

# What do spontaneous coronary artery dissection survivors want to support their recovery? a qualitative study

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Received 18 August 2022; revised 5 January 2023; accepted 17 January 2023; published 19 January 2023

## Aims

Spontaneous coronary artery dissection (SCAD) is increasingly recognized as an important cause of myocardial infarction predominantly affecting women aged younger than 50 years. There is limited research addressing female and male SCAD survivors' experience of, or requirements for, support post-SCAD. This study explored what SCAD survivors wanted to support recovery.

## Methods and results

A qualitative study using semi-structured video and telephone interviews. Data were analysed through thematic analysis using the framework approach. We interviewed 20 participants (19 females) with a mean age of 54.6 (+/-SD 8.5 years). Three overarching themes encapsulated participants' views about support requirements. (i) Education and information. Participants thought healthcare professionals involved in diagnosis and supporting recovery required greater awareness of SCAD and the psychological effect of SCAD. They wanted accessible SCAD information immediately post-event and during the educational component of cardiac rehabilitation. (ii) Physical activity. Requirements were for advice tailored to individuals' specific needs, physical capabilities, and physical activity preferences. Participants suggested that utilizing wearable technology was helpful to encourage a safe return to activity. (iii) Psychosocial support. Participants wanted formal psychosocial support immediately post-event, during cardiac rehabilitation and in the longer term.

## Conclusion

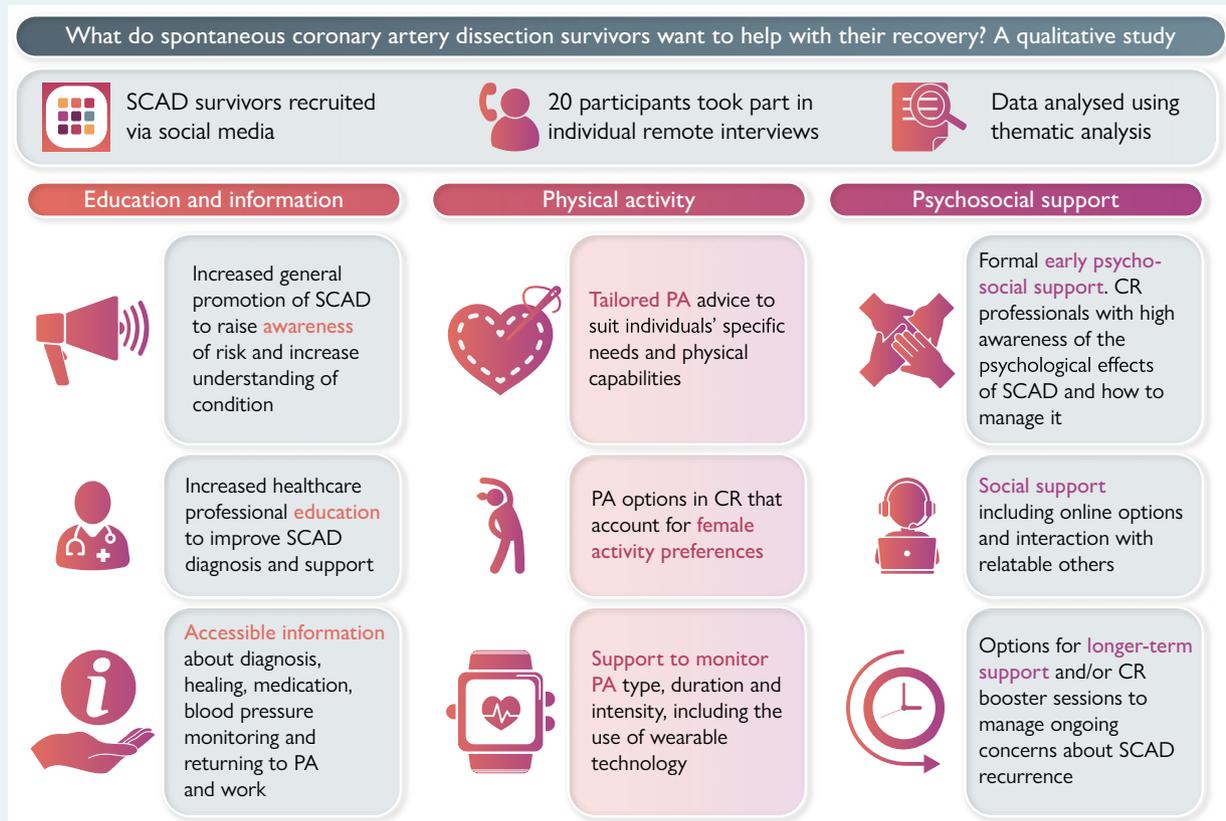
Better healthcare professional training may improve diagnosis, and increase support and awareness of SCAD. SCAD support programmes should provide early SCAD specific education utilizing online sources, individually tailor physical activity prescription, offer wearable technology to support a return to being active, and provide short- and long-term psychosocial support. As SCAD is predominately a female condition, programmes should consider female physical activity preferences.

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## Graphical Abstract



## Keywords

Cardiac rehabilitation • Coronary vessel anomalies • Exercise • Health education • Psychosocial intervention • Spontaneous coronary artery dissection

## Novelty

SCAD survivors in this study suggested that:

- Healthcare professionals involved in diagnosis require a greater awareness of SCAD and those involved in supporting recovery more awareness of the psychological effect of SCAD.
- Information about SCAD needs to be more easily accessible in general, immediately post-SCAD, and during the educational component of cardiac rehabilitation.
- The physical activity component of cardiac rehabilitation for SCAD survivors should be tailored to individuals' needs, physical capabilities, utilise wearable technology and consider physical activity preferences.
- SCAD specific psychosocial support is required prior to, within cardiac rehabilitation and in the longer term.

