

# Patients' perspective of quality-of-care and its correlation to quality-of-life following spontaneous coronary artery dissection

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## Aims

Spontaneous coronary artery dissection (SCAD) is an under-recognized cause of myocardial infarction. We aimed to investigate SCAD survivors' perceptions of their quality-of-care and its relationship to quality-of-life.

## Methods and results

An anonymous survey was distributed online to SCAD survivors involved in Australian SCAD support groups, with 172 (95.3% female, mean age  $52.6 \pm 9.2$  years) participants in the study. The survey involved assessment of quality-of-life using a standardized questionnaire (EQ-5D<sup>TM</sup>-3L). Respondents rated the quality-of-care received during their hospital admission for SCAD with a median of 8/10 [interquartile range (IQR) 7–10]. Respondents  $\leq 50$  years vs.  $>50$  years were more likely to perceive that their symptoms were not treated seriously as a myocardial infarction ( $\chi^2 = 4.127$ ,  $df = 1$ ,  $P < 0.05$ ). Participants rated clinician's knowledge of SCAD with a median of 4/10 (IQR 2–8) and 7/10 (IQR 3–9) for Emergency and Cardiology clinicians, respectively ( $P < 0.05$ ). The internet was the most selected source (45.4%) of useful SCAD information. The mean EQ-5D<sup>TM</sup> summary index was 0.79 (population norm 0.87). A total of 47.2% of respondents reported a mental health condition diagnosis, with 36% of these diagnosed after their admission with SCAD. Quality-of-life was significantly associated with perceived quality-of-care: EQ-5D<sup>TM</sup> index/(1-EQ-5D<sup>TM</sup> index) increased by 13% for each unit increase in quality-of-care after adjusting for age and comorbidities ( $P < 0.001$ ).

## Conclusion

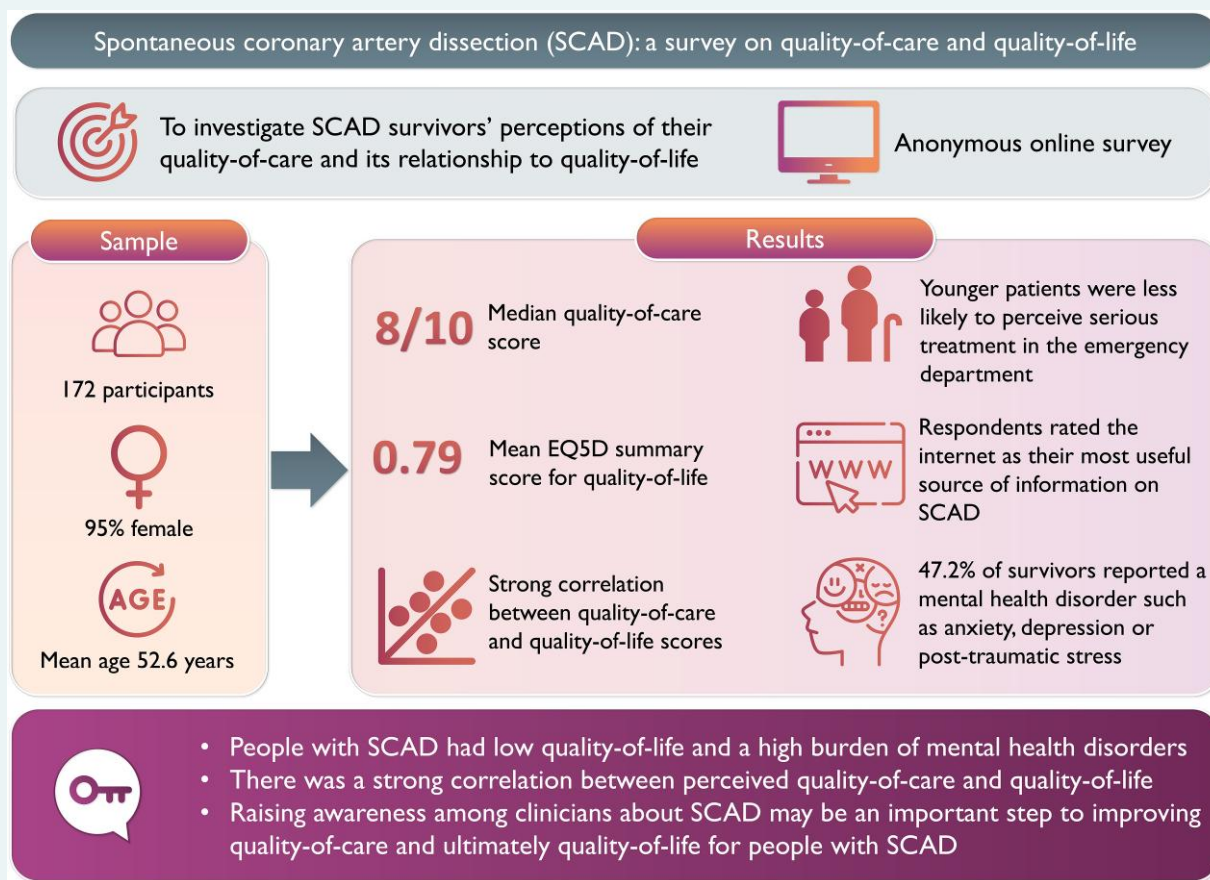
While SCAD survivors rated their overall hospital care highly, healthcare providers' knowledge of SCAD was perceived to be poor, and the most common source of SCAD information was the internet. Mental health conditions were common, and a significant association was observed between perceived quality-of-care and SCAD survivors' quality-of-life.

