

The Patient Experience After Spontaneous Coronary Artery Dissection

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Objective

There is considerable burden of anxiety, depression, and post-traumatic stress disorder in patients with spontaneous coronary artery dissection (SCAD), yet research is limited on the experience and impact of SCAD from the patient perspective. This literature review sought to describe the current state of the literature on the patient experience of SCAD and consequences for patients following a SCAD event from the patient perspective. To better understand how people's experiences of SCAD affect their wellbeing, quality of life, lifestyles, and identity, and what would be useful from the patient perspective, an integrative review was performed.

Methods

An integrative literature review was conducted to understand the experience of SCAD and the post-event implications. Five databases were searched. Search terms included 'spontaneous coronary artery dissection', 'SCAD', 'patient', 'experience', 'perspective', and 'opinion'. English-language, peer-reviewed primary research in people with a diagnosis of SCAD that reflected the patient experience was included. Data indicating the SCAD experience including distress prevalence were extracted into an Excel spreadsheet, and narrative synthesis of included studies followed.

Findings

From 325 identified studies, five were included for review, yielding a combined sample of 447 participants. Patients with SCAD reported a lack of information about SCAD and the recovery process, and use of the internet for obtaining information. Patients with SCAD reported challenges in recovery including anxiety associated with fear of recurrence and uncertainty, and a need for greater support. A wide range of negative emotions was reported during and after the SCAD event. Participants reported participating in support groups, with mixed reviews of their appropriateness and effectiveness.

Keywords

Spontaneous coronary artery dissection • SCAD • Psychosocial • Experience • Perspective

Introduction

Spontaneous coronary artery dissection (SCAD) is increasingly recognised as a cause of acute myocardial infarction (AMI) cases [1]. First described in 1931, SCAD was thought to be a rare and fatal condition [2]. Technological advances in coronary angiography and intravascular imaging have revealed that SCAD accounted for up to 4% of AMI overall [2]. A systematic review investigating the clinical characteristics

and outcomes of patients with SCAD found that 84% of patients with SCAD were women with a mean age of 51.1 years [3]. Cases of SCAD have also been reported among younger men after intense exercise [4].

The cause of SCAD is unknown, but it is thought to be related to various triggers including emotional stress, strenuous physical stress (e.g., Valsalva manoeuvre or intense isometric exercise), or hormonal changes, such as those occurring during pregnancy [5]. Genetic changes related to

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migraine, fibromuscular dysplasia, and cervical artery dissection have been documented in patients with SCAD [5]. However, a large prospective multicentre study (n=750) conducted by Saw *et al.* [6] concluded that in 50.1% of cases, SCAD was idiopathic. In the absence of clinical trials, current treatment guidelines are based on expert opinion and recommend conservative (i.e., non-invasive) management of SCAD, except in cases of clinical instability [3]. There is no current treatment to prevent SCAD recurrence [3] which is reported to re-occur in between 5% and 30% of cases over a 2-year period [2]. Further, there are no specific guidelines for longer-term physical activity after SCAD [7].

Consequently, patients with SCAD are unique in that they are a younger cohort with an under-researched, potentially life-threatening heart condition. Psychological distress, identified as an individual's internal experiences deemed to be troubling, disturbing, and confusing [8], can be heightened after SCAD in the context of a lack of evidence to guide treatment, reduce recurrence, and inform secondary prevention [1]. Following a SCAD event, patients may struggle to accept a diagnosis of an unexpected and potentially life-threatening condition, particularly if young and without traditional cardiovascular risk factors [4]. People may feel alone, unable to find appropriate information to support their recovery, and may live in fear of SCAD recurrence [9]. Indeed, there is a substantial psychosocial burden of anxiety, depression, and post-traumatic stress disorder (PTSD) in patients with SCAD [2,10,11], suggesting the need for psychosocial support after SCAD.