## Introduction

Spontaneous coronary artery dissection (SCAD) was previously thought to be rare but is now recognized as an important cause of myocardial infarction (MI) in middle-aged women.<sup>1</sup> SCAD has been reported to be the cause of acute coronary syndrome (ACS) in 1.7–4.0% cases<sup>2–4</sup> and is thought to be influenced by sex, hormonal fluctuations, underlying arteriopathies, genetics, and environmental, physical

and emotional precipitants.<sup>1</sup> SCAD occurs independently of atherosclerosis due to the formation of an intramural haematoma within the tunica media of the coronary artery, leading to stenosis of the coronary arterial lumen and resulting in ACS.<sup>5</sup> People who experience SCAD usually have fewer cardiovascular disease (CVD) risk factors than the atherosclerotic ACS population,<sup>1</sup> but a recent systematic review reported that hypertension, dyslipidaemia, and smoking history were common among SCAD survivors.<sup>6</sup>

Precipitating factors associated with SCAD have been reported to include high levels of emotional stress (50%), and participating in unusually intense physical activity (PA) (29%) prior to SCAD.<sup>7</sup> Chest pain is common post-SCAD, and between 10 and 30% of SCAD survivors will have a further SCAD.<sup>1</sup> Unsurprisingly, those affected report high rates of anxiety, depression, insomnia and PTSD.<sup>8</sup> Support to aid physical and psychological recovery is therefore important.<sup>1</sup>

Cardiac rehabilitation (CR) is a multidisciplinary secondary prevention intervention recommended after cardiac events. CR includes psychosocial support, medical and cardiovascular risk factor modification, PA and education.<sup>9</sup> CR reduces mortality and the recurrence of cardiac events;<sup>10</sup> however, the evidence for this is mainly generated by studies undertaken in populations with atherosclerosis. We identified only small three studies focused on SCAD CR.<sup>11–13</sup> Two reported increases in cardiovascular fitness, one an increase in exercise duration, and one a reduction in depression.<sup>11</sup> However, results must be interpreted with caution due to small sample sizes.<sup>6</sup> These studies used a conservative approach to exercise, and qualitative studies indicate that PA advice is limited due to lack of guidelines.<sup>14</sup> SCAD survivors consider this advice too restrictive and inconsiderate of individuals' lifestyles.<sup>15</sup> The provision of psychosocial support for SCAD survivors during CR is suggested to reduce the burden of distress<sup>16</sup> and prevent avoidance of PA.<sup>7</sup> Optimal management strategies to aid SCAD recovery are still to be defined.

The lack of studies that focus on CR for SCAD means that knowledge of what works is sparse. SCAD survivors have previously suggested that CR did not meet their requirements<sup>17</sup> and understanding what SCAD survivors want from CR is deemed essential to developing SCAD specific guidelines for clinical practice.<sup>18</sup> Therefore, this study explored what support SCAD survivors wanted to help with their recovery.

## Methods

### Study design

This qualitative study employed an exploratory inductive approach using semi-structured video or telephone interviews to increase understanding of what SCAD survivors want to help with recovery. We report results using the Consolidated criteria for Reporting Qualitative Research.<sup>19</sup> A favourable ethical opinion for the study was given by Edinburgh Napier University School of Health and Social Care Research and Integrity Committee (REF: AHP-007-2022). The study conforms to the principles outlined in the Declaration of Helsinki.<sup>20</sup>

### Sample

We recruited a convenience sample of participants via social media advertising (Facebook and Twitter) using the Beat SCAD<sup>21</sup> patient-led charity and Edinburgh Napier University academics' accounts with global followings over a 1-week period in April 2022. Individuals interested in participating accessed the study via an online link in the social media advertisement and gave online consent after reading the participant study information. Researchers then contacted participants via email or telephone to arrange a convenient interview time. Men and women aged  $\geq 18$  years, who had experienced SCAD, and were able to conduct an interview in English were eligible. Within this group, there were no exclusions.

### Data collection

We developed an interview guide consisting of open-ended questions based on literature about SCAD recovery and previous research conducted by the team (Supplementary file 1). Topics included the SCAD event, PA, CR experiences, and what participants wanted to support their recovery. K.B. (a female masters level physiotherapy student) pilot tested the interview guide with an experienced CR researcher (S.M.). No changes were made, but feedback was given on interview technique.

