What are the Care Needs of Families Experiencing Cardiac Arrest Care? A Survivor and Family-Performed Systematic Review and Qualitative Meta-Synthesis Protocol

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Abstract

Background: Sudden cardiac arrest is a leading cause of death. Family members can be deeply impacted by sudden loss or uncertainty about survivor outcomes. The objective of this systematic review will be to identify, appraise, and meta-synthesize qualitative evidence regarding family care-needs when experiencing cardiac arrest. Methods: This systematic review of qualitative studies and meta-synthesis will be conducted by multidisciplinary researchers in partnership with patient and family partners who have lived-experience of cardiac arrest. We will search MEDLINE, Embase, CINAHL, Theses and Dissertations Global, SocIndex, Scopus, Web of Science, PsycINFO, and Google Scholar. We will include qualitative research describing the experience and care needs of family members. We will also search reference lists, conduct forward citation searches, and contact content experts. We will assess the methodological quality of included studies using the Critical Appraisal Skills Programme tool. Two team members will independently review studies, extract data, and assess methodological quality. Disagreements will be resolved by consensus. We will use thematic framework analysis to analyze and synthesize narrative data, after which the review team and stakeholders discuss the findings and make any necessary changes. Our thematic synthesis will follow three steps: (i) initial coding and grouping of codes, (ii) formation of descriptive themes, and (iii) transcending the data to form novel insights and theories (analytical themes). The review will be reported in accordance with the ENTREQ and GRIPP2 guidelines. We will apply the Confidence in the Evidence from Reviews of Qualitative (CERQual) research to assess the robustness of our findings. Review Registration: This protocol has been registered with the International Prospective Register of Systematic Reviews (PROSPERO), registration number CRD42021236431 and Open Science Framework https://osf.io/fxp5g.

Keywords

qualitative meta-analysis/synthesis, meta-synthesis, mixed methods, methods in qualitative inquiry, participatory action research

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Background

Sudden cardiac arrest (SCA), the sudden loss of functional mechanical cardiac activity and systemic circulation, is a leading cause of death and disability (Wong et al., 2019). Survival after out-of-hospital cardiac arrest (OHCA) is low, often in single digits (Yan et al., 2020). Moreover, over-half of cardiac arrest survivors face long-term cognitive and/or physical disabilities (Coute et al., 2019; Cronberg et al., 2015; Green et al., 2015; Sawyer et al., 2020). The death of a family member is commonly described as the single most distressful life event (Keyes et al., 2014) even more so when the deceased is a child (McLaughlin et al., 2012). When facing SCA in a loved-one, families experience significant, and often under-acknowledged, emotional distress. This results in care needs in family members, regardless of outcome, which are not always addressed (Compton et al., 2011; Jabre et al., 2014; Shear et al., 2013). This review is intended to identify their care needs using a novel patient-public-practitioner partnership (PPPP).

Cardiac arrests occur both in and out of hospital. Annually, 275,000 people in Europe experience OHCA, but only 29,000 survive to hospital discharge (Atwood et al., 2005). Regarding out of hospital cardiac arrest, rates of survival to hospital discharge are 3.0% in Asia, 6.8% in North America, 7.6% in Europe, and 9.7% in Australia (Berdowski et al., 2009). America from 2003–2007 reported 211,000 annual cases, or 6–7 inhospital cardiac arrests (IHCA) per 1000 admissions (Merchant et al., 2011). In the United Kingdom, IHCA affected 1.6 per 1000 admissions (Nolan et al., 2014) and had a survival rate of approximately 25% (Nolan et al., 2014). Among seven Australian hospitals, IHCA resulted in 30% mortality, 50% being admitted to ICU, and only 26% eventually able to return home (Australia and New Zealand, 2019). For every cardiac arrest, there are countless family members impacted, whether it occurs in our outside of hospital.

