Spontaneous Coronary Artery Dissection (SCAD)

FEMALE SURVIVORS' EXPERIENCES OF STRESS AND SUPPORT

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Purpose: Spontaneous coronary artery dissection (SCAD) is a nonatherosclerotic type of acute myocardial infarction that primarily affects young, healthy women without typical risk factors for heart disease. Few investigations have examined psychosocial variables in this population and none have looked at patient perceptions of the experience and stresses associated with having a SCAD event or the resources currently available to SCAD survivors. This investigation describes survivors' subjective experiences of SCAD. Participants also provided information about types and helpfulness of resources available to them post-SCAD, including cardiac rehabilitation.

Methods: Participants were recruited online and completed a one-time questionnaire.

Results: Participants (n = 409) completed a questionnaire concerning their experiences with their SCAD event in the 1 y and 2 wk prior to the SCAD event. Their responses reflected moderate to high perceptions of stress. Participants experienced the SCAD event as highly stressful and frightening and their heart health presents as a moderate-severe source of current, post-diagnosis stress. Spontaneous coronary artery dissection–based informational support was frequently rated as inadequate, whereas other supportive resources varied in their helpfulness and accessibility. Participants reported positive experiences in cardiac rehabilitation and strong interest in SCAD-specific, professionally led, online patient education and support groups.

Conclusions: This study is the largest to date investigation of SCAD survivors and their experiences in this understudied and perhaps underrecognized condition. Opportunities for researchers and providers to develop, tailor, and disseminate SCAD-specific interventions are discussed.

Key Words: acute myocardial infarction • cardiac rehabilitation • psychosocial factors • spontaneous coronary artery dissection (SCAD) • women's cardiovascular disease

Spontaneous coronary artery dissection (SCAD) is an infrequent, nonatherosclerotic type of acute myocardial infarction (AMI). Spontaneous coronary artery dissection occurs when a coronary vessel develops a tear or hematoma where blood can accumulate and interrupt coronary blood flow to the myocardium.[1] A recent investigation estimated the risk of recurrence, death, AMI, and heart failure as 47% in the 10 y following an initial SCAD.[2] The precise etiology of SCAD is unclear, though there is evidence that SCAD may be precipitated by a confluence of factors including peripartum or menopausal status, hormone therapy, connective tissue disease, emotional stress, and intense physical exertion.[1,3,4] No definitive treatment guidelines existed for this subset of AMI patients at the time of the current investigation.[2,3]

Spontaneous coronary artery dissection was previously thought to be rare; as recently as 2012, the prevalence of SCAD was estimated to be between 0.07% and 1.1% of all coronary angiograms.[2] Current research has identified SCAD among 1% to 4% of patients undergoing cardiac catheterization[3] and 24% to 40% of AMIs among women younger than 50 y.[1,3] Young, physically active, otherwise healthy women are disproportionally impacted by SCAD[3]; current estimates suggest that 80% to 92% of SCAD survivors are women aged 42 to 52 y,[1–4] which is notably younger than the typical (ie, non-SCAD) female AMI patient.[5]

Although overall death rates attributable to AMI have declined significantly in the past decade, this trend has not been observed among young women aged 35 to 54 y. This discrepancy may be due to different pathophysiology of AMI in this patient demographic, as well as gendered psychosocial stressors that interact with health behaviors and biology (eg, disproportionate vulnerability to emotional stress).[5] Anecdotal reports suggest numerous psychosocial precursors and consequences of SCAD, but there is a paucity of empirical data regarding SCAD survivors' perceptions of affect, stress, or social support. Among the few investigations conducted to date, a trend has been observed for a relationship between SCAD and heightened negative affectivity. Liang and colleagues[6] found high rates of depression and anxiety symptomatology among a sample of 158 SCAD survivors. Notably, symptom severity was highest among younger females and women who experienced peripartum SCAD.[6] Another study found rates of anxiety and depression symptomatology to be comparable between SCAD and typical AMI patients.[7]