**Table 1** Participant characteristics

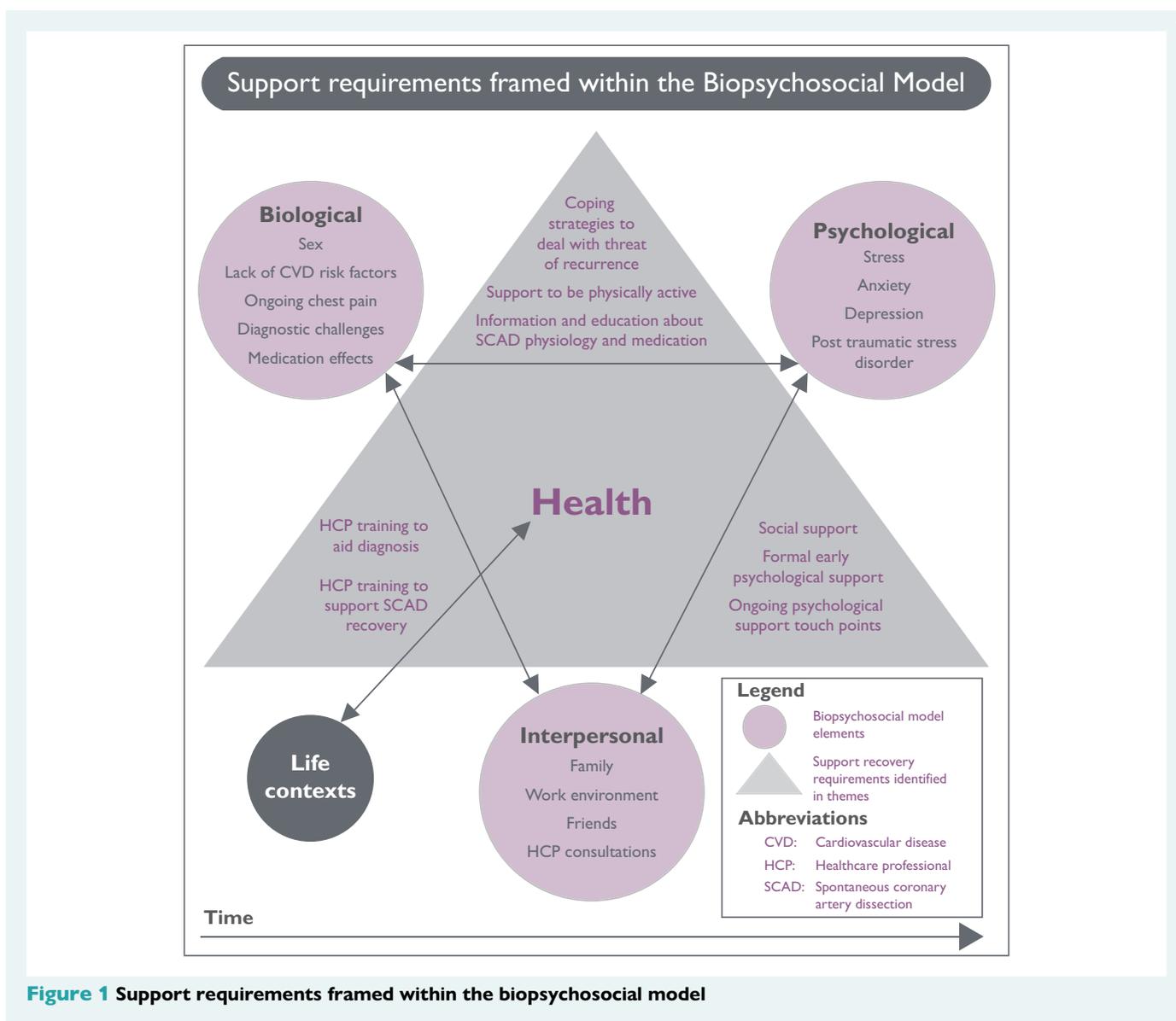
Characteristics	Category	n	%
Age	<54years	9	45
	>55 years	11	55
Gender	Female	19	95
	Male	1	5
Time since most recent cardiac event	< 3 years	12	60
	3–5 years	3	15
	> 5 years	5	25
Cardiac rehabilitation	Attended	18	90
	Did not attend	2	10
Country of residence	Within the UK	17	85
	Outside the UK	3	15
Number of spontaneous coronary artery dissections	1	18	90
	>1	2	10
Self-reported risk factors	Hypertension	3	15
	Hyperlipidaemia	1	5
	Fibromuscular dysplasia	3	15
Self-perceived triggers	Physical activity prior to SCAD	6	30
	Stressful life situation	9	45
	Pregnancy	1	5
	No trigger	4	20

Data were collected via one-to-one semi-structured interviews during April and May 2022. These were conducted using Microsoft Teams (Microsoft Corporation, Bellevue, Washington, USA), or telephone, and recorded using an encrypted audio recorder. Field notes were taken immediately after each interview and a reflective diary kept to document contextual information. This captured context, quality of the interaction, and reflections on potential researcher bias.

### Data analysis

Interview scripts were transcribed verbatim and imported into NVivo20 (QSR International, Melbourne, Australia), which was used as an organisational tool for data analysis. Identifiable data were removed during transcription and participants given a numeric identity code. Data were analysed via thematic analysis<sup>22</sup> using the framework approach.<sup>23</sup> During the familiarization phase, two researchers (K.B., C.L.H.) read and re-read the transcripts and listened back to the audio recordings to ensure accuracy. Both researchers independently created inductive open codes ( $n = 49$ ) for the first five transcripts. This helped to organize the data into meaningful patterns. In the identification phase, we held a data workshop with all researchers. K.B. presented data, with input from C.L.H. L.N. and S.M. acted as 'critical friends' to challenge ideas, explore bias and encourage reflexivity. In the initial framework, six themes were identified: cardiac event, information, CR expectations, CR experience, PA, and psychosocial elements. In the indexing phase, K.B. coded five more transcripts. C.L.H. checked coding and theme accuracy before K.B. coded all remaining transcripts. In the charting phase, we held a further workshop with all researchers, where we explored and rearranged the data according to the themes and compared these within and across all cases. Prior to final analysis, during the mapping phase, all researchers (K.B., C.L.H., L.N., and S.M.) reviewed the framework and agreed three final overarching themes.

This process also highlighted similarities with concepts from the Biopsychosocial (BPS) model, which emphasises the importance of considering biological, psychological and social variables influencing health.<sup>24</sup> More recently, expansions to the BPS model have been suggested to include



**Figure 1** Support requirements framed within the biopsychosocial model

casual pathways (influences and interactions) between the elements of the original model,<sup>25</sup> the addition of contextual effects and a recognition that the dynamics of each element change over time.<sup>26</sup> We mapped relevant elements identified in our inductively derived themes to the three areas of the BPS model and highlighted pathways to explain how support programmes can help with recovery from SCAD.

