

Psychosocial and survivorship care needs following young out-of-hospital sudden cardiac arrest: a rapid scoping review

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Abstract

Importance: Sudden cardiac arrest (SCA) and sudden cardiac death (SCD) are significant public health issues globally. SCA incidence is highest among older adults, however occurrence among young individuals (<50 years) carries a disproportionate impact due to premature mortality, family burden, and economic impact. SCA occurring in a young person is more likely to be caused by inherited cardiovascular conditions, resulting in additional familial implications and profound psychosocial impacts. 'Survivorship care' refers to long-term, holistic care supporting a patient's wellbeing, integrating cognitive, psychological, social and functional aspects of long-term recovery. Although survivorship care following SCA has been increasingly prioritized, the psychosocial care needs specific to young SCA/SCD populations have not been collectively reviewed to date.

Objectives: We performed a rapid scoping review to synthesize evidence on survivorship care needs following young (<50 years) SCA and identify gaps to inform future intervention development.

Evidence review: MEDLINE, Embase, PsycInfo and CINAHL were searched on 1 July 2025 and the search re-run on 12 July 2026 for peer-reviewed primary articles published since 2015. Eligible studies were those which reported care needs, or the psychosocial, cognitive, functional, informational, or survivorship-related outcomes. These were used to infer care needs among young SCA survivors, co-survivors, and SCD bereaved family members.

Findings: Twenty studies met our inclusion criteria. Findings were related to both adult and pediatric survivors as well as bereaved family members; none of the included studies focused exclusively on co-survivors. Adult survivors commonly experience anxiety, depression, posttraumatic stress symptoms, cognitive impairment, impacted sense of self, and challenges returning to work, pointing to support needs in these areas. Pediatric survivors have persistent neurocognitive and adaptive functioning challenges, return to school difficulties and other ongoing support needs. Bereaved family members report psychological distress, prolonged grief, and unmet needs for counselling, peer support, timely information, and coordinated follow-up care.

Conclusions and relevance: Young SCA/SCD may represent a distinct survivorship context characterized by life stage, family disruption, potential genetic risk, and different recovery trajectories. Our findings suggest a need for targeted research into survivorship care pathways that integrate psychosocial care into the young SCA/SCD context.

Key points

Question

What are the survivorship care needs of survivors, co-survivors, and bereaved family members affected by young (<50yo) sudden cardiac arrest (SCA) and sudden cardiac death (SCD)?

Findings

We performed a rapid scoping review and identified 20 studies reporting survivorship-related outcomes following young SCA/D; Frequent care needs included psychological support, neurocognitive and functional rehabilitation, return-to-work or school support, postmortem genetic testing, peer support, timely information, and coordinated follow-up care. Evidence was most substantial for adult survivors and bereaved family members, while no studies focused exclusively on co-survivors.

Meaning

We highlight the need to move beyond generic survivorship care and towards survivorship models that address the distinct age-specific impacts of young SCA and SCD across survivors, co-survivors, and bereaved relatives.

Introduction

Sudden cardiac arrest (SCA) is characterized by the sudden loss of cardiac electrical activity, resulting in sudden cardiac death (SCD) when resuscitation is unsuccessful.^{1–3} Mortality rates remain high globally, with only around 10% of cases surviving to hospital discharge.^{4,5} SCA incidence increases with age and is highest among older adults,^{3,6} yet occurrence among individuals aged under 50 years (young SCA) carries disproportionate impact due to premature mortality, family burden, and economic impact.^{7,8} According to an Australian study, out-of-hospital SCA accounted for approximately one-third of all deaths in people aged 1–50 years, with an annual incidence of 16.5 per 100,000.⁹ Causes in this young age group are more likely inherited conditions such as cardiomyopathies or channelopathies, introducing risk for family members that is less common among older SCA populations.^{1,10,11}

Surviving a young SCA marks the beginning of a long-term trajectory that has impacts beyond physical health and the individual.^{12–18} ‘Survivorship care’ refers to holistic care supporting a patient’s wellbeing following acute illness until end of life, integrating cognitive, psychological, social and functional aspects of long-term recovery.¹⁹ When SCA/SCD occurs in the young, survivorship care spans those who survive the arrest, their families (co-survivors), and bereaved family members.

Among SCA survivors, high rates of depression, anxiety and posttraumatic stress symptoms have been reported.^{14,20} Co-survivors experience significant psychological distress and caregiver burden.^{17,18,21–25} Families bereaved by young SCD face profound grief and emotional distress compounded by heritable risk, necessitating clinical and genetic evaluation of relatives to minimize risk of further mortality.^{11,26,27} Survivors, co-survivors, and bereaved families consistently identify a need for improved support, yet intervention studies to date predominantly concern older-aged cohorts.^{28–32}

A systematic review and meta-synthesis investigated the care needs of SCA survivors, co-survivors, and SCD family members, providing a framework for family-centered support.²² However, the contributory evidence reflects older adult populations and does not address the life-stage, developmental, or genetic

implications inherent to young SCA/SCD survivorship. This rapid scoping review therefore synthesizes the existing literature and identifies evidence gaps in the survivorship care needs of survivors, co-survivors, and bereaved family members in the context of young SCA/SCD. The findings are intended to inform age- and role-specific interventions to improve long-term outcomes for affected families affected.