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## Graphical Abstract



## Keywords

Quality-of-care • Quality-of-life • Spontaneous coronary artery dissection

## Novelty

- There is a deficit in communication between clinicians and spontaneous coronary artery dissection (SCAD) survivors, with a perceived lack of knowledge among clinicians and the internet being the most useful source of information for survivors.
- People with SCAD of younger age were more likely to perceive that their symptoms were taken less seriously in the emergency department.
- Quality-of-life of SCAD survivors was lower than population norm, with high burden of mental health disorders.
- Perceived quality-of-care of SCAD was highly associated with quality-of-life.

## Introduction

Spontaneous coronary artery dissection (SCAD) is a cause of acute myocardial infarction, typically affecting younger women without traditional cardiovascular disease (CVD) risk factors. Previously thought to be a rare condition, SCAD is now known to cause 2–4% of acute coronary syndrome, with a strong female (~90%) predominance.<sup>1–4</sup> Our understanding of SCAD is still incomplete. While the first clinical consensus documents to guide the management of SCAD were published in 2018,<sup>5,6</sup> it is likely that many clinicians still have a limited understanding of the disorder. Recent qualitative work has shown that patients with SCAD feel that they receive insufficient and inadequate information from their healthcare providers at the time of diagnosis.<sup>7,8</sup> The internet is more commonly rated as the most helpful information

source, than are doctors or other healthcare professionals.<sup>9</sup> This lack of awareness of SCAD in clinicians is likely to contribute to mental distress following SCAD<sup>7,9</sup> and may impair the quality-of-care received. A 2020 survey reported that up to a third of patients with SCAD were not diagnosed at the time of their myocardial infarction (MI).<sup>10</sup>

Spontaneous coronary artery dissection is far from a benign condition, with the rate of in-hospital and long-term major adverse cardiovascular events as high as 10% and 20%, respectively.<sup>11–14</sup> As SCAD predominantly affects young and middle-aged women (median age: 51 years), its impact on survivors' quality-of-life and mental health is likely to be significant. A recent study<sup>15</sup> suggested that younger age was associated with poorer treatment in the emergency department (ED), perhaps related to the perception that younger women are less likely to have MI. Numerous studies have demonstrated high levels

of stress, anxiety, and other mental health challenges during the first year after SCAD.<sup>9,16–18</sup> Indeed, there is evidence that rates of anxiety, depression, and distress may be higher in SCAD survivors than in those with typical atherosclerotic MI.<sup>10,19–21</sup> It is unclear if SCAD is a risk factor for the development of mental health issues, or if mental health issues are risk factors for SCAD, particularly given that stress is commonly cited as a precipitating trigger for SCAD.<sup>5,22–25</sup> No studies have yet investigated the relationship between SCAD onset, the quality-of-care received, and mental health status.

Therefore, the aim of this study was to investigate SCAD survivors' perceptions of their healthcare providers' knowledge of SCAD, the quality-of-care received at the time of their SCAD diagnosis and treatment, and the relationship between these factors and SCAD survivors' quality-of-life and mental health. A secondary aim of the study was to investigate the relationship between SCAD survivors' age and perceptions of the quality-of-care received.