Strong links exist between stress and AMI broadly,[8,9] and social support is widely recognized as a promoter of more favorable health outcomes following a major medical diagnosis. Prior work has found associations between perceived inadequate social support and negative health outcomes, including suppressed immune functioning, prolonged recovery from illness or injury, increased risk of disease, and early mortality.[10–13] Conversely, perceived effective social support has been shown to reduce hypothalamic-pituitary-adrenal-axis reactivity[14] and reduce depression severity among AMI patients.[15]

Cardiac rehabilitation (CR) is a common referral for AMI patients, and prior work with typical coronary heart

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disease patients has found evidence for reduced stress and improved medical outcomes when stress management skills are imbedded within CR programing.[16] However, only a handful of studies have examined the impact of CR on patients' physical and emotional recovery from SCAD.[17–19] More information regarding SCAD patients' experience with CR is needed to better meet the needs of this population subset.

Spontaneous coronary artery dissection presents diagnostic and treatment challenges because of its unique pathophysiology and its presentation primarily among younger women. Informed by aforementioned gaps in the literature, the present study has 3 central aims: (1) to examine the role of stressful events during both the year and the 2 wk prior to the participants' first/initial SCAD; (2) to assess patient perceptions of stress associated with SCAD pre- and post-diagnosis; and (3) to assess patient perceptions of the helpfulness of post-SCAD resources, especially CR.

METHODS

PARTICIPANTS

Participants were recruited by responding to an online announcement of a SCAD questionnaire survey that linked to a Qualtrics survey. Recruitment announcements were widely distributed on social media outlets (eg, Facebook, Twitter) by the SCAD Alliance, a nonprofit patient advocacy and support group. Advertisements indicated that the study team was interested in contacting SCAD survivors to better understand their experience with SCAD, as well as their immediate and long-term needs post-SCAD. Recruitment materials were also distributed to other cardiovascular patient support organizations (eg, Mended Hearts, American Heart Association, and Women's Heart Alliance), cardiology groups with whom members of the SCAD Alliance collaborate, and cardiologists who treat SCAD patients. A link to access the online survey was provided at the end of the advertisements.

Eligible respondents were required to be at least 18 y of age and had experienced at least 1 SCAD by self-report. Medical verification of SCAD diagnosis was not required for entry into this study. Because there were too few men represented in the sample (n = 9) to have confidence in the generalizability of these data or to make meaningful comparisons between male and female experiences, and because 33 participants declined to identify their gender, only the data from the 367 female SCAD survivors are reported in the results.

PROCEDURES

All procedures were approved by the University of Colorado Boulder institutional review board. Recruitment announcements were widely distributed on social media (eg, Facebook, Twitter) by SCAD Alliance, a nonprofit patient advocacy and support group. Announcements indicated that the study team was interested in hearing from SCAD survivors to better understand their experiences and their immediate and long-term needs post-SCAD. At the start of the online survey, participants read an informed consent document and were required to provide consent in order to participate.

MEASURES

Stressful Life Events

The Social Readjustment Rating Scale[20] was developed to measure stressful life events experienced over the past year and has been shown to correlate positively with illness.[21] The original scale includes 43 stressful life events (eg, "death of spouse," "dismissal from work," "change in frequency of arguments"). Although the scale has been widely used, it does not account for individual perceptions of stressful events. To make the scale more accessible to participants and to capture participants' perceptions of stress, revisions were made to the original scale, resulting in a 16-item scale. First, 9 original scale items were collapsed (eg, from the original scale, 4 items, "major change in financial state," "took on a mortgage," "foreclosure on mortgage," and "taking on a loan" were reduced to a single item, "change in financial state"). Second, participants were asked about stressful events that occurred in the last year and in the 2 wk prior to their first or only SCAD in order to gather information about long- and short-term stressors present in participants' lives prior to SCAD. Third, 2 items of possible relevance to SCAD survivors were added: "conflict with a close family member or friend" and "extreme or unusual physical exertion" in the 2 wk prior to the incident of SCAD. Finally, participants rated their experience of each event using a 10-point scale ranging from 1= "not at all stressful" to 10 = "extremely stressful."

