

Section 8

Quality of life

Section 8: Quality of life

Impact on quality of life

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Most commonly, the descriptions suggested that there was an overall negative impact on quality of life (65.96%). Others described overall a minimal impact on quality of life (10.64%), overall positive impact on quality of life (8.51%), overall no impact on quality of life (6.38%), and a mix of positive and negative impact on quality of life (4.26%).

The most common themes in relation to a negative impact on quality of life were emotional strain, including family or change in relationship dynamics (38.30%), reduced capacity for physical activity, needing to slow down (29.79%), and managing side effects and symptoms (23.40%). Other themes included emotional strain on self (21.28%), reduced social interaction (17.02%), altering lifestyle to manage condition (8.51%), and inability to work or changes with their work (8.51%).

The most common theme in relation to a positive impact on quality of life were that it brings people together and highlights supportive relationships (14.89%).

Impact on mental health

In the structured interview, participants were asked if there had been an impact on their mental health. Most commonly, the descriptions suggested that overall, there was at least some impact on mental health (70.21%). There were 4 participants (8.51%) that indicated no impact and 10 participants (21.28%) that did not describe impact on mental health or had a mixed experience.

Regular activities to maintain mental health

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common responses were consulting a mental health professional (21.28%), mindfulness and/or meditation (21.28%), and the importance of physical exercise (17.02%). Other activities included remaining social and having hobbies (8.51%), and taking medication (8.51%).

Regular activities to maintain health

In the structured interview, participants were asked what were some of the things they needed to do everyday to maintain their health. The most common activities for general health were doing physical exercise or being physically active (46.81%), self care for example more rest, accepting help, pacing themselves (40.43%), and maintaining a healthy diet (36.17%). Other activities included complying with treatment or management of their condition (23.40%), mindfulness and/or meditation (19.15%), making healthy lifestyle changes (10.64%), maintaining a healthy weight (8.51%), and managing stress (8.51%).

Experience of vulnerability

In the structured interview, participants were asked if there had been times that they felt vulnerable. The most common responses were that they felt vulnerable because of interactions with the medical team (17.02%), and when experiencing side effects from treatment or symptoms from condition (17.02%). Other times they felt vulnerable included during diagnostic procedure (14.89%), thinking about disease course or that they have an incurable condition (14.89%), during or after treatments (10.64%) and when feeling sick/unwell (8.51%). There were 7 participants (14.89%) that did not feel vulnerable.

Methods to manage vulnerability

In the structured interview, participants described ways that they managed feelings of vulnerability. The most common ways to manage vulnerability were using self-help methods (resilience, acceptance, staying positive) (10.64%), and being unsure how vulnerability can be managed (4.26 %).

Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Most commonly, the descriptions suggested that overall, there was a negative impact on relationships (38.30%), and overall, there no impact on relationships (31.91%). Other themes included overall, there was a positive impact on relationships (14.89%), and overall, there was an impact on relationships that was both positive and negative (10.64%).

The most common themes in relation to having a negative impact on relationships were from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition (31.91%), and from people not knowing what to say or do and withdrawing from relationships (10.64%). Other themes included because of people not believing the impact that condition has on health (6.38%), and because of intimacy challenges (4.26%).

The most common themes in relation to having a positive impact on relationships were from people being well-meaning and supportive (17.02%), and from family relationships being strengthened (8.51%).

Burden on family

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Most commonly, the descriptions suggested that overall, there was not a burden on their family (51.06%), overall, there was a burden on their family (44.68%), and overall, there was not a burden on their family now but they anticipate this will change in the future (6.38 %).

The main reason that participant described their condition being a burden were the extra household duties and responsibilities that their family must take on (17.02%), that the burden was temporary or only during treatment (14.89%), and the mental/emotional strain placed on their family (10.64%).

The main reason that participant described their condition not being a burden were that they were very independent (14.89%), and they have a very supportive family and were not a burden (6.38%).

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. The most common descriptions were that overall, there was at least some cost burden (51.06%), and overall, there was no cost burden (23.40%).

Where participants described a cost burden associated with their condition, it was most commonly in relation to the cost of treatments (including repeat scripts) (27.66%), diagnostic tests and scans (17.02%), and needing to take time off work (17.02 %). Other themes included the cost specialist appointments (14.89%), cost of gap payments (12.77%), needing to buy special equipment (10.64%), allied health care (8.51%), and GP appointments (8.51%).

Where participants described no cost burden associated with their condition, this was because nearly everything was paid for through the public health system (17.02%), the participant was able to afford all costs (10.64%), and nearly everything was paid for through the private health system (8.51 %).

Overall impact of condition on quality of life

In the online questionnaire, participants were asked to rate the overall impact their condition on quality of life. Quality of life was rated on a Likert scale from one to seven, where one is Life was very distressing and seven is life was great.

The average score was in the Life was a little distressing to average range (median=3.50, IQR=3.00).

Experience of anxiety related to disease progression

The **Fear of Progression** questionnaire measures the level of anxiety people experience in relation to their conditions. On average fear of progression score for participants in this study indicated moderate levels of anxiety.

Impact on quality of life

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Most commonly, the descriptions suggested that there was an overall negative impact on quality of life (65.96%). Others described overall a minimal impact on quality of life (10.64%), overall positive impact on quality of life (8.51%), overall no impact on quality of life (6.38%), and a mix of positive and negative impact on quality of life (4.26%).

The most common themes in relation to a negative impact on quality of life were emotional strain, including family or change in relationship dynamics (38.30%), reduced capacity for physical activity, needing to slow down (29.79%), and managing side effects and symptoms (23.40%). Other themes included emotional strain on self (21.28%), reduced social interaction (17.02%), altering lifestyle to manage condition (8.51%), and inability to work or changes with their work (8.51%).

The most common theme in relation to a positive impact on quality of life were that it brings people together and highlights supportive relationships (14.89%).

Experience described suggests that there was an overall negative impact on quality of life

I would say yes. I don't. I don't go to the gym anymore. So my son and my oldest son and I used to go to the gym all the time. I just a lot of strain to go there and do all that. I don't go mountain bike riding with my friends anymore. So yeah, there's it has limited my my socialization there. You know it's put a lot of I guess my kids are aware of everything as well. So you know they know when I'm tired, they know when you know how far I can walk and and all that sort of stuff. So they try to be really upbeat and everything about it for me.

Participant 028_2023AUHBV

PARTICIPANT: My quality of life now, I just stay home because I'm too embarrassed to go out and I'm too ashamed to go out. A couple of times, people, they've spoken to me in general conversation. I got more confused. I been laughed at. That's why, now, I don't go anywhere now.

INTERVIEWER: I get the sense it's been really difficult for you.

PARTICIPANT: It has been very hard.

Participant 042_2023AUHBV

Look it definitely affects it. There's a lot of stuff that I don't do. I don't go roller-skating with my daughter. I don't go jogging with my son. If, they were to go snow skiing in the winter I don't feel that I could do that. I think I'd get halfway through you know as I'm with them, and I'd be exhausted. There is a lot that I don't do. I have adapted to that fact, and there's a lot of stuff that we do, do together instead of. It doesn't affect me mentally like it used to. I've adjusted emotionally to the fact that what I can't do anymore. It definitely has affected my quality of life. For sure.
Participant 036_2023AUHBV

Well, I had to stop working immediately. Basically had close to two years without working with no income at all. Yes, my social life and everything else, I had quite a young...I had a five-year-old at the time. All that stuff that I used to be able to do was significantly impacted. Yes, from time to time even now there are times where I can't get off the couch.
Participant 043_2023AUHBV

Experience described suggests that there was overall a minimal impact on quality of life

Initially, it probably did. My children were all a bit wary about how much I could do to help with the grandchildren and stuff. But then as time went on and and all the issues were resolved and, you know, that hasn't been an issue any longer and it certainly hasn't affected anything, you know, with my husband and I.
Participant 013_2023AUHBV

With my family now? No. Maybe before.
Participant 026_2023AUHBV

Experience described suggests that there was an overall positive impact on quality of life

Yeah. Yeah. So I guess the answer, it's like I'm gonna actually just go out on the thing and say that it's affected it and in a the overall bottom line, it's like a more positive thing. Yep. Yeah. Yeah. And that's just cuz I probably have more awareness of my body. And for me I am someone that hey, like if I take the time to do some some research and you know and and take some extra steps and behavior change because I've I've I've made some positive changes. I you know I kind of get that effect that mental health effect where it's like hey like I'm getting like good endorphins. I'm doing a bit more exercise and yeah, like, I'm just receiving some, some upside because I've made some

of these behavior changes, lifestyle changes, yeah. So it's overall good. It's a plus.
Participant 001_2023AUHBV

No, I think if anything, my family's. Become a lot more closer, a lot more supportive with the diagnosis. Certainly they haven't distanced themselves which has been great. So it's all been very positive on that front. And you know, if I need to talk though, they're very good listeners.
Participant 011_2023AUHBV

My family, I've got two boys. One's in LOCATION OVERSEAS and one's in LOCATION METROPOLITAN. They both ring me. The one in LOCATION OVERSEAS rings me, and we go on FaceTime for half an hour or so, the one in LOCATION METROPOLITAN ringed me every two or three days, and I ring him too. My wife's family keep touch with me, but not a lot. My younger sister-in-law is in the same boat as me, she is very healthy but she has lost her husband, and she understands my problems, I suppose, because she's got the same things on her. She helps me and I help her
Participant 048_2023AUHBV

Experience described suggests that there was overall no impact on quality of life

No, I don't think so.
Participant 005_2023AUHBV

I don't think it has had a great deal of effect because I've been pretty active. I get tired, but I just put that down to just running around after everybody. But I don't put it down to my heart condition. I sort of don't think about it.
Participant 037_2023AUHBV

Experience described suggests that there was a mix of positive and negative impact on quality of life

PARTICIPANT: Long-term, it doesn't anymore. I think initially because I had to rely on my husband quite a lot, and he was looking after a new-born and me, it made it quite stressful for him. For me, it meant we had to rely on family a lot, a lot more than I would've liked too. But now, I mean our quality of life is fantastic. We have no, it basically doesn't really impact us long-term. That's as my health has improved.

INTERVIEWER: Just that your little boy is going to be an only child?

PARTICIPANT: Yes. But that was quite difficult initially, but we've very much come to terms with that. So we went through a grieving process, that we couldn't have any more children, but now we are okay with that and he's a very, very happy loved little boy. So there's no, we feel like there are things that we can give him more of now that we can't have, so while we have had some loss in that, we've also had some gains.
Participant 035_2023AUHBV

Table 8.1: Impact on quality of life

Impact on quality of life	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Experience described suggests that there was an overall negative impact on quality of life	31	65.96	13	72.22	18	62.07	4	44.44	12	70.59	15	71.43	17	62.96	14	70.00
Experience described suggests that there was overall a minimal impact on quality of life	5	10.64	2	11.11	3	10.34	2	22.22	1	5.88	2	9.52	3	11.11	2	10.00
Experience described suggests that there was an overall positive impact on quality of life	4	8.51	2	11.11	2	6.90	2	22.22	2	11.76	0	0.00	2	7.41	2	10.00
Experience described suggests that there was overall no impact on quality of life	3	6.38	1	5.56	2	6.90	1	11.11	1	5.88	1	4.76	2	7.41	1	5.00
Experience described suggests that there was a mix of positive and negative impact on quality of life	2	4.26	0	0.00	2	6.90	0	0.00	0	0.00	2	9.52	1	3.70	1	5.00
No particular comment	2	4.26	0	0.00	2	6.90	0	0.00	1	5.88	1	4.76	2	7.41	0	0.00

Impact on quality of life	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Experience described suggests that there was an overall negative impact on quality of life	31	65.96	18	69.23	13	61.90	13	54.17	18	78.26	11	73.33	20	62.50	15	60.00	16	72.73
Experience described suggests that there was overall a minimal impact on quality of life	5	10.64	3	11.54	2	9.52	3	12.50	2	8.70	0	0.00	5	15.63	4	16.00	1	4.55
Experience described suggests that there was an overall positive impact on quality of life	4	8.51	3	11.54	1	4.76	3	12.50	1	4.35	2	13.33	2	6.25	3	12.00	1	4.55
Experience described suggests that there was overall no impact on quality of life	3	6.38	2	7.69	1	4.76	2	8.33	1	4.35	1	6.67	2	6.25	1	4.00	2	9.09
Experience described suggests that there was a mix of positive and negative impact on quality of life	2	4.26	0	0.00	2	9.52	2	8.33	0	0.00	1	6.67	1	3.13	1	4.00	1	4.55
No particular comment	2	4.26	0	0.00	2	9.52	1	4.17	1	4.35	0	0.00	2	6.25	1	4.00	1	4.55

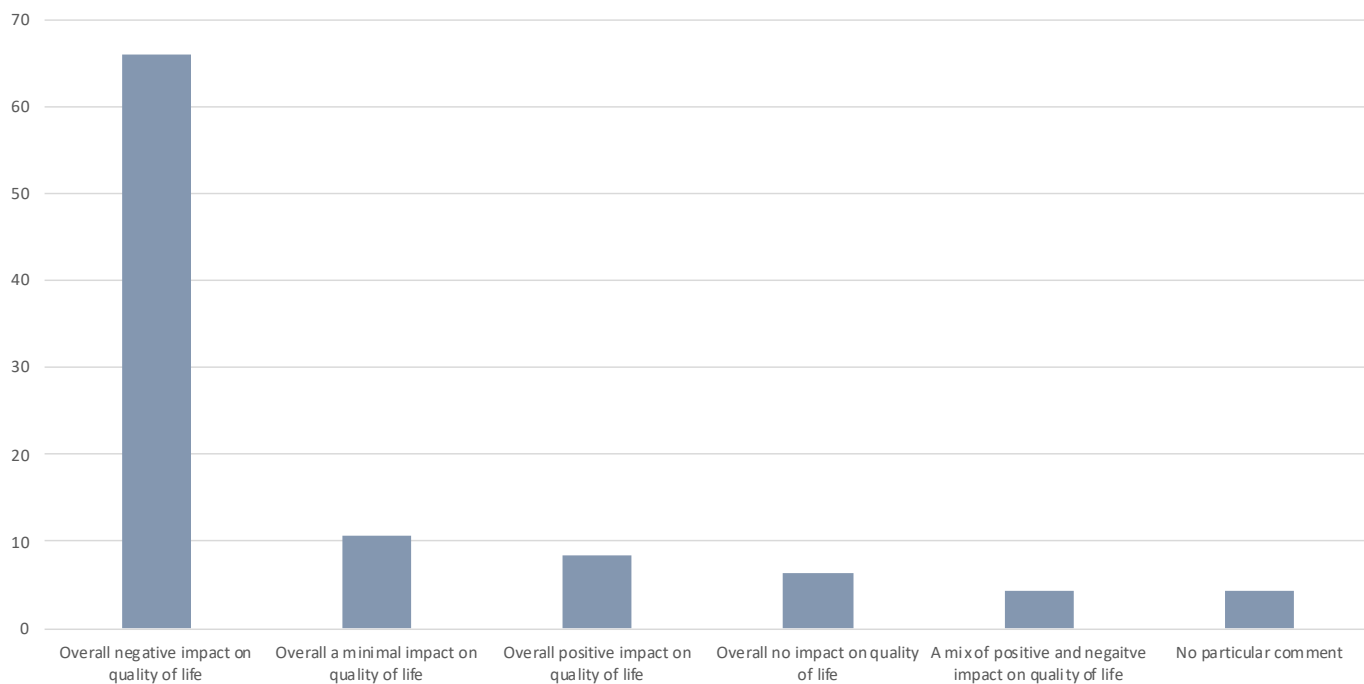


Figure 8.1: Impact on quality of life

Table 8.2: Impact quality of life – subgroup variations

Impact on quality of life	Reported less frequently	Reported more frequently
Experience described suggests that there was an overall negative impact on quality of life	High cholesterol under 50 years of age Aged 25 to 44	Aged 45 and older
Experience described suggests that there was overall a minimal impact on quality of life	Regional or remote	High cholesterol under 50 years of age
Experience described suggests that there was an overall positive impact on quality of life	-	High cholesterol under 50 years of age

Table 8.3: Impact on quality of life (Reasons)

Impact on quality of life (reasons)	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes a negative impact on quality of life due to the emotional strain (including family/change in relationship dynamics)	18	38.30	6	33.33	12	41.38	3	33.33	6	35.29	9	42.86	9	33.33	9	45.00
Participant describes a negative impact on quality of life due to reduced capacity for physical activity/need to slow down	14	29.79	4	22.22	10	34.48	2	22.22	4	23.53	8	38.10	7	25.93	7	35.00
Participant describes a negative impact on quality of life due to managing side effects and symptoms	11	23.40	5	27.78	6	20.69	3	33.33	4	23.53	4	19.05	6	22.22	5	25.00
Participant describes a negative impact on quality of life due to the emotional strain on self	10	21.28	4	22.22	6	20.69	1	11.11	1	5.88	8	38.10	6	22.22	4	20.00
Participant describes a negative impact on quality of life due to reduced social interaction	8	17.02	6	33.33	2	6.90	3	33.33	3	17.65	2	9.52	4	14.81	4	20.00
Participant describes a negative impact on quality of life due to altering lifestyle to manage condition (including being immunocompromised)	4	8.51	2	11.11	2	6.90	0	0.00	2	11.76	2	9.52	3	11.11	1	5.00
Participant describes a negative impact on quality of life due to inability to work/changes with their work	4	8.51	2	11.11	2	6.90	1	11.11	1	5.88	2	9.52	4	14.81	0	0.00
Participant describes a negative impact on quality of life due to being unable to travel/adapt significantly in order to travel	3	6.38	0	0.00	3	10.34	0	0.00	0	0.00	3	14.29	2	7.41	1	5.00
Participant describes a minimal impact on quality of life that has a general or temporary impact	5	10.64	2	11.11	3	10.34	1	11.11	2	11.76	2	9.52	3	11.11	2	10.00
Participant describes a positive impact on quality of life because it brings people together/highlights supportive relationships	7	14.89	3	16.67	4	13.79	2	22.22	2	11.76	3	14.29	4	14.81	3	15.00
Participant describes no impact on quality of life	3	6.38	1	5.56	2	6.90	1	11.11	1	5.88	1	4.76	2	7.41	1	5.00