## Methods

### Study population and recruitment procedure

The study was approved by the Human Research Ethics Committee (HREC) of Western Sydney Local Health District, Australia. Eligible participants were those who had been diagnosed with SCAD and were aged over 18. Eligible individuals were invited to participate in an online anonymous survey, between September and October 2022, which was distributed as follows: (i) posting the details and link to the survey on the Australian SCAD Survivors Facebook group, a private social media group for individuals diagnosed with SCAD, or (ii) emailing SCAD survivors on the email list of SCAD Research Incorporated, an Australia non-government funded charity dedicated to SCAD research and awareness. The social media group consisted of 1100 members, and the email list consisted of 90 email addresses. Therefore, the maximum number of people who were approached to participate in the survey was 1190. The Facebook post and email were repeated twice to increase participant recruitment. Study data were collected and managed using REDCap electronic data capture tools hosted at the University of Sydney. Research Electronic Data Capture (REDCap) is a secure, web-based software platform designed to support data capture for research studies. The REDCap database could only be accessed by authorized researchers with password-protected accounts. The database also recorded audit trails for tracking data manipulation and export procedures.

### Measures

The survey involved completing an online questionnaire that included a set of demographic questions, namely age, identified gender, place of residence (postcode), and ethnicity (choice of one out of seven options, and one free text option, in case the participant could not choose any of the provided options). Medical information collected included past medical history, number of SCAD episodes, time since most recent SCAD episode, symptoms of SCAD, and time from symptom onset to medical attention. To assess quality-of-care from a patient's perspective, participants rated their overall care (scale of 1—'Incredibly poor care' to 10—'Best care'), time from presentation to consideration of SCAD diagnosis, level of satisfaction with provided SCAD information (five-level Likert scale from 'Completely satisfied' to 'Completely dissatisfied'), most useful source of information (free text), the receipt of treatment for SCAD (antiplatelets, beta-blockers, statins, percutaneous coronary intervention, or coronary bypass surgery), screening for fibromuscular dysplasia (FMD) (Yes/No), referral to cardiac rehabilitation (Yes/No), and cardiologist follow-up (Yes/No). To assess for the seriousness of treatment in the ED, participants rated the statement 'In the Emergency Department, my symptoms were treated seriously as a heart attack (myocardial infarction)' using a five-level Likert scale from strongly disagree to strongly agree. Participants rated the level of knowledge of SCAD of their treating clinicians (e.g. emergency physicians and attending cardiologists) on a scale of 1—'not knowledgeable at all' to 10—'very knowledgeable'. The EuroQol-5 Dimensions-3 Levels (EQ-5D<sup>TM</sup>-3L) health outcomes instrument was used to assess quality-of-life. The five-item EQ-5D<sup>TM</sup>-3L has been shown to have good psychometric properties when used with cardiac patients.<sup>26</sup> Participants rated their own health on the EQ-5D<sup>TM</sup> Visual Analogue Scale

(from 0 to 100). An EQ-5D<sup>TM</sup> summary index (EQ index) was calculated using a formula validated for the Australian population.<sup>27</sup> Chest pain symptoms were assessed using the Seattle angina questionnaire, which has been used previously with SCAD and cardiac patients.<sup>19,28–30</sup> Participants indicated whether they had been diagnosed with a mental health illness, including depression, anxiety, or post-traumatic stress disorder (PTSD) and the timing of this relative to their first episode of SCAD. Finally, participants were asked to make comments (free text) regarding their priority for future research with regards to SCAD. The full survey is shown in [Supplementary material online, File S1](#).

### Statistical analyses

Findings were reported as counts and frequencies for all variables. Means and standard deviations were calculated and reported for parameters with normal distribution while median and interquartile range were reported for non-normally distributed ones. Chi-square tests were used to assess associations for categorical variables and paired *t*-tests for continuous variables. When assumptions were violated, the Mann–Whitney *U* test was used. The primary objective was assessed using a beta regression with a logit link function and a transformation  $([EQ\ index(N - 1) + 1/2]/N)$ , where *N* is the sample size) to deal with a EQ index score of 1, adjusting for age and whether the patient had any comorbidities. The data were analysed using IBM SPSS Statistics (Version 29).

## Results

A total of 183 questionnaire responses were received, with 11 excluded as responses had been left blank, leaving 172 responses eligible for analysis.

### Demographic and clinical characteristics of respondents

Participants' demographic and clinical characteristics are shown in [Table 1](#). The median age of participants was 52 years, with a median of 22.0 and 15.5 months having elapsed since the time of their first and most recent SCAD diagnosis, respectively. The majority of participants was female (95.3%) and Caucasian (92.4%). Few respondents had cardiovascular risk factors. A total of 30.2% respondents had a diagnosed mental health condition prior to their SCAD diagnosis, most commonly depression and/or anxiety. Most reported that their SCAD episode was managed conservatively and 61% reported screening for FMD.