Methods

This scoping review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-analysis Statement for Scoping Reviews.³³ Methods were developed using Arksey and O'Malley's scoping review methodology.³⁴ We applied rapid review methodological approaches endorsed by the Cochrane Rapid Reviews Methods Group,⁴⁰ including a date restriction of 2015 onward to reflect contemporary clinical practice; restriction to peer-reviewed databases and primary research, exclusion of randomized clinical trials and case reports; omission of backward citation searching; and single-reviewer screening. We searched the Cochrane Database of Systematic Reviews and Open Science Framework to ensure that no similar reviews were underway. A protocol was registered using Open Science Framework on 22 September 2025.³⁵

Eligibility

Eligibility criteria and the population, concept, and context (PCC) are outlined in Table 1.

Table 1
Inclusion and exclusion criteria. SCA = sudden cardiac arrest

Component	Inclusion	Exclusion
Population	<ul style="list-style-type: none"> • Survivors of SCA • SCA survivors' family members • Families bereaved to SCA 	<ul style="list-style-type: none"> • Average > 50years at time of arrest and results not provided stratified by age • In-hospital arrest • Clinician, healthcare provider, or first-responder perspective • Unrelated bystanders or witnesses
Concept	<ul style="list-style-type: none"> • Psychosocial and survivorship care needs • Psychological support needs • Grief and bereavement support • Caregiver role and burden • Rehabilitation and neurocognitive care • Return to work or school • Genetic counselling • Follow-up coordination 	<ul style="list-style-type: none"> • Needs of the community / community response • Medical needs / medical comorbidities • Focus on arrest prevention • Focus on genetic science only
Context	<ul style="list-style-type: none"> • Post-discharge from arrest hospital admission • Post-death (from arrest) 	<ul style="list-style-type: none"> • Pre-hospital or pre-arrest • Acute response • In-hospital treatment
Study characteristics	<ul style="list-style-type: none"> • Primary evidence only (qualitative, quantitative, or mixed-methods) 	<ul style="list-style-type: none"> • Trials or interventions • Systematic, scoping or other literature review

Search strategy

We searched MEDLINE, Embase, PsycInfo and CINAHL on 01 July 2025, repeated on 12 July 2026. The search strategy (see Supplementary 1) was developed by authors NS, RC, ER and LY.

Study selection

Title and abstract screening was performed independently by two reviewers (NS/RC) using Covidence.³⁶ They achieved 93% proportionate agreement on pilot screening of 100 articles. Full text screening was

performed independently following dual review of 20% of records and establishment of substantial inter-rater agreement ($\kappa > 0.60$). Conflicts were resolved through discussion, or with a third reviewer (LY) (Supplementary 2).

Data extraction and narrative synthesis

Data extraction was performed in duplicate (NS/RC). Quantitative data were summarized descriptively using counts, percentages, and ranges. Qualitative findings were synthesized descriptively and data charting undertaken according to Arksey and O'Malley's scoping review guidelines.³⁴

Results

Study characteristics

Twenty studies were identified for inclusion (Table 2). Eleven studies included survivors, three of which included pediatric-only samples. One pediatric study reported briefly on the care needs of parents. Nine studies included bereaved family members, three of which provided results stratified by relationship to the deceased. No studies reported solely on the needs of co-survivors. Care needs were summarised using a triangle plot (Fig. 1). Fifteen studies (75%) were published since 2020, and four (20%) since 2025.

Table 2

Summary of included articles. SCA = sudden cardiac arrest; SCD = sudden cardiac death

Source	Country, study design, population, size, time since SCA/SCD, age of SCA/SCD affected person	Gender Distribution: (Male %, Female %, Other %)	Relationship to SCA Case:	Psychosocial Domains:
Allan et al. (2023)	<p>Country: Canada</p> <p>Study design: Qualitative</p> <p>Population: Bereaved family members</p> <p>Sample size: n = 19</p> <p>Time since SCA/SCD: not defined</p> <p>Age of SCA/SCD victim: 12–45 years (M = 28.6, SD = 11.3)</p>	Male 52.6%, Female 47.4%	Spouse/Partner; Sibling; Child; Parent	Information needs; Follow-up coordination; Bereavement support; Social and financial resourcing
Allan et al. (2026)	<p>Country: Canada</p> <p>Study design: Mixed-methods observational</p> <p>Population: Bereaved family members</p> <p>Sample size: n = 50</p> <p>Time since SCA/SCD: not defined</p> <p>Age of SCA/SCD victim: 38 ± 12 years</p>	Female sex at birth 74%, self-identified as female 70%.	Spouse/Partner; Parent; Sibling; Child	Information needs; Follow-up coordination; Bereavement support.