SCAD-Specific Stress Ratings

Three items were developed to specifically assess participants' subjective SCAD experiences. Participants were asked the following: (1) "In the context of other life events you have experienced, how stressful do you believe your SCAD was?" and (2) "To what extent does your heart health continue to be a source of stress for you?" Participants responded to these items using a 10-point scale ranging from 1 = "minimally stressful" to 10 = "maximally stressful." A third open-ended item asked participants to "describe the experience of SCAD using 1 word."

SCAD-Specific Information

Two items assessed participants' opinions about the information they received about SCAD following diagnosis. Specifically, participants were asked to report (1) what sources of information they were provided by their provider about SCAD at the time of their original diagnosis, (2) how they would rate the adequacy of the information they received using a categorical response format: "adequate/easy to understand," "insufficient/inadequate," or "too much/too difficult to understand," and (3) the most helpful SCAD information sources they had found post-diagnosis.

Post-SCAD Resources/Referrals

Participants reported the resources they were referred to post-SCAD (eg, counseling, stress management, CR) and how helpful they perceived each resource to be on a 10-point scale ranging from 1 = "Not at all helpful" to 10 = "Extremely helpful." Participants were also given the opportunity to provide additional comments regarding their experience with these referral sources and to report their interest in SCAD-specific patient psychosocial education and support groups on a 10-point scale ranging from 1 = "Not interested" to 10 = "Extremely interested." In addition, participants reported their preferred format for such a group (ie, in-person, online, with a professional leader, with a peer leader).

STATISTICAL ANALYSIS

Descriptive statistics only were reported. These included number and/or percentage or mean ± standard deviation.

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RESULTS

As expected, the sample was predominantly female (97.6% of participants who reported their gender on the survey). Age at the time of first SCAD ranged from 26 to 71 y (44.55 ± 8.82 y). The modal response for age at the time of first SCAD was 37 y, and the median response was between 43 and 44 y of age, nearly at the mean. Participants reported experiencing between 1 and 4 SCAD events in their lifetimes (1.26 ± 0.55), and time since last (or only) SCAD ranged from 2 wk to 27 y (2.68 y ± 3.68 y); however, 75% of the sample were within 3 y, 65% were within 2 y, and 44% were within 1 y of their most recent SCAD at the time of the survey. In addition, although the average amount of time since last (or only) SCAD was more than 2 y, the modal response on this construct was 1 mo. A total of 409 individuals provided informed consent. For the participants for whom geographical data was available (n = 379), the majority of participants were from the United States (n = 230), but responses were also collected from survivors residing in Europe (n = 63), Australia or New Zealand (n = 50), Canada (n = 35), and South Africa (n = 1).

Stressful life events experienced 1 y and 2 wk prior to the incident SCAD are reported in Table 1. Interpersonal events were prominently endorsed. The most commonly cited stressful event experienced 1 y prior to the first SCAD was "change in employment or responsibilities at work," and the next 3 most frequently cited events were "change in health of a family member," "intimate partner conflict," and "death of a close family member or friend." Regarding sources of stress in the 2 wk prior to SCAD, the most commonly endorsed item was "extreme or unusual physical exertion." The next 3 most frequently cited events were "intimate partner conflict," "change in employment status/responsibilities," and "conflict with a close family member or friend."

On average, participants experienced the SCAD itself as highly stressful (mean stress rating = 8.62 ± 1.79) and reported that their heart health continues to be a source of stress in their daily lives (6.81 ± 2.42). Notably, when asked to describe the experience of SCAD in 1 word, the most commonly reported descriptor category was "scary" (30.24%), followed by "surprising" (13.90%), "life changing" (12%), "traumatic" (10.35%), and "uncertain" (7.63%).