Developing a deeper, more nuanced understanding of how patients experience SCAD will contribute to improved support and health care after a SCAD event. Patient experience, along with clinical effectiveness and safety, is recognised as a major factor affecting the provision of quality health care [12]. Patient experience is a broad concept related to both managing emotional and physical changes, as well as examining and maximising the patient's physical, emotional, and social wellbeing [13]. Additionally, an examination of patient experience explores the interactions that patients have with the health care system [14]. To better understand how people's experiences of SCAD affect their wellbeing, quality of life, lifestyles, and identity, and what would be useful from patients' perspectives, an integrative review was performed.

Methods

An integrative literature review model was used to allow for the inclusion of a diversity of research for the purpose of exploring differing perspectives to understand a complex phenomenon such as the patient experience after SCAD [15]. The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) reporting guidelines were followed [16]. In consultation with the university librarian, a systematic search strategy was designed (see [Supplementary Information](#)). Search terms used were 'spontaneous coronary artery dissection' and its abbreviation 'SCAD' combined with terms including 'patient', 'experience', 'perspective',

and 'opinion' to capture the patient experience or perspective. Additionally, search terms for research methods including interview, questionnaire, survey, focus group, and fieldwork were added to capture research on the patient experience. Databases searched were CINAHL, Embase, Medline, and Scopus, and were searched for relevant literature up to June 2023. The results from these searches were downloaded into the citation management software EndNote (Clarivate, London, UK). Reference lists of full-text articles were also reviewed.

Studies were included if they were peer-reviewed and reported primary research studies written in the English language that described the patient experience following a SCAD event. This included studies that reported perceived physical and/or emotional responses or changes after SCAD, changes to wellbeing, identity, and perspectives or opinions on personal experiences in management strategies after SCAD. Qualitative, quantitative, and mixed-methods studies were considered for inclusion if they reported on participant perspectives of their experiences. Publications such as case reports (such as a single-patient case study), pathophysiology report articles, letters, editorials, conference abstracts, poster presentations, clinical guidelines, and grey literature were excluded. One author (E.A.T.) conducted title and abstract review, and full-text eligibility was established by the first and final authors. Any disagreements on inclusion were discussed between authors until consensus was achieved. Quality assessment was conducted to assess the authenticity of the included literature and value of the information presented [15], and to examine the methodological coherence [17], rather than as a basis for exclusion. Quality assessment was conducted by the first author (E.A.T.) with the use of the appropriate quality assessment instruments from the JBI (formerly, Joanna Briggs Institute) [18].

Initially, data were extracted from each study into an Excel spreadsheet to populate columns depicting aim, study design, participant characteristics, results, and limitations. Integrative data analysis was performed on results extracted, through a process of identifying important patterns and themes to summarise the literature on the SCAD patient experience [15]. An iterative process of analysis was then conducted following the steps of ordering, coding, categorising, and summarising to create a cohesive conclusion about the review's aim to describe the current body of literature on the patient experience after SCAD [15].

Results

The first author conducted the search wherein 325 articles were retrieved. After removing duplicates, 169 articles remained. Following screening against inclusion criteria by the first author and in consultation with the final author, 22 articles remained for abstract screening. Another 17 articles were excluded after full-text review, leaving five articles ([Figure 1](#) [16]). Reference lists of full-text articles did not yield further relevant material.