Impact on quality of life (reasons)	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes a negative impact on quality of life due to the emotional strain (including family/change in relationship dynamics)	18	38.30	9	34.62	9	42.86	9	37.50	9	39.13	7	46.67	11	34.38	7	28.00	11	50.00
Participant describes a negative impact on quality of life due to reduced capacity for physical activity/need to slow down	14	29.79	8	30.77	6	28.57	5	20.83	9	39.13	5	33.33	9	28.13	5	20.00	9	40.91
Participant describes a negative impact on quality of life due to managing side effects and symptoms	11	23.40	7	26.92	4	19.05	5	20.83	6	26.09	3	20.00	8	25.00	5	20.00	6	27.27
Participant describes a negative impact on quality of life due to the emotional strain on self	10	21.28	8	30.77	2	9.52	3	12.50	7	30.43	2	13.33	8	25.00	4	16.00	6	27.27
Participant describes a negative impact on quality of life due to reduced social interaction	8	17.02	5	19.23	3	14.29	4	16.67	4	17.39	3	20.00	5	15.63	5	20.00	3	13.64
Participant describes a negative impact on quality of life due to altering lifestyle to manage condition (including being immunocompromised)	4	8.51	2	7.69	2	9.52	2	8.33	2	8.70	1	6.67	3	9.38	3	12.00	1	4.55
Participant describes a negative impact on quality of life due to inability to work/changes with their work	4	8.51	2	7.69	2	9.52	1	4.17	3	13.04	0	0.00	4	12.50	0	0.00	4	18.18
Participant describes a negative impact on quality of life due to being unable to travel/adapt significantly in order to travel	3	6.38	1	3.85	2	9.52	1	4.17	2	8.70	1	6.67	2	6.25	1	4.00	2	9.09
Participant describes a minimal impact on quality of life that has a general or temporary impact	5	10.64	3	11.54	2	9.52	2	8.33	3	13.04	1	6.67	4	12.50	4	16.00	1	4.55
Participant describes a positive impact on quality of life because it brings people together/highlights supportive relationships	7	14.89	3	11.54	4	19.05	5	20.83	2	8.70	5	33.33	2	6.25	5	20.00	2	9.09
Participant describes no impact on quality of life	3	6.38	2	7.69	1	4.76	2	8.33	1	4.35	1	6.67	2	6.25	1	4.00	2	9.09

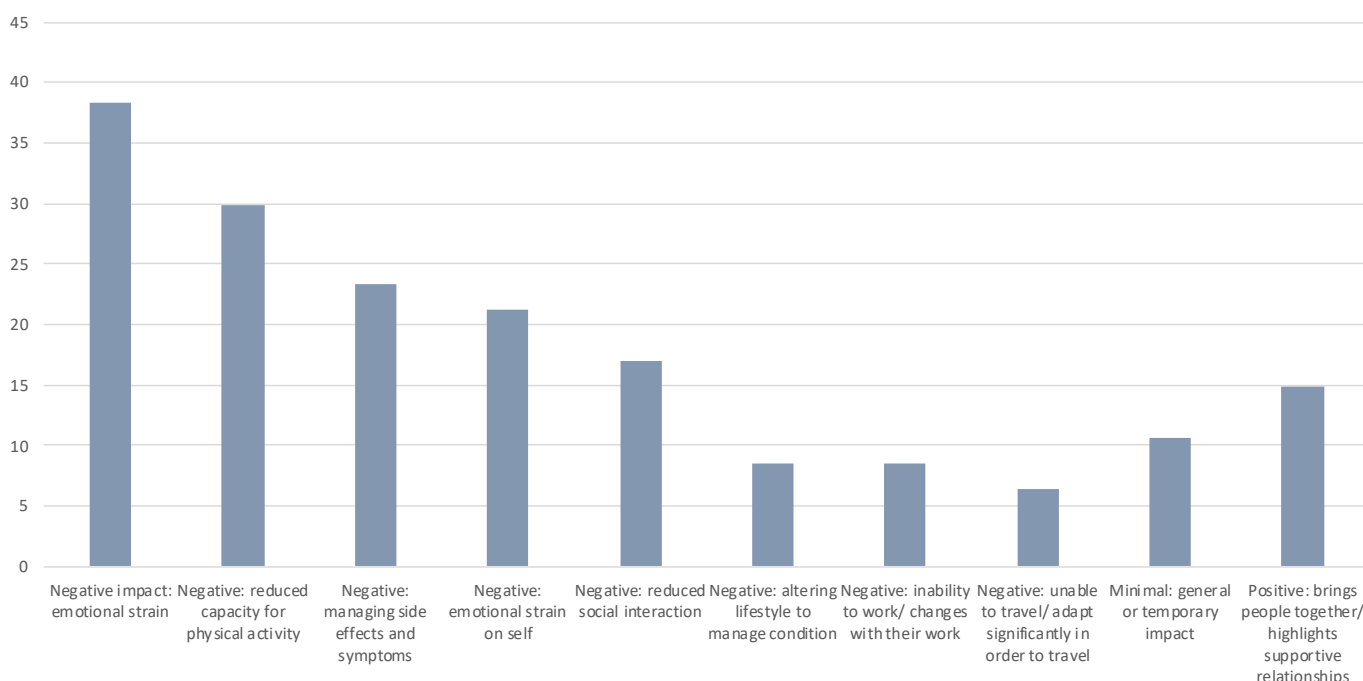


Figure 8.2: Impact on quality of life (Reasons)

Table 8.4: Impact on quality of life (Reasons)– subgroup variations

Impact on quality of life (reasons)	Reported less frequently	Reported more frequently
Participant describes a negative impact on quality of life due to the emotional strain (including family/change in relationship dynamics)	Mid to low socioeconomic status	Higher socioeconomic status
Participant describes a negative impact on quality of life due to reduced capacity for physical activity/need to slow down	-	Higher socioeconomic status
Participant describes a negative impact on quality of life due to the emotional strain on self	High cholesterol under 50 years of age Blood vessel conditions Male	Heart conditions
Participant describes a negative impact on quality of life due to reduced social interaction	Did not had LP(a) test	Had LP(a) test High cholesterol under 50 years of age
Participant describes a positive impact on quality of life because it brings people together/highlights supportive relationships	-	Regional or remote

Impact on mental health

In the structured interview, participants were asked if there had been an impact on their mental health. Most commonly, the descriptions suggested that overall, there was at least some impact on mental health

(70.21%). There were 4 participants (8.51%) that indicated no impact and 10 participants (21.28%) that did not describe impact on mental health or had a mixed experience.

Table 8.5: Impact on mental health

Impact on mental health	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Experience described suggests that overall, there was at least some impact on mental health	33	70.21	14	77.78	19	65.52	6	66.67	17	100.00	10	47.62	17	62.96	16	80.00
Other or mixed experience	10	21.28	2	11.11	8	27.59	1	11.11	0	0.00	9	42.86	7	25.93	3	15.00
Experience described suggests that overall, there was no impact on mental health	4	8.51	2	11.11	2	6.90	2	22.22	0	0.00	2	9.52	3	11.11	1	5.00

Impact on mental health	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Experience described suggests that overall, there was at least some impact on mental health	33	70.21	21	80.77	12	57.14	18	75.00	15	65.22	12	80.00	21	65.63	20	80.00	13	59.09
Other or mixed experience	10	21.28	4	15.38	6	28.57	4	16.67	6	26.09	3	20.00	7	21.88	2	8.00	8	36.36
Experience described suggests that overall, there was no impact on mental health	4	8.51	1	3.85	3	14.29	2	8.33	2	8.70	0	0.00	4	12.50	3	12.00	1	4.55

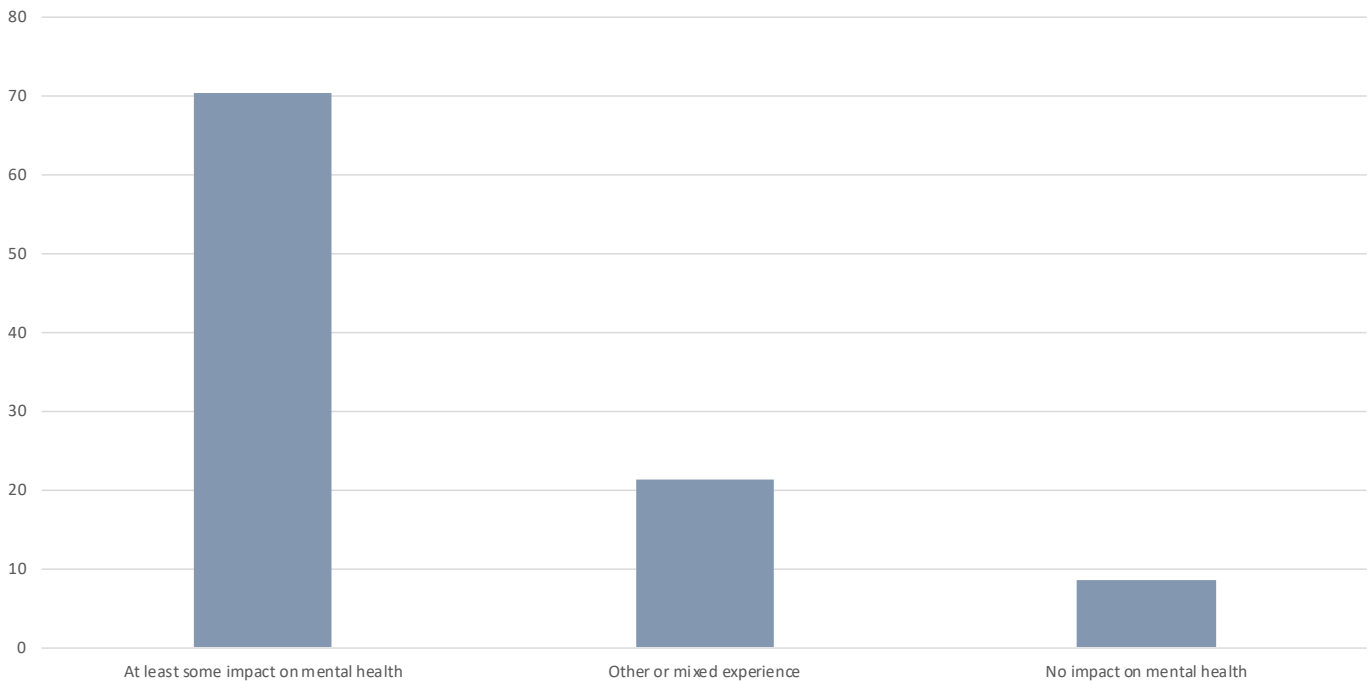


Figure 8.3: Impact on mental health

Table 8.6: Impact on mental health – subgroup variations

Impact on mental health	Reported less frequently	Reported more frequently
Experience described suggests that overall, there was at least some impact on mental health	Heart conditions Male Higher socioeconomic status	Blood vessel conditions Female
Other or mixed experience	Had LP(a) test High cholesterol under 50 years of age Blood vessel conditions	Heart conditions Higher socioeconomic status
Experience described suggests that overall, there was no impact on mental health	Mid to low socioeconomic status	High cholesterol under 50 years of age

Regular activities to maintain mental health

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common responses were consulting a mental health professional (21.28%), mindfulness and/or meditation(21.28%), and the importance of physical exercise (17.02 %). Other activities included remaining social and having hobbies (8.51%), and taking medication (8.51%).

Participant describes consulting a mental health professional to maintain their mental health

Yes. It's very emotional. Some days I'm really good and others are not. I did see a psychologist for a while to help with that. Probably a grieving of how my life had changed. It is something I probably should do all the time.

Participant 047_2023AUHBV

I just see my psychiatrist every three weeks. I see my doctor every week. That's basically it.

Participant 042_2023AUHBV

Yes. And yes. It's. It's definitely increases my anxiety as I've lent into the chaos. Yeah, really wanting to find out more information. So yeah, increasing anxiety and it having regular counseling appointments and also discussing the up to date things with the close family and friends.

Participant 003_2023AUHBV

Participant describes mindfulness and/or meditation to maintain their mental health

So I work with my GP around mindfulness and breathing and meditation. She's actually quite holistic in that regard, which I quite like live near the beach. So I quite often like to, even if I'm not well enough to walk, I'm going and get a close car park and just sit and watch the world go by and and be like work on my mental health, work on stress and a big thing. Like, I wouldn't say that I suffer from anxiety, but the fact of not having an income has really been a big source of anxiety for me and the fact that I can't help that right now. So yeah, that mindfulness, I I don't go to like a psychologist or anything like that. My cardiologist, when I told him that I just wanted my life back and I ended up crying with him last last appointment. That was before I started the culture saying last appointment and he prescribed antidepressants for me and that was not helpful at all. I'm not depressed. I don't want to end my life. I want my life back. There is a huge bring the two. So my my GP was really quite upset that that happened because my mental health at that point was good and then I started doubting myself about things. But anyway, I've come, I started it, it was awful. I've come off it. I don't have depression. I'm just frustrated.

Participant 014_2023AUHBV

One of the things I learned early was I needed to retrain my brain. Setting off on that adventure and being positive about it meant that the depression disappeared. That having a goal and creating a goal was probably the most important thing I could have done in terms of my rehab. My mental health is quite sound. Mentally, I get frustrated when my memory fails. Like most stroke survivors, your memory is at its weakest when you're tired. I feel frustration. I no longer feel sadness or depression, I just get pretty bloody frustrated when I can't remember somebody's name.

Participant 045_2023AUHBV

Participant describes the importance of physical exercise to maintain their mental health

Yes, I do. I walk every morning when I'm out there. I'm meditating. Most mornings, me and my dog, we go walking. It's good for my mental health, you know, and my emotions, you know.

Participant 025_2023AUHBV

It hasn't. How would I say this? It hasn't made a big change to my mental health yet but sees it's only early days and I'm still trying to work hard being hopeful at getting back to where I was. If that doesn't work, I think I'm going to go through a grieving process. If I can't drive that's going to really affect me because I'll be-- Because I'm a single woman it'll really change my life and that will be hard. I do all most physical activities which help mental health and I keep myself busy in my house that helps mental health. I've not been a good person with social media, I don't really understand it. I've not been able to develop a social media contact with people and I don't own a computer, I just own a phone. That's probably something I need to work on otherwise I'm going to get really lonely if I can't drive.

Participant 041_2023AUHBV

I think the the the main problem that I have at the moment is not not being able to do as as much as I want. And so I'm working with a exercise physiologist because it it it it's quite hard and frustrating when because it takes a long time to build up your energy levels and what you can do. It doesn't just happen overnight. You can sometimes think oh I'm I'm never going to get get there and so I'll give up But with the exercise physiologist you know you can talk through those things and work out strategies and where where you will be and those sorts of things. So it just keep keeps you motivated to and to keep on track. And I found it going out to sort of organized app aerobics and things like that helpful because if you're just doing it at home on yourself by yourself, your motivation means and you don't do it. Whereas if you've got a fixed time, fixed day where the classes are run, you can actually make yourself get there. So I found that helpful as well. And I've been lucky because the classes that I've gone to, the people have been very sort of welcoming. They're older people and they're very welcoming and friendly and so, you know, you haven't got a sterile environment or competitive environment that you're you're going into, which is nice. You feel that you can just get on and do as much as you can. Nobody's judging or trying to make you do more that sort of thing.