Table 2 reports SCAD-specific information received or obtained post-diagnosis. A majority of participants reported receiving "verbal information from their doctor" (66%) at the time of their SCAD diagnosis, but more than one-quarter reported receiving "no information about SCAD" (26%). A substantial majority of participants (82%) reported that the quality of the information they received at the time of SCAD diagnosis was "insufficient/inadequate." Far fewer (17%) reported that the information was "adequate/easy to understand." More than half of the sample (52%) identified "internet searches" as the most helpful SCAD information source they found post-diagnosis. In contrast, only 9% of participants identified information provided by "doctors and/or other health care professionals" as most helpful.

Table 3 displays the referrals participants received post-SCAD, as well as average helpfulness ratings: 72% of survey participants were referred to CR, and the 2 highest helpfulness ratings were attributed to CR and "exercise programs other than CR," which participants described as customized exercise programs. The average helpfulness rating for these customized exercise programs was similar to that reported for CR (7.00 vs 6.84).

Participants reported strong interest overall in participating in a SCAD-specific patient psychosocial education or support group with a notable preference for online patient groups with a professional leader. Far fewer participants reported interest in an online or in-person peer-facilitated group (see Table 3).

DISCUSSION

Spontaneous coronary artery dissection is an understudied cardiac event that is more prevalent among young women who typically do not display traditional heart disease risk factors. Unfortunately, there remains a dearth of data addressing the psychosocial experiences of this unique group. The goals of this study were to describe the experience of stress

Table 1

Social Readjustment Rating Scale Ratings: 1 y and 2 wk Prior to First (or Only) SCAD Event[a]

Stressful Life Events[b]	1 y Prior to First (or Only) SCAD		2 wk Prior to First (or Only) SCAD	
Death of a close family member or friend	68 (19)	7.79 ± 1.75	22 (6)	7.95 ± 1.79
Divorce or separation from spouse/partner	24 (7)	8.22 ± 2.41	6 (2)	8.00 ± 2.00
Personal injury or illness	68 (19)	6.57 ± 2.22	46 (13)	6.91 ± 2.20
Change in employment status/responsibilities	121 (33)	7.13 ± 2.16	57 (16)	7.71 ± 1.82
Change in employment status for spouse/partner	39 (11)	6.13 ± 2.65	9 (3)	7.22 ± 2.05
Change in health of family member	90 (25)	7.44 ± 2.01	39 (11)	7.89 ± 2.09
Pregnancy	61 (16)	5.69 ± 2.71	42 (11)	6.19 ± 2.71
Intimate partner conflict	88 (24)	7.56 ± 1.64	68 (19)	7.30 ± 1.75
Conflict with close family member or friend	67 (18)	7.52 ± 1.97	51 (14)	8.04 ± 1.92
Change in financial state	65 (18)	7.09 ± 1.95	27 (7)	7.22 ± 1.60
Son or daughter leaving home	38 (10)	6.03 ± 2.52	11 (3)	7.00 ± 2.72
Begin or end school	25 (7)	6.36 ± 2.38	18 (5)	6.22 ± 2.56
Change in living conditions or residence	59 (16)	6.86 ± 2.37	18 (5)	7.78 ± 1.40
Change in recreation or social activities	44 (12)	5.32 ± 2.79	14 (4)	4.79 ± 2.69
Legal problems	17 (5)	8.00 ± 1.66	6 (2)	8.00 ± 1.67
Extreme or unusual physical exertion[c]	n/a	n/a	119 (32)	6.3 ± 2.76

Abbreviations: n/a, not available; SCAD, spontaneous coronary artery dissection.

[a]Data reported as number (%) or mean ± standard deviation.

[b]Life event stressfulness rated on a 10-point Likert-type scale ranging from 1 = "Not at all stressful" to 10 = "Extremely stressful."

[c]Ratings for "extreme or unusual physical exertion" only collected for the 2-wk prior time period prior to first (or only) SCAD.

