationships and interactions with service providers arising as a result of a sudden death.
In existing literature, no single definition of sudden death has been identified. Mason defines it as “unexpected death following so rapidly from the onset of symptoms that the cause of death could not be certified with confidence by a medical practitioner familiar with the patient”. In terms of the period between the onset of symptoms and the death of the patient, the World Health Organization specifies sudden death, where the cause is unknown, as taking place within 24 hours. These definitions refer to death by natural causes. Although not encompassed in the aforementioned definitions, unnatural deaths such as those occurring as a result of an accident, suicide or homicide may also be perceived by relatives as a “sudden death”. Given the lack of clarity as to what constitutes a sudden or unexpected death (natural or unnatural), for the purposes of this review, the death will be deemed to be sudden or unexpected (whether natural or unnatural) if the above or analogous terms are contained within the literature reviewed.

In Scotland, all sudden deaths are subject to investigation by the Crown Office Procurator Fiscal Service (COPFS), largely equivalent to coroner services in other countries. Current data identifies that the procurator fiscal service in Scotland investigates around 14,000 sudden deaths each year, the majority of which are found to be of natural cause. Investigation of deaths reported to the Procurator Fiscal may involve a post-mortem (autopsy) to identify the cause of death, and in some cases, a relative needs to identify the body before the post mortem takes place. These are aspects of sudden loss which family members may find particularly problematic. The COPFS recognizes that these can be distressing and indicates support is available.

In the UK, post-mortem practices have come under increased scrutiny as a result of the so-called organ retention scandal, and legislation was subsequently enacted to ensure procedures were improved and relatives kept informed. However, research conducted by the review team found that procedures surrounding post-mortem, particularly in the legal context, remain an area of potential distress to family members. In addition, when police investigations take place relatives experience services as challenging to negotiate and are frustrated by the lack of information sharing. In the UK, the police allocate a family liaison officer to a family when a death is under investigation. Their role includes provision of information and support for the family. In most cases, this is a highly valued person who provides sensitive and compassionate care at a time of high stress. However, experiences are varied and for some relatives tensions arise with the officer’s dual role of gathering information to inform the enquiry and providing support.

Viewing the body is an area of concern for family members who have been suddenly bereaved. This can mostly be facilitated within the range of services involved. However, after violent deaths, bodies may be mutilated, which hinders viewing and compromises the opportunities for relatives to say a last goodbye. In a qualitative interview study conducted in the UK, traumatically bereaved families who took part indicated that they appreciated having a choice about whether or not to view the body even though the experience may be emotionally challenging. Regardless of whether they chose to view or not, families who had been given the option usually felt they made the right decision. In some circumstances, confirmation of the death may take a protracted length of time while investigation continues, and in the extreme situations of war or disaster, families may never get to view the body. Ambiguous losses of this kind often lead to families being unable to mourn, with family dynamics permanently altered.
There is an assumption that being forewarned of a death means relatives are better prepared and are hence able to adjust more readily.\textsuperscript{11} One may consequently assume that those who are unprepared for a family member's death fare worse in bereavement. A literature review on sudden or violent death and mental health indicated that a substantial number of people bereaved in this way may be affected adversely.\textsuperscript{12} There were variations in the prevalence of disorders, including post-traumatic stress disorder (PTSD), major depression and prolonged grief disorder (PGD).\textsuperscript{12} However, across studies, people who were suddenly bereaved were found to be at a higher risk of mental health disorders, with their recovery being slower than those who experienced an expected death of a family member.\textsuperscript{12}

Bereavement is also known to adversely affect mortality.\textsuperscript{13,14} For example, using UK primary care databases, older people whose partner died unexpectedly were compared to those whose partner had a chronic disease diagnosis.\textsuperscript{14} Those bereaved suddenly had a hazard ratio of 1.61 (95% CI 1.39, 1.86), and those whose partner had an existing morbidity or high use of healthcare services had a hazard ratio of 1.21 (95% CI 1.14, 1.30). The difference in mortality risk was significant (p=.001), being higher in those bereaved suddenly. The study controlled for ethnicity and socioeconomic status. However, definition of unexpected death is challenging and the group who had expected death may include individuals whose partners had chronic conditions but whose death may, nonetheless, have been perceived as sudden. This was tested using health service usage as a proxy measure, revealing similar findings. Socio-economic status was estimated using area level measures in lieu of individual measures, and this analysis showed no confounding effects. The authors promoted the availability of support systems to meet the social and clinical needs of those whose relatives died suddenly.\textsuperscript{14}

Adaptation to grief is affected by a range of mediating factors as described by Worden,\textsuperscript{15} and one such mediator is the nature of the death. Certain circumstances may be particularly difficult for surviving relatives to comprehend, adapt and cope with, including trauma, violence, suicide and homicide. In Western countries, about 5% of all deaths are attributed to these causes.\textsuperscript{12} In addition, the nature of such deaths can also impact on the "social acceptance of public displays of mourning".\textsuperscript{16,p13} Violent or traumatic deaths destroy people's outlook on life and challenge their sense of making meaning of life.\textsuperscript{17} These types of losses are in general unexpected, which is further argued to be a factor impacting on adaption to grief.\textsuperscript{15} However, perceptions of expectation differ between individuals and affect the processing of grief.