Participant 017_2023AUHBV

Participant describes remaining social and hobbies to maintain their mental health

*Yes, I think initially it really did. And there and and it and when I've had these I recall those whoopsie turns that that does upset me and it affects me because it's something I would rather not happen and I have to try and work out how we're going to stop it happening. But I when I'm you know identifying why the cause. Yeah. So then you think well what can I do. And it's about relieving I and I and I've worked out myself that it's stressed, so I've, you know, changed some things in my life to remove that level of stress, all those external things. I've always been a very active community person and taken on lots of jobs and things which I'm not doing now.
Participant 013_2023AUHBV*

So it does on occasion, but I never have a great. Two week anniversary in July, August so and I I had my defib, my defib was implanted on my birthday. So it sort of had it. It's a bit triggering because it wasn't a great day in my life in some ways, but and I have had ups and downs along the way. When I'm told you know you, you think that there's an end goal like in 12 months time I'll be able to run again and then it's like, no, no, no, you can't do that ever again. Like so you have ups and downs, but day-to-day I I don't have an ongoing anxiety or depression or I don't feel down about it. I have days where I think you know, that was you know, you know what? What with me moments where I think, bloody hell, you know, I could have been doing. 1/2 marathon or something And you know, stop winding that you don't like running, at least you can run like I, but we all have days like that, you know. So it's really, I'd say the worst, that it's going well and

*to be going. And I did seek help through psychologists at at the time when it was the worst initially. I just find other ways. I can't run anymore, but I do other things just to, you know, just doing the voids. So, you know, not, not anything in particular.
Participant 009_2023AUHBV*

Participant describes pacing and taking medication to maintain their mental health

*From the stroke, I got anxiety. I take medication for that. I have a psychologist I see on a regular basis. I've been seeing a psychologist for 30-odd years now just to keep me on track. I hate the person I am because of the stroke, because I could do so many other things before my stroke that I can't do now and that I miss. It's also about I'm alive and I can function pretty well, so I'm lucky to be here. It has a negative and a positive thing.
Participant 049_2023AUHBV*

*Well, it did it. It gave me all sorts of anxiety to begin with. And I'm I was medicated for that and I've chosen to stay on that medication. So that I don't go back to being like that. Excellent, because it was quite frightening.
Participant 005_2023AUHBV*

Participant describes no activities to maintain mental health to maintain their mental health

*I don't and I should. I know I should because my emotion-- I've sort of developed a very short temper, unfortunately.
Participant 043_2023AUHBV*

Table 8.7: Regular activities to maintain mental health

Regular activities to maintain mental health	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes consulting a mental health professional to maintain their mental health	10	21.28	3	16.67	7	24.14	3	33.33	5	29.41	2	9.52	6	22.22	4	20.00
Participant describes mindfulness and/or meditation to maintain their mental health	10	21.28	4	22.22	6	20.69	1	11.11	5	29.41	4	19.05	6	22.22	4	20.00
Participant describes the importance of physical exercise to maintain their mental health	8	17.02	5	27.78	3	10.34	2	22.22	4	23.53	2	9.52	4	14.81	4	20.00
Participant describes remaining social and hobbies to maintain their mental health	4	8.51	2	11.11	2	6.90	1	11.11	2	11.76	1	4.76	2	7.41	2	10.00
Participant describes pacing and taking medication to maintain their mental health	4	8.51	2	11.11	2	6.90	0	0.00	4	23.53	0	0.00	2	7.41	2	10.00
Participant describes no activities to maintain mental health to maintain their mental health	3	6.38	3	16.67	0	0.00	1	11.11	1	5.88	1	4.76	2	7.41	1	5.00
Participant describes pacing and not taking on too much/saying 'no' to maintain their mental health	3	6.38	2	11.11	1	3.45	0	0.00	1	5.88	2	9.52	2	7.41	1	5.00

Regular activities to maintain mental health	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes consulting a mental health professional to maintain their mental health	10	21.28	6	23.08	4	19.05	5	20.83	5	21.74	3	20.00	7	21.88	7	28.00	3	13.64
Participant describes mindfulness and/or meditation to maintain their mental health	10	21.28	6	23.08	4	19.05	7	29.17	3	13.04	6	40.00	4	12.50	7	28.00	3	13.64
Participant describes the importance of physical exercise to maintain their mental health	8	17.02	7	26.92	1	4.76	7	29.17	1	4.35	4	26.67	4	12.50	5	20.00	3	13.64
Participant describes remaining social and hobbies to maintain their mental health	4	8.51	3	11.54	1	4.76	2	8.33	2	8.70	1	6.67	3	9.38	3	12.00	1	4.55
Participant describes pacing and taking medication to maintain their mental health	4	8.51	3	11.54	1	4.76	1	4.17	3	13.04	2	13.33	2	6.25	2	8.00	2	9.09
Participant describes no activities to maintain mental health to maintain their mental health	3	6.38	1	3.85	2	9.52	2	8.33	1	4.35	0	0.00	3	9.38	0	0.00	3	13.64
Participant describes pacing and not taking on too much/saying 'no' to maintain their mental health	3	6.38	2	7.69	1	4.76	1	4.17	2	8.70	1	6.67	2	6.25	3	12.00	0	0.00

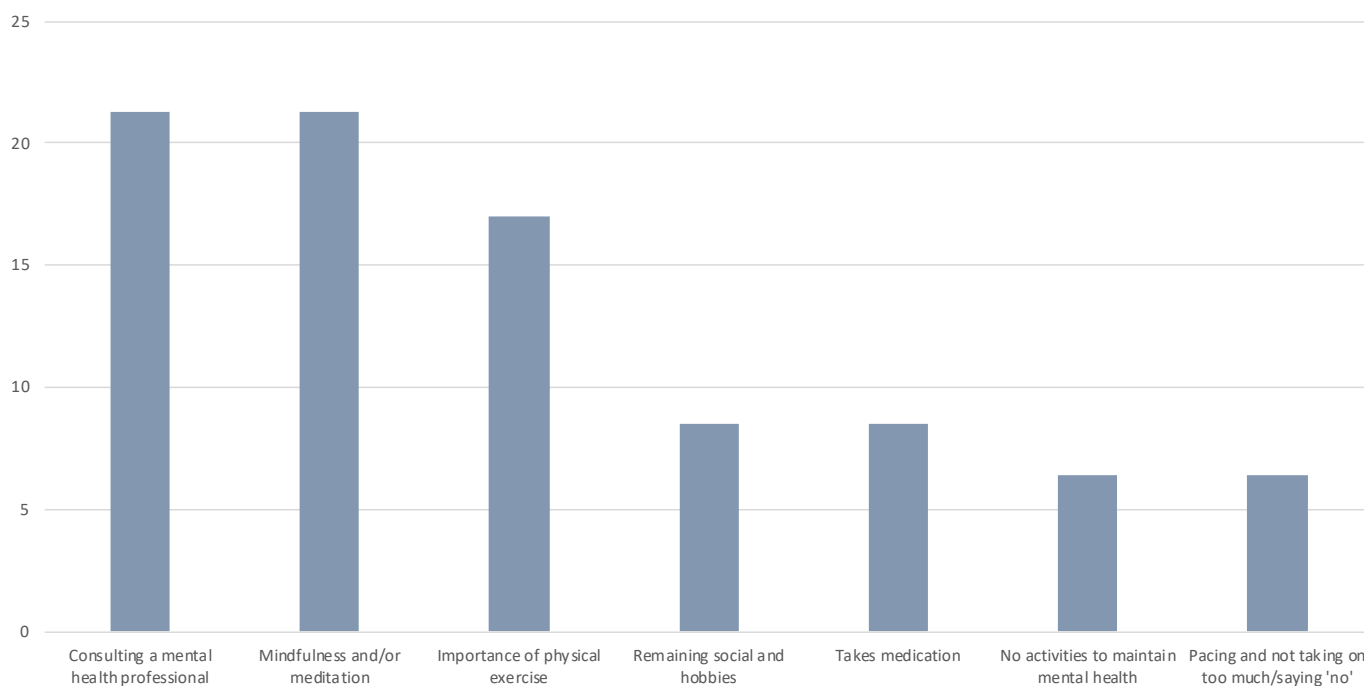


Figure 8.4: Regular activities to maintain mental health

Table 8.8: Regular activities to maintain mental health – subgroup variations

Regular activities to maintain mental health	Reported less frequently	Reported more frequently
Participant describes consulting a mental health professional to maintain their mental health	Heart conditions	High cholesterol under 50 years of age
Participant describes mindfulness and/or meditation to maintain their mental health	High cholesterol under 50 years of age	Regional or remote
Participant describes the importance of physical exercise to maintain their mental health	Male Aged 45 and older	Had LP(a) test Aged 25 to 44
Participant describes pacing and taking medication to maintain their mental health		Blood vessel conditions
Participant describes no activities to maintain mental health to maintain their mental health		Had LP(a) test

Regular activities to maintain health

In the structured interview, participants were asked what were some of the things they needed to do everyday to maintain their health. The most common activities for general health were doing physical exercise or being physically active (46.81%), self care for example more rest, accepting help, pacing themselves (40.43%), and maintaining a healthy diet (36.17 %). Other activities included complying with treatment or management of their condition (23.40%), mindfulness and/or meditation (19.15%), making healthy lifestyle changes (10.64%), maintaining a healthy weight (8.51%), and managing stress (8.51%).

Participant describes the importance of doing physical exercise/physically active in maintaining their general health

What I what I do is I walk most days. I won't say every day, but I do walk most days. And again I set a time for that. So if I'm watching a program or I might say right, I'll go for walk after that finished or at 12:00 I'll go for a walk. I do do my three classes a Week 2 aerobics, water aerobics and one is in in the gym. So I I do that and I'm hoping to build, build up on that, put, you know, put more weights on, make them more

strenuous. I don't think it would be every day, but at least just increasing what I do on those days.

Participant 017_2023AUHBV

I work out. I find going to the work out when I'm not-so I find going to the gym very helpful. I work out because you get your body fit can help your mind to think.

Participant 039_2023AUHBV

Yeah, it's it's just keeping up with sort of my newer habits. Yeah. Because if I can do some exercises throughout the week, I mean, I I've got my, I'm keeping my physical conditioning and and then, of course, my mental health stays intact because I already get the pleasure of knowing that I've looked after my body, you know?

Participant 001_2023AUHBV

Participant describes the importance of self care e.g. more rest, accepting help, pacing in maintaining their general health

I need to make sure that I get lots of sleep. I need to make sure that I don't overdo things and if I overdo things I need to stop and just sleep. I also need to recognise that when I can feel that I am starting to get tired that I stop then and I don't push through things.

Participant 047_2023AUHBV

Well, I have to rest a huge amount. I have to pace myself really well. So do something and then lie down and rest and and try not to do things unless I'm able to. OK, very difficult.

Participant 019_2023AUHBV

I just need to watch my workload more than anything. I really need to really monitor how much I do in a particular day to make sure I'm not really sick the following day.

Participant 043_2023AUHBV

Participant describes the importance of maintaining a healthy diet in maintaining their general health

Yeah, I think about what I do, what size of portions etcetera so that I can control my cholesterol.

Participant 026_2023AUHBV

I definitely, yeah, definitely have a better diet now. Definitely take care of myself. I don't really ever drink. I've been drinking for months now. Yeah, it's just little basics I guess like that, that I've just changed up a bit to help myself beneficial in the future.

Participant 029_2023AUHBV

PARTICIPANT: Sleep is the main one. I just need to make sure I get a good night's sleep, and not overexert myself. My daughter got married last week.

INTERVIEWER: Oh that's lovely.

PARTICIPANT: The lead up to that was exhausting. I'm still exhausted. The wedding was on Friday and we're now what, Wednesday and I still feel like I could take a nap today, because of everything that has gone on then, and since. Yeah, so rest. I need to not exert myself too much. I need to make sure that I eat healthy for the most part. I still treat myself occasionally but I usually make sure I have fruit and veg. I'm not a huge meat eater. I just make sure I eat a little bit of protein through the day. I watch the weather app a lot. I'm always checking how hot it's going to be, and LOCATION METROPOLITAN is killing me today. I watch the weather and plan my activities around the weather. Rest and food. And that's about it. That's my life is revolving doors. Watching all those through things.

Participant 036_2023AUHBV

Participant describes the importance of complying with treatment/management in maintaining their general health

Because it does take it out of me, but I've been consistently going for six months now and I think that that's why I am where I am. So exercise has really helped. Of course, taking medication when you had to take it and how frequently you had to take it. Yeah. I think that those two things have helped me get my life back because I live here, I have no family up here and my husband works away, so he's away nine months of the year. So it's just me and the kids. And I think I have kids that are capable as well. So I think that helps.

Participant 014_2023AUHBV

So basically I need to take my medication. I need to pace myself into what I'm doing. You know at the end of the day if I go at something to pull like a ball at a gate or over exert myself, I'm going to end up out of breath and with chest pain and yeah then nothing's going to get done. You know I suppose it's that whole you know slow and steady wins the race scenario. You know I just need to be mindful of what I'm doing, how I'm doing it and yeah literally not over exert myself I suppose. And one of the best examples of that is, is lifting things is one of those, you know. So obviously if I put too much strain on my right arm, I'll cause injury and and severe pain with the painkillers I take. I don't notice it when it's happening either.

Participant 018_2023AUHBV

Participant describes the importance of mindfulness and/or meditation in maintaining their general health

I'm very lucky. There's nothing I need to do other than other than stick to not raising my heart rate above where where I'll set my DC off. There's nothing I actually need to do. I probably just need to keep my keep, keep a positive mindset, just not let it get on top of me that you know. While we've made. But no, I'm lucky in that sense.

Participant 009_2023AUHBV

I need to keep moving. I can't allow myself to dwell on this unfortunate thing that happened to me. I need to turn what was an unfortunate experience into a positive experience. The thing that I've learned to do is to, "All right. I had a stroke. It knocked me around. What are you going to do about it?" That's why I volunteered with the Stroke Foundation. I refused to allow a stroke to upset my life and the life of my friends and my family. The best thing I've discovered is to decide not to be a victim.

Participant 045_2023AUHBV

Yeah. So the main things is to make sure that I get enough sleep and I do my meditation just to control my breathing and just keep my head in check and just just to make sure that I'm reassuring myself that everything's good.

Participant 028_2023AUHBV

Participant describes the importance of making healthy lifestyle changes in maintaining their general health

Again, Is there anything I do every day I well, like I said, I go about smoking or that happened when the heart attack happened. Yep, that's finished. OK per detail of a few other things and just hard to take. Worked on taking things a lot easier, but like impact, impulse, active, just fix the matter right now.

Participant 006_2023AUHBV

I just think I need to well manage my alcohol intake. That's that's important because I've been a drinker and not, well, we have a drink. But I'm just saying just to make sure I never, you know, exceed that limit. That's one thing. Not that I've ever had an issue then, but it is one of the things. Exercise is the other thing. And diet, Yeah, they're probably the things that I look

at on a regular basis. Yeah. And and stress managing that stress.

Participant 013_2023AUHBV

Participant describes the importance of maintaining a healthy weight in maintaining their general health

First of all, I need to make sure that I am diligent with my medication. I need to make sure that I keep active and that I exercise, that I walk or keep myself fit. I also need to maintain a proper diet. Last year, since all the issues, I've put on a couple of kilos. I know that I need to lose it because it just impacts on a whole lot of things, sugar level, the way my heart works, and feeling tired, all of that, so all those things.

Participant 034_2023AUHBV

Go for a walk three times a week, lose weight. But, you know, that's all part of the fun and games. But you know, yeah, yeah, life's pretty good. You know, it could be worse, but why do people worse off for me? But you know, I'm pretty happy.

Participant 004_2023AUHBV

Participant describes the importance of managing stress in maintaining their general health

I need to have time off. Like I need to have a couple of days in a row where I don't have to do anything, so I don't have any stress. I don't have any anxiety about going to do things. And the anxiety isn't about my health. It's about like just doing stuff. I've always had that sort of thing. Like I stress. Yes, I stress about things rather. Participant 015_2023AUHBV

I think just trying to decrease my, my risk for future cardiac episodes, so ensuring that I get you know a good optimum amount of sleep every day, every night sit between 6:00 and 8:00 hours trying to decrease my stress, looking at my nutrition. So and also because lipoproteinase can be highly inflammatory. So I'm looking at things like, you know, adding more turmeric to my diet and garlic and increasing my fruit and veg and my salmon and things like that.

Participant 011_2023AUHBV

Table 8.9: Regular activities to maintain health

Regular activities to maintain general health	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes the importance of doing physical exercise/physically active in maintaining their general health	22	46.81	8	44.44	14	48.28	6	66.67	6	35.29	10	47.62	14	51.85	8	40.00
Participant describes the importance of self care e.g. more rest, accepting help, pacing in maintaining their general health	19	40.43	8	44.44	11	37.93	3	33.33	7	41.18	9	42.86	11	40.74	8	40.00
Participant describes the importance of maintaining a healthy diet in maintaining their general health	17	36.17	6	33.33	11	37.93	6	66.67	4	23.53	7	33.33	9	33.33	8	40.00
Participant describes the importance of complying with treatment/management in maintaining their general health	11	23.40	3	16.67	8	27.59	1	11.11	3	17.65	7	33.33	9	33.33	2	10.00
Participant describes the importance of mindfulness and/or meditation in maintaining their general health	9	19.15	3	16.67	6	20.69	2	22.22	5	29.41	2	9.52	5	18.52	4	20.00
Participant describes the importance of making healthy lifestyle changes in maintaining their general health	5	10.64	2	11.11	3	10.34	1	11.11	1	5.88	3	14.29	2	7.41	3	15.00
Participant describes the importance of maintaining a healthy weight in maintaining their general health	4	8.51	0	0.00	4	13.79	0	0.00	0	0.00	4	19.05	3	11.11	1	5.00
Participant describes the importance of managing stress in maintaining their general health	4	8.51	2	11.11	2	6.90	1	11.11	1	5.88	2	9.52	1	3.70	3	15.00

Regular activities to maintain general health	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes the importance of doing physical exercise/physically active in maintaining their general health	22	46.81	12	46.15	10	47.62	12	50.00	10	43.48	9	60.00	13	40.63	11	44.00	11	50.00
Participant describes the importance of self care e.g. more rest, accepting help, pacing in maintaining their general health	19	40.43	9	34.62	10	47.62	11	45.83	8	34.78	5	33.33	14	43.75	8	32.00	11	50.00
Participant describes the importance of maintaining a healthy diet in maintaining their general health	17	36.17	11	42.31	6	28.57	11	45.83	6	26.09	6	40.00	11	34.38	8	32.00	9	40.91
Participant describes the importance of complying with treatment/management in maintaining their general health	11	23.40	6	23.08	5	23.81	5	20.83	6	26.09	3	20.00	8	25.00	5	20.00	6	27.27
Participant describes the importance of mindfulness and/or meditation in maintaining their general health	9	19.15	4	15.38	5	23.81	4	16.67	5	21.74	6	40.00	3	9.38	6	24.00	3	13.64
Participant describes the importance of making healthy lifestyle changes in maintaining their general health	5	10.64	3	11.54	2	9.52	3	12.50	2	8.70	0	0.00	5	15.63	3	12.00	2	9.09
Participant describes the importance of maintaining a healthy weight in maintaining their general health	4	8.51	2	7.69	2	9.52	1	4.17	3	13.04	1	6.67	3	9.38	2	8.00	2	9.09
Participant describes the importance of managing stress in maintaining their general health	4	8.51	3	11.54	1	4.76	0	0.00	4	17.39	1	6.67	3	9.38	2	8.00	2	9.09