Family members are being increasingly recognized as part of the healthcare team, and their role in decision-making is being formalized (Institute for Patient- and Family-Centered Care, 2017). Family-centered care acknowledges the importance and contribution of family members, including as caregivers, representatives, and decision-makers (Strull, 1984). Accordingly, health care services are being targeted toward families, not only for individual patients. This requires a deeper understanding of family and care-provider collaboration, family context, and family needs (Kokorelias et al., 2019).

Family-centered care includes greater opportunity for families to be at the bedside, including during SCA resuscitation. While this initiative is not universally supported at this time, it has been promoted by guidelines, (Bossaert et al., 2015) professional societies, (Society of Critical Care Medicine, 2020) hospital systems, (Goldberger et al., 2015), and health care personnel (de Mingo Fernández et al., 2020). Experiences of family members present during resuscitation vary but include the following: (i) being involved in initial resuscitation efforts, (ii) communicating with their relative and the care team, (iii) witnessing the reality of death, and (iv) seeing things that could be highly distressing or comforting. (De Stefano et al., 2016) Offering family presence is a useful first step in family centered cardiac arrest care, but a greater understanding of families’ experiences and needs is required. Accordingly, this meta-synthesis analyzes and synthesizes qualitative data from our systematic search of the published literature. We explore family experiences and care needs during cardiac arrest events and how they can be met.

Objective

To systematically review and synthesize qualitative data exploring the experience and care needs of families experiencing cardiac arrest care of a family member.

Methods

Study Design

A meta-synthesis is a structured, rigorous, qualitative method for (i) examining experiences and perspectives, (ii) analyzing and interpreting multiple studies, and (iii) developing a cohesive understanding through the synthesis of primary studies (Barnett-Page & Thomas, 2009). In short, meta-synthesis aims for a greater understanding than that gleaned from individual studies interpreted in isolation (Lee et al., 2015).

Patient and Public Involvement in the Proposed Review

This work is a partnership with co-investigators and collaborators who have lived experience of cardiac arrest: as either survivors or as family members of persons who experienced a cardiac arrest (both survivors and non-survivors). We engage our patient/family co-investigators through an equitable collaboration at all stages, from conception of the study idea through dissemination of results/findings (Allen et al., 2016). Co-investigators and collaborators participated in the development of the review question and search strategy, and will participate in the screening and extraction of articles, the analysis of review findings, and manuscript preparation and dissemination. This meta-synthesis is part of a larger family-centered cardiac arrest care project co-designed by investigators and members of the public with lived experience, and includes a scoping review, qualitative document analysis, exploratory interviews, and other research outputs (https://osf.io/fxp5g/).

Review Question

Our review questions are as follows: (1) What are the experiences and perceptions of individuals experiencing cardiac arrest of their family member? (2) What care needs do family
members express for themselves and/or the person in cardiac arrest? (3) What strategies for meeting care needs do family members identify?

Sudden cardiac arrest is not experienced by everyone the same way, and the circumstances, outcome, and duration can vary greatly. We defined cardiac arrest event duration (when it begins and when it ends) through team consensus. There was consensus that the event is generally defined as beginning with loss of responsiveness, collapse, irregular breathing, seizure, and/or an alarm on a cardiac monitor. There was also consensus that cardiac arrest care begins with recognition, activation of an emergency response system, and life support maneuvers. Importantly, from the perspective of the family, the event was deemed to last until the deceased family member becomes inaccessible (i.e., is moved to the morgue) or there was greater certainty about the family member’s survival status, (which could be days or weeks). Importantly, these family- and survivor-informed durations contrast with the prevailing biomedical definition that limits cardiac arrest to the period of circulatory standstill to either declaration of death or return of spontaneous circulation.

See Table 1 for a description of the components of our research question in SPIDER format (Cooke et al., 2012).