All authors were female; three (C.L.H., S.M., and L.N.) were experienced qualitative CR researchers and practitioners. K.B. had no previous experience of SCAD or CR. K.B. received research methods training and mentoring from C.L.H. During analysis, we discussed the influence of personal and professional histories on data interpretation to mitigate bias.

## Results

Twenty-three people who expressed an interest were invited to participate. Three of these did not respond. We recruited 20 participants and interview duration ranged from 30–60 min. Mean age of participants was 54.6 +/-8.5 years. Most were female (n = 19, 95%), UK residents (n = 17, 85%) and were less than three years post-SCAD (n = 12, 60%) (Table 1).

## Overarching themes

The thematic analysis resulted in three overarching themes: education and information, physical activity, and psychosocial support. Mapping the analysis through the lens the BPS Model<sup>24</sup> enabled the creation of a conceptual framework to aid understanding of the biological, psychological and social dynamics that influence recovery from SCAD. The framework incorporates support requirements as potential interaction pathways that may improve the recovery journey. It acknowledges the influence of personal life context and time since event (Figure 1).

## Education and information

Within the education and information theme, three subthemes developed: education about SCAD, information post-SCAD and information provided within CR. Indicative quotes for subthemes are presented in Table 2. In the context of the BPS model, frustrating interpersonal interactions between participants and healthcare professionals (HCP) resulted in limited patient knowledge about the physiological aspects of

**Table 2** Education and information indicative quotes

Subtheme	Indicative quotes
Awareness of SCAD	<p>'Could this be a heart attack? But then I thought no, you know I'm healthy and you know that I can't be having a heart attack... It was a triggered by extreme stress, which is pretty common with SCAD' (Participant 14)</p> <p>'Basically, I had symptoms that many people would describe as a classic heart attack and incredible central pressure and pain in my chest and very quickly, a heavy dead numb left arm, waves of nausea, dizziness... They took one look at me and told me I was having a panic attack ... and this is a very common occurrence for female SCAD patients, I'm afraid' (Participant 8)</p> <p>'They were then talking about we think you might have had a SCAD but on the other hand, it could be a Takotsubo Cardiomyopathy' (Participant 7)</p> <p>'They didn't believe I was having a heart attack. A lot of people don't get treatment straight away like a GTN or an aspirin because they look healthy and young and 'it's not a cardiac patient'... So, I think education is key for professionals' (Participant 15)</p> <p>'I was left in A&amp;E for a long time because no one believed me. They thought was a panic attack until my troponin levels came back and then it was panic stations... There were lots of discussions about what to do because they hadn't seen it before... it's not a criticism, but they were totally unequipped to offer me any advice or anything... one of them (a nurse) vaguely remembered a woman a few months ago with similar things and she kind of acted as a mediator between us, but she said she didn't really know what to do' (Participant 11)</p>
Information Post-SCAD	<p>'I was given information from the British Heart Foundation about heart attacks while being told by the consultant, well, it isn't really a heart attack, but it is a heart attack, but it really isn't a heart attack, but it's a form of a heart attack. So that was the message I was getting, and you come out of hospital feeling pretty confused' (Participant 13)</p> <p>'I think that would have been useful if there's some way of having before you leave hospital... being given SCAD specific instructions on what you can expect and how much to rest and then how that you can then start to build up slowly, go for walks and then do the cardiac rehab... Then you leave hospital with a bag of medication and you think of my goodness and I have to take this, you know, for forever and you know, and I think it's mainly all the unknowns' (Participant 9)</p> <p>'The SCAD expert on the unit came and talked to me and I mean, she sat down... she pulled a chair up and she sat down and went through it all with me and said, you know, this, this is where you can find information' (Participant 7)</p> <p>'There is actually a lot of info out there, so it's probably only a matter of pulling together a lot of info, so that, you know, someone can point you to the trustworthy information, rather than, you know, necessarily reading everything that it says about it' (Participant 4)</p>
Information provided within CR	<p>'I expected more guidance on what I could do and what I couldn't do' (Participant 10)</p> <p>'The whole of the structure of the sessions was geared towards if you've had a heart attack because your cholesterol was too high, and you are overweight and you smoke and you drink... So, I think if there could be like a separate thing about SCAD with the latest information on it that gets delivered in whatever format, because to be honest, I would have taken anything, a printout, a meeting, you know because it feels like you have to scabble around to find your own information when it happens to you' (Participant 11)</p> <p>'I didn't learn anything specific about SCAD, which was very disappointing for me' (Participant 14)</p>

SCAD, leading to increased anxiety. This could be addressed by improved HCP training and better patient information and education.

### Awareness about SCAD

Many participants expressed disbelief that they could have been having an MI, despite reporting similar symptoms to an atherosclerotic MI (chest pain, shortness of breath, nausea, and indigestion like symptoms). Most perceived a lack of CVD risk factors. Some reported that emotional stress (family life, occupation), pregnancy or PA (such as heavy lifting) triggered their SCAD, while others thought there was no trigger. Participants suggested a need for increased general awareness of SCAD so that those at risk of SCAD were aware of triggers and symptoms, and other people understood what had happened to those who had experienced SCAD.

In addition, participants stated a need for HCP to have increased education about, and awareness of, SCAD. Misdiagnosis was reported to be common, causing anxiety and frustration. Some participants reported an initial diagnosis of Takotsubo Cardiomyopathy or misdiagnosis of SCAD as a panic attack, stating they felt this was because they were female. Participants also reported disbelief from HCP regarding diagnosis and related this to a lack of CVD risk factors.