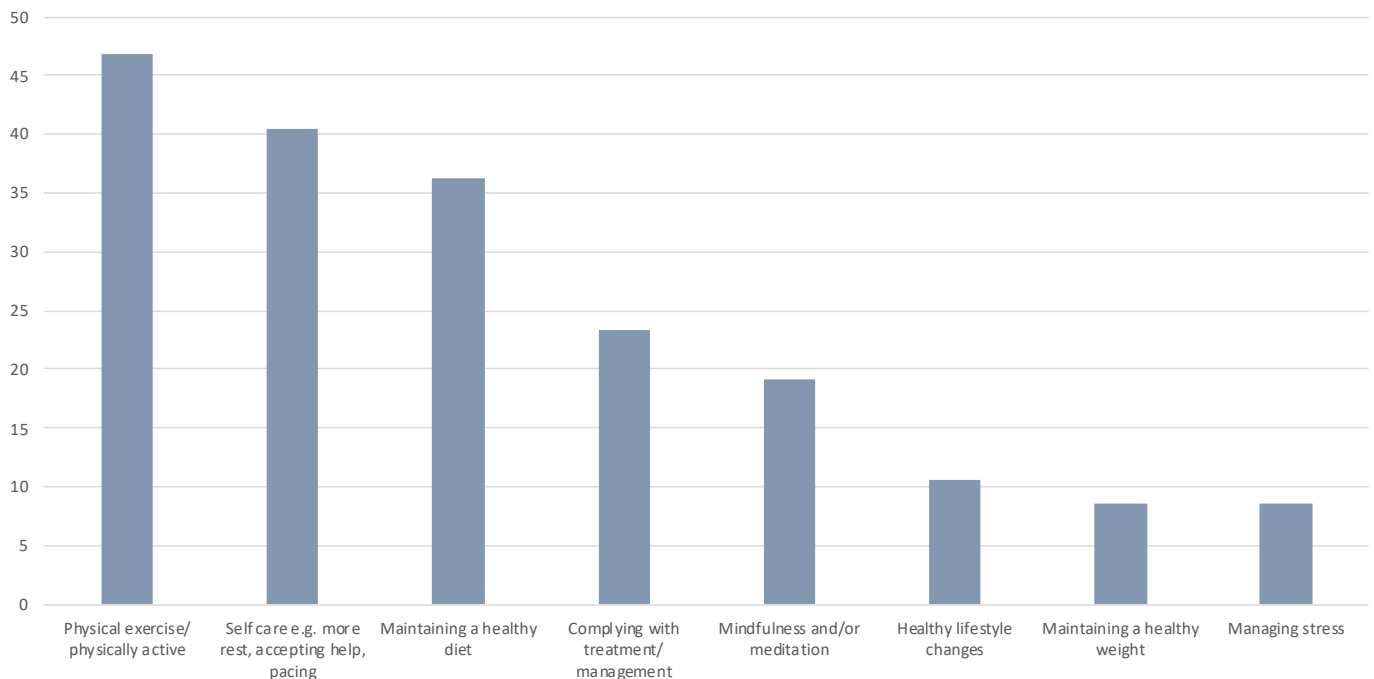


Figure 8.5: Regular activities to maintain health

Table 8.10: Regular activities to maintain health – subgroup variations

Regular activities to maintain general health	Reported less frequently	Reported more frequently
Participant describes the importance of doing physical exercise/physically active in maintaining their general health	Blood vessel conditions	High cholesterol under 50 years of age Regional or remote
Participant describes the importance of maintaining a healthy diet in maintaining their general health	Blood vessel conditions Aged 45 and older	High cholesterol under 50 years of age
Participant describes the importance of complying with treatment/management in maintaining their general health	High cholesterol under 50 years of age 6 to 11 other conditions	-
Participant describes the importance of mindfulness and/or meditation in maintaining their general health	-	Blood vessel conditions Regional or remote
Participant describes the importance of making healthy lifestyle changes in maintaining their general health	Regional or remote	-
Participant describes the importance of maintaining a healthy weight in maintaining their general health	-	Heart conditions

Experience of vulnerability

In the structured interview, participants were asked if there had been times that they felt vulnerable. The most common responses were that they felt vulnerable because of interactions with the medical team (17.02%), and when experiencing side effects from treatment or symptoms from condition (17.02%). Other times they felt vulnerable included during diagnostic procedure (14.89%), thinking about disease course or that they have an incurable condition (14.89%), during or after treatments (10.64%) and when feeling sick/unwell (8.51%). There were 7 participants (14.89%) that did not feel vulnerable.

Participant describes feeling vulnerable because of interactions with the medical team

I had an incident in 2019 (I think) where I experienced double vision for a few hours and had lots of follow ups, MRIs and a hospital admission. The neurologist who reviewed me at the Royal Melbourne Hospital said he believes that I never had a stroke and that it was actually an atypical migraine, and that I coincidentally have some damage in my cerebellum that is unrelated. He never saw my original scans though so it's hard to know what to make of the differing opinions between neurologists
Participant 046_2023AUHBV

I think in the beginning, when I was in and out of hospital and the medications weren't working, you sort of, I don't know, you feel like they're not listening properly to you.
Participant 008_2023AUHBV

Many times. I felt vulnerable when no-one was listening to me. I felt vulnerable when I needed help in hospital and there was no-one to help me.
Participant 032_2023AUHBV

Participant describes feeling vulnerable experiencing side effects from treatment or symptoms from condition

*Yeah, I've had a few moments like that, Not many. It's all to do with my surgery and if I have a major attack, which I've had a couple in the last 10, 15 years as well. I felt vulnerable then because waiting for an ambulance and after doing heart surgery and the way I felt. It felt like I was having a full on heart attack. Yeah, that made me very vulnerable. Probably twice over the last 10, 15 years I felt vulnerable*Participant 025_2023AUHBV

I tend to feel really vulnerable when I'm exhausted
Participant 041_2023AUHBV

Often when I'm fatigued and no one really understands
Participant 048_2023AUHBV

Participant describes feeling vulnerable during diagnostic procedure

Yeah, I felt vulnerable when I didn't, when they hadn't, when they didn't have a clue why I was blacking out. So you think, you know, I can't. What can I do? I can't have my grandchildren here because I had one. One time here when I had one of my grandchild was only three, you know, And it was, yeah, I felt very vulnerable after that because they didn't know what was causing it. And you know like she was pretty switched on 3 year olds and was yeah, that was pretty, pretty awful. But yeah, that's when I felt vulnerable and they didn't know what the the cause was. Yeah. Participant 013_2023AUHBV

100%? So I mean, right at the very beginning, you know, when it's kind of a shock, you know, when you're 40,41 years of age that someone tells you that you've got a heart issue. You know, you know, on top of dealing with everything that came with a motorcycle accident. You know, it was just one of those things I'm like, you know, you know, because I wasn't sure at that time, you know, whether the irregularities were caused because my heart stopped or, you know, whether whether or something else. So, you know, prior to to all the testing and that, like, I was absolutely terrified. I had no idea, you know, what was going on. So yeah, it was good after that, I guess.
Participant 021_2023AUHBV

Participant describes that they did not feel vulnerable

No, no, I wouldn't say that.
Participant 029_2023AUHBV

PARTICIPANT: No, I think I'm, uh, no, I I don't think I spend a lot of time focusing on it. Just sort of in the past and as you get older you get a bit wiser and. Yeah, 69 now, so you know it's. Yeah, it's just something that happens that. Out of the blue and you dealt with it, Yeah.
Participant 005_2023AUHBV

Participant describes feeling vulnerable thinking about disease course/incurable condition

*Yeah, definitely when I was in hospital and not remembering while I was in hospital. You know, waking up in the morning and not knowing where I was, things like that, definitely very vulnerable because your life suddenly in other people's hands, you, you even, you know everything you're not and and knowing that I've been in a coma, that makes you feel very vulnerable. And I think when we first come home from when I first come home from hospital, you know, even in hospital you just. You're continually at the mercy of what other people are deciding for you, which is a good thing because I can't decide how to cure or how to fix or how to attend to what I had. But you are completely putting your hand. You know all your faith has to go into these people that are making decisions that you don't understand. So that's, you know, you do feel vulnerable. And when when I came home to come home, not really understanding what happened, what happens next? You've had people around you. You know, I've had people around me for two weeks. I was in hospital for for almost, well, for 14 days. So. And all of a sudden you're at home and your husband goes back to work and your kids are back at work and school and doing all. You've still got a support network, but you're at home on your own and you don't really know what if something happens? What if I have an arrest now? Who? So you it takes a little while to not feel like you know You know you put on a brave face, but you. I I personally felt quite vulnerable for quite a probably quite a quite a while and and when you have an arrest you lose your license. So you know becoming quite dependent and a lot of people doesn't help you you know for everything. So I'd say that. Definitely. I mean and then you get a confidence back and off you go, but but definitely that's a couple of weeks in hospital and probably the first I'd say three or four months
Participant 009_2023AUHBV*

*I think sometimes I feel more vulnerable like some, like I often lose sleep over it, I think. Gosh, you know what's going to happen in 10 years time or in five years time or tomorrow kind of thing. So I guess emotionally it's just been a bit of a roller coaster. But I wouldn't say I'm depressed or anything like that. But you know how you just get you just get your lows sometimes and and I find that you, you know, I've been, I think about it at night, especially when I'm trying to go to sleep and then I'll not off to sleep and then it's happening again the next day.
Participant 011_2023AUHBV*

Participant describes feeling vulnerable during/after treatments

*I was involved in a car accident and spent a week in hospital
Participant 039_2023AUHBV*

*When your stuck in hospital and can't control anything
Participant 038_2023AUHBV*

Participant describes feeling vulnerable when feeling sick/unwell

*When I was really sick and potentially couldn't advocate for myself?
Participant 014_2023AUHBV*

*I feel vulnerable when I get sick or if I have to have a procedure. There are a couple of reasons for that: 1. Because I'm on blood thinners I have related issues such as bleeding. 2. I feel vulnerable because I now take longer to get better when I'm sick or if something happens.
Participant 034_2023AUHBV*

Table 8.11: Experience of vulnerability

Experience of vulnerability	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes feeling vulnerable because of interactions with the medical team	8	17.02	3	16.67	5	17.24	1	11.11	1	5.88	6	28.57	4	14.81	4	20.00
Participant describes feeling vulnerable experiencing side effects from treatment or symptoms from condition	8	17.02	2	11.11	6	20.69	1	11.11	5	29.41	2	9.52	4	14.81	4	20.00
Participant describes feeling vulnerable during diagnostic procedure	7	14.89	2	11.11	5	17.24	2	22.22	1	5.88	4	19.05	4	14.81	3	15.00
Participant describes that they did not feel vulnerable	7	14.89	4	22.22	3	10.34	1	11.11	2	11.76	4	19.05	4	14.81	3	15.00
Participant describes feeling vulnerable thinking about disease course/incurable condition	7	14.89	2	11.11	5	17.24	2	22.22	4	23.53	1	4.76	4	14.81	3	15.00
Participant describes feeling vulnerable during/after treatments	5	10.64	1	5.56	4	13.79	0	0.00	2	11.76	3	14.29	1	3.70	4	20.00
Participant describes feeling vulnerable when feeling sick/unwell	4	8.51	2	11.11	2	6.90	1	11.11	0	0.00	3	14.29	2	7.41	2	10.00

Experience of vulnerability	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes feeling vulnerable because of interactions with the medical team	8	17.02	7	26.92	1	4.76	4	16.67	4	17.39	2	13.33	6	18.75	4	16.00	4	18.18
Participant describes feeling vulnerable experiencing side effects from treatment or symptoms from condition	8	17.02	5	19.23	3	14.29	5	20.83	3	13.04	3	20.00	5	15.63	4	16.00	4	18.18
Participant describes feeling vulnerable during diagnostic procedure	7	14.89	5	19.23	2	9.52	5	20.83	2	8.70	4	26.67	3	9.38	6	24.00	1	4.55
Participant describes that they did not feel vulnerable	7	14.89	5	19.23	2	9.52	4	16.67	3	13.04	1	6.67	6	18.75	3	12.00	4	18.18
Participant describes feeling vulnerable thinking about disease course/incurable condition	7	14.89	5	19.23	2	9.52	3	12.50	4	17.39	3	20.00	4	12.50	5	20.00	2	9.09
Participant describes feeling vulnerable during/after treatments	5	10.64	3	11.54	2	9.52	1	4.17	4	17.39	2	13.33	3	9.38	4	16.00	1	4.55
Participant describes feeling vulnerable when feeling sick/unwell	4	8.51	3	11.54	1	4.76	2	8.33	2	8.70	3	20.00	1	3.13	4	16.00	0	0.00

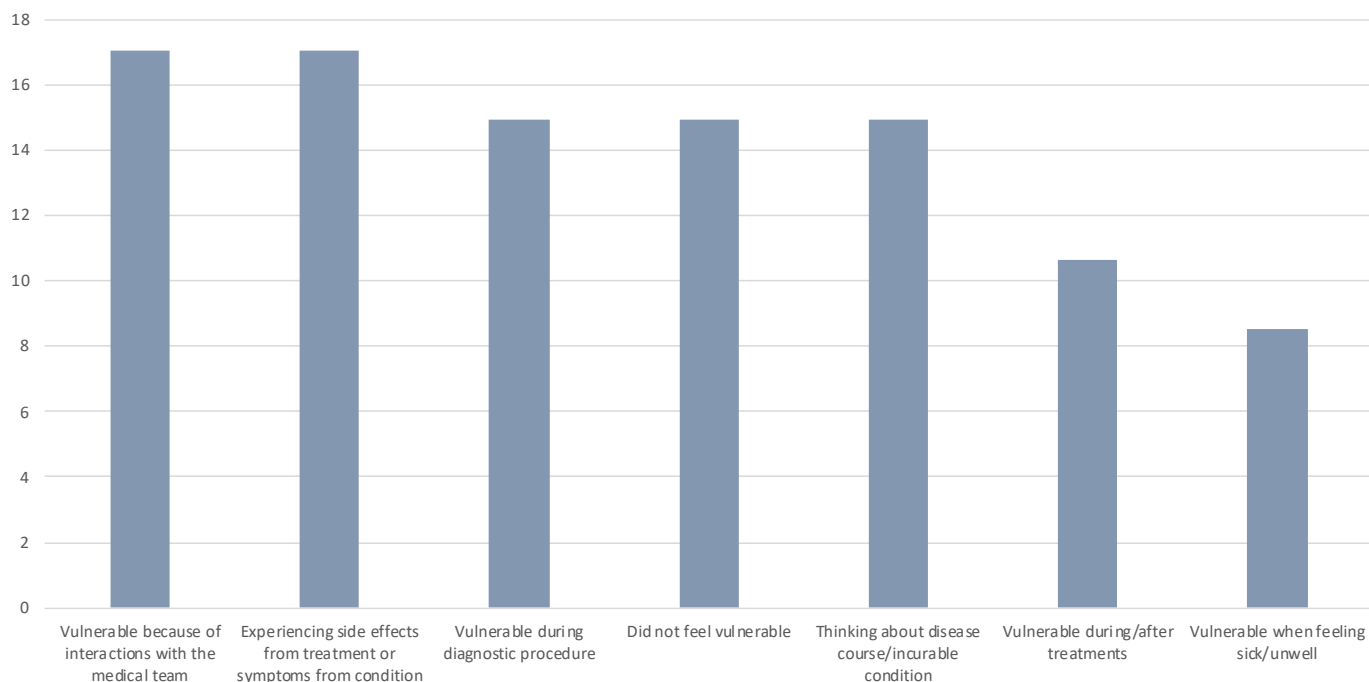


Figure 8.6: Experience of vulnerability

Table 8.12: Experience of vulnerability – subgroup variations

Experience of vulnerability	Reported less frequently	Reported more frequently
Participant describes feeling vulnerable because of interactions with the medical team	Blood vessel conditions Male	Heart conditions
Participant describes feeling vulnerable experiencing side effects from treatment or symptoms from condition	-	Blood vessel conditions
Participant describes feeling vulnerable during diagnostic procedure	Higher socioeconomic status	Regional or remote
Participant describes feeling vulnerable thinking about disease course/incurable condition	Heart conditions	-
Participant describes feeling vulnerable during/after treatments	High cholesterol under 50 years of age	-
Participant describes feeling vulnerable when feeling sick/unwell	-	Regional or remote

Methods to manage vulnerability

In the structured interview, participants described ways that they managed feelings of vulnerability. The most common ways to manage vulnerability were using self-help methods (resilience, acceptance, staying positive) (10.64%), and being unsure how vulnerability can be managed (4.26%).

Participant describes using self-help methods (resilience, acceptance, staying positive) to manage the feeling of vulnerability

Yes, but I'm very motivated and try not to give in.
Participant 047_2023AUHBV

I'm a positive person. In 2022 I went overseas to a foreign country and lived in a remote jungle area. I had medical clearance from my doctor.
Participant 031_2023AUHBV

Yes, most of the time.... I'm dealing with people and everyone has emotions. I have been able to keep those feelings in check and I don't feel they have got to out of control.
Participant 049_2023AUHBV

Participant describes unsure how vulnerability can be managed

Past 9 months I have tried several different strategies not a thing works massive meltdowns 24/7 it feels like quick sand I just dig and dig I don't get anywhere.
Participant 044_2023AUHBV

When I was diagnosed with cancer on top of cardiomyopathy I felt very isolated due to Covid. Not sure that I managed my feelings of vulnerability very well.