Sudden death is challenging for survivors who are forced to live in a world of unfamiliarity, uncertainty and changed roles affecting both them as individual family members, and the family systems within which they operate.\textsuperscript{18} Following a sudden death, family members find it hard to understand what has happened and may feel shocked, angry, isolated and lonely. In the longer term, some feel depressed and may even be suicidal.\textsuperscript{1} Support from friends and family is essential for the nearest relatives of the deceased, particularly around the time of the death and in the weeks and months afterwards. For some, this support is enough to enable adaptation but for those whose grief is complicated, other sources of support may be necessary.\textsuperscript{19}

The provision of emotional and practical support by the service providers to family members who have been suddenly bereaved seems essential to aid adaptation. This review will explore and identify the needs of relatives who have been suddenly bereaved from their perspective. The review will also attempt to define the concept of support, and how people experience the support they receive over the sudden death period. Within this, particular areas of interest will be the difficulties relatives experience
in interactions with services, and what is missing in terms of support when someone dies suddenly. It is intended for the review to provide direction for the development of bereavement support within the range of services for families who have been suddenly bereaved.

An initial search of the Joanna Briggs Institute Database of Systematic Reviews and Implementation Reports, ASSIA, CINAHL, the Cochrane Library, Prospero and Medline revealed no existing systematic reviews looking specifically at sudden death and bereavement in adults. Two reviews of support for parents and families at the time of the death of a child\(^{21}\) and for those who have experienced perinatal loss, fetal death, stillbirth, or death of an infant up to one month after birth\(^{22}\) were identified. Grastang et al.\(^{21}\) found that parents need opportunities in the midst of events to say goodbye to the child; they need timely and appropriate information about their child’s death, and to be supported emotionally by attending professionals. In terms of death of a baby, Gold\(^{22}\) found that professionals may have a supportive attitude and assist grieving, or display poor communicative skills that lead to additional stress and anguish for parents. The nature of interactions with healthcare providers impacts on parents’ experiences and memories of the loss, and may affect adaptation. The current review will not cover these aspects of sudden death by excluding deaths of children under 18 years of age and neonatal death or stillbirth.

A current JBI protocol was found which aims to explore primary bereavement care across a range of health care settings and contexts, and which will focus on both adult and infant/child deaths.\(^{20}\) Whilst that systematic review will cover some areas of similarity, this proposed review will have a tighter focus on sudden death and will explore the experiences and support needs of bereaved family members in a wider context, including interaction with other services such as the coroner services, procurator fiscal services, police liaison officers, pathologists, mortuary staff, and representatives of the criminal justice system or their equivalents worldwide. The additional concentrated focus on the medico-legal setting is a distinctive feature of the proposed review. This review will also include a focus on loss through disaster (natural or otherwise), where experiences and support needs are potentially impacted upon by the nature and scale of the disaster, and the potential involvement of the survivor. Deaths occurring in war will also be included in this review. Given the paucity of systematic reviews in this area, both reviews will provide much needed insight for interested parties and inform the development of bereavement care practice in a wide range of settings and contexts.

**Keywords**

Sudden death; adult; family; bereavement; experience; support; needs; care

**Inclusion criteria**

**Types of participants**

This review will consider studies that include adult family members of the deceased where the deceased is also an adult aged 18 or above. There will be no upper age limit for either family members or the deceased. The decision to focus only on adults (both family members and the deceased) was taken as children and young people are likely to have specific age related needs that differ from adult family members. In a similar vein, the experiences and support needs of family members (parents, grandparents, step parents) who lose a child under the age of 18 is again likely to be distinctive, hence they will not be included in this review.
The term "family member" encompasses a person having the following relationship to the deceased: spouse or partner including civil or same sex partner, parent, child, brother or sister, grandparent or grandchild, niece or nephew, stepmother, stepfather, half-brother or half-sister. These relationships are deemed to be “qualifying relationships” for the giving of consent for a post-mortem to take place (Human Tissue Act 2004). The Human Tissue (Scotland) Act 2006 further includes partners of over six months, uncle or aunt or cousin as “relatives” who can give authorization for a post-mortem to take place. However, definitions of “family member” proscribed by law do not necessarily encompass other cross cultural perceptions of family. For the purposes of this systematic review, studies that include the aforementioned and other analogous terms will be included. The term “family member” is believed to be sufficiently broad to incorporate cross cultural differences.

In considering the experiences and support needs of bereaved (adult) family members following sudden adult death, there will be no time limit set on the period between the death of the deceased and their involvement in a research study. This decision was taken in order to capture the short, medium and longer term experiences and support needs of family members. It also acknowledges the potentially long lasting impact of the loss of a family member on the health and well-being of relatives.

Exclusion criteria
This review will not include studies which:

• focus on the perspectives of health care professionals or other service providers in relation to the needs and experiences of family members whose relative have died suddenly.