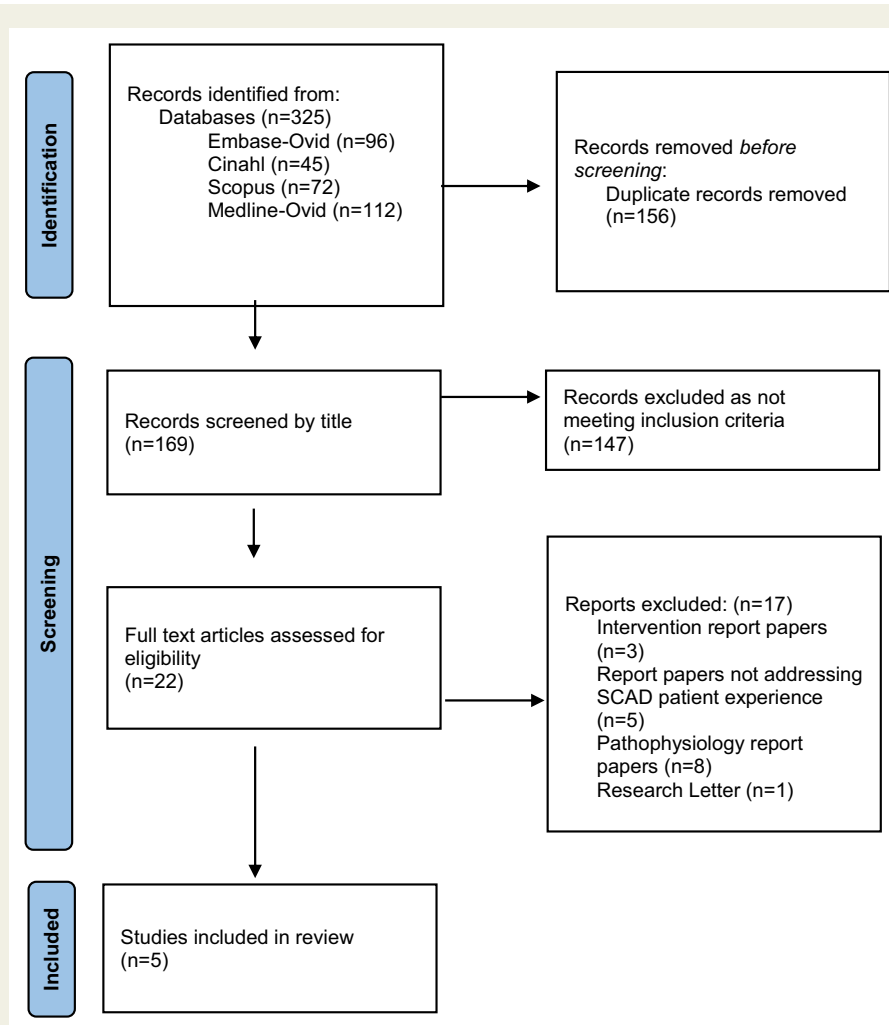


Figure 1 PRISMA diagram [16].

Abbreviations: PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses; SCAD, spontaneous coronary artery dissection.

Quality assessment scores indicated variable quality. Studies were scored positively across aspects including ethical standards, representation of participants, and interpretation of data. However, there were some negative scores on methodological considerations including a lack of clarity around congruence of the methodological position underpinning the research with research methods used and researcher reflexivity. In view of the debate on the requirement of quality appraisal within qualitative reviews [15,17], the small number of relevant articles, and the various aspects of the SCAD experience represented, all articles were included following quality assessment.

Study Characteristics

One article used a cross-sectional study design [19]. Three articles reported on qualitative studies that included interviews with patients with SCAD about their perspectives of the SCAD experience, including psychosocial and emotional

responses and effects on wellbeing, identity, lifestyle changes, and recovery needs [20–22], while one reported on qualitative data collected from the conduct of focus groups [23].

Participant Characteristics

The included studies were conducted in the United States [19], Canada [20,22], Australia [23], and the United Kingdom [21]. All included studies were conducted within large tertiary hospital centres for cardiology or major SCAD research settings. Participants were recruited from specialised SCAD programs or treatment centres [20,22,23] or through advertisements placed on social media SCAD support groups [19,21]. Participant sample sizes ranged from 7 to 367, with a total of 447 participants. Participants ranged in age from 30 to 71 years and were mainly female, ranging from 60% to 100% of participants. All studies reported on populations that were mainly White. Participants reported that time since SCAD event ranged from 2 weeks to 27 years.

Findings

Patient perspectives on the impact of SCAD on their lifestyle and their wellbeing, the challenges they faced in recovery after SCAD, and their opinions on service delivery were reported. A summary of findings is shown in [Table 1](#). A perceived lack of information about SCAD for patients was a prominent theme of this review. Minor themes included living with emotional responses after SCAD and recovery needs after SCAD.