### Table 1. Research Question Framework (SPIDER).

| Sample | Persons experiencing cardiac arrest care of a family member in any setting, both in and out of hospital. Family-membership is determined by the patient or, in the case of minors or those without decision-making capacity, by their surrogates. Family members may be unrelated to the patient; they are individuals who provide support and with whom the patient has a significant relationship. (Society of Critical Care Medicine, 2020) |
| Phenomena of Interest | Cardiac arrest care begins with collapse, abnormal breathing, or physiologic monitor alarm and continues until the family member’s body is inaccessible or the family member’s status becomes more certain, that is, they emerge from coma. The needs of families including formal and informal services and tangible and intangible supports. This may include information, presence, resources, and follow-up. |
| Design | Meta-synthesis of research using interviews, focus group discussions, observation, and in-depth or key informant interviews. |
| Evaluation | Narrative findings describing family members’ experience of cardiac arrest and any care needs, preferences, or wishes they express. |
| Research type | Qualitative research, and no time or language restrictions. |

### Types of Studies

This systematic review and meta-synthesis will include studies that employ qualitative data collection methods such as interviews or focus groups, and qualitative methods for data analysis such as content and thematic analysis. We will include study designs such as personal narrative, grounded theory, phenomenology, narrative inquiry, and ethnography. We will exclude studies that collect data using qualitative methods but analyze the data using quantitative methods, as well as qualitative comments from quantitative surveys and editorials.

### Types of Participants

Studies that describe family experiences and preferences will be included. Family-membership is determined by the patient or, in the case of minors or those without decision-making capacity, by their surrogates. In this context, the family may be related or unrelated to the patient; family members are defined as individuals who provide support and with whom the patient has a significant relationship.

Studies involving a family member in cardiac arrest who is unborn or stillborn will be excluded, otherwise there are no age restrictions on the family member in cardiac arrest. We will exclude studies on expected deaths such as palliative care, hospice care, and medical assistance in dying. We will not include studies of persons with a “do not resuscitate” (DNR) or “do not attempt resuscitation” (DNAR) order in place.

### Types of Settings

We will include studies from any geographical region and from any setting where cardiac arrest care may occur, both in and out of hospital, as well as private and public spaces. We will exclude studies of family care needs in “post cardiac arrest” settings such as rehabilitation and palliative care settings.

### Types of Interventions

To be included in our review, the family member experiencing the SCA must have undergone cardiac arrest care that includes (but is not limited to) activation of the emergency response system, cardiopulmonary resuscitation, defibrillation, medication administration, airway management, family presence, shared decision-making, death notification, application of termination of resuscitation guidelines, organ donation, post-mortem care, or family debriefing.

### Types of Outcomes

We will include studies that describe persons’ experience of the cardiac arrest care of their family member. We will focus
on any identified care needs, preferences or wishes, and any patient- or family-reported outcomes related to the cardiac arrest care of the family member.

**Search Methods for Identification of Studies**

Our search strategy will follow the recommendations of the Cochrane Qualitative Research Methods group (Harris et al., 2018) and will search electronic databases including MEDLINE, Embase, CINAHL, Theses and Dissertations Global, SocIndex, Scopus, Web of Science, PsycINFO, and Google Scholar. We will not apply date or language restrictions. We will contact the corresponding author/s of all potentially relevant studies directly when articles are electronically unattainable. Included study authors will also be consulted at the completion of the search to identify any studies that may be missed.

An academic librarian (LD) with expertise in identifying literature within healthcare and social sciences will direct our search strategy and its execution. A preliminary search was conducted in Medline by two reviewers using a search strategy including relevant MeSH headings and keywords such as “heart arrest/or out-of-hospital cardiac arrest” and “(family-centred* or family-centered*).mp.” The complete pilot strategy and results are in Table 2.

To minimize selection bias, at least two team members (including patient and family partners) will independently screen the search results for eligible studies, compare selections, and resolve disagreements by discussion and consensus. These team members will also independently screen the full text of potentially eligible articles to check if the articles fulfill inclusion criteria defined by the types of studies, participants, settings, interventions, and outcomes. A kappa statistic will be calculated to assess inter-rater reliability (Viera & Garrett, 2005). The search results will be presented in a flow diagram.