### Ratings of quality-of-care and clinician's knowledge of spontaneous coronary artery dissection

Parameters related to the quality-of-care of patients with SCAD are provided in [Table 2](#). A diagnosis of SCAD was considered on the day of presentation in 57.9% of respondents, and not diagnosed at all during their index admission in 14.5%. Two-thirds (66.3%) of respondents agreed that their symptoms of SCAD were treated seriously as a MI in the ED, and over half (53.5%) were satisfied or completely satisfied with the information about SCAD provided by their doctors. Participants rated their overall care as a median 8 out of 10 (IQR 7–10). Respondents rated their emergency clinicians knowledge of SCAD significantly lower than that of their cardiology clinicians (mean 4.6 vs. 6.4,  $t = -6.459$ ,  $df = 126$ ,  $P < 0.001$ ). A small proportion (9.4%) of respondents did not attend cardiac rehabilitation despite being referred to it, with the most common barrier to attendance being 'discomfort of being with dissimilar fellow patients (26%)'. Of those who did attend cardiac rehabilitation ( $n = 106$ ), most (78.9%) found that the programme was helpful yet most

**Table 1** Demographic and clinical characteristics of respondents

| Respondent characteristics                                    | n (%)           |
|---|-----------------|
| Age (median in years, interquartile range), n = 170           | 52 (IQR 46–58)  |
| Female, n = 172   | 164 (95.3%)     |
| Ethnicity, n = 167  |                 |
| Caucasian   | 159 (92.4%)     |
| Aboriginal and/or Torres Strait Islander                      | 4 (2.3%)        |
| Asian   | 3 (1.7%)        |
| African   | 1 (0.6%)        |
| Other   | 5 (2.9%)        |
| Comorbidities and CVD risk factors                            |                 |
| Hypertension  | 31 (18%)        |
| Hypercholesterolaemia   | 7 (4.1%)        |
| Diabetes  | 3 (1.7%)        |
| Cigarette smoking (ever)                                      | 35 (20.3%)      |
| Autoimmune/connective tissues disease/FMD                     | 28 (16.3%)      |
| Other   | 31 (18.0%)      |
| Family history of cardiovascular disease                      | 41 (23.8%)      |
| Mental health diseases prior to SCAD—n = 159                  | 48 (30.2%)      |
| Depression  | 34 (21.4%)      |
| Anxiety   | 31 (19.5%)      |
| PTSD  | 11 (6.9%)       |
| Number of SCAD episodes, n (%), n = 170                       |                 |
| 1   | 132 (77.6)      |
| 2   | 27 (15.9)       |
| 3   | 10 (5.9)        |
| 4   | 1 (0.6)         |
| Time since first SCAD episode (months), median (IQR), n = 169 | 22.0 (5.8–52.0) |
| Time since most recent SCAD episode (months), median (IQR)    | 15.5 (4.3–35.8) |
| Symptoms of SCAD  |                 |
| Chest pain  | 119 (69.2%)     |
| Arm pain  | 79 (45.9%)      |
| Nausea/vomiting   | 60 (34.9%)      |
| Dizziness   | 54 (30.8%)      |
| Neck or throat pain   | 50 (29.1%)      |
| Shortness of breath   | 45 (26.2%)      |
| Syncope   | 8 (4.7%)        |
| Time from symptom onset to first medical contact, n = 159     |                 |
| <24 h   | 141 (88.7%)     |
| >24 h   | 17 (10.7%)      |
| Uncertain   | 1 (0.6%)        |

N = 172.

FMD, fibromuscular dysplasia; SCAD, spontaneous coronary artery dissection; PTSD, post-traumatic stress disorder; CVD, cardiovascular disease; IQR, interquartile range.

(77.4%) were interested in a SCAD-specific cardiac rehabilitation programme. In terms of the most useful source of information about SCAD, almost half (45.4%) the respondents nominated the

internet whereas only one in five (19.7%) nominated healthcare providers.

## Correlation between quality-of-care and quality-of-life

Quality-of-life was highly associated with perceived quality-of-care [odds ratio (OR) = 1.13,  $P < 0.001$ ] after adjusting for age and patient comorbidities. The interpretation of the beta regression model with a logit link is that the EQ index on the odds scale [EQ index/(1-EQ index)] increased by 13% for each unit increase in perceived quality-of-care. The EQ index increased by 22% for every decade of increasing age (OR = 1.02,  $P = 0.022$ ) and decreased by 31% in the presence of a comorbidity (OR = 0.69,  $P = 0.023$ ).