Source	Country, study design, population, size, time since SCA/SCD, age of SCA/SCD affected person	Gender Distribution: (Male %, Female %, Other %)	Relationship to SCA Case:	Psychosocial Domains:
Bates et al. (2018)	<p>Country: Australia</p> <p>Study design: Cross-sectional</p> <p>Population: Bereaved family members</p> <p>Sample size: n = 33</p> <p>Time since SCA/SCD: Mean: 8 years +/-6 years (range: 2–31 years)</p> <p>Age of SCA/SCD victim: 22 ± 10 years (range 0.2–39 years)</p>	24% Male	Spouse/Partner; Sibling; Child; Parent	Emotional wellbeing; Information needs
Cooper et al. (2025)	<p>Country: United Kingdom</p> <p>Study design: Qualitative</p> <p>Population: Bereaved family members</p> <p>Sample size: n = 24 individuals (n = 20 families)</p> <p>Time since SCA/SCD: Range 1–5 years</p> <p>Age of SCA/SCD victim: 1–3 years (n = 13); 4–6 years (n = 2); 6–8 years (n = 0), 8–10 years (n = 1), 11–17 years (n = 4).</p>	Not reported	Parent	Follow-up coordination
Darring et al. (2026)	<p>Country: Denmark</p> <p>Study design: Retrospective cohort</p> <p>Population: Survivors</p> <p>Sample size: total n = 9383; aged 18–39 n = 494; aged 40–59 n = 2817</p>	Male 73.6%	Survivor of SCA	Emotional wellbeing

Source	Country, study design, population, size, time since SCA/SCD, age of SCA/SCD affected person	Gender Distribution: (Male %, Female %, Other %)	Relationship to SCA Case:	Psychosocial Domains:
	<p>Time since SCA/SCD: <1 year (13.3%), 1–4 years (43.8%), 5–9 years (28.4%), > 10 years (14.6%)</p> <p>Age of SCA/SCD victim: aged 18–39 years (5.3%), aged 40–59 (30.2%)</p>			
Frisch et al. (2017)	<p>Country: Germany</p> <p>Study design: Retrospective cohort</p> <p>Population: Survivors</p> <p>Sample size: n = 38</p> <p>Time since SCA/SCD: m: 13 months, med: 9.5 months, Range: 1 – 67 months</p> <p>Age of SCA/SCD victim: 17–74, mean 45</p>	71% male, 29% female	Survivor of SCA	Cognition
Grand et al. (2023)	<p>Country: Denmark</p> <p>Study design: Prospective cohort</p> <p>Population: Survivors</p> <p>Sample size: n = 288</p> <p>Time since SCA/SCD: 3 months</p> <p>Age of SCA/SCD victim: mean 59 years. Results stratified for young versus old, and by sex. Mean age of females significantly lower; 52yo.</p>	<p>82% male</p> <p>18% female</p>	Survivor of SCA	Emotional wellbeing; Cognition; Quality of Life
Gunmalm et al. (2026)	<p>Country: Denmark</p> <p>Study design: Cross-sectional</p> <p>Population: Survivors</p>	<p>overall: male 81.3% (n = 2075), female 18.7% (n = 477). <35yo male 53.6%, female</p>	Survivor of OHCA	Emotional wellbeing

Source	Country, study design, population, size, time since SCA/SCD, age of SCA/SCD affected person	Gender Distribution: (Male %, Female %, Other %)	Relationship to SCA Case:	Psychosocial Domains:
	<p>Sample size: n = 2552</p> <p>Time since SCA/SCD: overall: 37.9% <4 years since arrest, 31.4% 4–8 years since arrest, 30.6% >8 years since arrest. <35yo 28.8% <4 years since arrest, 26.4% 4–8 years since arrest, 44.8% >8 years since arrest. 35-44yo 28.2% <4 years since arrest, 26.2% 4–8 years since arrest, 45.7% >8 years since arrest. 45-54yo 30.1% <4 years since arrest, 33.6% 4–8 years since arrest, 36.2% >8 years since arrest.</p> <p>Age of SCA/SCD victim: overall mean: 58.6 at time of arrest. stratified < 35yo (n = 125), 35-44yo (n = 206), 45-54yo (n = 574)</p>	<p>46.4%, 35-44yo male 74.3%, female 25.7%, 45-54yo male 79.4%, female 20.6%.</p>		
Hardeland et al. (2022)	<p>Country: Norway</p> <p>Study design: Qualitative</p> <p>Population: Survivors</p> <p>Sample size: n = 18</p> <p>Time since SCA/SCD: 2.8–5.7 years</p> <p>Age of SCA/SCD victim: 19–49 (median 43)</p>	<p>78% male (n = 14), 22% female (n = 4)</p>	Survivor of SCA	<p>Emotional wellbeing;</p> <p>Cognition;</p> <p>Information needs;</p> <p>Family functioning;</p> <p>Return to work/role adjustments;</p> <p>Follow-up coordination</p>
Hickson et al. (2023)	<p>Country: United States of America</p> <p>Study design: Cross-sectional</p> <p>Population: Survivor, Co-survivors</p>	<p>43% female</p>	Survivor of SCA; Parents	<p>Emotional wellbeing;</p> <p>Cognition; Family functioning;</p> <p>Follow-up coordination;</p> <p>Education support,</p>