Participant 037_2023AUHBV

Table 8.13: Methods to manage vulnerability

Methods to manage vulnerability	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes using self-help methods (resilience, acceptance, staying positive) to manage the feeling of vulnerability	5	10.64	1	5.56	4	13.79	1	11.11	3	17.65	1	4.76	4	14.81	1	5.00
Participant describes Not applicable, no vulnerability	5	10.64	4	22.22	1	3.45	1	11.11	1	5.88	3	14.29	2	7.41	3	15.00
Participant describes unsure how vulnerability can be managed	2	4.26	1	5.56	1	3.45	0	0.00	1	5.88	1	4.76	2	7.41	0	0.00

Methods to manage vulnerability	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes using self-help methods (resilience, acceptance, staying positive) to manage the feeling of vulnerability	5	10.64	2	7.69	3	14.29	2	8.33	3	13.04	1	6.67	4	12.50	0	0.00	5	22.73
Participant describes Not applicable, no vulnerability	5	10.64	3	11.54	2	9.52	3	12.50	2	8.70	1	6.67	4	12.50	3	12.00	2	9.09
Participant describes unsure how vulnerability can be managed	2	4.26	0	0.00	2	9.52	1	4.17	1	4.35	0	0.00	2	6.25	1	4.00	1	4.55

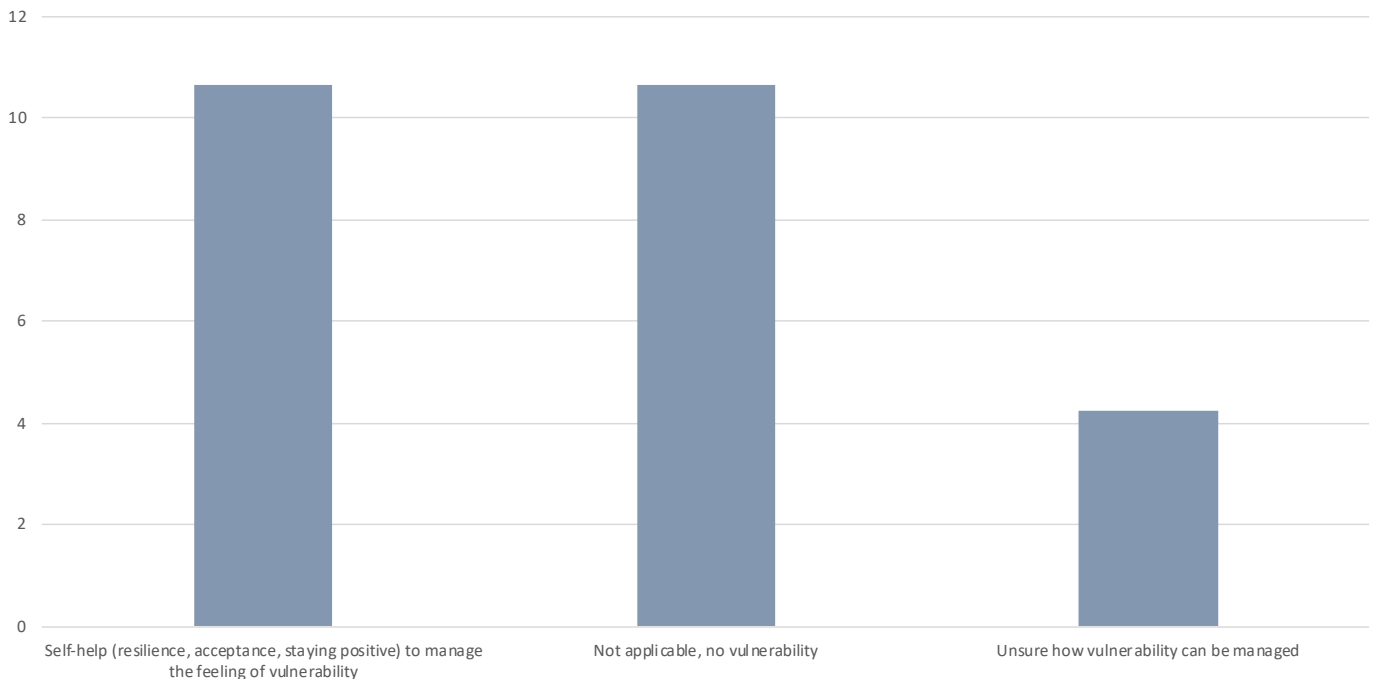


Figure 8.7: Methods to manage vulnerability

Table 8.14: Methods to manage vulnerability– subgroup variations

Methods to manage vulnerability	Reported less frequently	Reported more frequently
Participant describes using self-help methods (resilience, acceptance, staying positive) to manage the feeling of vulnerability	Mid to low socioeconomic status	Higher socioeconomic status
Participant describes Not applicable, no vulnerability	-	Had LP(a) test

Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Most commonly, the descriptions suggested that overall, there was a negative impact on relationships (38.30%), and overall, there no impact on relationships (31.91%). Other themes included overall, there was a positive impact on relationships (14.89%), and overall, there was an impact on relationships that was both positive and negative (10.64%).

The most common themes in relation to having a negative impact on relationships were from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition (31.91%), and from people not knowing what to say or do and withdrawing from relationships (10.64%). Other themes included because of people not believing the impact that condition has on health (6.38%), and because of intimacy challenges (4.26%).

The most common themes in relation to having a positive impact on relationships were from people being well-meaning and supportive (17.02%), and from family relationships being strengthened (8.51%).

Participant describes that overall, there was a negative impact on relationships

It did it first. Going back years ago, but not so much now. I'm talking about friends, not so much the family. It affected the family, but we worked through that and we were OK with that. But with friends, I don't know. It was like, it's like getting married and all your friends went somewhere else. They just weren't around anymore, you know, They seem to just. Well, it's not like I tried to work it out, I think because all my friends, we lived the lifestyle we lived in, like drinking and smoking, you know, we're all in pubs every night and I couldn't do that anymore, you know? But naturally I stopped doing it all straight away, you know. So I think that's what separated the relationships. Yeah, makes sense. Then I found new friends at work. So I went to work and I build a new set of friends at work. But the original friends, I think it was just our lifestyle. They were still in the pubs drinking and smoking and I didn't.

Participant 025_2023AUHBV

PARTICIPANT: Yes, I do.

INTERVIEWER: In what way?

PARTICIPANT: It's sometimes hard to communicate exactly what you're feeling. They get frustrated because you can't do what they want you to do. It

takes time to have a shower and get dressed and everything like that, and then it's frustrating. I can get angry and frustrated, cry and get fatigued. It takes a toll because they want you to be better than what you are, but it is what it is, and I can't change that.

INTERVIEWER: Well, PARTICIPANT, it sounds like you're doing your best. That's all we can do. Please, don't be hard on yourself.

PARTICIPANT: No, I don't anymore. I used to.
Participant 049_2023AUHBV

It certainly has, and certainly makes you know who your real friends are.

Participant 044_2023AUHBV

Participant describes that overall, there no impact on relationships

No, no, I don't think so,
Participant 007_2023AUHBV

Not overly, no. Not from my point of view. I don't think so.

Participant 043_2023AUHBV

No. No, not at all.

Participant 005_2023AUHBV

Participant describes that overall, there was a positive impact on relationships

No, I don't. If it has affected them, it's probably affected them for the better, not for the worse. Yeah.

Participant 009_2023AUHBV

Yeah, I think so. But not in a negative way. I think it's actually been, I hate saying it, but I think it was a good thing in terms of, I think my husband and I actually grew closer through our experience rather than it doing negative things. We were stronger in our relationship, and also even with my family I think I grew closer to both our families through the experience.

Participant 035_2023AUHBV

I don't think it has. I think if anything we've become a lot closer. I think I've got quite a supportive family and they listen to me and and I listen to them and we just we just have a good relationship and yeah it's it's it's been wonderful like I think that.

Participant 011_2023AUHBV

Participant describes that overall, there was an impact on relationships that was both positive and negative

Yes, we no longer do many things with friends at night because it's too tiring for me. It has brought us together as a family a lot closer. We spend more time together. We make sure we get good quality time but we have to choose what that is and what's important to do together, so that I still get that rest that I need to do.

Participant 047_2023AUHBV

That's a tricky one. I think it changes things for the positive, actually, in that there's a greater sense of appreciation for someone who has been in a life-threatening situation. It's a hard one to answer because there's people who can't deal with it, and they can't respond, and they don't know how to respond for their own reasons, but it can create more distance, but on the other hand, for me, there's a group of people who I'm probably closer to now. So it's also just where you choose to focus, I guess. Yeah. So for me it's mostly been positive, I would say.

Participant 023_2023AUHBV

Table 8.15 Impact on relationships

Impact on relationships	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes that overall, there was a negative impact on relationships	18	38.30	7	38.89	11	37.93	2	22.22	8	47.06	8	38.10	8	29.63	10	50.00
Participant describes that overall, there no impact on relationships	15	31.91	9	50.00	6	20.69	4	44.44	6	35.29	5	23.81	10	37.04	5	25.00
Participant describes that overall, there was a positive impact on relationships	7	14.89	1	5.56	6	20.69	1	11.11	2	11.76	4	19.05	4	14.81	3	15.00
Participant describes that overall, there was an impact on relationships that was both positive and negative	5	10.64	1	5.56	4	13.79	1	11.11	1	5.88	3	14.29	3	11.11	2	10.00
No particular comment	2	4.26	0	0.00	2	6.90	1	11.11	0	0.00	1	4.76	2	7.41	0	0.00

Impact on relationships	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes that overall, there was a negative impact on relationships	18	38.30	13	50.00	5	23.81	6	25.00	12	52.17	6	40.00	12	37.50	8	32.00	10	45.45
Participant describes that overall, there no impact on relationships	15	31.91	9	34.62	6	28.57	10	41.67	5	21.74	3	20.00	12	37.50	7	28.00	8	36.36
Participant describes that overall, there was a positive impact on relationships	7	14.89	2	7.69	5	23.81	4	16.67	3	13.04	4	26.67	3	9.38	6	24.00	1	4.55
Participant describes that overall, there was an impact on relationships that was both positive and negative	5	10.64	1	3.85	4	19.05	3	12.50	2	8.70	2	13.33	3	9.38	2	8.00	3	13.64
No particular comment	2	4.26	1	3.85	1	4.76	1	4.17	1	4.35	0	0.00	2	6.25	2	8.00	0	0.00

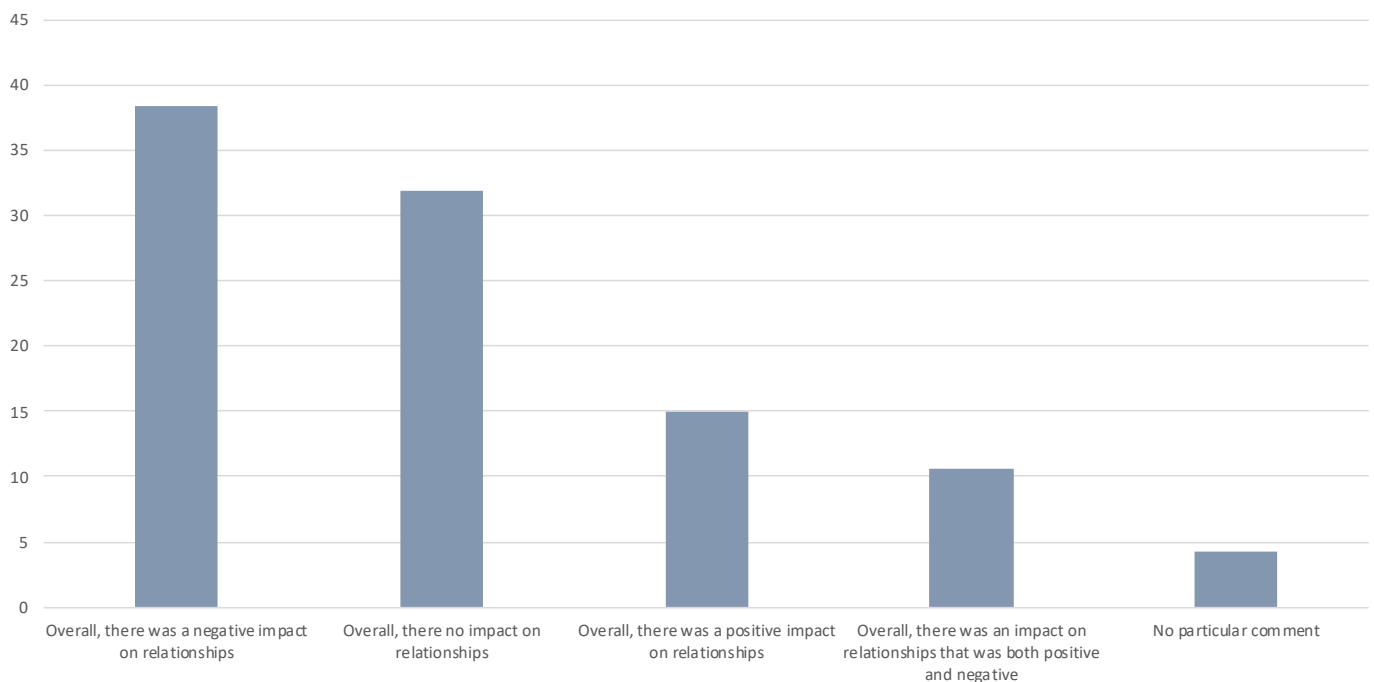


Figure 8.8: Impact on relationships

Table 8.16: Impact on relationships – subgroup variations

Impact on relationships	Reported less frequently	Reported more frequently
Participant describes that overall, there was a negative impact on relationships	High cholesterol under 50 years of age Male Aged 25 to 44	6 to 11 other conditions Female Aged 45 and older
Participant describes that overall, there no impact on relationships	Did not had LP(a) test Aged 45 and older Regional or remote	Had LP(a) test High cholesterol under 50 years of age
Participant describes that overall, there was a positive impact on relationships	Higher socioeconomic status	Regional or remote

Table 8.17: Impact on relationships (Reason for impact)

Impact on relationships -(Reason for impact)	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes a negative impact on relationships from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition	15	31.91	6	33.33	9	31.03	3	33.33	4	23.53	8	38.10	7	25.93	8	40.00
Participant describes a positive impact on relationships from people being well-meaning and supportive	8	17.02	2	11.11	6	20.69	2	22.22	1	5.88	5	23.81	3	11.11	5	25.00
Participant describes a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships	5	10.64	1	5.56	4	13.79	0	0.00	4	23.53	1	4.76	2	7.41	3	15.00
Participant describes a positive impact on relationships from family relationships being strengthened	4	8.51	0	0.00	4	13.79	0	0.00	2	11.76	2	9.52	3	11.11	1	5.00
Participant describes a negative impact on relationships because of people not believing the impact that condition has on health	3	6.38	1	5.56	2	6.90	0	0.00	0	0.00	3	14.29	2	7.41	1	5.00
Participant describes a negative impact on relationships because of intimacy challenges	2	4.26	0	0.00	2	6.90	0	0.00	0	0.00	2	9.52	0	0.00	2	10.00
Participant describes a negative impact on relationships in general (no specifics articulated)	2	4.26	0	0.00	2	6.90	0	0.00	2	11.76	0	0.00	1	3.70	1	5.00

Impact on relationships -(Reason for impact)	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes a negative impact on relationships from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition	15	31.91	9	34.62	6	28.57	7	29.17	8	34.78	6	40.00	9	28.13	4	16.00	11	50.00
Participant describes a positive impact on relationships from people being well-meaning and supportive	8	17.02	3	11.54	5	23.81	5	20.83	3	13.04	4	26.67	4	12.50	6	24.00	2	9.09
Participant describes a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships	5	10.64	3	11.54	2	9.52	1	4.17	4	17.39	0	0.00	5	15.63	3	12.00	2	9.09
Participant describes a positive impact on relationships from family relationships being strengthened	4	8.51	1	3.85	3	14.29	1	4.17	3	13.04	2	13.33	2	6.25	2	8.00	2	9.09
Participant describes a negative impact on relationships because of people not believing the impact that condition has on health	3	6.38	3	11.54	0	0.00	2	8.33	1	4.35	1	6.67	2	6.25	1	4.00	2	9.09
Participant describes a negative impact on relationships because of intimacy challenges	2	4.26	1	3.85	1	4.76	1	4.17	1	4.35	0	0.00	2	6.25	0	0.00	2	9.09
Participant describes a negative impact on relationships in general (no specifics articulated)	2	4.26	2	7.69	0	0.00	0	0.00	2	8.70	1	6.67	1	3.13	2	8.00	0	0.00

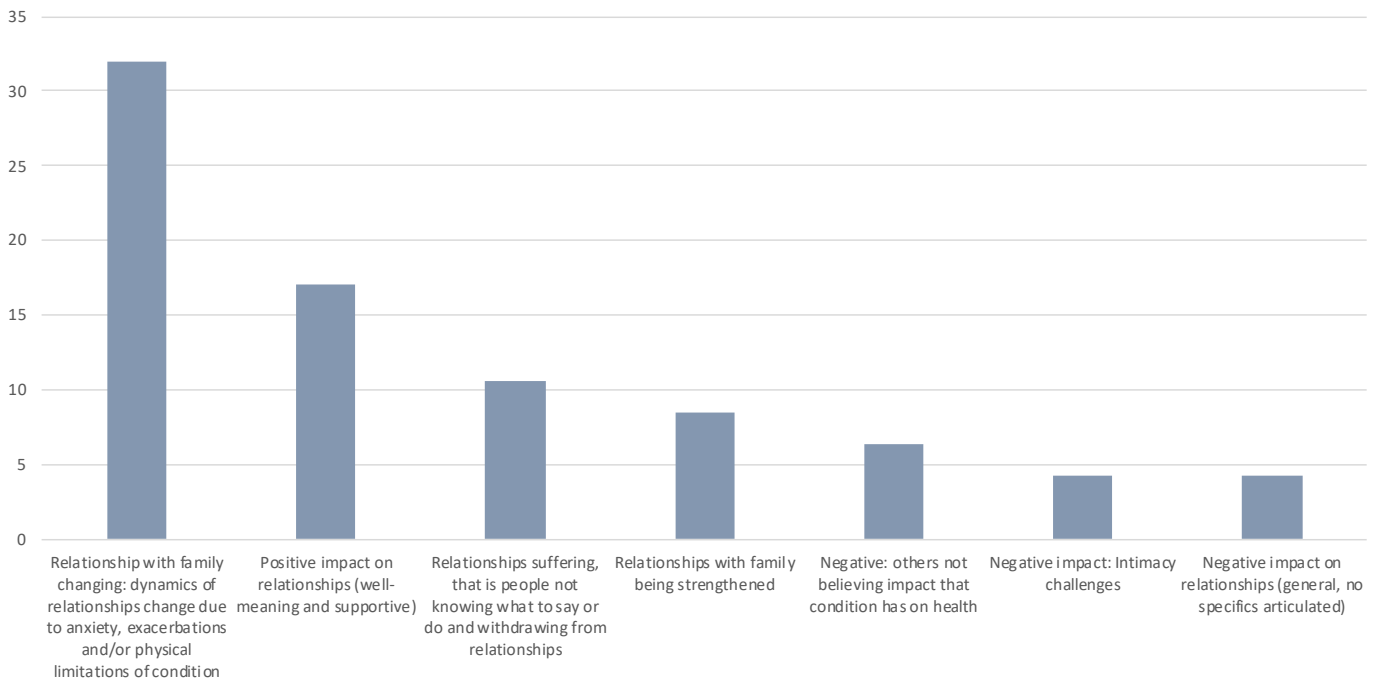


Figure 8.9: Impact on relationships

Table 8.18: Impact on relationships: Reason for impact – subgroup variations

Impact on relationships -(Reason for impact)	Reported less frequently	Reported more frequently
Participant describes a negative impact on relationships from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition	Mid to low socioeconomic status	Higher socioeconomic status
Participant describes a positive impact on relationships from people being well-meaning and supportive	Blood vessel conditions	-
Participant describes a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships	High cholesterol under 50 years of age Regional or remote	Blood vessel conditions

Burden on family

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Most commonly, the descriptions suggested that overall, there was not a burden on their family (51.06%), overall, there was a burden on their family (44.68%), and overall, there was not a burden on their family now but they anticipate this will change in the future (6.38 %).

