

Themes and Example Quotes

Themes	Example Quote
<i>Challenges in Recovery</i>	
Navigating uncertainties associated with the disease	<p>What they [patients with SCAD] are interested in is, what's new with this diagnosis, is this gonna happen again, how do I know if it happens again, what can I do to prevent it and the worst problem is, it's probably nothing. There's nothing that you can do. And that's hard...especially for those of us who like to be in control and willing to take accountability. To me that is one of the biggest issues and I think we need to talk more about that.</p> <p>You have fear in the hospital but there's this bit of comfort that these people know what to do. Then you go home and then you have this whole numbing fear. Stone cold fear...and then you get past that and get most of your physical life back and you overcome most of those basic fears. At least on the surface. But there's this sort of residual anxiety...it turns into a need to understand and frustration that there is no standard of care.</p>
Living with anxiety	<p>I keep thinking that this will happen again...it feels so uncertain...that is what is killing me. I used to avoid things...it was really bad. I was constantly afraid and I took it to the extremes. It crippled me completely. It's been three years and now I don't think constantly about death but I am still so scared that I will have another SCAD. I feel better but it is still there. It is always in the background.</p> <p>I tell myself, come on, have some hope. Nobody has said that its inevitable that you're gonna have another one. But its just not satisfactory enough to ease me...I always thought that I was built better than this. I thought I was stronger than this...I think about my mortality more...everything is fleeting. I think about life and death a lot. I dare not make plans so far in the future because I could have another one. I leave instructions everywhere in case I am taken.</p>
Reconciling pre-and post-SCAD identities	<p>There is this conflicting dialogue. I would like to do all the things that I did before. And then you have to kind of check yourself and say, okay, put it in perspective, so smarten up...For me that was the hardest part. You just want to be the same and you don't want people to look at you any different...After the event my life changed and I was always trying to build back to what it was like, the old me. And I was failing. I needed to develop a new stage of life. Like this is my new reality and moving forward.</p> <p>I was always able to see the bright side, push through challenges. Not be gripped all the time. I want to mimic something that reminds me of pre these events. But at the same time you have to grapple with these new thoughts daily. That event for me is kind of like the knife that split</p>

my life in half. There was then and there is now. It is very difficult to grasp that there was a 'then.'

Accurately identifying symptoms and experiencing a sense of isolation in recovery due to gender and young age

I thought that maybe I was having a heart attack, but at my age, I mean come on. The ambulance driver thought that I was having an anxiety attack and that it was nothing. When I found out that it was a heart attack I was in disbelief. The scariest part of it all was that they didn't know about SCAD...they did in general but not very detailed. I remember feeling so upset when they didn't want to help me at first.

There were other people there [CR] and were asking questions like, when can I golf again? I was like, I have three kids, how am I going to mother them? Like, you're worried about golf? I was very resentful. Very bitter...their concerns were very different than my concerns...that was a bad moment.

Managing changing family dynamics and family members' stress

My husband kept saying, 'when are you going to be normal again?' Would it be lovely if [I] never had to hear that again? If he understood that things have changed. Permanently. There's hurt there. [I] feel bad now. [I] feels less than. [I] feel burdened. What if he leaves? And now [I'm] stressed and now that's more draining on him...I pretty much handled most things on my own...So now that I am ready to share my burden, they [family members] don't know how to do that with me.

She [patient's wife] was the gatekeeper and I think that was much harder for her...she was constantly fielding texts and emails and phone calls and you don't think of that, right? She was feeling the double stress of dealing with it and being the gatekeeper, communicator. It didn't really dawn on me until later.

Rehabilitative Intervention Needs

Addressing unique demographic and cardiovascular profiles when designing programs for cardiac rehabilitation

I was in CR and surrounded by people who were nearly twice my age... It didn't really give me much confidence to get up to my athletic level...I felt that I wasn't pushing myself hard enough. I am here to see if I can rehabilitate my cardiovascular system and be safe to do the level of exertion that I was doing before.

I meet none of the checkboxes. So I think if we have efforts by the medical community to focus on us, if we have community groups that makes up feel comforted and supported, if we have protocols that are based on us and not based on something similar to what we've got...I just think we need to catch up.

Providing more psychological and peer support resources to address

For some people, all they really need is a place to be heard and a place to be understood and to know that other people have gotten through this, so can I...But I think there should be a kind of training for these leaders.

anxiety and sense of isolation

The emotional management is the big piece because that is what makes SCAD hard, because it is so shocking and that it hits people who are in a different place in their life than most cardiac patients...there is a lot of fear...that is the root of all challenges. I think we need to address the emotional component sooner rather than later...We should have an emotional and physical rehab. I think rehab needs to be more holistic.

Disseminating information of rapidly evolving SCAD research

SCAD patients are like the orphans of the cardiovascular world. We don't belong to anybody, we don't belong anywhere, and so I think that needs to change. And its going to change with more and more research done on SCAD and evaluation and clinical trials... Having more SCAD specific information available to patients will go a long way to making people feel like they belong to the cardiovascular family.

I think providing more information to patients and family members is so important. Information sessions where you can talk about what is new. Information about SCAD specifically is vital to feel like we are recognized and that there is progress being made. The lack of knowledge about SCAD is the most difficult thing...when you don't know, you are blind. You just hope, hope is all you have and sometimes that is not enough.

Acknowledging the role of the family system in recovery from SCAD and providing resources to help support families affected by SCAD.

I think I was worried about me but I am a grown up. My kid got nothing to support [him]. He's got his Dad, don't get me wrong. It got to the point where it felt like he needed to be perfect. He made his bed he did the dishes; he walked the dog; he did everything. That's not what you want. A 12-year-old doesn't do that. A 12-year-old talks back and makes a mess and wants to go play with his friends and not sit at the end of the bed reading to make sure his Mom is okay...I think he needed someone else to say 'none of this is on you.'

Carers take on a lot of stuff too and they don't get much support. And people don't think that the guy who is saying 'when you gonna get back to normal' is actually saying 'I'm lonely, where are you?... Everyone was focused on me. I was focused on me. It would be great to provide a session on how you can support your spouse and how you can support your children...Especially when your catchment group is primarily female, primarily young and healthy, it might be something they are freaking out about.