**Data Extraction and Analysis**

Our team will develop a standardized data extraction form to extract relevant qualitative data from the included studies. We will pilot the data extraction form on at least six studies identified from the list of eligible studies. We will extract data regarding the first author, publication year, journal, language, participants, setting (country, rural/urban, and type of facility), research methods (method of data collection and analysis framework used), potential or actual care needs of involved family members, and outcomes (including any reported barriers and facilitators) and any other categories that are identified from our pilot. Furthermore, we will modify the form as needed following team input. Two authors will independently extract data. Any disagreements will be resolved through consensus, or by a third reviewer.

**Quality Assessment of Included Studies**

There is ongoing debate about how best to assess methodological quality in qualitative research. We will use the Critical Appraisal Skills Programme (CASP) quality assessment tool for qualitative studies for our review (Critical Appraisal Skills Programme, 2018; Long et al., 2020). Two review authors will independently apply the CASP tool. Any disagreements will be resolved by discussion or by the primary investigator. Studies will not be excluded on the basis of quality. However, we will apply the CASP tool (Critical Appraisal Skills Programme, 2018) as part of the Confidence in the Evidence from Reviews of Qualitative research (CERQual) approach for assessing confidence in the findings of the systematic review (Lewin et al., 2015).

**Data Synthesis**

We will use a thematic framework analysis approach to analyze and synthesize data (Dixon-Woods, 2011). This review will follow five stages of framework synthesis.

**Stage 1:** Familiarization with the data: Team members will begin by becoming familiar with the data as it pertains to the aims of the review and will note recurrent themes.

**Stage 2:** Identifying the thematic framework: We will develop a framework based on themes that are generated from our analysis.

**Stage 3:** Indexing: Two team members will independently read the extracted information, searching for themes. The framework will be revised as new themes are constructed. This will be done following discussion and agreement with the research team. All studies will be read until no new themes are identified. Identified themes will lead to code creation. Each study will be indexed using the codes related to the themes of the framework.

**Stage 4:** Charting: We will sort data by theme and present themes in the form of an analysis table. The columns and rows of the table will reflect the studies and constructed themes.

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**Table 2. Pilot Search Results (June 15th, 2020).**

| Search Query                                                                 | Count |
|------------------------------------------------------------------------------|-------|
| 1. heart arrest/or out-of-hospital cardiac arrest/                            | 32960 |
| 2. (((cardiac or heart or cardiopulmonary or circulat*) adj                  | 108000|
| (arrest or standstill or asystol* or resuscitation)) or                     |       |
| ventricular-tachycardia or ventricular-fibrillat* or                        |       |
| asystole or pulseless electrical activity).mp.                              |       |
| 3. 1 or 2                                                                   | 108000|
| 4. (family-centred* or family-centered*).mp.                                | 4657  |
| 5. ((family or families or guardian* or parent or parents or                | 213204|
| parental or spouse* or partner* or adult children) adj                      |       |
| (involve* or care or caring or needs or support* or                       |       |
| satisfaction or perspectives or grief or emotional distress                 |       |
| or PTSD or traumatic stress)).mp.                                           |       |
| 6. Professional-Family Relations/                                            | 14783 |
| 7. 4 or 5 or 6                                                              | 220408|
| 8. 3 and 7                                                                  | 813   |
which will allow us to compare findings of the studies across different themes and subthemes.

Stage 5: Mapping and interpretation: We will use the tables to define the identified concepts and map the range and nature of the phenomena. Associations between themes will be explored to explain findings. We will map and interpret findings in line with the review objectives and construct themes through our analysis.

We will present findings as a “Summary of qualitative findings” table that will summarize our key findings, our confidence judgment for each finding, and a related explanation of the assessment.

Subgroup Analysis and Investigation of Heterogeneity
We will assess any heterogeneity of findings, or differences in the views of the included participants, by conducting subgroup analyses according to the family member’s relationship to the patient (i.e., adult child or parent) or etiology of arrest (i.e., medical cause or traumatic injury). Refer to Table 3 for potential subgroup analysis categories. We will also consider other contexts and concepts that may be identified through synthesizing the available evidence.