Perceived Lack of Information

One study reported that a quarter of participants stated that they received no information about SCAD after diagnosis, while most (82%) of the remainder of participants described the information they did receive as “insufficient or inadequate” [19]. Patients with SCAD perceived a lack of information on the aetiology of SCAD both in terms of the patient’s own experience, for example the ‘triggers’ of their own event, and in the broader context of SCAD [20]. In qualitative studies, participants described a lack of information across a range of areas, in regard to the cause of their SCAD, management strategies, and the prognosis after SCAD [21–23]. They described a lack of knowledge held by health professionals from the time of their diagnosis right through to continuing management later in their experience [23]. Participants also described inconsistency within the information they were provided [22]. They noted that informational content pertained more to atherosclerotic AMI, with less specific relevance to SCAD, which left an unmet need for information around physical activity and medication treatment after SCAD [21]. Indeed, very few SCAD participants (9% of $n=367$) indicated that information from a health care professional was the most helpful source they received [19].

Patients with SCAD reported that they felt the provision of more information would alleviate anxiety related to the uncertainty that they experienced following the SCAD event [20]. Furthermore, patients with SCAD felt a lack of control over their condition and feelings of being isolated and alone arising from insufficient information [20]. To overcome this problem and allay uncertainty and anxiety, SCAD participants advocated for the rapid dissemination of research to health care providers and to patients with SCAD themselves [20].

In the face of this perceived lack of information, SCAD participants explained that they conducted internet searches to find information specific to SCAD [21–23]. Reputable sources such as the Mayo Clinic or the Victor Chang Cardiac Research Institute were particularly helpful [23]. Social media support groups were also described as beneficial in recovery from SCAD for some participants, although there were some mixed reports due to inconsistency of the information provided, lack of support, or negative interactions within the groups [21–23].

Living With Emotional Responses After SCAD

Participants with SCAD also described living with a range of emotions during and after their SCAD event. One study asked SCAD participants ($n=367$) to describe their experience in one word: “scary” was the most often used word at 30.24%, while other words used were “surprising” (13.90%), “life-changing” (12%), and “traumatic” (10.35%) [19]. Other SCAD participants reported that they were “caught off guard” because of the sudden nature of SCAD, and that they felt they did not “fit” the image of an AMI patient [22]. A wide range of emotional responses were reported to have occurred at the time of the SCAD event [23]. Participants with SCAD had believed themselves to be fit and healthy before their event, and described a “roller-coaster of emotions” including shock, disbelief, confusion, fear, and anxiety in the aftermath of a SCAD event [23]. Emotional responses after SCAD had had a negative impact on participants’ mental health and could persist for months or years after SCAD [21]. Emotional responses such as anxiety accompanied a fear of recurrence and a sense of uncertainty, particularly in the context of a paucity of research and understanding about SCAD itself, its aetiology and management, and a perceived lack of control [20]. Patients with SCAD described feelings of frustration and exasperation as a result of a lack of knowledge about SCAD among health care professionals [23].

Patients with SCAD described changes to their identities and lifestyles, and a sense of isolation. Participants reported that restrictions on their lifestyles were the “most confronting” feature of having SCAD, together with a sense of grief and loss [23]. They described a loss of confidence in carrying out daily activities, of trust in their bodies, and of their identities in terms of being “not the same person as before” [23]. Patients with SCAD also reported that they reduced their participation in perceived stressors such as employment and home responsibilities in an effort to reduce their perceived risk of recurrence [20]. Other SCAD participants spoke of the difficulties in balancing several roles within families and employment that continue despite their having had SCAD, and in managing the emotional effects of SCAD on family members [23].

Recovery Needs After SCAD

In terms of recovery after SCAD, support for both physical and emotional recovery was deemed paramount. Participants with SCAD suggested that the ideal recovery program would reflect both their preference for web-based resources and a tailored cardiac rehabilitation program specifically for patients with SCAD [19]. They wanted current information about SCAD delivered in an accessible manner that addressed their information needs [19], and a tailored recovery support program with greater psychosocial support for people after SCAD [21].