Source	Country, study design, population, size, time since SCA/SCD, age of SCA/SCD affected person	Gender Distribution: (Male %, Female %, Other %)	Relationship to SCA Case:	Psychosocial Domains:
	<p>Sample size: n = 44</p> <p>Time since SCA/SCD: Median 5.6 years (IQR 3.1–12.5)</p> <p>Age of SCA/SCD victim: (3.1–12.6, median 5.3 years, IQR 1.3, 12.6)</p>			<p>Neurobehavioral function;</p> <p>Quality of Life, Family Functioning (co-survivors)</p>
Hunfeldt et al. (2021)	<p>Country: the Netherlands</p> <p>Study design: Prospective cohort</p> <p>Population: Survivor</p> <p>Sample size: n = 49 (baseline), 27 (follow up)</p> <p>Time since SCA/SCD: t1 = 3–6 months, t2 = 24 months</p> <p>Age of SCA/SCD victim: t1 = 0–17 years, t2 = 2–15 years</p>	<p>67% male at time of arrest, 67% male at baseline and 67% male at 24 month follow up.</p>	Survivor of SCA	Cognition; Education support
Ingles et al. (2016)	<p>Country: Australia</p> <p>Study design: Cross-sectional</p> <p>Population: Bereaved family members</p> <p>Sample size: n = 103</p> <p>Time since SCA/SCD: M = 6.3 years (SD = 4.6)</p> <p>Age of SCA/SCD victim: m = 23; SD = 8</p>	42% male	Spouse/Partner; Sibling; Child; Parent	Emotional wellbeing; Bereavement support
Jensen et al. (2024)	<p>Country: Denmark</p> <p>Study design: Prospective cohort</p> <p>Population: Survivor</p>	<p>78% male for total sample - not specified for younger age group</p>	Survivor of SCA	Cognition

Source	Country, study design, population, size, time since SCA/SCD, age of SCA/SCD affected person	Gender Distribution: (Male %, Female %, Other %)	Relationship to SCA Case:	Psychosocial Domains:
	<p>Sample size: 96 (age-stratified sub-sample < 56 years)</p> <p>Time since SCA/SCD: 3-months post-hospital discharge</p> <p>Age of SCA/SCD victim: <56 strata mean not reported</p>			
Lee et al. (2023)	<p>Country: South Korea</p> <p>Study design: Retrospective cohort</p> <p>Population: Survivor</p> <p>Sample size: n = 2373</p> <p>Time since SCA/SCD: Median follow-up = 5.1 years (IQR, 3.6–7.2 years)</p> <p>Age of SCA/SCD victim: 18–39 years - N = 416 (18.0%)</p> <p>40–49 years - N = 519 (21.0%)</p>	Overall sample – 78% male	Survivor of SCA	Emotional wellbeing
McDonald et al. (2020)	<p>Country: Australia</p> <p>Study design: Cross-sectional</p> <p>Population: Bereaved family members</p> <p>Sample size: n = 38</p> <p>Time since SCA/SCD: 2–17 years</p> <p>Age of SCA/SCD victim: 23+/- 10years</p>	21% male	Parent	Emotional wellbeing; Information needs; Follow-up coordination; Peer or social support; Spiritual support, Social and financial resourcing
Nielsen et al. (2023)	<p>Country: Denmark</p> <p>Study design: Cross-sectional</p>	76% male	Survivor of SCA	Emotional wellbeing; Cognition; Return to work/role

Source	Country, study design, population, size, time since SCA/SCD, age of SCA/SCD affected person	Gender Distribution: (Male %, Female %, Other %)	Relationship to SCA Case:	Psychosocial Domains:
	<p>Population: Survivors</p> <p>Sample size: n = 184 (81 responders)</p> <p>Time since SCA/SCD: 0–12 months</p> <p>Age of SCA/SCD victim: Median age 49 years</p>			adjustments; Quality of Life
Palijevic et al. (2019)	<p>Country: United States of America</p> <p>Study design: Qualitative</p> <p>Population: Bereaved family members</p> <p>Sample size: n = 5</p> <p>Time since SCA/SCD: 1–10 years</p> <p>Age of SCA/SCD victim: 6–45 years of age</p>	Female 80%	Spouse/Partner; Parent	Emotional wellbeing; Information needs; Bereavement support; Genetic testing / counselling
Slomine et al. (2016)	<p>Country: United States of America</p> <p>Study design: Prospective cohort</p> <p>Population: Survivors</p> <p>Sample size: n = 85</p> <p>Time since SCA/SCD: 12 months</p> <p>Age of SCA/SCD victim: 1.1–18.9 years of age</p>	Male 73%	Survivor of SCA	Cognition; Neurobehavioral function; Educational support

Source	Country, study design, population, size, time since SCA/SCD, age of SCA/SCD affected person	Gender Distribution: (Male %, Female %, Other %)	Relationship to SCA Case:	Psychosocial Domains:
Steffen et al. (2020)	Country: United Kingdom Study design: Qualitative Population: Bereaved family members Sample size: n = 19 Time since SCA/SCD: 3–5 years (14.3%), 6–10 years (47.6%), 11 + years (38.1%) Age of SCA/SCD victim: <35 years	73.7% Female	Spouse/Partner; Parent	Emotional wellbeing; Information needs; Peer or social support; Bereavement support
Van den Heuvel et al. (2023)	Country: Australia Study design: Qualitative Population: Bereaved family members Sample size: n = 18 Time since SCA/SCD: Mean years = 8.1 (SD = 4.9) Age of SCA/SCD victim: M = 24.9 years (SD = 9.1)	Male 38.9%	Spouse/Partner; Sibling; Parent	Emotional wellbeing; Information needs; Follow-up coordination; Bereavement support; Genetic testing / counselling