## Respondents' quality-of-life and mental health

Quality-of-life, post-SCAD mental health disorders, and the results of the Seattle angina questionnaire are reported in [Table 3](#). The mean EQ-5D<sup>TM</sup>-3L index score and mean visual analogue scale score were 0.79 and 71.78, respectively. Quality-of-life appeared to be mostly affected in the three domains of usual activities, pain/discomfort, and anxiety/depression, while mobility and self-care were relatively unaffected. A total of 15.7% of respondents reported developing a mental health disorder after their first episode of SCAD, and amongst those who reported this, anxiety (11%) and PTSD (8.7%) were most common.

## Association between spontaneous coronary artery dissection survivors' age and ratings of care received

Respondents aged  $\leq 50$  were more likely than their older counterparts (aged  $> 50$  years) to feel that their MI had not been treated seriously in the ED ( $\chi^2 = 4.730$ ,  $df = 1$ ,  $P = 0.03$ ). The overall quality-of-care rating was similar for both age groups (mean score 7.4 and 8.1, respectively; Mann-Whitney  $U = 3232.5$ ,  $P = 0.24$ ). Levels of satisfaction with the information on SCAD provided by their doctor did not vary significantly by age (Mann-Whitney  $U = 3213.5$ ,  $P = 0.38$ ) ([Table 4](#)).

## Spontaneous coronary artery dissection survivor's research priorities and concerns

The following research priorities were identified by SCAD survivors, in order of frequency: (i) understanding the underlying reason for SCAD, (ii) improving the quality of medical care for SCAD, (iii) research into the best medical treatments for SCAD, (iv) improving the public awareness of SCAD, and (v) improving understanding of the genetic basis for SCAD.

A total of 133 participants answered the question regarding priority for future research in SCAD using free text. Many also used this free text field to make comments on their experience with SCAD. The overarching theme of these comments was a lack of information, including as follows: (i) a lack of awareness among healthcare providers and the public, (ii) a need for SCAD-specific rehabilitation, and (iii) the mental health and quality-of-life impact of SCAD on survivors. Detailed comments are available in [Supplementary material online, File S2](#).

## Discussion

This study investigated Australian SCAD survivors' perception of their quality-of-care and their healthcare provider's knowledge of SCAD. While SCAD survivors rated their overall quality-of-care as a median

**Table 2** Quality-of-care parameters of patients with spontaneous coronary artery dissection

| Respondent characteristics   | n (%)       |
|--|-------------|
| Self-reported time from presentation to consideration of SCAD diagnosis—n = 159  |             |
| <1 day   | 92 (57.9%)  |
| 2–3 days   | 32 (20.1%)  |
| >3 days  | 12 (7.5%)   |
| Not diagnosed at index presentation  | 23 (14.5%)  |
| Overall quality-of-care rating out of 10, mean (SD)—n = 156  | 7.8 (2.4)   |
| Survivor's perception that their symptoms were treated seriously as a heart attack in the emergency department—n = 159 |             |
| Strongly agree   | 75 (43.6%)  |
| Agree  | 39 (22.7%)  |
| Neither agree nor disagree   | 12 (7%)     |
| Disagree   | 17 (9.9%)   |
| Strongly disagree  | 16 (9.3%)   |
| Satisfaction with information about SCAD provided by the doctor—n = 159  |             |
| Completely satisfied   | 31 (19.5%)  |
| Satisfied  | 54 (34%)    |
| Neutral  | 29 (18.2%)  |
| Dissatisfied   | 34 (21.4%)  |
| Completely dissatisfied  | 11 (6.9%)   |
| Clinicians' knowledge of SCAD rating   |             |
| Emergency department, median out of 10 (IQR)—n = 134   | 4 (2–8)     |
| Cardiology department, median out of 10 (IQR)—n = 147  | 7 (3–9)     |
| Most useful source for SCAD information  |             |
| Internet   | 60 (45.4%)  |
| Support groups   | 45 (34.1%)  |
| Healthcare providers   | 26 (19.7%)  |
| Other  | 1 (0.8%)    |
| Medical and surgical treatment received for SCAD   |             |
| Aspirin  | 143 (83.1%) |
| Second antiplatelet agent  | 100 (58.1%) |
| Beta-blockers  | 136 (79.1%) |
| Statins or other cholesterol reducing agents   | 93 (54.1%)  |
| ACEI/ARB   | 5 (2.9%)    |
| Stenting or balloon angioplasty  | 16 (9.3%)   |
| Coronary artery bypass surgery   | 4 (2.3%)    |
| Attended cardiologist follow-up after SCAD episode—n = 159   |             |
| Yes  | 151 (95%)   |
| No/uncertain   | 8 (5%)      |
| Awareness that FMD is associated with SCAD—n = 160   |             |
| Yes  | 142 (88.8%) |
| No/uncertain   | 18 (11.2%)  |