Table 1 Characteristics of included studies

Author Year Country	Aim	Design Method/ Methodology Measures or analysis	Participant characteristics (n, gender, age range, time since SCAD)	Results
Wagers et al., 2018 [19] USA	To examine the role of stressful events and patient perceptions of stress associated with SCAD before and after diagnosis, and to assess patient perceptions of the helpfulness of post-SCAD resources	Cross-sectional survey Online survey Stressful events: social readjustment rating scale (modified)	n=367 97% female International cohort, mainly from USA Age, 26–71 years Range, 2 weeks to 27 years after SCAD	SCAD event was rated as highly stressful, with stressful events or extreme/unusual physical exertion in the week before the event. Post-SCAD: received verbal information from providers (72%); inadequate support (82%); most helpful information came from the internet (52%); interest in an online support group with professional leader (42%).
Bouchard et al., 2021 [20] Canada	To investigate challenges with recovery and the intervention needs of patients with SCAD	Qualitative semi-structured interviews Thematic analysis	n=15 86.7% female Age, 30–70 years	Major themes: “challenges in recovery” included navigating uncertainty, living with anxiety, and changes to identity and social isolation; “intervention needs” included unique needs including provision of additional psychosocial and peer support, and dissemination of information.
Clark et al., 2021 [22] Canada	To explore women’s descriptions of recovery after SCAD, with a focus on lifestyle management	Qualitative semi-structured interviews Interpretive description	n=7 100% female Age, 44–54 years Range, 3–18 months after SCAD	Major theme: “being lost in an unfamiliar diagnosis” Subthemes: <ul style="list-style-type: none"> • Being diagnosed with a rare disease • Swirling in an information vacuum • Finding support • Adjusting and resuming a more normal life
Murphy et al., 2022 [23] Australia	To investigate the experiences of SCAD survivors with a focus on the psychosocial effects of SCAD; to provide an in-depth understanding of the stresses and concerns faced by SCAD survivors; and to identify support needs and preferences	Qualitative focus groups Thematic analysis	n=30 in seven focus groups 90% female Age, 35–71 years (mean, 52.2 years) Mean, 6.9+/-3.4 months after SCAD	Major themes: <ul style="list-style-type: none"> • “Lack of information” • Emotional effects • Problems with self-management • Problems with family • Effects on work life • Support needs
Binnie et al., 2023 [21] UK	To explore preferences of SCAD survivors for their recovery	Qualitative semi-structured interviews Thematic analysis	n=20 95% female Age, 54.6+/-8.5 years <3 years since SCAD 60%	Major themes: <ul style="list-style-type: none"> • Education and information • Physical activity • Psychosocial support

Abbreviations: USA, United States of America; SCAD, spontaneous coronary artery dissection; UK, United Kingdom.

Online support groups provided the opportunity to meet others with SCAD and allowed participants to feel supported and not as alone in their recovery [22]. Conversely, participants in focus groups reported that they did not gain emotional support from social media groups and would prefer health care professional-facilitated face-to-face support groups [23].

Discussion

To date, the literature on the patient experience after SCAD is limited. Contained within the five articles were experiences and perspectives of patients with SCAD who accessed specialist services. Perspectives of individuals not affiliated or volunteering for research are absent. Although four in-depth qualitative studies have now been conducted with patients with SCAD [20–23], the nuanced SCAD patient experience outside developed English-speaking countries such as the United States, Canada, The Netherlands, the United Kingdom, and Australia has not been described. The included studies reported on largely White cohorts, despite SCAD having been reported in most geographical locations and within most ethnic groups [24]. Perspectives missing from the literature were those of male patients with SCAD and of families and unpaid caregivers of patients with SCAD.

This review contributes to a greater understanding of how SCAD affects wellbeing, quality of life, and lifestyle after SCAD, from the patient perspective. The included studies reported on the profound effect that SCAD had on survivors' psychosocial health and wellbeing: a wide range of emotional responses were reported, including shock, uncertainty, anxiety, and loss [22,23]. This is consistent with existing SCAD research which highlights negative psychosocial outcomes. The development of PTSD is of particular concern in survivors, with a 43% rate of PTSD reported in one SCAD sample [10]. Furthermore, younger patients with SCAD have been reported to have higher scores on both depression and anxiety measures [11].