### Information post-SCAD

A lack of information within hospitals about SCAD and CR meant that participants were discharged without a clear recovery pathway. Many participants stated that they required clear, timely information about their SCAD health status (healing & diagnosis) to reduce worry and frustration. Participants also required more SCAD specific guidance, as most information provided was more relevant to an atherosclerotic MI. Where SCAD specific information was provided by HCP, this was considered helpful in transitioning out of hospital, as was being directed towards other SCAD information, such as online sources. A few participants reported that attending a consultation with a SCAD specialist was informative and reassuring.

Two other areas where information was required immediately post-SCAD were highlighted: PA and medication. Most participants reported receiving some general advice on returning to exercise, and specific guidance to avoid heavy lifting, extreme physical exertion and to keep heart rate within certain parameters while exercising. Where participants did not receive PA guidance, they were left feeling uncertain and emphasised the need for an exercise plan. Some participants also stated that they required information about why medications were prescribed and how long they were expected to take them.

**Table 3** Physical activity indicative quotes

Subtheme	Indicative quotes
PA Prior to SCAD	<p><i>'I've always been quite active, always done quite a lot of outdoor activities and I've always run a lot and at the time of the SCAD, I was, as I said, preparing for my first road marathon. So, I was running three or four times a week and doing some strength training a couple of times a week, yoga and a lot of kind of walking and outdoor activities generally, so fairly fit and healthy generally' (Participant 16)</i></p> <p><i>'Yeah, I like walking in the fresh air cause down here it's so beautiful and, I mean, that's really does it for me. I don't particularly like indoor exercise. I have been to a gym in the past and I've done it and it's dead boring, I'd rather do something I can enjoy... I was, you know, I was pretty fit' (Participant 3)</i></p> <p><i>'I used to do Zumba as well and adult tap dancing. It was more of a fun thing... I prefer the stuff like the dance... I like the sense of achievement, for sure, and I just like that I'm getting out of the house' (Participant 5)</i></p> <p><i>'Oh, it's just not really for me. It's not, it's just never really. Yeah, you know what I'm like, a bookworm and a TV person. Yeah so I've never really like sports or activities or like that' (Participant 11)</i></p>
PA post-SCAD	<p><i>'So yeah, I'm very aware about being active and you know trying to do exercise? I am aware of it. I don't always manage it, but I'm aware that I should be' (Participant 13)</i></p> <p><i>'To be honest now, since having SCAD, I'm a little scared of cardio activity completely. I wasn't a huge fan of it before, but I certainly wasn't scared of it but now I am' (Participant 17).</i></p> <p><i>'I feel better when you've done 20 000 steps a day, that sort of thing, so yeah, I would track it all. I say it certainly helped to improve my fitness... but I don't know what effect the beta blockers have on that heart rate score' (Participant 1)</i></p> <p><i>'I was very anxious about my health, and I didn't think it would help me to be constantly monitoring because I went through a period of hypervigilance where every little sort of misbeat, or anything could set off a period of anxiety' (Participant 8)</i></p>
Support to be physically active during CR	<p><i>'I expected a bit of physical activity so trying activities whilst hooked up to monitors or whilst being monitored in some way and a little bit of a sense of sort of guidance and progression for what you could go and do afterwards' (Participant 16)</i></p> <p><i>'I think if there was an active persons cardiac rehab that would be perfect, but in reality, if they're just going to do one cardiac rehab for anybody who's had a heart attack, they're going to have to tailor it to the people who've had a traditional arteriosclerotic heart attack, aren't they?' (Participant 3)</i></p> <p><i>'Very good cardiac rehab, where you can exercise in a very safe environment' (Participant 6)</i></p> <p><i>'The place where I went it was with just women, you know, one of the upsides. One of the reasons a lot of women liked it was because a lot, you know, some had never gone to gyms before and were quite self-conscious and so it just made it more comfortable. I wasn't like that, I kind of just love the idea of it you know' (Participant 14)</i></p> <p><i>As a young woman (I thought was young), I know what they were trying to do, but it needed to be far more individualized. (Participant 5)</i></p>

## Information provided within cardiac rehabilitation

Education within CR was frequently reported to be lifestyle advice that was more appropriate to atherosclerotic MI patients. Few considered the educational component of CR to be beneficial, as it contained minimal detail about SCAD and especially lacked information on the psychological impact of SCAD. To counteract this, some reported locating their own information, mainly through online search engines such as Google. Participants stated that education within CR needs to be specific to SCAD, and include medication, chest pain management, physiology of SCAD, blood pressure monitoring, and occupational advice (returning to work).

## Physical activity

Within the physical activity theme, three subthemes developed; PA pre-SCAD, PA post-SCAD and support required to be physically active during CR. Indicative quotes for subthemes are presented in [Table 3](#). Within the BPS model, the context of previous PA was important in perceptions of about PA post-SCAD. Biological factors such as ongoing chest pain resulted in fear of SCAD recurrence during PA. This could be addressed by tailored support to return to PA.

## Physical activity pre-SCAD

Many participants reported engaging in PA pre-SCAD and some said that they were physically very able. Only a few were limited by comorbidities or stated that COVID-19 had made PA difficult. Some participants engaged in exercise in a gym or indoor setting, but the majority reported enjoying outdoor lifestyle activities such as walking. Some reported that they chose fun activities such as Zumba and enjoyed the feeling achievement, but others stated that they did not like exercise.