Continued

**Table 2** Continued

| Respondent characteristics   | n (%)           |
|--|-----------------|
| FMD screening—n = 159  |                 |
| Yes  | 104 (65.4%)     |
| No/uncertain   | 55 (34.6%)      |
| FMD diagnosis  |                 |
| Yes  | 24/104 (23.1%)  |
| No/uncertain   | 80/104 (76.9%)  |
| Cardiac rehabilitation referral—n = 158                              |                 |
| Yes  | 119 (75.3%)     |
| No   | 39 (24.7%)      |
| Cardiac rehabilitation engagement—n = 170                            |                 |
| Fully completed programme/still in the programme                     | 88/117 (75.2%)  |
| Attended the programme but did not fully complete                    | 18/117 (15.4%)  |
| Did not attend the programme   | 11/117 (9.4%)   |
| Cardiac rehabilitation type—n = 165                                  |                 |
| General cardiac rehabilitation                                       | 107/112 (95.5%) |
| SCAD-specific cardiac rehabilitation                                 | 5/112 (4.5%)    |
| Helpfulness of cardiac rehabilitation—n = 170                        |                 |
| Helpful  | 48/104 (46.2%)  |
| Somewhat helpful   | 34/104 (32.7%)  |
| Neutral  | 10/104 (9.6%)   |
| Somewhat unhelpful   | 5/104 (4.8%)    |
| Unhelpful  | 7/104 (6.7%)    |
| Barriers to cardiac rehabilitation attendance                        |                 |
| Discomfort of being with dissimilar fellow patients                  | 31/119 (26.0%)  |
| Unsuitable rehabilitation programme                                  | 19/119 (16.0%)  |
| Lack of time   | 14/119 (11.8%)  |
| COVID-19-related   | 11/119 (9.2%)   |
| Rehabilitation centre not being nearby                               | 10/119 (8.4%)   |
| Interest in a SCAD-specific cardiac rehabilitation programme—n = 106 |                 |
| Yes  | 82 (77.4%)      |
| No/not sure  | 16 (22.6%)      |

N = 172.

ACEI, angiotensin-converting-enzyme inhibitor; ARB, angiotensin receptor blocker; SCAD, spontaneous coronary artery dissection; FMD, fibromuscular dysplasia; COVID-19, coronavirus disease.

8 out of 10, healthcare provider's knowledge of SCAD was perceived to be poor, and the most common source of information on SCAD was the internet. Pre-existing mental health conditions were common in SCAD survivors, occurring in 30.2%, with a new mental health diagnoses post-SCAD reported in 17%. While the majority of SCAD survivors agreed their symptoms had been treated seriously as a MI, younger patients were significantly less likely than their older counterparts to report this. We found a significant association between SCAD survivors' perceived quality-of-care and their quality-of-life.

We found that SCAD survivors' perception of their treating clinicians' knowledge on SCAD, particularly within the ED, was poor. Two-thirds of respondents reported that their condition had been treated seriously in the ED; findings consistent with a recent study by Stevens *et al.*<sup>15</sup> with 71% of their cohort reporting serious treatment and 10% reporting dismissal treatment. While emergency clinicians

**Table 3** Quality-of-life parameters

| EQ-5D™ questionnaire                     |               |           |                  |                 |                    |
|--|---------------|-----------|------------------|-----------------|--------------------|
|  | Mobility      | Self-care | Usual activities | Pain/discomfort | Anxiety/depression |
| Level 1, n (%)                           | 141 (90%)     | 154 (98%) | 92 (59%)         | 82 (52%)        | 77 (49%)           |
| Level 2, n (%)                           | 16 (10%)      | 3 (2%)    | 62 (39%)         | 75 (48%)        | 71 (46%)           |
| Level 3, n (%)                           | 0 (0%)        | 0 (0%)    | 3 (2%)           | 0 (0%)          | 8 (5%)             |
| EQ-5D™ summary index, mean (±SD)         | 0.79 (±0.16)  |           |                  |                 |                    |
| EQ-5D™ visual analogue scale, mean (±SD) | 71.78 (±15.6) |           |                  |                 |                    |
| Seattle angina questionnaire             |               |           |                  |                 |                    |
| Physical limitation—n = 152              | 78.9 (±19.9)  |           |                  |                 |                    |
| Angina frequency—n = 154                 | 84 (±18.3)    |           |                  |                 |                    |
| Quality-of-life—n = 154                  | 63.4 (±25.7)  |           |                  |                 |                    |
| Summary score—n = 152                    | 67.7 (±17.2)  |           |                  |                 |                    |
| Post-SCAD mental health issues—n = 159   |               |           |                  |                 |                    |
| Depression                               | 12 (7.5%)     |           |                  |                 |                    |
| Anxiety                                  | 19 (11.9%)    |           |                  |                 |                    |
| PTSD                                     | 15 (9.4%)     |           |                  |                 |                    |

N = 172.