Adult SCA survivors

The most frequently reported psychosocial concerns among adult survivor cohorts (Table 3) related to emotional wellbeing (N = 7),^{37–43} cognitive function (N = 4),^{37,38,44,45} and return to work and role adjustments (N = 2).^{37,40}

Emotional wellbeing

At hospital discharge, 33% (n = 25/81) of SCA survivors demonstrated clinically significant anxiety, and 17% (n = 12/81) depression symptoms according to a Danish study.⁴⁰ Another study reported 18% (n =

172/945) were newly diagnosed with anxiety or depression within 1-year of their arrest.³⁹ One study measured symptoms of posttraumatic stress using the Posttraumatic Stress Disorder Checklist for DSM-5 (PCL-5) three months post-arrest, demonstrating younger females had more PTS symptoms and anxiety than males and older females, and further that anxiety was inversely associated with age across the cohort.³⁸ Similarly, using the Hospital Anxiety and Depression Scale (HADS), SCA survivors aged < 44 years had worse anxiety scores compared to older survivors.⁴³ In a qualitative study, survivors' reported emotional sensitivity, irritability, and low mood, descriptively linked to physical, identity, and capacity-related changes.⁴² The incidence of new-onset psychiatric disorders was highest in the first year post-arrest.⁴²

Cognitive function

A Danish study assessed SCA survivor cognitive and executive function through multi-source testing and provided results stratified by age.⁴⁵ Performance-based measures captured deficits that were missed by self-reported or informant-reported measures of executive function.⁴⁵ Neurologic outcomes at hospital discharge, namely Cerebral Performance Category (CPC) and Modified Rankin Scale (mRS), were not associated with executive function at 3-months.⁴⁵ In a retrospective study, cognitive impairment was assessed using performance-based measures of executive function.⁴⁴ Apathy, defined as diminished goal-directed behaviour or emotional engagement distinct from depression, was assessed using medical records.⁴⁴ Apathy was identified in 68% (n = 26/38) and correlated with attention and long-term memory deficits.⁴⁴ Apathy occurred at similar rates among participants with and without depression, suggesting this may reflect underlying neurobehavioral changes.⁴⁴ Qualitative evidence similarly suggests that SCA survivors experience a post-arrest decline that is independent of depressive symptoms.³⁷

Return to work

A Danish study found return-to-work in young adult SCA survivors improved over time; 60% (n = 110/184) of survivors were receiving paid sick leave at hospital discharge, 43% (n = 80/184) at 3-months post-discharge, and 20% at 12-months.⁴⁰ Older age at SCA was associated with prolonged sick leave or exiting the workforce (OR = 10.6), suggesting better return-to-work with for younger SCA survivors.⁴⁰ However, there was substantial work disruption across the cohort with 20% (n = 37/184) still on paid sick leave, and 11% (n = 20/184) having left the workforce by 12-months.⁴⁰ In a qualitative study, survivors described disruption to their occupation was not consistently linked with physical sequelae post-arrest.³⁷ Further, survivors expressed receiving highly variable support from their employers.³⁷

Follow-up support

In one study, SCA survivors described receiving insufficient guidance about safe levels of physical exertion, symptom monitoring, navigating new routines, and long-term expectations of recovery.³⁷ These suggest unmet needs for personalised information and education, as well as ongoing care coordination.

Pediatric SCA survivors

Studies of pediatric cohorts (Table 3) focused on neurobehavioral functioning and cognition (n = 3),^{46–48} return to school (n = 2),^{46,47} emotional wellbeing (n = 1),⁴⁶ and follow-up support needs (n = 1).⁴⁶

Emotional wellbeing

Child survivors reported levels of anxiety and depression within the normal range compared to the general population.⁴⁶ Parents reported their children had significantly elevated physical complaints up to 11 years post-arrest, although this was not evident among parents of preschool children.⁴⁶ These findings may reflect ongoing medical issues or parental vigilance, rather than physical manifestations of emotional distress.⁴⁶

Neurobehavioral function and cognition

Two studies used performance-based, norm-referenced tests of neurobehavioral outcomes demonstrating persistent cognitive impairments in pediatric SCA survivors at 12- and 24-month follow-up.^{47,48} Attentional and executive functioning deficits were prominent, including impairments to cognition impacting intelligence test scores,⁴⁸ and to processing speed, attention, and cognitive flexibility.⁴⁷ Intellectual functioning was significantly reduced, with almost 25% obtaining scores in the very low or low ranges (IQ < 70).⁴⁸ Two studies used the Vineland Adaptive Behavior Scale (VABS) to assess communication, daily living skills, socialization, and motor skills, as reported by a caregiver.^{46,48} Significant deterioration was demonstrated across all domains.⁴⁸ Approximately half (n = 42/85) scored in the 'low' range at 12-month follow-up, correlating with impaired cognitive functioning.⁴⁸ In contrast, another study showed a majority of children had functioning in the 'average' range on VABS at follow-up (median 5.6 years post-arrest), however those with unfavorable neurological outcomes at discharge were significantly more likely to report deficits at follow-up.⁴⁶