This review found that in addition to known negative mental health outcomes such as depression and anxiety, psychological distress including social isolation and loneliness experienced after SCAD was also of concern, in particular among younger patients [20]. However, regardless of age, participants from the included studies reported negative effects on their wellbeing and quality of life after SCAD [21–23]. Participants reported an impact on their quality of life in terms of loss of identity, confidence, social roles, and relationships [23], and difficulties in managing changes in their identity after SCAD [20]. These reported effects on patients after SCAD are consistent with the literature on 'cardiac distress', describing not only widespread emotional responses but also changes to people's sense of self and independence [25].

The review found that a perceived lack of information exacerbates the negative effects of SCAD on patient

wellbeing and quality of life. Higher rates of distress after SCAD may be attributed to a lack of understanding of the disease process and uncertainty about why SCAD occurred, further compounded by lack of information from health care providers [20]. Indeed, this mirrors the literature pertaining to uncertainty in illness across both acute and chronic health conditions, including cancer and cardiovascular disease. Illness uncertainty is viewed as a stressor, and the associated anxiety reflects the fundamental negativity of the illness experience [26].

Education and psychosocial support can be key to addressing challenges in SCAD recovery [21]. Participants with SCAD in qualitative studies observed the need for a tailored approach to management programs, and for the provision of both psychological and peer support, as well as support for the family members [20,21,23]. A tailored approach to management is important given the feasibility of providing SCAD-specific service to a small group [27], particularly for those who do not have access to a major SCAD referral centre. Additionally, given the higher pre-AMI event functioning observed in patients with SCAD, tailored intervention for recovery after SCAD seems particularly important [28]. A tailored approach could also incorporate resilience training; patients with SCAD with higher resilience had lower rates of anxiety and depression [29]. A cognitive behavioural therapy-based program was reported to be beneficial to patients with SCAD for coping and adjustment following the event. Such non-pharmacological initiatives may be useful in recovery programs [30].

Peer support groups were recommended as generally beneficial by SCAD survivors, both in-person and online. Support groups provide the opportunity to meet fellow SCAD survivors who could understand their experience, although the recommendations were given with the caveat that they can be overwhelming or negative [20–23]. Health providers reported that they refer patients to such groups but cautioned against misinformation that could arise from a lack of group moderation by health professionals or if the support group has unskilled peer group leaders [27]. Greater education opportunities for health care professionals in supporting patients with SCAD can play a role in increasing the psychosocial support that professionals can offer. Communication of high quality information to both patients and their family members throughout a hospital stay is expected by patients, and when communication is poor, patients reported feeling isolated, disempowered, and frustrated [31]. The delivery of personalised care and partnership with patients are associated with an engaged patient cohort, which in turn leads to better outcomes [13].

Limitations

There are several limitations to this review. The review was limited to studies reported in the English language and the databases searched. Consequently, articles reporting on the

SCAD patient experience in non-English speaking cultures may have been missed. The heterogeneity in study design among the included articles limited the data analysis to an integrative literature review model. However, these limitations serve to underline the importance of research into psychosocial distress after SCAD and the unique needs of SCAD survivors.

Conclusion

This review found that patients with SCAD have only recently been given opportunities to provide the nuanced and detailed information that will inform service delivery and the SCAD research community at large. A perceived lack of information provided to patients with SCAD is the major theme in existing qualitative research. Patients with SCAD report a range of emotional responses in the aftermath of their condition. Psychosocial interventions, such as cognitive behavioural therapy-based groups and online peer support, have been shown to benefit patients with SCAD and can be integrated into standard care after SCAD.

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Competing Interest Statement

We report no competing interest associated with the work reported in this manuscript.

Conflicts of Interest

There are no conflicts of interest to disclose. All authors meet the four ICMJE (International Committee of Medical Journal Editors) criteria for authorship.

Author Contributions

All authors have read and approved submission of the manuscript, and the manuscript has not been published and is not being considered for publication elsewhere in whole or part in any language except as an abstract.

Appendices

Supplementary data associated with this article can be found, in the online version, at <https://doi.org/10.1016/j.hlc.2023.09.023>.

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