## Physical activity post-SCAD

Most participants reported being physically active post-SCAD and thought that PA was important. However, many noticed feeling less physically able post-SCAD, which was frustrating for some. PA post-SCAD left participants feeling concerned about the possibility of another event, especially when undertaking cardiovascular exercise, and for some this resulted in disengagement or a cautious approach. To combat this, participants reported using wearable technology to monitor lifestyle activity, mostly through counting steps or to monitor heart rate to limit exertion. There were concerns about a lack of knowledge about the effect medication had on exercise heart rate and for a few that monitoring using wearables could cause anxiety.

**Table 4** Psychosocial support indicative quotes

Subtheme	Indicative quote
Early psychological support	<p>'What I really needed was somebody to say you know it is ok, your response is perfectly normal, experiencing this anxiety or, you know, apprehension at your chest pain ... you're obviously struggling a wee but do you know it's normal to be feeling like this and let's explore what the reasons are and how we help you' (Participant 1)</p> <p>'I do remember being really upset one day and I couldn't help myself when I was crying. This nurse, I will never forgive her for as long as I live. She said to me, (name), maybe you just need to get over yourself a little bit and get back to work. I was like, what are you actually joking me? So I was in tears, obviously. She said she felt I was being self-indulgent but I wasn't.' (Participant 5)</p> <p>'I paid for counselling because I didn't know how long it would take for it to come through on the health service' (Participant 3)</p> <p>'I think from my point of view, an increase in psychological support and actually, maybe support for your family' (Participant 10)</p> <p>'I thought it would be purely physical support. I wasn't expecting to get any psychological support there' (Participant 11)</p>
Social support	<p>'The support of the group. I mean that is just ... I can't tell you or express how much comfort I've had from that online group' (Participant 6)</p> <p>'I think that that there are some hindrances like the SCAD Facebook group is really great, and they're really kind people, but there's a lot of drama on that Facebook group, and that can make you feel a little bit doom and gloom' (Participant 18)</p> <p>'Family and friends and stuff who I talked to, they'd be really supportive and that's what I've needed' (Participant 12)</p> <p>'I would have found it easier if we'd been a group of women I don't know, or maybe even some women. It might have been easier, but there was just nobody in a similar situation to myself and that I find hard' (Participant 10)</p> <p>'So I think probably or having a buddy or somebody who's been through it before ... Finding somebody who can work with somebody and encourage them and get them to do things when feeling safe.' (Participant 3).</p>
Long term support	<p>'I guess in an ideal world, they'd also be some sort of aftercare program' (Participant 16)</p> <p>'I suppose in a way I had thought perhaps I would hear from my cardiac nurse again, but obviously they discharged me and that was the end of it ' (Participant 7)</p> <p>'Or even a check in so even after rehab they phone you after a month just to say we are checking how you're doing and not just focusing on exercise but focusing on the mental' (Participant 2)</p> <p>'I don't feel from my perspective that I would need anything ongoing' (Participant 6)</p>

## Support to be physically active during cardiac rehabilitation

During CR participants expected to engage in monitored PA and receive continued guidance to improve their physical ability in a safe environment. Participants suggested that an individualised exercise plan was necessary for them to feel supported. Some participants stated that they had negative preconceptions about CR due to it being gym-based. There were mixed reviews about PA experiences in CR. Some had positive experiences with staff present for monitoring and support. Others reported that CR was not suitable for their level of fitness. Some women expressed feeling more comfortable undertaking PA in a female specific CR environment, as they had not been in a gym environment prior to this. Not all participants received in-person CR, either because it was not offered or because they felt that it was not appropriate as they were struggling physically post-event. One participant stated that heart rate monitors should be provided by CR.

## Psychosocial support

Within the psychosocial support theme, three subthemes developed: early psychosocial support, long-term support, and social support. Indicative quotes for subthemes are presented in [Table 4](#). In the context of the BPS model, participants suggested that interpersonal interactions (social and more formal HCP support) where required help address psychological issues resulting from uncertainty around biological factors (unknown cause and ongoing chest pain).

## Early psychological support

Many described how their SCAD event negatively affected their psychological health. This was because participants tended to be younger

than those experiencing an atherosclerotic MI, and perceived that their SCADs were unexpected and largely unexplained by traditional CVD risk factors. Limited follow up post-SCAD and a lack of information about health status resulted in anxiety and a need for formal psychosocial support immediately post hospital discharge.