Return to school

In a Dutch study, 83% of school-aged survivors (n = 20/24) had returned to school at the 3–6 month timepoint, with 81% (n = 26/32) attending school at 24 months.⁴⁷ Significant educational adjustments were noted for one student at 3–6 months, who was moved to a lower educational level.⁴⁷ At 24-months, two primary-age students had transferred to smaller-group schools and two secondary-age students had moved to lower educational levels due to cognitive problems.⁴⁷ Another study identified more than half of survivors (n = 23/44) required disability support or individual education plans at long-term follow-up.⁴⁶

Follow-up support

Approximately one-third of child survivors required physical therapy (n = 14/44) and/or occupational therapy (13/44), and 20% (n = 9/44) received home-based care services at a median of 5.6 years post-arrest.⁴⁶ Behavioural health services were utilized by 16% (n = 7/44) of survivors, with a further 9% (n = 4)

of caregivers reporting unmet mental health care needs for their child.⁴⁶ One study measured health related quality of life (HR-QoL), administering the validated Pediatric Quality of Life Inventory (PedsQL) five years post-arrest.⁴⁶ HR-QoL scores were within normal ranges, regardless of neurologic outcomes at discharge.⁴⁶

Co-survivors

No studies reported exclusively on co-survivors, however one included parent-scored measures of family functioning and HR-QoL.⁴⁶ Assessment using the PedsQL Family Impact Module (PedsQL FIM) identified impact on caregiver and family functioning.⁴⁶ Parents of children with unfavorable neurological outcomes at discharge had lower median scores on the PedsQL FIM, reflecting family disruption and reduced HR-QoL among parents.⁴⁶ No identified studies assessed siblings, partners, or children of survivors.

Bereaved

The most commonly reported domains (Table 3) were emotional wellbeing (n = 6),^{49–55} postmortem genetic testing (n = 3),^{51,53,55} follow-up support (n = 5),^{50,52,55–57} and peer support (n = 3).^{52,54,55}

Emotional wellbeing

PTS symptoms were reported among 44% (n = 44/103) of family members and higher among mothers (59%, n = 19/34) and witnesses to the arrest (67%, n = 10/28) in an Australian study.⁴⁹ Depression, anxiety and stress scores were also higher than the general population.⁴⁹ Twenty percent of family members experienced prolonged grief; 36% (n = 10/34) among mothers, and 42% (n = 10/28) among witnesses.⁴⁹ Qualitative studies described emotional distress compounded by uncertainty and isolation during coronial investigations or waiting periods.^{53–55} There was a perceived lack of direction from healthcare professionals about coping with grief, and variable satisfaction with grief counselors and psychologists.⁵⁵ Grief was compounded when the cause of death was unclear.⁵⁰ Families expressed a desire for professional counselling with specific expertise in young SCD, counselling for children, and relational therapy.^{52,55}

Postmortem genetic testing

Postmortem genetic testing was described as a source of both hope and worry.⁵⁵ One study found thirty-six percent of first-degree relatives (n = 11/31) reported poor psychological adaptation following results of postmortem genetic testing.⁵¹ When a genetic cause was identified, predictive genetic testing for relatives provoked further anxiety.⁵³ A needs analysis of bereaved parents identified that provision of 'medical information' was highly endorsed as an important need.⁵² This included understanding cause of death, and medical implications for relatives; almost one third of participants reported an unmet need for additional medical information.⁵² Identifying a genetic cause was endorsed as an important need by 72% (n = 26/36) and 67% (n = 18/27) of participants reported this as unmet.⁵² Families valued

empathetic, trauma-informed communication from individuals experienced in young SCD.^{54,56} Among family members who had poor adaptation to results of postmortem genetic testing, 82% (n = 9/11) received a variant of uncertain significance, compared with 50% (n = 10/20) in the better adapted group, although this was not statistically significant.⁵¹

Peer support

Referral to someone with similar lived experience was endorsed in one study by 42% (n = 16/38) of participants and reported as unmet for 69% (n = 11/16).⁵² In a qualitative study, bereaved parents described a desire for peer support.⁵⁵ Access to specialized peer support groups offered hope, normalization, and understanding.⁵⁴ Participation in advocacy or fundraising activities was important for families to honor the deceased, and supported coping.^{50,54}

Follow-up coordination

Bereaved families expressed a need for clear, timely and empathetic communication from the medico-legal department in their country.⁵⁷ Suggestions included providing a warning before sending information about the death investigation, and repetition of information.⁵⁷ Care coordination needs were highlighted, particularly in the immediate period post-SCD.⁵⁵ For those who attended a specialized cardiac genetics clinic, the period between the death and the appointment was isolating due to lack of contact and direction.⁵⁵ Families desired a primary contact to oversee questions, referrals, and signpost appropriate ongoing care.^{50,55,56} Onward cardiology referral for family screening was not automatic, necessitating independent navigation of the healthcare system, which was distressing for families.^{55,56} Participants called for early contact with a knowledgeable care coordinator skilled in trauma-informed communication.^{50,52,55,56}