EQ-5D™, EuroQol 5-Dimensions; PTSD, post-traumatic stress disorder; SCAD, spontaneous coronary artery dissection.

**Table 4** Association between age and quality-of-care

|  |                        | ≤50<br>years old | >50<br>years old | P<br>value |
|--|------------------------|------------------|------------------|------------|
| Serious treatment<br>received in ED            | Agree                  | 41               | 71               | 0.03       |
|  | Neutral or<br>disagree | 25               | 20               |            |
| Overall quality-of-care score,<br>median (IQR) |                        | 8 (6.25–<br>10)  | 8 (7–10)         | 0.24       |

N = 157.

IQR, interquartile range; ED, emergency department.

were perceived to be less knowledgeable about SCAD than cardiologists, even the latter received a broad range of scores (1 through to 10/10), showing significant heterogeneity in perceived SCAD knowledge. In a recent qualitative study on the psychosocial impact of SCAD, the lack of information about SCAD, particularly from treating clinicians, was found to be a major issue for SCAD survivors.<sup>7</sup> In a survey reported by Wagers *et al.*<sup>9</sup>, SCAD information was rated as inadequate by 82% of largely American respondents. In the current study, we found that 28% of Australian SCAD survivors were not satisfied with the information provided by their treating doctors; the lower response in our study perhaps reflecting an improvement in clinicians' knowledge about SCAD over the 5+ years since the Wagers *et al.*<sup>9</sup> study. Nevertheless, consistent with Wagers *et al.*, the internet remains the most useful source of information about SCAD: our finding that 45% of respondents rated the internet as the most useful information source is only slightly lower than the 52% reported by Wagers *et al.* in 2018. The lack of information provided to patients with SCAD, coupled with low levels of knowledge about SCAD among clinicians, likely worsens the psychological impact of a SCAD event. Our findings highlight the need for education of clinicians about SCAD, particularly

emergency clinicians, and improved communication of this knowledge to their patients.

Recent international consensus documents on SCAD<sup>5,6</sup> advocate for antiplatelet and beta-blocker therapy as well as a cardiac rehabilitation referral and FMD screening. In our study, 37% of SCAD survivors reported receiving all of these recommendations, which is slightly higher than the 30% reported in a cohort of SCAD survivors in the USA.<sup>31</sup> Cardiac rehabilitation has been shown to be safe for patients with SCAD and can improve well-being.<sup>32–34</sup> In our study, 75% were referred for cardiac rehabilitation, comparable to previous US studies.<sup>9,16,31,33</sup> Most of the participants in our survey attended a general cardiac rehabilitation programme, rather than a SCAD-specific one. Similar to previous work,<sup>8,33</sup> we found that the main barrier to cardiac rehabilitation attendance was the poor suitability of the programme to SCAD patients, who are usually younger and much more likely to be female than people with atherosclerotic myocardial infarction. The development of SCAD-specific cardiac rehabilitation programmes, therefore, may facilitate participation and play a role in improved well-being of SCAD survivors.

Fibromuscular dysplasia has been well-established to be associated with SCAD, with screening in all patients being advocated.<sup>5,6</sup> In clinical practice however, FMD screening has been inconsistent across the world, ranging from 0% to near 100%.<sup>11,12</sup> In our study, 61% of participants reported being screened for FMD. It is interesting to note that the number of SCAD survivors who reported knowledge of the association of FMD with SCAD was higher than the number referred for FMD screening (142 vs. 104 people). This suggests that participants gained this knowledge by means other than their doctors. This is consistent with the finding that the internet and support groups were the two most common useful sources of information for the participants. Once again, our findings highlight the importance of education of clinicians to improve awareness of SCAD and the need for screening to look for extracardiac manifestations.