• detail the implementation or evaluate the effectiveness of specific interventions with bereaved adult family members (in the short, medium or longer term) in the context of sudden death which seek to ameliorate outcomes associated with bereavement.

• are wholly and/or predominately concerned with the donation of organs and tissues, where the donor is being artificially ventilated.

Types of intervention(s)/phenomena of interest
The phenomena of interest for the study are the experiences of care received by bereaved adult relatives following a sudden death from service providers, and their support needs, met and unmet. By reviewing and understanding relatives’ experiences and needs, guidance for appropriate care may be developed for service providers working with bereaved relatives.

Context
The context of interest is the care provided in the clinical or community setting where the death occurs, as well as other places where relatives interact with service providers.

Types of studies
This review will consider studies that focus on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research.
Search strategy

The search strategy aims to find both published and unpublished studies. A three-step search strategy will be utilized in this review. An initial limited search of MEDLINE and CINAHL will be undertaken followed by an analysis of the text words contained in the titles and abstracts, and of the index terms used to describe the articles. A second search using all identified keywords and index terms will then be undertaken across all included databases. Thirdly, the reference list of all identified reports and articles will be searched for additional studies. Studies published in English from 1990 until present (2016) will be considered for inclusion in this review. This will ensure the contemporariness of the review and that conclusions relevant to current practice are developed.

The databases to be searched include:

ASSIA
CINAHL
HeinOnline
MEDLINE
PILOTS
Sociological Abstracts
Social Services Abstracts
Web of Science
Westlaw

The search for unpublished studies will include:

Docuticker
Google ScholarMednar
NHS evidence
OpenDOAR
Open Grey
EthOS
Social Care Online
Social Science Research Network

The following terms are proposed as suitable descriptors to initiate the search and will be adapted to suit the requirements of each database:

Sudden death or Unexpected death or Accidental Death or Traumatic Death or Violent Death or Military Death or Suicide or Homicide or Murder.

Family member* or Relative* or Spouse* or Parent*

Bereave* or Mourn* or Grie*
Need*
Experience*
Support*
Adult*
Hospital* or Emergency Department* or Community or Out-of-Hospital
Procurator Fiscal*
Coroner*
Forensic*
Post-mortem*
Criminal justice
Qualitative

Assessment of methodological quality
Qualitative papers selected for retrieval will be assessed by two independent reviewers for methodological validity prior to inclusion in the review using standardized critical appraisal instruments from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI) (Appendix I). Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer.

Data extraction
Qualitative data will be extracted from papers included in the review using the standardized data extraction tool from JBI-QARI (Appendix II). The data extracted will include specific details about the interventions, populations, study methods and outcomes of significance to the review question and specific objectives.

Where studies include data relating to individuals other than the adult bereaved (e.g. children) then the relevant findings will be extracted, where possible.

Data synthesis
Qualitative research findings will, where possible be pooled using JBI-QARI. This will involve the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings (Level 1 findings) rated according to their quality, and categorizing these findings on the basis of similarity in meaning (Level 2 findings). These categories will then be subjected to a meta-synthesis in order to produce a single comprehensive set of synthesized findings (Level 3 findings) that can be used as a basis for evidence-based practice. Where textual pooling is not possible the findings will be presented in narrative form.

Where there is sufficient data to justify it, findings will be synthesized by family relationship group (e.g. spouse, parent, grandparent). If there is insufficient data, the findings will be combined.
Conflicts of interest

The authors have no conflicts of interest to declare.

Acknowledgements

We thank Lyn Mair, Faculty Information Co-ordinator and Colin Maclean, Liaison Librarian, Faculty of Health and Social Care, for their assistance with developing the database search strategy.
References

9. Chapple A, Ziebland S. Viewing the body after bereavement due to a traumatic death: qualitative study in the UK. BMJ. 2010;340 (c2032).


Appendix I: Appraisal instruments

QARI appraisal instrument

### JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research

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<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Unclear</th>
<th>Not Applicable</th>
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<td>1. Is there congruity between the stated philosophical perspective and the research methodology?</td>
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<td>6. Is there a statement locating the researcher culturally or theoretically?</td>
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<td>7. Is the influence of the researcher on the research, and vice- versa, addressed?</td>
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<td>8. Are participants, and their voices, adequately represented?</td>
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<td>9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?</td>
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<td>10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?</td>
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Overall appraisal: ☐ Include ☐ Exclude ☐ Seek further info. ☐

Comments (including reason for exclusion)

________________________________________________________________________

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Appendix II: Data extraction instruments

QARI data extraction instrument

JBI QARI Data Extraction Form for Interpretive & Critical Research

Reviewer __________________________ Date __________________________

Author __________________________ Year __________________________

Journal, __________________________ Record Number __________________________

Study Description

Methodology

Method

Phenomena of interest

Setting

Geographical

Cultural

Participants

Data analysis

Authors Conclusions

Comments

Complete Yes □ No □
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<th>Findings</th>
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Extraction of findings complete: Yes ☐ No ☐