Financial support

Bereaved families discussed a need for support managing financial implications of the death. In a qualitative study, unanticipated financial strain contributed to stress, with absence from work needed to cope with trauma.⁵⁰ Around 30% (n = 13/34) of parents identified a need for financial support information, which was often unmet (n = 5/13).⁵² This included managing the deceased's finances, and understanding reimbursable medical costs.⁵²

Discussion

Investigation into survivorship following SCA is increasing,^{58–64} however research specifically focusing on young SCA/SCD remains relatively limited. Twenty studies met eligibility criteria. Several consistent findings appear common across both younger and older cohorts including a need for psychosocial support, follow-up care coordination, and unmet informational needs. Young SCA/SCD populations,

however, may have unique considerations related to the possibility of inherited disease, family risk, and life-stage that are poorly addressed in literature largely focused on older-aged SCA/SCD cohorts.

Guidelines recommend that all survivors undergo screening for cognitive and psychological issues following SCA.^{65,66} A systematic review of older adult SCA survivors (mean age 52–65 years) reported rates of depression, anxiety, and PTSD among survivors comparable with those identified in our current review.⁶⁷ Age, however, was non-significant as a moderator of depression, and could not be assessed in relation to anxiety or PTSD.⁶⁷ In contrast, our review found two articles wherein younger age at arrest was associated with higher rates of anxiety and PTSD.^{38,43} Cognitive impairment appears common to both older adult and younger SCA cohorts and is heterogeneous in both its nature, and its assessment.^{44,45,68,69} Current guidelines broadly recommend that cognitive screening is undertaken in all SCA survivors within 3 months of arrest,^{70,71} however there is considerable variability in current use of assessment methods.⁷² Discrepancies in assessment may result in executive dysfunction being overlooked among young SCA survivors.⁴⁵

Three studies of pediatric survivors met inclusion criteria. A subset exhibited cognitive deficits and required educational and therapeutic support.^{46–48} A recent narrative review of psychological outcomes following pediatric cardiac arrest drew predominantly on cohorts that combined in-hospital cardiac arrest and out-of-hospital cardiac arrest cases, despite evidence that these populations differ substantially in etiology, resuscitation dynamics, and outcomes.^{73,74} To our knowledge, the current review contains the first OHCA-specific synthesis of pediatric survivors, although the small number of included studies underscores the need for larger dedicated cohorts and longitudinal follow-up.

Only one study assessed parents of pediatric survivors, documenting reduced caregiver HR-QoL.⁴⁶ This suggests a need for improved caregiver support, however, none of the included studies addressed siblings, partners, or children of young SCA survivors. Wider literature suggests that co-survivors of older-aged SCA cohorts experience high rates of anxiety, depression, posttraumatic stress and sleep disturbance.^{12,13,24,64} Psychological distress in co-survivors can persist for months to years, and is closely linked to wider family functioning.^{31,60,75} Caregiver burden is also associated with poorer recovery of SCA survivors.^{76,77} The near-complete absence of research characterizing care needs among co-survivors of young SCA highlights a critical gap, and a group whose care needs remain largely unexamined.

Bereavement following young SCD involves distinct care needs. Untimely and unexpected loss is an established risk factor for prolonged grief and posttraumatic stress,⁷⁸ and mothers and witnesses to the arrest are the highest-risk subgroups in young SCD cohorts.⁴⁹ Young SCD families must navigate postmortem investigation, cardiogenetic evaluation, and risk assessment of surviving relatives. These care pathways are less common in older-adult SCD, wherein autopsy and genetic referral are less frequently indicated.⁷⁹ Consistent with this, the current review identified that families bereaved by young SCD desired support from services with young SCA/SCD-specific expertise.

Genetic considerations distinguish young SCA/SCD survivorship from arrest in older adults across all three affected groups. In young SCA survivors, the arrest may be attributable to an inherited cardiovascular condition, with implications for the survivor's own long-term management and for cascade evaluation of first-degree relatives. Co-survivors in young SCA may be at-risk relatives themselves, and may require clinical screening, genetic counselling, or predictive genetic testing. In bereaved families, postmortem genetic testing can identify an underlying genetic cause in a substantial proportion of young SCD cases, enabling predictive genetic testing for at-risk relatives.^{80–83} This contrasts with older cohorts, in which coronary artery disease predominates as cause of SCA/SCD and the diagnostic yield of genetic testing is substantially lower.⁶ Despite guideline recommendations for genetic counselling and testing, our review did not identify any studies concerning these needs in young SCA survivors or co-survivors, and only two in bereaved families.^{53,55} This exposes a substantial evidence gap relating to a differentiating aspect of young SCA/SCD care needs.

Limitations

Non-English language studies, and studies published prior to 2015 were excluded. Studies were heterogeneous in design, follow-up, and outcome measures and many relied on small, single-center cohorts, limiting generalizability. The small number of included studies, a lack of validated SCA-specific outcome measures, and the limited inclusion of participants from diverse ethnic backgrounds restrict the applicability of findings.