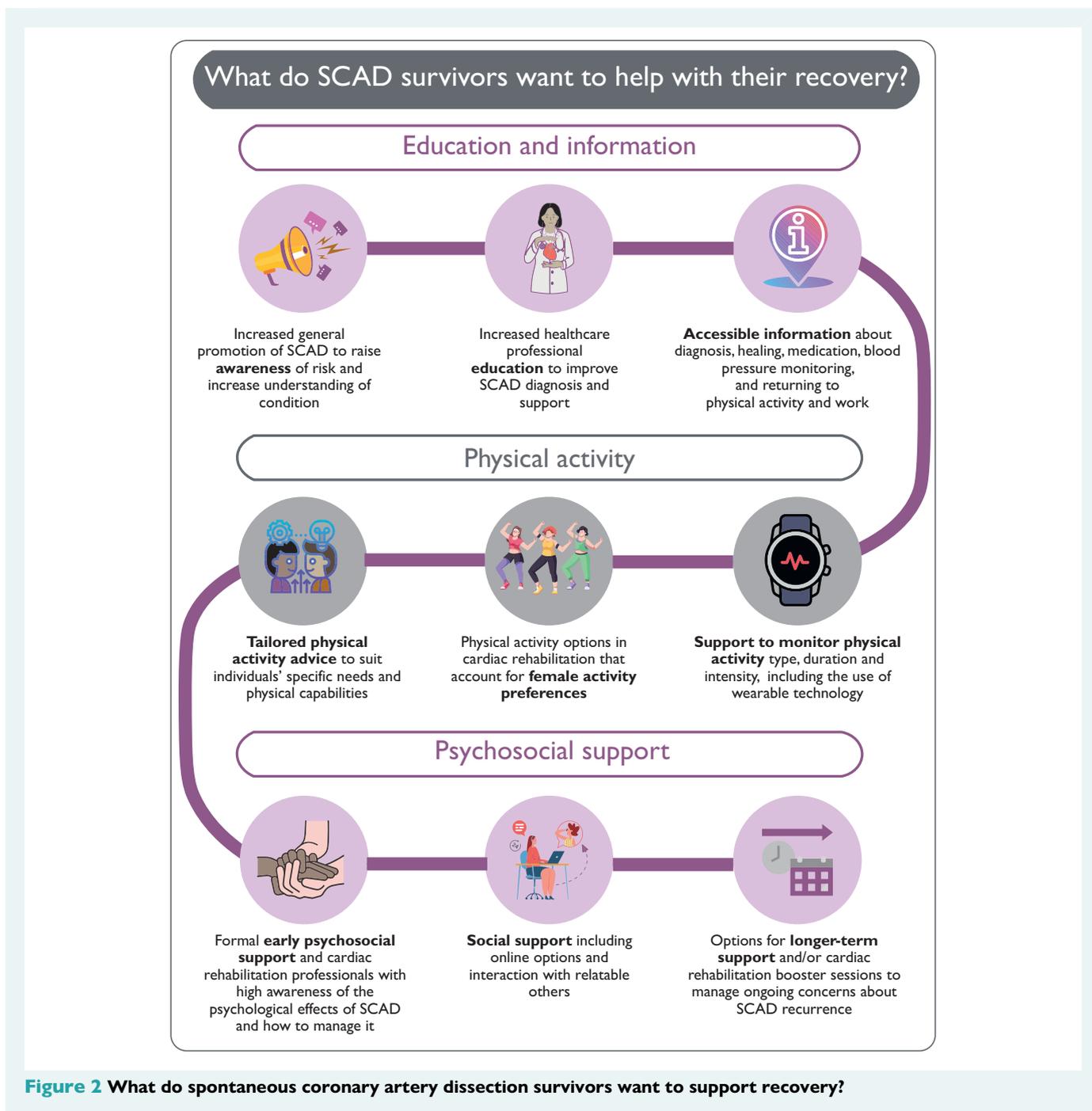
There were mixed expectations about psychosocial support during CR. Some reported expecting that CR would be focused on physical recovery, while others stated that they thought psychosocial support would be provided. Some participants were satisfied with the psychological support offered within CR, but others reported that CR professionals required more awareness of the psychological effects of SCAD and how to manage it. They also suggested that there could be more psychological support, a greater awareness of SCAD support groups, and extended support for families of those affected.

## Social support

Peer support was also deemed important, although family and friends sometimes negated the requirement for formal support. Online SCAD groups were reported to offer ongoing beneficial support, with only a few participants expressing the view that these were not required or that online interactions were negative. Some participants specifically wanted peer support to give reassurance about PA post-SCAD, and there was support for female specific CR to enable participants to receive relatable peer support from others.

## Long-term support

Psychosocial issues continued to affect participants for many months and/or years post-SCAD. This was in part due to ongoing concerns about the possibility of having a further SCAD and learning to live



with this was considered challenging. Participants expressed a need for ongoing, long-term psychological support after CR to manage this and suggested longer time-periods for CR, or a booster session after CR. Participants suggested that booster sessions were not required to be intensive but just needed to be a check in. Not all participants required follow up support.

Together these themes created understanding about what SCAD survivors want to support their recovery (Figure 2).

## Discussion

SCAD survivors in this study suggested several areas that required development to better support their recovery. First, HCP involved in

diagnosis need to have a greater awareness of SCAD and those involved in supporting recovery need to have more awareness of the psychological effect of SCAD. Second, SCAD information needs to be easily accessible in general, immediately post-SCAD and during the educational component of recovery support programmes. Online information and support were considered appropriate. Third, the PA component of recovery support programmes needs to be tailored to individuals' specific needs, physical capabilities and consider PA preferences. Wearable technology should be utilized to encourage a return to PA and to monitor heart rate and lifestyle activities. Finally, there needs to be more psychosocial support within recovery support programmes and in the longer term. Our participants reported that existing CR was often unsuitable for their needs and instead focused on those with atherosclerotic CVD.

## Education and information

Participants in our study reported SCAD symptoms were similar to that of an atherosclerotic MI and as in other studies, chest pain was the most frequent symptom of SCAD.<sup>27</sup> HCP are more likely to underdiagnose ACS in women (who are the majority of SCAD patients), despite them more frequently describing typical pain than men.<sup>28</sup> As reported in other studies, in our study SCAD was misdiagnosed as panic attacks, Takotsubo Cardiomyopathy or atherosclerotic ACS.<sup>29,30</sup> The need to ensure accurate diagnosis by heightening awareness of SCAD amongst HCP has been highlighted by leading SCAD experts.<sup>16</sup> Our study adds to this by suggesting a need for increased HCP education, and awareness raising for the general population about SCAD to inform people of their risk and increase understanding of the condition.

Some participants reported leaving hospital without CR information but only two did not attend. This is contrary of current evidence suggesting low rates of CR referral and participation for SCAD patients,<sup>11,31</sup> compounded by known inequalities in female CR referral,<sup>32</sup> and uptake.<sup>33</sup> Many of our participants accessed online support groups and it is possible that they accessed CR information via these. In addition to raising awareness of the condition, there is a need for more HCP education about the benefits and safety of CR for SCAD patients, and systems to ensure referral.