Assessment of Confidence in the Review Findings
We will apply the CERQual approach to assess (and report) our confidence in this systematic review’s findings (Lewin et al., 2015). This approach draws on the Grading of Recommendations, Assessment, Development, and Evaluation (GRADE) approach to confidence in review findings based on four components:

1. the methodological limitations of included studies,
2. the relevance of the included studies to the review question,
3. the coherence of the findings, and
4. the adequacy of data contributing to the review findings (Lewin et al., 2018).

Any concerns will be noted and considered when making an overall CERQual assessment of confidence statements. The CERQual assessment and written justification will appear in a summary of qualitative findings table.

Table 3. Subgroup Analysis.

| Sub group #1: Relationship to patient | Sub group #2: Etiology of arrest |
|--------------------------------------|---------------------------------|
| Adult children of elderly parent in cardiac arrest | Traumatic causes of cardiac arrest |
| Adult partner of person in cardiac arrest (married, common-law, intimate partners) | Medical causes of cardiac arrest |
| Children or youth of an adult parent in cardiac arrest | Suicide and homicide |
| Parents of child in cardiac arrest | |

Reporting of Protocol and Systematic Review
We will report our synthesis of qualitative research in accordance with the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) statement (Tong et al., 2012) and the Preferred Reporting Items for Systematic review and Meta-Analysis Protocols (PRISMA-P) guidelines (PRISMA-P Group et al., 2015). Furthermore, this protocol and the meta-synthesis will be reported in accordance with the Guidance for Reporting Involvement of Patients and the Public (GRIPP2) (Staniszewska et al., 2017).

Patient and Public Involvement in Protocol Creation
By partnering with co-investigators who have lived-experience, we believe we have better targeted concepts relevant to our meta-synthesis objectives. Moreover, our partnership influenced our review question development, extraction methods, and dissemination plan. Reflecting on our use of patient and public involvement, we found it to slow the progress of protocol development and add a layer of complexity. However, we believe the improvement in potential impact greatly outweighs any potential loss in efficiency. See Table 4 for GRIPP2 short form for further descriptions of patient and public involvement.

Reflexivity
To address the potential for bias—namely, the potential for our review teams’ perspectives, experiences, and worldviews, to excessively influence the subjective nature of qualitative research—we will undertake reflexive exercises

Table 4. GRIPP2 Short Form.

| Section and topic | Item | Reported on Page |
|-------------------|------|-----------------|
| 1: Aim | Report the aim of PPI in the study | 5 |
| 2: Methods | Provide a clear description of the methods used for PPI in the study | 5 |
| 3: Study results | Outcomes—Report the results of PPI in the study, including both positive and negative outcomes | 10 |
| 4: Discussion and conclusions | Outcomes—Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects | 10 |
| 5: Reflections/ critical perspective | Perspective—Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience | 10 |
(Braun & Clarke, 2006). Members of our review team include nurses, physicians, cardiac arrest survivors, and family members of persons who experienced cardiac arrest. Throughout the review process, team members’ preconceptions will be inventoried, discussed, and considered when making key decisions relating to the review and analysis. A reflexive journal of the review and analysis processes will be kept by the primary investigator as a record of decisions made and to evaluate any team member’s individual influence on the review.

Ethics and Dissemination

This review is a retrospective study, drawing on publicly available data, and does not require formal ethical review. Our patient and family partners are co-investigators and collaborators, not research participants nor subjects; therefore, their involvement was not appropriate for institutional research board review. We will disseminate the findings through publication in a peer-reviewed journal and via local and national conference presentations. We shall also prepare an executive review summary and disseminate to key groups involved in cardiac arrest care provision. We will discuss our review’s findings and applicability in line with our review question, relevance to the implementation of family-centered cardiac arrest care guidelines.

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