The main reason that participant described their condition being a burden were the extra household duties and responsibilities that their family must take on (17.02%), that the burden was temporary or only during treatment (14.89%), and the mental/emotional strain placed on their family (10.64%).

The main reason that participant described their condition not being a burden were that they were very independent (14.89%), and they have a very supportive family and were not a burden (6.38%).

Participant describes that overall, there was not a burden on their family

Look, I don't think so. Not working is really like I can't work. There's no way that I'd be able to work right now, but I think having kids that are a little bit older means that I can delegate a bit to them as well. So I don't think at this point in time I don't have people doing stuff for me. Like obviously I can't bend down. I love gardening, but I can't, I can't bend to weed or anything like that. So that sort of thing is all out of the question. But around the house, I feel like I'm functioning by myself okay. It's just that I have a little routine and a schedule and I can't. I just have to listen to my body and I can't go and be 3 hours of cleaning. I have to go and do a job and then come back and recover and I think that's just come with time.
Participant 014_2023AUHBV

Well no, I'm pretty independent. So, I wouldn't say the chronic heart failure is the burden. It's more the whole condition. And, no, when I go to the hospital, I don't even tell them until the next day.
Participant 032_2023AUHBV

No, because I find that I'm very independent. I will do stuff myself. My dad's really good. He comes around and helps me do stuff often. There's nothing I can't do that I want to do. I don't set myself unrealistic goals. I just painted my bathroom a couple weeks ago but I just took my time to do it. But I still did it. It just took me ages. As, I said I don't set unrealistic goals. I think that would be the thing. I don't feel like a burden, no.
Participant 036_2023AUHBV

Participant describes that overall, there was a burden on their family

Oh, that's periodic. There are times, yeah, when I need extra help, but I try to be very self-sufficient as well. Yeah, so that's, it varies, so there are times, especially when I've had surgery or I'm not well, that yeah, they will have a bigger role. Yeah, yeah. But then there's times when they're not well, or that they need extra help, and I'm offering them help as well, so I suppose it all works out in the end. So there's a lot of other people that are in a lot worse situation than I am, and yeah -- So I'm just very blessed that yeah, that I still function with my condition.
Participant 030_2023AUHBV

PARTICIPANT: Not anymore, no.
INTERVIEWER: But in that initial period when you were juggling your new diagnosis and your new baby?
PARTICIPANT: Yeah, that was, that definitely, yeah that was quite for long, for family. They happily did it, but I didn't like how much I needed to rely on them.
Participant 035_2023AUHBV

Yes, I do. Yeah, I try not to ask for help, just between very independent and stubborn, I suppose. But but there's times when I yeah, where I've had to and it's really hard.
Participant 019_2023AUHBV

Participant describes that overall, there was not a burden on their family now but they anticipate this will change in the future

No. Like later on, but not at the moment. I'm the one doing all the assisting. It hasn't affected them at all. Participant 037_2023AUHBV

I'm thinking at the moment it's OK because I don't need extra care or assistance, but if I do worry that if

anything did happen in the future I'd be. I'd feel like maybe a bit of a burden. I I kind of hope I don't feel that way. But you can't help thinking, Gee, maybe, you know, if somebody has to look after me or I wouldn't want to put them through that kind of thing. But I guess we just have to cross that path if it happens.

Participant 011_2023AUHBV

Table 8.19: Burden on family

Burden on family	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes that overall, there was not a burden on their family	24	51.06	10	55.56	14	48.28	7	77.78	7	41.18	10	47.62	14	51.85	10	50.00
Participant describes that overall, there was a burden on their family	21	44.68	7	38.89	14	48.28	2	22.22	9	52.94	10	47.62	11	40.74	10	50.00
Participant describes that overall, there was not a burden on their family now but they anticipate this will change in the future	3	6.38	1	5.56	2	6.90	1	11.11	1	5.88	1	4.76	2	7.41	1	5.00
No particular comment	2	4.26	1	5.56	1	3.45	0	0.00	1	5.88	1	4.76	2	7.41	0	0.00

Burden on family	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes that overall, there was not a burden on their family	24	51.06	15	57.69	9	42.86	14	58.33	10	43.48	8	53.33	16	50.00	15	60.00	9	40.91
Participant describes that overall, there was a burden on their family	21	44.68	10	38.46	11	52.38	9	37.50	12	52.17	7	46.67	14	43.75	10	40.00	11	50.00
Participant describes that overall, there was not a burden on their family now but they anticipate this will change in the future	3	6.38	2	7.69	1	4.76	2	8.33	1	4.35	1	6.67	2	6.25	2	8.00	1	4.55
No particular comment	2	4.26	1	3.85	1	4.76	1	4.17	1	4.35	0	0.00	2	6.25	0	0.00	2	9.09

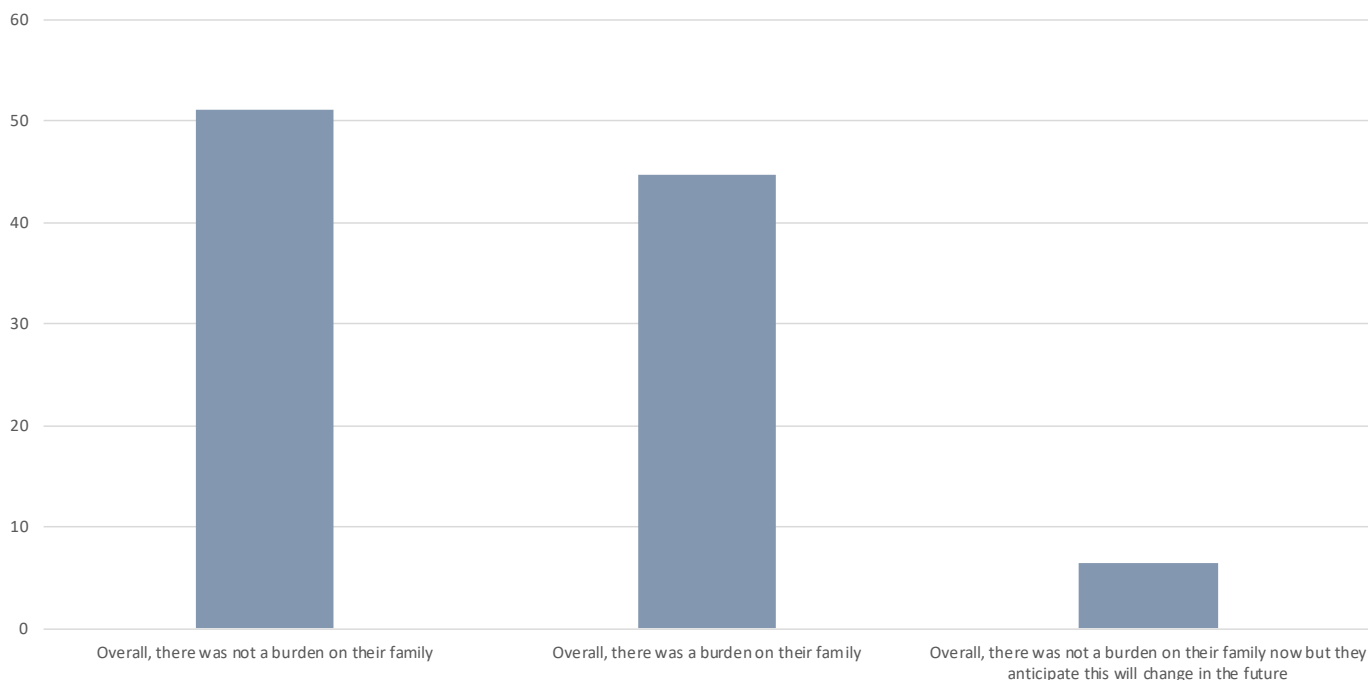


Figure 8.10: Burden on family

Table 8.20: Burden on family – subgroup variations

Burden on family	Reported less frequently		Reported more frequently	
	Higher socioeconomic status	High cholesterol under 50 years of age	High cholesterol under 50 years of age	-
Participant describes that overall, there was not a burden on their family				
Participant describes that overall, there was a burden on their family				

Table 8.21: Burden on family (description)

Burden on family (Description)	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes their condition not being a burden in general (No specific examples) as a burden on their family	15	31.91	7	38.89	8	27.59	5	55.56	6	35.29	4	19.05	8	29.63	7	35.00
Participant describes the extra household duties and responsibilities that their family must take on as a burden on their family	8	17.02	4	22.22	4	13.79	1	11.11	3	17.65	4	19.05	5	18.52	3	15.00
Participant describes that the burden on family was temporary or only during treatment	7	14.89	2	11.11	5	17.24	1	11.11	2	11.76	4	19.05	4	14.81	3	15.00
Participant describes being independent and not a burden on their family	7	14.89	3	16.67	4	13.79	1	11.11	2	11.76	4	19.05	4	14.81	3	15.00
Participant describes their condition being a burden in general (No specific examples) as a burden on their family	6	12.77	1	5.56	5	17.24	0	0.00	4	23.53	2	9.52	3	11.11	3	15.00
Participant describes the mental/emotional strain placed on their family as a burden on their family	5	10.64	1	5.56	4	13.79	1	11.11	1	5.88	3	14.29	2	7.41	3	15.00
Participant describes that they have a supportive family and were not a burden	3	6.38	1	5.56	2	6.90	1	11.11	0	0.00	2	9.52	1	3.70	2	10.00

Burden on family (Description)	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes their condition not being a burden in general (No specific examples) as a burden on their family	15	31.91	9	34.62	6	28.57	9	37.50	6	26.09	4	26.67	11	34.38	9	36.00	6	27.27
Participant describes the extra household duties and responsibilities that their family must take on as a burden on their family	8	17.02	3	11.54	5	23.81	3	12.50	5	21.74	3	20.00	5	15.63	5	20.00	3	13.64
Participant describes that the burden on family was temporary or only during treatment	7	14.89	3	11.54	4	19.05	2	8.33	5	21.74	2	13.33	5	15.63	3	12.00	4	18.18
Participant describes being independent and not a burden on their family	7	14.89	4	15.38	3	14.29	2	8.33	5	21.74	3	20.00	4	12.50	4	16.00	3	13.64
Participant describes their condition being a burden in general (No specific examples) as a burden on their family	6	12.77	4	15.38	2	9.52	3	12.50	3	13.04	2	13.33	4	12.50	3	12.00	3	13.64
Participant describes the mental/emotional strain placed on their family as a burden on their family	5	10.64	2	7.69	3	14.29	2	8.33	3	13.04	2	13.33	3	9.38	2	8.00	3	13.64
Participant describes that they have a supportive family and were not a burden	3	6.38	1	3.85	2	9.52	2	8.33	1	4.35	3	20.00	0	0.00	3	12.00	0	0.00

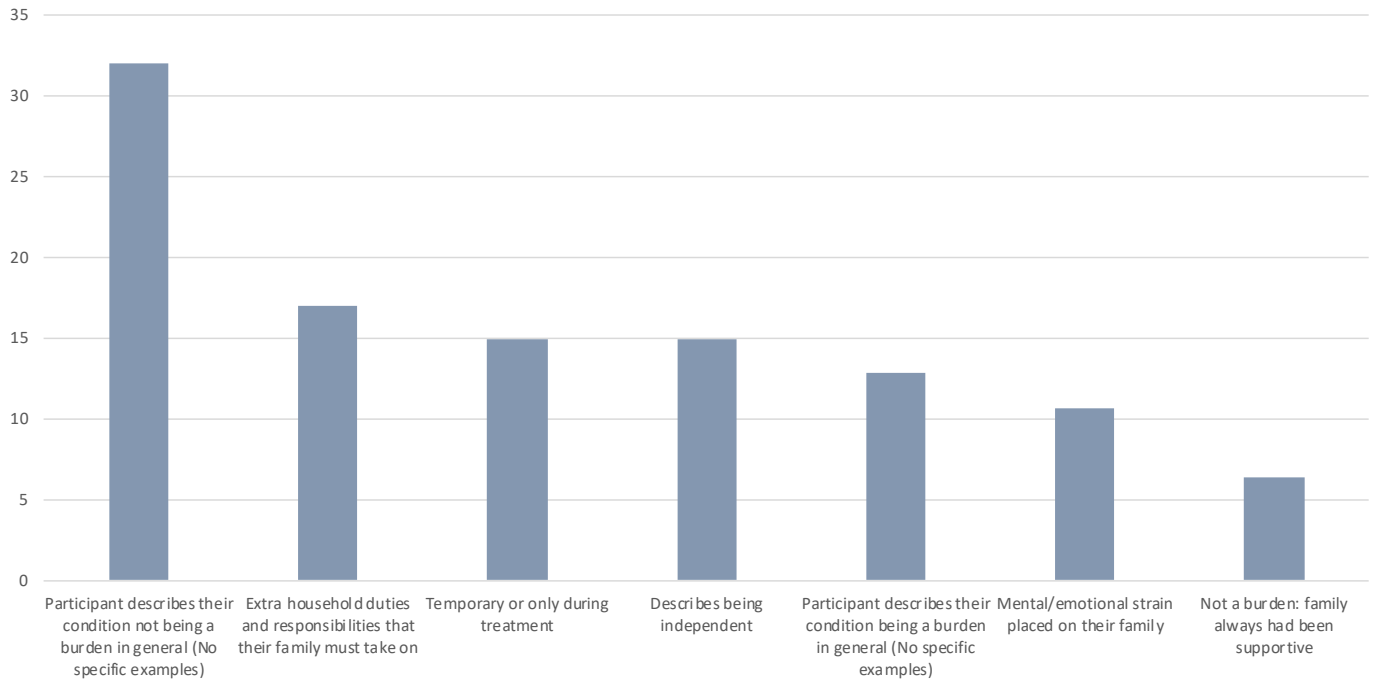


Figure 8.11: Burden on family (description)

Table 8.22: Burden on family (description)– subgroup variations

Burden on family (Description)	Reported less frequently		Reported more frequently	
Participant describes their condition not being a burden in general (No specific examples) as a burden on their family	Heart conditions		High cholesterol under 50 years of age	
Participant describes their condition being a burden in general (No specific examples) as a burden on their family	High cholesterol under 50 years of age		Blood vessel conditions	
Participant describes that they have a supportive family and were not a burden	-		Regional or remote	

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. The most common descriptions were that overall, there was at least some cost burden (51.06%), and overall, there was no cost burden (23.40%).

Where participants described a cost burden associated with their condition, it was most commonly in relation to the cost of treatments (including repeat scripts) (27.66%), diagnostic tests and scans (17.02%), and needing to take time off work (17.02 %). Other themes included the cost specialist appointments (14.89%), cost of gap payments (12.77%), needing to buy special equipment (10.64%), allied health care (8.51%), and GP appointments (8.51%).

Where participants described no cost burden associated with their condition, this was because nearly everything was paid for through the public health system (17.02%), the participant was able to afford all costs (10.64%), and nearly everything was paid for through the private health system (8.51 %).

Cost burden in relation to the cost of treatments (including repeat scripts)

It's been pretty significant by the time you add up all the the emergency room visits, the medications, the different diagnostic tests like halter monitors and echocardiograms and things like that. So even though we had private health, the out of pocket's been pretty, pretty significant, yeah. And then the ablations and things like that as well.

Participant 008_2023AUHBV

It's been very expensive, Very, very. And it's ongoing expense because I've got whatever number of drugs I have to get every month. And then I've got my \$400.00 monitor beside the bed that I pay and I've got my cardiologist and my echocardiogram. Or not that, that. It's that. What'd you say, that echo? It's it's an echo cardiogram or an angio thing. Something anyway. One of those think supposed to go to the GP every so often because they only see the specialist once a year.

Participant 015_2023AUHBV

Everyone, everyone involved, you know, needs to be paid, I guess. And then the surgeries are astronomical, like the piece of machinery in my chest is far as I'm aware, a few 100 grand. I didn't even look at the last bill because I didn't want to look at it. But and then

even the thing that sits next to my bed, the little, the reader that gets sent off, as far as I'm aware that's a few \$100 as well. It is, it is extremely expensive. But we we've been pretty fortunate and I think, you know I'm in a position now where luckily I can prioritize the cost of my health and those sorts of things. And then also you get pretty used to paying out extensive amounts of money. So you just sort of kitty that sort of stuff away. When you start to get a bit older and realize how how expensive it is to be someone with a condition like this, you just have a little bit of sitting somewhere just in case. But I've still got, I still pay my private health cover, which is way more expensive than anyone else's private health cover my age.
Participant 012_2023AUHBV

Cost burden in relation to diagnostic tests and scans

It's been pretty significant by the time you add up all the the emergency room visits, the medications, the different diagnostic tests like halter monitors and echocardiograms and things like that. So even though we had private health, the out of pocket's been pretty, pretty significant, yeah. And then the ablations and things like that as well.