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Table 2

Spontaneous Coronary Artery Dissection–Specific Information Received or Obtained Post-Diagnosis

	n (%)
Information provided by provider at the time of SCAD diagnosis[a]	
Verbal information from medical provider	265 (72)
No information about SCAD	97 (26)
Written information from a SCAD- or heart-focused organization (eg, SCAD Alliance, American Heart Association)	45 (12)
Scientific papers about SCAD	16 (4)
Information about a cardiovascular/heart disease other than SCAD	9 (3)
Recruitment information for SCAD-related research study	5 (1)
Information about SCAD obtained from the internet	5 (1)
Information from other sources not listed	5 (1)
Perceived quality of information received from provider at the time of diagnosis	
"Too much/too difficult to understand"	2 (0.5)
"Adequate/easy to understand"	64 (17)
"Insufficient/inadequate"	299 (82)
Most helpful sources of SCAD information obtained post-diagnosis	
Internet search	191 (52)
Support/education associations	97 (26)
Academic/professional journal articles	36 (10)
Doctor and/or other health care professionals	32 (9)
Facebook page for SCAD survivors	7 (2)
Other survivors' word of mouth	4 (1)

Abbreviation: SCAD, spontaneous coronary artery dissection.

[a]Percentages not cumulative because participants were asked to select all options that applied.

prior to, during, and after SCAD, as well as the kinds of, and preferences for, supportive resources for patients post-SCAD.

Stress experienced at work and among family, negative life events, and deficient social networks are all known to contribute to risk for cardiovascular disease among women.[22,23] The present study is only suggestive in this regard, but the finding that SCAD patients experienced similar psychological stressors prior to their SCAD as what has been observed among female patients with cardiovascular disease more broadly warrants attention. Post-SCAD, respondents described their heart health as an ongoing source of worry and stress, consistent with the few investigations previously conducted on the relationship between SCAD and negative affectivity.[6,7]

The possible role of intense physical exertion in relation to SCAD has been noted elsewhere,[1,3,5] and our finding that nearly one-third of the sample engaged in extreme or unusual physical exertion in the 2 wk prior to their SCAD further underscores the possibility of a connection between intense physical exertion and SCAD. A recent study by Smyth and colleagues[9] found associations between exertion, stress, and AMI but did not specify whether SCAD survivors were represented in the sample. Future work should seek to further elucidate the pathophysiological mechanisms that link these factors in SCAD and AMI more broadly.

In general, participants reported that the information they received from their providers was "insufficient/inadequate," which may reflect providers' relative unfamiliarity with SCAD. As a result, survivors may seek information on the internet. In the present study, more than half of the sample indicated internet sources as the most helpful SCAD resources obtained post-diagnosis. Our results suggest that SCAD survivors are searching for more informational support than they can currently access, which may have important implications for their post-SCAD stress and coping strategies. Health literacy, the degree to which individuals can obtain, process, understand, and apply health-related information, is associated with better health outcomes, improved patient compliance, and reduction of health care costs.[24] To this end, education of health care personnel who interact with SCAD patients is critical, as is the provision of accessible, thorough, and accurate didactic materials for survivors.

Among our sample, CR programs were the most common referral source and were perceived as quite helpful by many participants, consistent with previously cited reports finding both physical and emotional benefits of CR for SCAD survivors.[17–19] Nonetheless, some participant comments revealed that the focus of a "typical" CR program was not a good fit for their age, gender, and/or prior activity level. For example, 1 participant noted that she felt "isolated during cardiac rehabilitation." She continued, "I was female, much younger, athletic, a non-smoker and otherwise very active and physically fit." Another noted that the activities in her CR program "were geared towards your standard heart attack patient." A third participant observed that in her health care community, "all of the help available is for elderly people with heart disease."