The educational component of CR was reported to lack SCAD specificity and instead was tailored towards atherosclerotic ACS patients. Information provided was inadequate to meet the needs of SCAD survivors. Other studies have reported that CR-based SCAD education is inadequate due to lack of HCP knowledge,<sup>18</sup> but is essential to reduce anxiety resulting from the uncertainty surrounding SCAD,<sup>15</sup> and when included is associated with positive well-being outcomes.<sup>11</sup> We recognize that there are unlikely to be high numbers of SCAD patients accessing local CR services at any one time. We also recognize the importance of patient-led support groups such as Beat SCAD<sup>21</sup> in disseminating information and supporting patients. Like Bouchard et al., (2021), we recommend that information from SCAD specialists should more widely accessible through online resources such websites and webinars, as well in-person. Furthermore, we suggest that tailoring current CR to SCAD survivors' needs may not be the most appropriate solution. Instead, we propose a need to develop and pilot new SCAD specific recovery support programmes that are co-designed with SCAD survivors.

## Physical activity support

Our study highlighted that PA support post-SCAD was not offered to everyone and when it was, it was not always tailored to meet the individual preferences of participants, 95% of whom were women. Some expressed reservations about a gym-based CR delivery mode. In the UK, 61% of women have reported that CR non-attendance was due to the way that services were delivered,<sup>34</sup> and a recent systematic review indicated that globally, few CR services offered alternative PA options that appeal to women.<sup>35</sup> We have previously identified that women are more likely to choose fitness classes after completion of PA referral schemes than gym or circuit classes,<sup>36</sup> suggesting potential alternative delivery modes that could be piloted to increase understanding of what PA support works best to aid SCAD recovery. Additionally, the current study findings suggest that nature-based PA options are worthy of investigation. SCAD recovery support programme providers could also consider individualized telehealth, community, or home-based support, which are proven to be effective alternative modes of delivery for CR.<sup>37</sup>

PA intensity prescription for SCAD remains challenging due to a lack of exercise guidelines. Concerns exist about the safety of different activities, making it difficult for CR staff to navigate activity type and intensity prescription.<sup>16,38</sup> The insufficient or unclear PA prescription reported by some in this study, and the frustration this causes, is

reflected in other SCAD PA studies.<sup>15,39</sup> However, the potential for higher PA intensity prescription must be balanced against fear about, and risks of, physical exertion triggering another SCAD.<sup>1,16</sup> The findings of our study indicate that utilising wearable technology post-SCAD to monitor heart rate and lifestyle activity can help to alleviate concerns. There is an urgent need for studies that investigate safe and effective exercise levels for SCAD survivors, and once established, how to support people to confidently achieve these levels.

## Psychosocial support requirements

Participants in this study reported a high psychological burden after SCAD and this is reflective of other research that SCAD survivors are susceptible to anxiety and depression, where about one third reported receiving medication or behavioural therapy post-SCAD.<sup>40</sup> SCAD survivors are at higher risk of psychological issues due to younger age at event, being female and uncertainties surrounding diagnosis and management.<sup>16</sup> These issues were reported by our study participants. To address them they suggested that CR professionals needed more awareness of the psychological effects of SCAD and ways in which this could be managed. HCP have previously acknowledged having additional training needs to support SCAD patients, and noted the difficulties in providing reassurance due to uncertainties associated with SCAD.<sup>14</sup> Our study also highlighted the importance of social support reported by other SCAD and female CR studies.<sup>18,35</sup> We suggest offering buddy and/or group-based opportunities for social contact either in-person or online, and that SCAD recovery support programmes should consider how they can cater for the differing psychological needs of women.<sup>35,41</sup> Finally our study suggests that psychosocial support needs to be ongoing after formal support (CR) finishes, as previously highlighted by Johnson et al., 2020.<sup>42</sup>

## Strengths & limitations

Qualitative research is subjective and influenced by the views and biases of the researcher. However, the first author had no previous knowledge of SCAD, reducing the potential for bias when interviewing and interpreting data. Many participants accessed CR, and this may represent a self-selection bias. Recruiting via social media may have limited sample diversity and attracted participants with strong views about SCAD recovery. We did not collect data about level of education, ethnicity, and socio-economic status, so were unable to assess sample diversity using these factors. Length of time since SCAD varied in our sample meaning that some participants were reflecting on events from some years previously, which may have led to inaccurate recall. There was only one male participant involved in the study, so the male voice is not represented, and further studies are required to explore the needs of the male SCAD population.

## Conclusion

Increased HCP training may improve diagnosis, support for, and awareness of SCAD. SCAD recovery support programmes should be developed and piloted that provide SCAD specific education utilising online information sources, individually tailoring physical activity, offering wearable technology to support a return to being active, and providing short- and long-term psychosocial support. Research is urgently needed to establish safe and effective exercise guidelines for SCAD recovery.

## Author contributions

Conceptualization, K.B., C.L.H., L.N.; methodology, C.L.H., L.N., K.B., S.M.; formal analysis, K.B., C.L.H., S.M., L.N.; investigation, K.B.; writing—original draft preparation, K.B., C.L.H., L.N., S.M.; writing—review

and editing, K.B., C.L.H., L.N., S.M.; All authors have read and agreed to the published version of the manuscript.

## Supplementary material

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

## Acknowledgements

We wish to thank Beat SCAD for their help in recruiting participants for this study.

## Funding

No funding was received for this study.

**Conflict of interest:** The authors declare that there are no conflicts of interest.

## Data availability

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

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