Participant 008_2023AUHBV

Yeah, so there's been massive costs actually, but we've had, my mom and dad were pretty lucky with, I don't know why, but as little kids they put us on the private health, which was, you know, huge expense for them like mom and dad weren't. We never really went without, but they weren't overly wealthy, but they put us onto a pretty good, pretty high level of private health from a very young age. So in that sense we we were really fortunate, especially when this all started to come out. I know how much like the testing is expensive. Like the ECGs are a lot. They're for \$500 now. I don't know how much they were back then. Stress tests, they were have a cost. Everyone, everyone involved, you know, needs to be paid, I guess.

Participant 012_2023AUHBV

Cost burden in relation to needing to take time off work

OMG, being chronically ill is the most expensive job in the world. Being chronically ill for me often means a period of unemployment. You think about it, you're on a pension. The 40-year olds that I know are talking about, and I know we can't do it right now, but let's

put the pandemic aside. They're talking about traveling overseas, getting married, having kids, buying houses. I'm looking for the next \$5 to pay for my medication. My priorities are very different to a lot of my friends.

Participant 050_2023AUHBV

Cost burden in relation to the cost specialist appointments

Yeah, it's been OK. Probably the biggest cost for me was the coronary calcium score. I think it was about \$150.00 and that was fine. The cardiologist always costs a bit of money to go to the cardiologist, but but I find out, well you know you need to do it, so just budget for it. But I know it is. It would be difficult for a lot of people, especially in today's economy, to be able to to afford a lot of a lot of those things

Participant 011_2023AUHBV

Initially, the MRI and things didn't cost because I was still a patient of the hospital. Travelling to see the neurologist had quite extensive cost because I couldn't travel down and back on one day we needed me to stay in an accommodation to let me recover enough, to go to the appointment. Which meant my husband had to take time off work. My mom and dad had to come to look after the children when we weren't here. We now have the ongoing cost of medication. Also the lack of income because I can't work full-time anymore.

Participant 047_2023AUHBV

Cost burden in relation gap payments

Yeah, for the I guess it cost me. It was all private than that, but it still cost me a few \$1000 to get all this done. I just wasn't willing to go through the public system for it, so I wanted to get it sorted. I just it's one of those things I didn't wanna have to deal with if everything was OK. But yeah, it cost me. It cost me a few grand.

Participant 028_2023AUHBV

Cost burden in needing to special equipment

Yes, there's been cost. My son has had time off from work so that's costed him. I don't know how much that is. I've had costs obviously and I think I estimated about \$200 a week just for equipment, for physio and for drugs and for going to doctors, the cost of doctors. That might not be accurate, that might be too little I'm not sure.

Participant 041_2023AUHBV

There has been cost involved in getting time off work. To go to doctor's appointments is probably the biggest problem.

Participant 020_2023AUHBV

Cost burden in relation to allied health care

Work would be huge. I've lost because of the I stuff up with income protection. I'm potentially losing 8 grand after tax per month by having this costs also associated with travel, so any tests I have to have, it's a three hour round trip to LOCATION 1 or 6 hour round trip to LOCATION 2 Medication so we don't have access to Chemist Warehouse or any cheaper place. I know I could go online, but when you're sick, that's too overwhelming. And sometimes you don't have your ducks in a row and you just need to put it in the hands of the local pharmacist. But I know that my IVA braiding when I get it at Chemist Warehouse in LOCATION 1 is potentially 10 to \$15 cheaper than what I can get it here in LOCATION 3. So yeah, there's lots of financial thing, you know, you get 5 when you've got chronic health issue, you get 5 free sessions with the exercise physiologist, but that's nowhere near enough. If you've got a chronic health condition, you're talking long term, you're not talking. It's not like you wanna go and do weights training, you know what I mean? Like it's, I don't know that five is enough when you're living with something like this. So it all adds up.

Participant 014_2023AUHBV

Cost burden in relation to GP appointments

Yeah, I mean, obviously there's been costs involved. It costs to go to the breathing specialist, it costs to go to the GP, It costs to go to the cardiologist, It costs to purchase the medication, do the tests. Yes. So yes, there's.

Participant 019_2023AUHBV

Generally, anything that's going to cost me hundreds of dollars, I just don't do because of the fact that I can't afford to do it. As I said, the appointments with my GP are being pushed right out now because to go and see my GP is literally 10% of my income. It's actually more than 10%. But yeah, you know, I've got an appointment with my GP on Monday, which is \$103.80 or something, you know, don't get me wrong, I can change GPs and that'll go back to bulk billing, but it comes down to a point of that, you know, hey, I'm comfortable with my GP. My GP knows all of my history. ... As for so medication wise, I generally I'm not too fast with the cost of the medication. Again, I

hit the PBS fairly quickly every year. So I generally generally every year by March I've hit the PBS and my medications free for the rest of the year. You know, I suppose it's it's now just literally the GP that the expensive part, if he sends me for a scan or something like that that's going to be expensive. I generally go back and say I can't afford it. He'll get one of the specialists to write the referral for whatever it is. So for example, I had to have a PET scan not long back and the cost of that was 600 odd dollars. I went back to him and said, yeah, I can't afford that. So he got one of the billionay specialists there to write the referral for me, which made it free with the specialist referral. Yeah. Anything else that's sort of like outside of the realms, he'll say to me, OK, this is what you need done, but the only way to get this done charge is to go to the hospital. So, you know, generally he'll write me the referral to the hospital, I'll go to the hospital, it'll get done that way and I'll go back to my GP a week later or whatever it is to get the results

Participant 018_2023AUHBV

The cost of equipment to use with one hand is crazy. That's extreme. I have had a lot of time off work because of fatigue. It has been a big cost in the early days up until probably 18 years ago. It was a financial burden. Now still, if I need something to assist me around the kitchen or just everyday things, to put shoes on or tie laces, it seems to cost a lot of money to get those things. It's not fair that it's so expensive.

Participant 049_2023AUHBV

No cost burden and that nearly everything was paid for through the public health system

No, I've had costs. Haven't been an issue for me. Really. No. Even when, even when I was trans, when I first had the heart attack and I was transferred over to the private hospital because I was a public patient going to that private hospital, there was no cost to me because obviously the public system paid for the fee. Yeah. So costs haven't been really an issue. We have private health cover and not that it's worth too much, but you know, yeah.

Participant 013_2023AUHBV

No, I was not out of pocket at all. I think my husband paid a \$20, I was in hospital for about 12 days and I think he paid a phone, phone charge and that was all of course the medication since then it's an ongoing

cost, but we reach our safety net sort of fairly about mid year. So that's not too bad either.

Participant 005_2023AUHBV

No cost burden as participant was able to afford all costs

I spend an absolute fortune on prescription drugs but that's just the way it is and I made it. To be completely honest with you, I'm a professional and I earn pretty good money so I've got no complaints. If I was not in the position that I am in, the cost of those medications would be a burden.

Participant 046_2023AUHBV

I work for EMPLOYER, so I'll work for three months, right? Yeah. And saying that I had four years worth of sick leave, that didn't seem to bother me too much at all. You know, I have 100. I have the highest level of had. I still have do I think highest level of private health cover. So you know, that didn't bother me much at all. There was a few out of pocket things that were, you know, probably for some people would probably think it was a significant amount of money, but I think it was a bad one. I think I had a pocket 25 grand something. You know, nothing

Participant 004_2023AUHBV

No cost burden and that nearly everything was paid for through the private health system

Well, luckily for me I had lots of leave for the work, so they will use that, although I did take my leave, but there was not really much cost. I just had to pay for just a blood test done to be done at a private lavatory and and just my medications as well. So it wasn't much at all because everything else was under, obviously, the health fund.

Participant 029_2023AUHBV

I was extremely lucky. I had accrued a lot of leave. I was off work for nine months. I was lucky that my employer, which was the EMPLOYER, was able to accommodate that. A lot of people aren't that lucky. I was able to use up all my leave. In terms of costs, I didn't experience any difficulty with the costs. We have medical insurance. [coughs] That wasn't an issue for me and my family

Participant 030_2023AUHBV

Table 8.23: Cost considerations

Cost considerations	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes that overall, there was at least some cost burden	24	51.06	8	44.44	16	55.17	4	44.44	12	70.59	8	38.10	12	44.44	12	60.00
Participant describes that overall, there was no cost burden	11	23.40	6	33.33	5	17.24	4	44.44	3	17.65	4	19.05	7	25.93	4	20.00
Other/No response	12	25.53	4	22.22	8	27.59	1	11.11	2	11.76	9	42.86	8	29.63	4	20.00

Cost considerations	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes that overall, there was at least some cost burden	24	51.06	14	53.85	10	47.62	13	54.17	11	47.83	9	60.00	15	46.88	15	60.00	9	40.91
Participant describes that overall, there was no cost burden	11	23.40	6	23.08	5	23.81	6	25.00	5	21.74	2	13.33	9	28.13	6	24.00	5	22.73
Other/No response	12	25.53	6	23.08	6	28.57	5	20.83	7	30.43	4	26.67	8	25.00	4	16.00	8	36.36

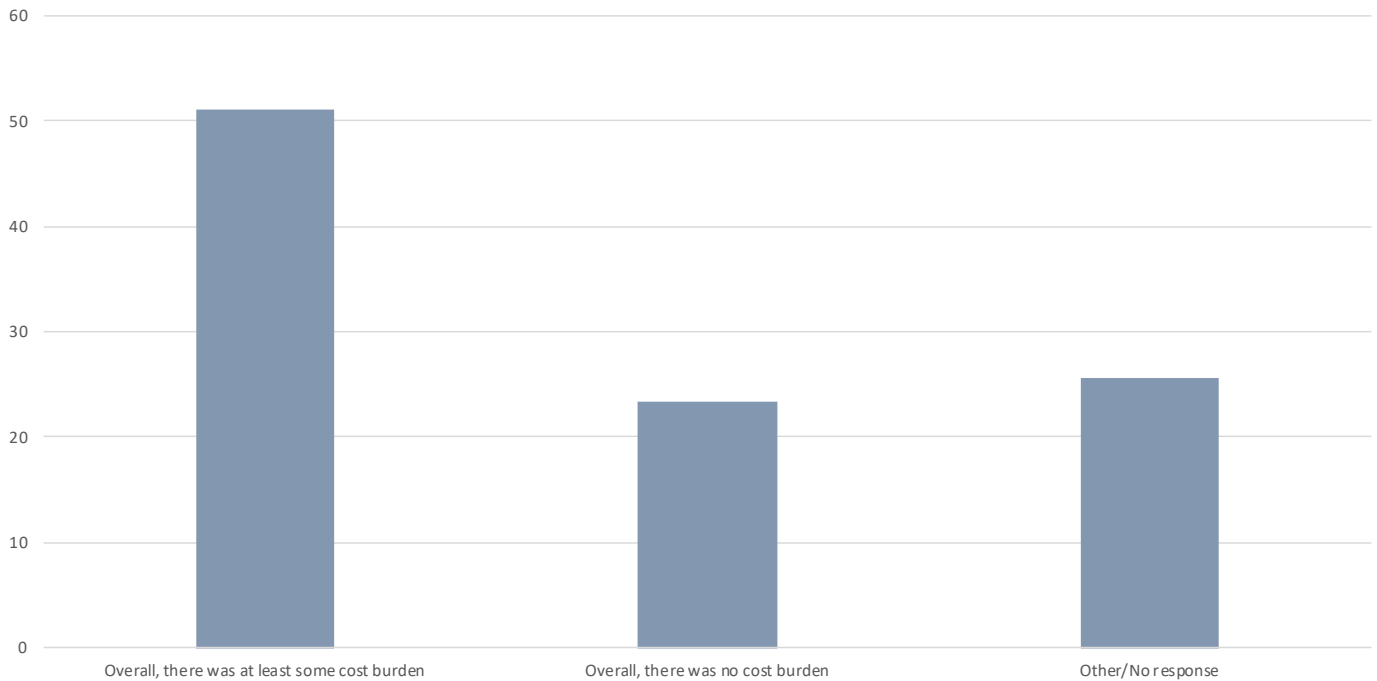


Figure 8.12: Cost considerations

Table 8.24: Cost considerations – subgroup variations

Cost considerations	Reported less frequently	Reported more frequently
Participant describes that overall, there was at least some cost burden	Heart conditions Higher socioeconomic status	Blood vessel conditions
Participant describes that overall, there was no cost burden	Regional or remote	High cholesterol under 50 years of age

Table 8.25: Cost considerations (Reasons for cost)

Cost considerations (reasons for costs)	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Cost burden in relation to the cost of treatments (including repeat scripts)	13	27.66	5	27.78	8	27.59	1	11.11	6	35.29	6	28.57	6	22.22	7	35.00
Cost burden in relation to diagnostic tests and scans	8	17.02	3	16.67	5	17.24	0	0.00	3	17.65	5	23.81	4	14.81	4	20.00
Cost burden in relation to needing to take time off work	8	17.02	2	11.11	6	20.69	1	11.11	5	29.41	2	9.52	4	14.81	4	20.00
Cost burden in relation to the cost specialist appointments	7	14.89	3	16.67	4	13.79	2	22.22	3	17.65	2	9.52	2	7.41	5	25.00
Cost burden in relation gap payments	6	12.77	1	5.56	5	17.24	1	11.11	1	5.88	4	19.05	3	11.11	3	15.00
Cost burden in needing to special equipment	5	10.64	1	5.56	4	13.79	0	0.00	3	17.65	2	9.52	0	0.00	5	25.00
Cost burden in relation to allied health care	4	8.51	1	5.56	3	10.34	0	0.00	3	17.65	1	4.76	2	7.41	2	10.00
Cost burden in relation to GP appointments	4	8.51	3	16.67	1	3.45	0	0.00	1	5.88	3	14.29	3	11.11	1	5.00
Cost burden in relation to a family member needing to take time off work	3	6.38	0	0.00	3	10.34	0	0.00	3	17.65	0	0.00	1	3.70	2	10.00
Cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	3	6.38	1	5.56	2	6.90	0	0.00	2	11.76	1	4.76	3	11.11	0	0.00
No cost burden and that nearly everything was paid for through the public health system	8	17.02	3	16.67	5	17.24	4	44.44	2	11.76	2	9.52	6	22.22	2	10.00
No cost burden as participant was able to afford all costs	5	10.64	2	11.11	3	10.34	2	22.22	1	5.88	2	9.52	3	11.11	2	10.00
No cost burden and that nearly everything was paid for through the private health system	4	8.51	1	5.56	3	10.34	0	0.00	2	11.76	2	9.52	2	7.41	2	10.00
No cost burden as participant was able to access paid medical leave	3	6.38	1	5.56	2	6.90	0	0.00	1	5.88	2	9.52	1	3.70	2	10.00
No cost burden: satisfied with experience	3	6.38	3	16.67	0	0.00	1	11.11	1	5.88	1	4.76	3	11.11	0	0.00

Cost considerations (reasons for costs)	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Cost burden in relation to the cost of treatments (including repeat scripts)	13	27.66	9	34.62	4	19.05	8	33.33	5	21.74	3	20.00	10	31.25	7	28.00	6	27.27
Cost burden in relation to diagnostic tests and scans	8	17.02	5	19.23	3	14.29	4	16.67	4	17.39	3	20.00	5	15.63	5	20.00	3	13.64
Cost burden in relation to needing to take time off work	8	17.02	5	19.23	3	14.29	4	16.67	4	17.39	4	26.67	4	12.50	5	20.00	3	13.64
Cost burden in relation to the cost specialist appointments	7	14.89	7	26.92	0	0.00	4	16.67	3	13.04	4	26.67	3	9.38	4	16.00	3	13.64
Cost burden in relation gap payments	6	12.77	3	11.54	3	14.29	3	12.50	3	13.04	3	20.00	3	9.38	5	20.00	1	4.55
Cost burden in needing to special equipment	5	10.64	3	11.54	2	9.52	2	8.33	3	13.04	1	6.67	4	12.50	1	4.00	4	18.18
Cost burden in relation to allied health care	4	8.51	4	15.38	0	0.00	2	8.33	2	8.70	2	13.33	2	6.25	3	12.00	1	4.55
Cost burden in relation to GP appointments	4	8.51	2	7.69	2	9.52	3	12.50	1	4.35	1	6.67	3	9.38	2	8.00	2	9.09
Cost burden in relation to a family member needing to take time off work	3	6.38	2	7.69	1	4.76	1	4.17	2	8.70	0	0.00	3	9.38	1	4.00	2	9.09
Cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	3	6.38	2	7.69	1	4.76	1	4.17	2	8.70	2	13.33	1	3.13	2	8.00	1	4.55
No cost burden and that nearly everything was paid for through the public health system	8	17.02	6	23.08	2	9.52	5	20.83	3	13.04	2	13.33	6	18.75	5	20.00	3	13.64
No cost burden as participant was able to afford all costs	5	10.64	4	15.38	1	4.76	4	16.67	1	4.35	1	6.67	4	12.50	4	16.00	1	4.55
No cost burden and that nearly everything was paid for through the private health system	4	8.51	2	7.69	2	9.52	1	4.17	3	13.04	2	13.33	2	6.25	2	8.00	2	9.09
No cost burden as participant was able to access paid medical leave	3	6.38	1	3.85	2	9.52	1	4.17	2	8.70	1	6.67	2	6.25	1	4.00	2	9.09
No cost burden: satisfied with experience	3	6.38	0	0.00	3	14.29	2	8.33	1	4.35	0	0.00	3	9.38	2	8.00	1	4.55