Future research

Future research should consider developing standardized SCA/SCD-specific outcome measures and evaluation of multidisciplinary, family-centered frameworks. Age-stratified analyses and registry-based longitudinal studies will be important, as well as targeted prioritization of ethnically diverse cohorts, and rural participants. Future studies should prioritise investigation of co-survivor care needs.

Conclusion

Evidence remains limited surrounding the care needs of young SCA survivors, co-survivors, and families bereaved by young SCD. There is a need to evaluate structured longitudinal family-centered models of survivorship care alongside further research to define and evaluate age-and role-specific approaches.

Declarations

Conflicts of interest:

Jl is a consultant for Kardigan, Inc. unrelated to this work. LY receives speaker fees from Bristol Myers Squibb. EP has received speaker and consultant fees from Bristol Myers Squibb, Pfizer, DKSH Healthcare and CSL Sequirus, all unrelated to this work. All remaining authors have nothing to disclose.

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Figures

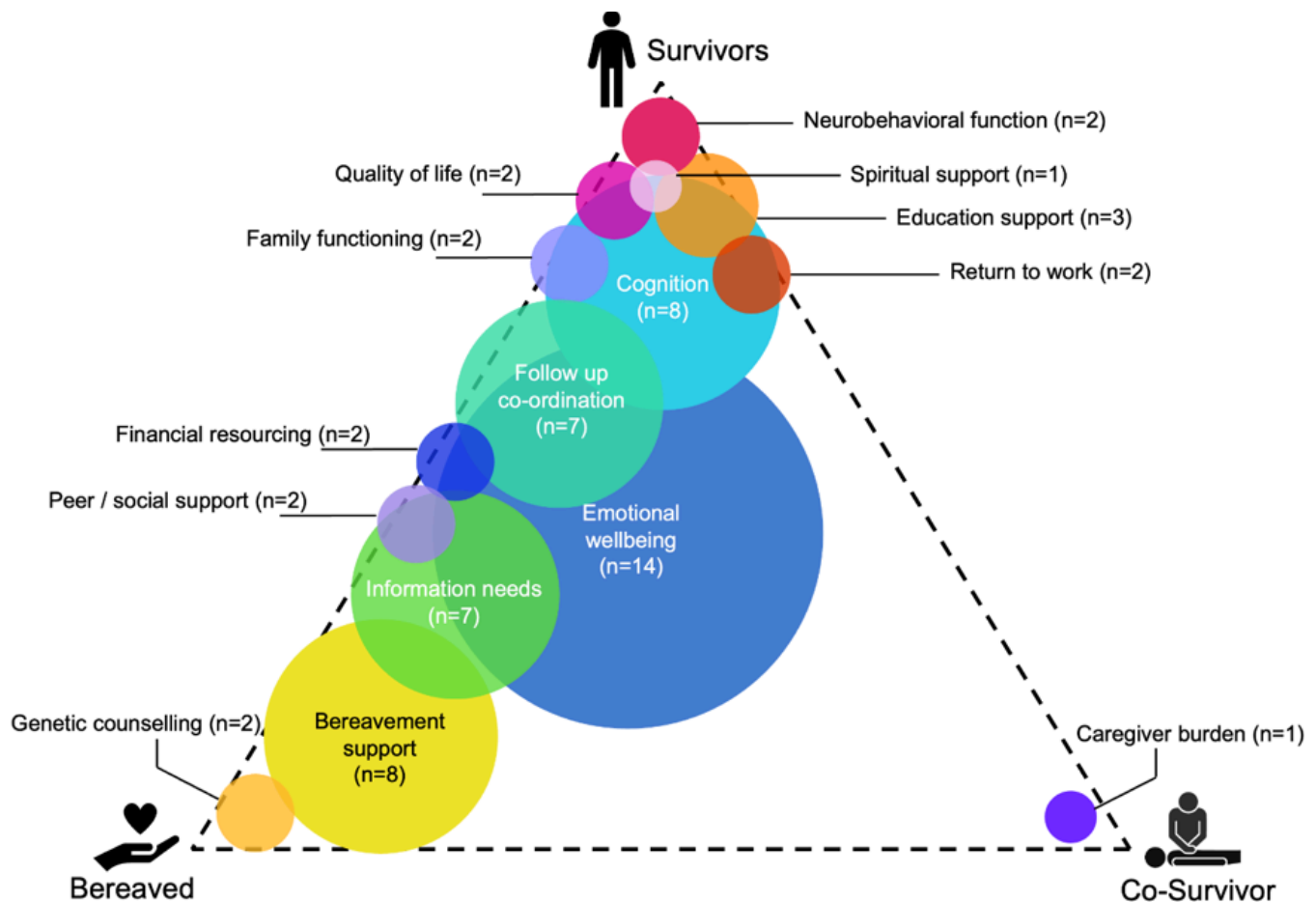


Figure 1

Mapping of Identified Themes of Care Domains Across Bereaved, Survivor, and Co-Survivor Groups.

Supportive care domains are mapped across Bereaved, Survivor, and Co-Survivor groups using a triangle plot. Circle positioning reflects the theme and proportional overlap among groups, while circle size indicates the frequency of reported themes, highlighting thematic clusters and group-specific gaps.

Supplementary Files

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