Table 3

Referral Resources and Preferred Post-SCAD Treatments[a]

		Perceived Program Helpfulness[b]
Referral resources offered post-SCAD		
Cardiac rehabilitation	265 (72)	6.84 ± 3.06
Counseling	91 (25)	6.25 ± 2.70
Heart-specific support groups	59 (16)	5.64 ± 3.11
Stress management	36 (10)	5.97 ± 2.61
Exercise programs other than cardiac rehabilitation	25 (7)	7.00 ± 3.06
"Other" sources of support	9 (3)	4.00 ± 3.37
Interest in psychosocial interventions post-SCAD		
Online patient education/support group with a professional leader	168 (46)	…
In-person patient education/support group with a professional leader	99 (27)	…
Online peer-facilitated patient education/support group	29 (8)	…
Not interested in participating in a psychosocial support group	31 (8)	…
In-person peer-facilitated patient education/support group	25 (7)	…
Interested in "other" psychosocial support group not listed	10 (3)	…

Abbreviation: SCAD, spontaneous coronary artery dissection.

[a]Data reported as number (%) or mean ± standard deviation.

[b]Program helpfulness rated on a 10-point Likert scale ranging from 1 = "Not at all helpful" to 10 = "Extremely helpful."

FUTURE DIRECTIONS

The appeal of an online SCAD-specific program is in keeping with the times. Support has been growing in the literature for web-based psychotherapy and psychoeducational interventions.[25,26] Spontaneous coronary artery dissection survivors may be an ideal population for such a dissemination strategy, given their inclination to utilize internet resources and potential to be widely dispersed geographically.

Chou and colleagues[19] investigated a dedicated CR program for SCAD patients, including a tailored exercise program with psychosocial components, and found that this resulted in improvements in SCAD patients' chest pain, exercise capacity, psychosocial well-being, and cardiac events.[19] The study by Chou et al, combined with the results presented in this study, suggests that integration of psychosocial services within a SCAD-specific CR program may help address needs of this unique population.

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Taken together, these findings suggest that an ideal intervention package would be one that considers SCAD survivors' preference for high-quality web-based resources (both educational and therapeutic) and their desire for tailored CR programs. Accessible educational content would provide the most up-to-date literature regarding SCAD pathology, treatment, and prognosis so as to bolster patients' health literacy. Similarly, therapeutic support (delivered by a professional via the web platform) would implement evidenced-based strategies for stabilizing negative effect, reducing stress reactivity, and supporting commitment to daily appointments/goals (eg, "attend CR"). Given the lack of consensus for post-SCAD exercise guidelines, survivors may experience confusion and stress regarding resumption of physical activity post-diagnosis. Our findings suggest potential benefit for creating tailored exercise programs for SCAD patients enrolled in CR. Uniting several lines of research, efforts are currently underway to develop and test the feasibility and effectiveness of an app-based intervention package for SCAD survivors.

LIMITATIONS

The population surveyed constituted a convenience sample of survivors who provided self-report information that could not be corroborated by medical records; thus, the results are subject to potential recall bias or including patients who may not have had SCAD. Another limitation of this study is that the experiences of individuals whose SCAD was ultimately fatal are not represented here. The use of author-generated revisions to an assessment battery without prior validation of changes may also be considered a limitation. More broadly, there may be differences between patients who frequent patient support group social media sites (ie, the SCAD Alliance Facebook page) and those who do not. However, given the low prevalence rates of SCAD, social media sites may pose the most efficient way to reach a wide range of survivors from around the world, as evidenced by the present investigation. Finally, future work in this area may benefit from a focused effort to sample more broadly from male SCAD survivors so as to better inform treatment planning and meet the diverse needs of this patient population. Despite these limitations, the present study represents the largest examination to date of SCAD survivors from around the world and their experiences with a condition that has been grossly understudied.

CONCLUSIONS

Although not as rare as previously thought, SCAD is an unusual and understudied diagnosis. Results suggest that survivors desire psychosocial support and high-quality, accessible information about SCAD. Given reports from respondents regarding a lack of quality information received from health care providers post-diagnosis, educating health care professionals about SCAD is essential. As SCAD patients are routinely referred to CR, CR programs may have unique opportunities to provide this population with tailored support, services, and information. Future intervention work may elucidate current questions regarding the feasibility and effectiveness of web-based psychosocial support and educational resources intended to enhance patients' post-SCAD adjustment.

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