Delays to diagnosis with SCAD are an important aspect of medical care. In our survey, just over half of the participants reported a diagnosis of SCAD within 24 h of presentation, while in 14.5%, the

diagnosis was not made during the index presentation. Due to the nature of an online survey, it was not possible to know the exact presentation i.e. MI with or without persistent ST-segment elevation. Without this information, it is difficult to judge whether lengthier times to diagnosis were explicable. Our number of delayed diagnoses is slightly higher than a previous study in the USA, where 10% of patients were discharged from the ED without a diagnosis.<sup>15</sup> We also found that, consistent with past research, younger people with SCAD ( $\leq 50$  years) identified as being treated less seriously by emergency clinicians, compared to older people. This may reflect clinicians' perception that younger people, particularly in the absence of traditional cardiovascular risk factors, are at low risk for an acute myocardial infarction. Raising awareness of alternate causes of MI, particularly among younger women, may help combat delays in diagnosis and management of SCAD.

The quality-of-life of participants in our survey, at a median of 15.5 months from the most recent SCAD diagnosis, was lower than that of the Australian population, with a mean EQ5D-3L index score of 0.79 [compared to population norm of 0.87<sup>35</sup> ( $P < 0.05$ )]. Similar to a previous study, quality-of-life of SCAD survivors in our survey was comparable or worse than patients 1 year after atherosclerotic MI (where EQ-5D<sup>TM</sup> index score was 83.7).<sup>19</sup> However, this comparison is limited by different cohort inclusion, median age, and different lengths in timing from event. In our study, perceived higher quality-of-care was positively correlated with better quality-of-life. Mental health is an important issue for SCAD survivors, with reports of a high prevalence of mental health disorders.<sup>10,16,17,36–38</sup> In a small survey, more than 78% were diagnosed with a mental health condition, and 73% of these patients reported that these conditions were related to the development of SCAD.<sup>17</sup> In our study, 47.2% of participants reported at least one mental health disorder and 36% of these were diagnosed after the first episode of SCAD. It is possible that mental health disorders are both a risk factor for, and a consequence of, SCAD. Therefore, it is important to screen for mental health conditions in patients with SCAD.

The presence of people with SCAD in our current study who identified as being of Aboriginal or Torres Strait Islander background (2.3%) is worth highlighting, as no previous study has reported SCAD in Australian First Nation's peoples. The gap in health outcomes between Aboriginal and Torres Strait Islander Australians and non-Indigenous Australians with cardiovascular disease in Australia has been well described.<sup>39–41</sup> However, the small number of such cases in our study limits any subgroup analyses. The currently recruiting Australian-New Zealand SCAD Registry (ANZ-SCAD)<sup>42</sup> will provide more information on this issue.

## Limitations

The study has several limitations that should be taken into account in interpreting the findings. This was an online, anonymous survey, with all data self-reported. The reliance on self-reporting means that the study is limited by a lack of core-laboratory adjudication and diagnosis of SCAD. For some participants with multiple episodes of SCAD, different experiences with the healthcare system may have occurred for each SCAD episode, with participants asked to rate their most recent SCAD admission. The variable length of time between the SCAD episode and completing the survey may itself contribute to the disparities in patients' scoring of their quality-of-care. The response rate was low however, is similar to that of other online surveys of this nature.<sup>43,44</sup> Due to the recruitment of participants from an online support group, selection bias may be present, as individuals with a higher socioeconomic background and/or English as their first language may be more likely to participate, and people actively seeking a support group might be more likely to perceive that there were gaps in their treatment or information received. Mental health issues were addressed by self-report that, once again, cannot be confirmed as physician-diagnosed

conditions. Furthermore, individuals with severe mental disorders may have declined completing the survey due to the discomfort raised when recalling events. The EQ5D and SAQ are well validated instruments used in patients with coronary artery disease,<sup>19,28–30,45,46</sup> and their use in SCAD while previously performed<sup>19</sup> has not been extensively studied.

## Conclusion

This online survey found that SCAD survivors reported a lack of knowledge and awareness about SCAD in their healthcare providers with quality-of-care significantly associated with quality-of-life. Raising awareness among clinicians about SCAD, including its presentation, diagnosis, and treatment, may be an important step in improving quality-of-care and ultimately quality-of-life in patients with SCAD.

## Supplementary material

Supplementary material is available at *European Journal of Cardiovascular Nursing* online.

## Author contributions

Q.D.: conceptualization, methodology, investigation, formal analysis, writing—original draft preparation. B.M.: writing—review and editing. R.G.: writing—review and editing. A.P.: writing—review and editing. S.F.: resources, writing—review and editing. S.M.: software, formal analysis, data curation, writing—review and editing. J.C.: writing—review and editing. S.M.: conceptualization, writing—review and editing, supervision.

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## Data availability

The data underlying this article will be shared on reasonable request to the corresponding author.

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