

Supplementary File 5. Major interview themes, frequency and illustrative quotes

Major Themes		Number of Interviewees	Illustrative Quote
Role of Exercise	Prior role of exercise was multifaceted	15 (94%)	“It’s always played a very important role in my life. I enjoy being, you know, fifty years old and be able to out do a lot of twenty year olds... There is many other benefits as well. It is a stress relief. I am in a very, very high stress business and it helps me keep an even keel there... And, also, the social aspect is there...” (Male, age 52, restricted 2 years)
	Prior role of exercise as social outlet	13 (81%)	“And it is a social thing for me. Always walking with my husband or my friends. I mean I walk alone too, but, you know, it’s a time to be together.” (Female, aged 67, restricted 2 years)
	Current role of exercise is minimal or not enough	8 (50%)	“I think it has a really low role. I think my daily activities is 180 degrees from my past.” (Female, age 62, restricted 18 years)
	Current role of exercise is to only maintain health	8 (50%)	“I loved the adrenaline and the action and the camaraderie, the competitiveness of the sport, but now I would say it’s more of understanding and realizing that I got to do it to stay healthy.” (Male, age 43, restricted 1 year)
Impact of Exercise Restrictions	Weight gain is a long-term negative effect	9 (56%)	“Because I had gained a good 20 pounds or so after getting the diagnosis and not exercising and then trying to deal with the stress of the diagnosis and I couldn’t do my exercise and I ended up eating more and that wasn’t helping the diabetes which added to the stress.” (Male, age 29, restricted 2 years)

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Uncertainty surrounding how to exercise safely is a long-term negative effect	8 (50%)	“So it was a kind of uncertainty about what was making my heart work too much and what was, you know, not making it work enough or what was really okay and that part became hard. Like, ‘how can I monitor this?’ ‘what can I trust?’” (Female, age 67, restricted 2 years)
Lack of long-term positive effects	8 (50%)	“I think, that’s such a, so no. I’ll be negative in the sense or neutral in saying there is nothing that has been positive relative to telling me I can’t do it.” (Female, age 42, restricted 19 years)
Coping Strategies	10 (63%)	“Oh, when I feel myself starting to get short of breath or strained from lifting something, I’ll stop, sit down for a minute and let myself catch my breath.” (Male, age 43, restricted 1 year)
	9 (56%)	“...I did a lot of research on my own because I wasn't able to get the information and the resources I felt comfortable with to push it too hard on the exercise front. I was afraid something would happen. I had fear about it.” (Female, age 63, restricted 19 years)
	9 (56%)	“So what I did was, I joined the HCM Association, and there was a seminar....” (Female, age 68, restricted 3 years)
Adaptation through involvement in HCM community	9 (56%)	“I started that then about a year later, I started advocating for AED’s in my school district and in my community... And I would kind of tell people [my story] and they’d be like, ‘that’s amazing.’ And it just made me feel very empowered and

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		<p>like ‘okay, I have a story that is, that resonates with other people.’ ” (Female, age 42, restricted 19 years)</p>
	9 (56%)	<p>“And none of my friends would say, they would never complain about listening to me, but having her [cousin with HCM] to talk to was just really helpful: 'I'm scared' or 'I feel like shit' or 'I'm just so tired of this,' the depression thing.” (Female, age 68, restricted 3 years)</p>
Patient Support Network	11 (69%)	<p>“They [doctors] totally educated me. I was, I had no idea what I was doing and I am glad that I was able to get some education cause otherwise I would have been in bad shape I think. I’m really happy for that.” (Male, age 43, restricted 1 year)</p>
	9 (56%)	<p>“My mom slowed down when we would go places together. She was the one that was most accepting and really understood.” (Female, age 54, restricted 9 years)</p>
	10 (63%)	<p>“We were talking over text and he was raving about this, oh god, it’s like this trampoline place ... where they put trampolines all along the floor and you can go and just like bounce around and apparently its really fun and he was all excited about this... and then he threw in ‘it’s too bad you wont be able to go too.’ Which, it is. I was already thinking that, but somehow him just sort of offhandedly like ‘oh yeah, it’s too bad you can’t make it’ was pretty harsh. That was pretty insensitive.” (Male, age 29, restricted 2 years)</p>

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Patients desire clear, concrete & individualized exercise recommendations	11 (69%)	“I think if I had known, if someone had asked me ‘what kind of sports do you do?’ or ‘what kind of sports have you done?’ Cause, if you play basketball and, you know, you might join another league or something... might have explained to me the different sports and why its not a good fit with HCM. Or helped me to then say, you do this, but at what rate and how in depth... still do that sport, but I would keep it at this level. That would have been really helpful.” (Female, age 62, restricted 18 years)