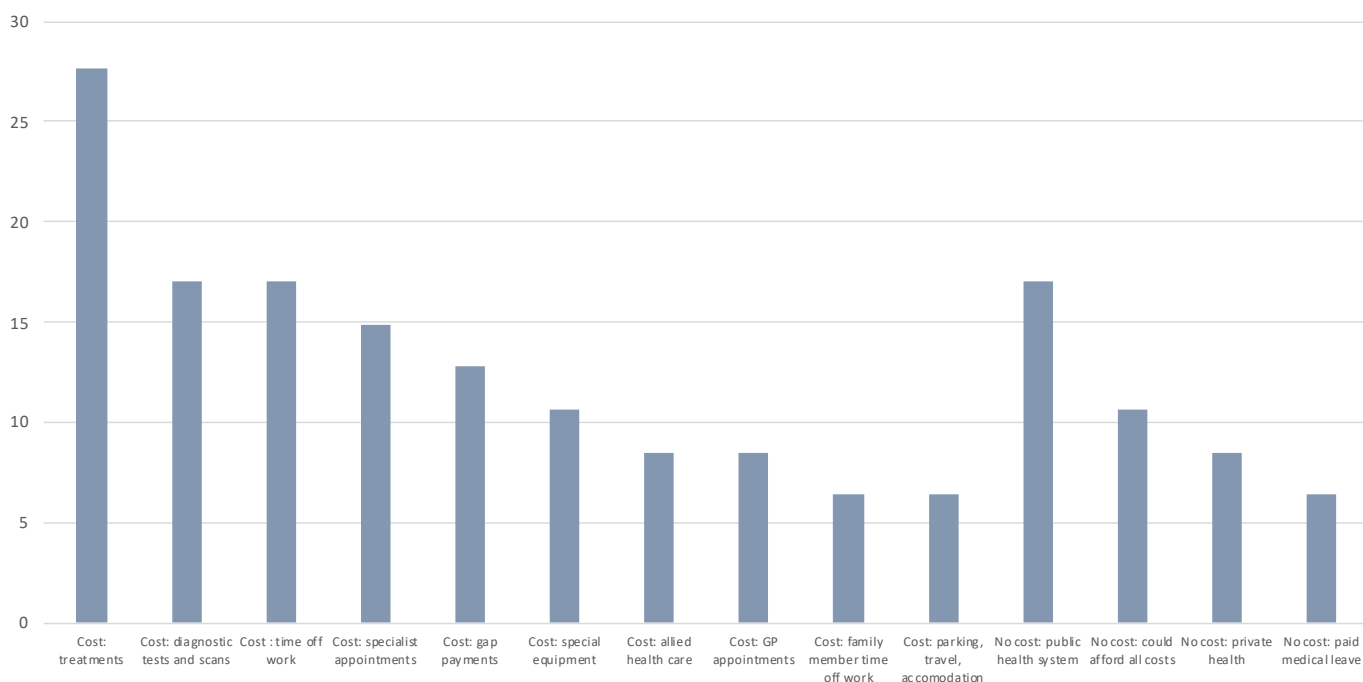


Figure 8.13: Cost considerations (Reasons for cost)

Table 8.26: Cost considerations (Reasons for cost)– subgroup variations

Cost considerations (reasons for costs)	Reported less frequently	Reported more frequently
Cost burden in relation to the cost of treatments (including repeat scripts)	High cholesterol under 50 years of age	
Cost burden in relation to diagnostic tests and scans	High cholesterol under 50 years of age	
Cost burden in relation to needing to take time off work		Blood vessel conditions
Cost burden in relation to the cost specialist appointments	Male	6 to 11 other conditions Female
Cost burden in needing to special equipment	High cholesterol under 50 years of age 0 to 5 other conditions	Regional or remote 6 to 11 other conditions
Cost burden in relation to a family member needing to take time off work		Blood vessel conditions
No cost burden and that nearly everything was paid for through the public health system		High cholesterol under 50 years of age
No cost burden as participant was able to afford all costs		High cholesterol under 50 years of age
No cost burden and that nearly everything was paid for through the private health system		
No cost burden: satisfied with experience		Had LP(a) test

Overall impact of condition on quality of life

In the online questionnaire, participants were asked to rate the overall impact their condition on quality of life. Quality of life was rated on a Likert scale from one to seven, where one is Life was very distressing and seven is life was great.

The average score was in the Life was a little distressing to average range (median=3.50, IQR=3.00).

Table 8.27: Overall impact of condition on quality of life

Impact of condition on quality of life	Number (n=48)	Percent
1 Life is/was very distressing	5	10.42
2 Life is/was distressing	12	25.00
3 Life is/was a little distressing	7	14.58
4 Life is/was average	8	16.67
5 Life is/was good	8	16.67
6 Life is/was very good	7	14.58
7 Life is/was great	1	2.08

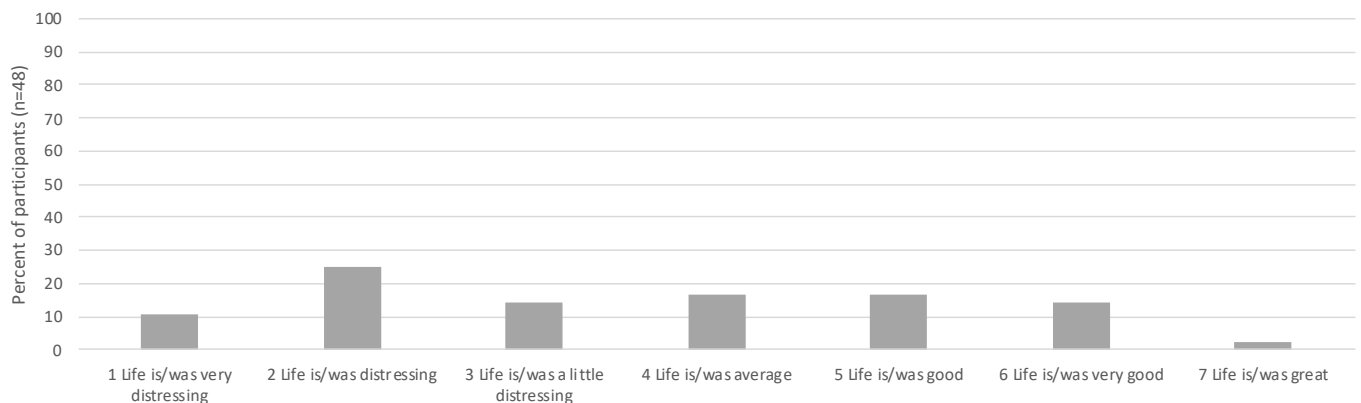


Figure 8.14: Overall impact of condition on quality of life

Experience of anxiety related to disease progression

Fear of progression

The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their conditions. The Fear of Progression questionnaire comprises a total score, between 12 and 60, with a higher score denoting increased anxiety. The overall scores for the cohort were in the middle quintile for Fear of progression: Total score (mean=33.68, SD=11.32) indicating moderate levels of anxiety.

Comparisons of Fear of Progression have been made by LP(a) test status, main condition, number of other health conditions, gender, age, location, and socioeconomic status.

The **Fear of Progression** questionnaire measures the level of anxiety people experience in relation to their conditions. On average fear of progression score for participants in this study indicated moderate levels of anxiety.

Table 8.28: Fear of progression summary statistics

Fear of progression (n=50)	Mean	SD	Median	IQR	Possible range	Quintile
Total score*	33.68	11.32	33.00	15.75	12 to 60	3

*Normal distribution use mean and SD as measure of central tendency

Fear of progression by LP(a) test

Comparisons were made by **LP(a) Test status** there were 19 participants (38.00%) that had an LP(a) test and, 31 participants (62.00%) that did not have an LP(a) test.

Assumptions for normality and variance were met, a two-sample t-test was used.

No significant differences were observed between participants by **LP(a) test** for any of the Fear of progression scales.

Table 8.29: Fear of progression total score by LP(a) test summary statistics and one-way ANOVA

Fear of progression	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Total score	Had LP(a) test	19	38.00	34.00	10.46	0.15	48	0.8775
	Not had LP(a) test	31	62.00	33.48	11.98			

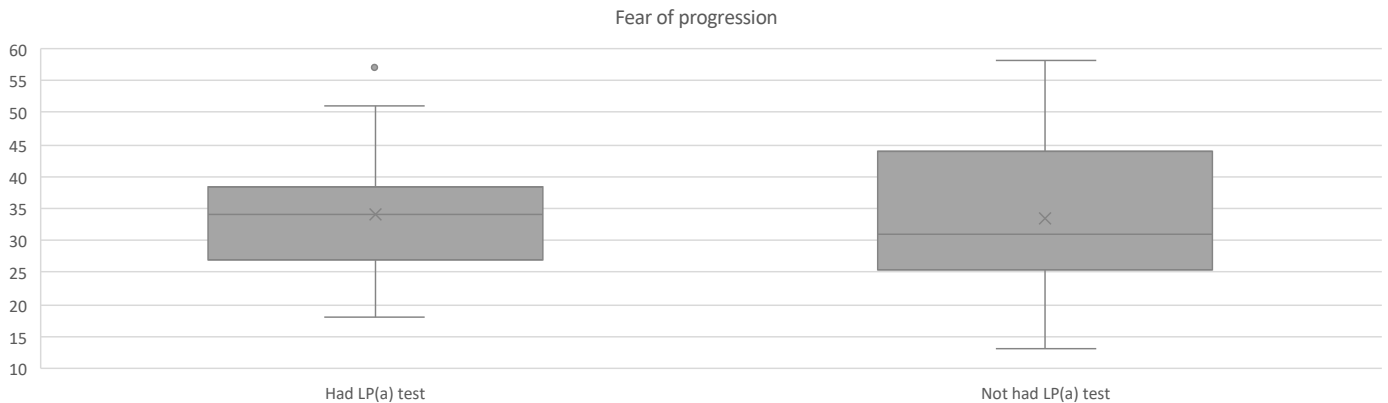


Figure 8.15: Boxplot of Fear of progression total score by LP(a) test

Fear of progression by main condition

Comparisons were made by the participants' **main condition**. There were 12 participants (24.00%) with high cholesterol aged under 50 years of age, 17 participants (34.00%) with blood vessel conditions, and 21 participants (42.00%) with heart conditions.

A one-way ANOVA test was used when the assumptions for response variable residuals were

normally distributed and variances of populations were equal.

No significant differences were observed between participants by **main condition** for any of the Fear of progression scales.

Table 8.30: Fear of progression total score by main condition summary statistics and one-way ANOVA

Fear of progression	Group	Number (n=50)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Total score	High cholesterol under 50 years of age	8	16.33	35.00	10.78	Between groups	140.00	2	69.88	0.54	0.59
	Blood vessel conditions	19	38.78	31.35	12.97	Within groups	6139.00	47	130.62		
	Heart conditions	22	44.90	34.81	10.42	Total	6279.00	49	200.50		

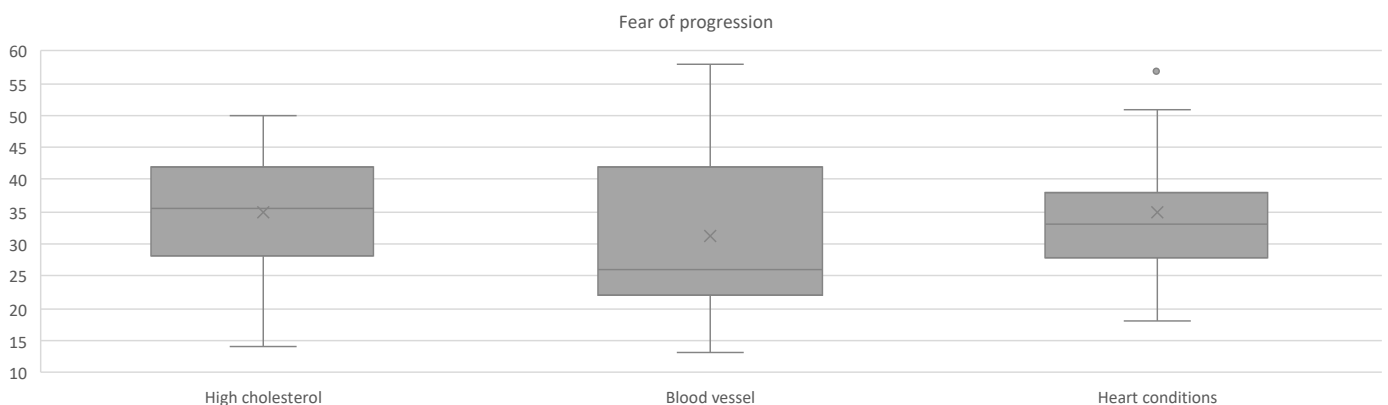


Figure 8.16: Boxplot of Fear of progression total score by main condition

Fear of progression by other conditions

Comparisons were made by **number of other health conditions** there were 27 participants (54.00%) with 0 to 5 other conditions and, 23 participants (46.00%) with 6 to 11 other conditions.

Assumptions for normality and variance were met, a two-sample t-test was used.

No significant differences were observed between participants by **other conditions** for any of the Fear of progression scales.

Table 8.31: Fear of progression total score by other conditions summary statistics and one-way ANOVA

Fear of progression	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Total score	0 to 5 other conditions	27	54.00	31.07	10.98	-1.80	48	0.0775
	6 to 11 other conditions	23	46.00	36.74	11.18			

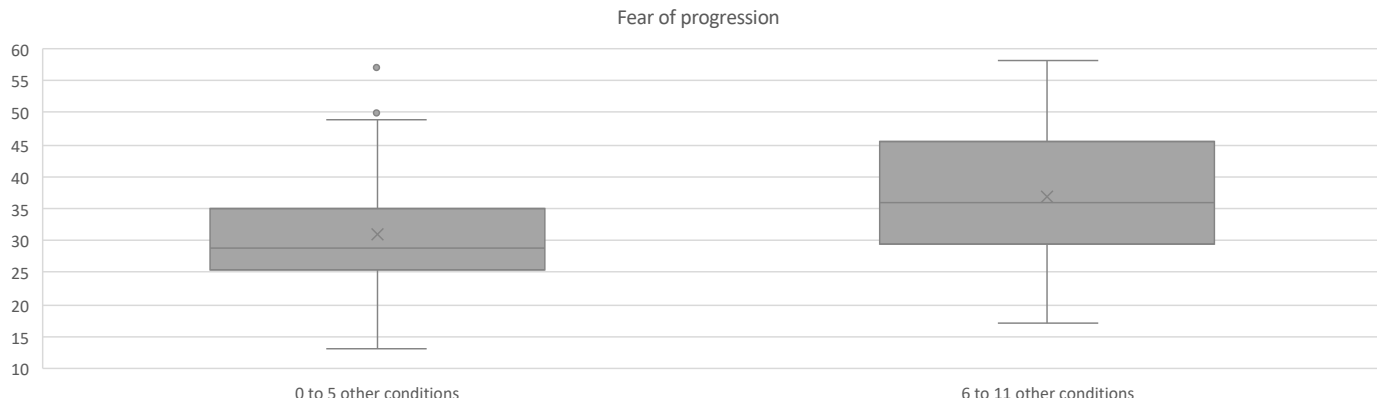


Figure 8.17: Boxplot of Fear of progression total score by other conditions

Fear of progression by gender

Comparisons were made by **gender**, there were 28 female participants (56.00%), and 22 male participants (44.00%).

No significant differences were observed between participants by **gender** for any of the Fear of progression scales.

Assumptions for normality and variance were met, a two-sample t-test was used.

Table 8.32: Fear of progression total score by gender summary statistics and one-way ANOVA

Fear of progression	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Total score	Female	28	56	33.82	11.89	0.10	48	0.9218
	Male	22	44	33.50	10.82			

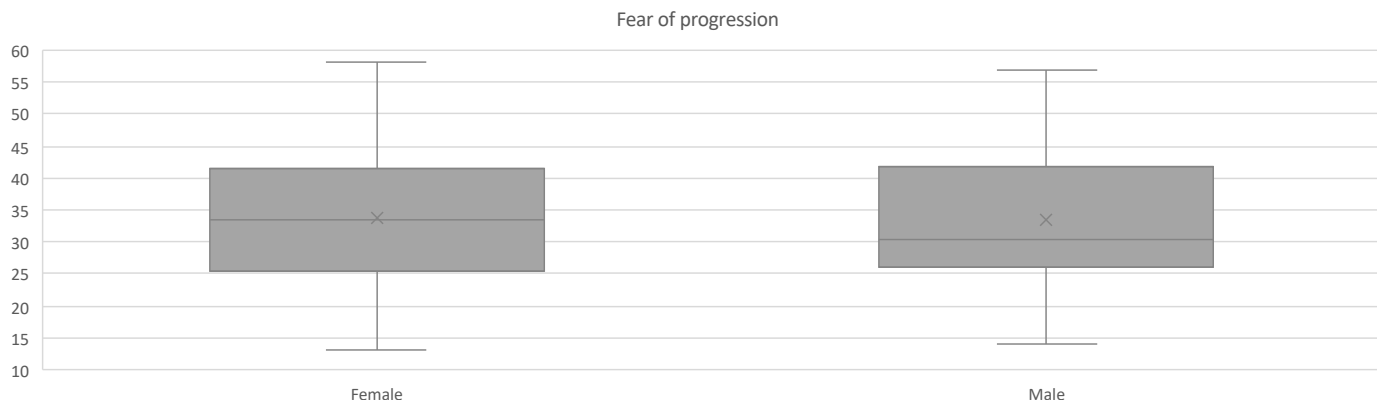


Figure 8.18: Boxplot of Fear of progression total score by gender

Fear of progression by age

Participants were grouped according to **age**, with comparisons made between participants aged 25 to 44 (n=27, 54.00%), and participants aged 45 and older (n=23, 46.00%).

Assumptions for normality and variance were met, a two-sample t-test was used.

No significant differences were observed between participants by **age** for any of the Fear of progression scales.

Table 8.33: Fear of progression total score by age summary statistics and one-way ANOVA

Fear of progression	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Total score	Aged 25 to 44	27	54.00	33.41	11.07	-0.18	48	0.8558
	Aged 45 and older	23	46.00	34.00	11.85			

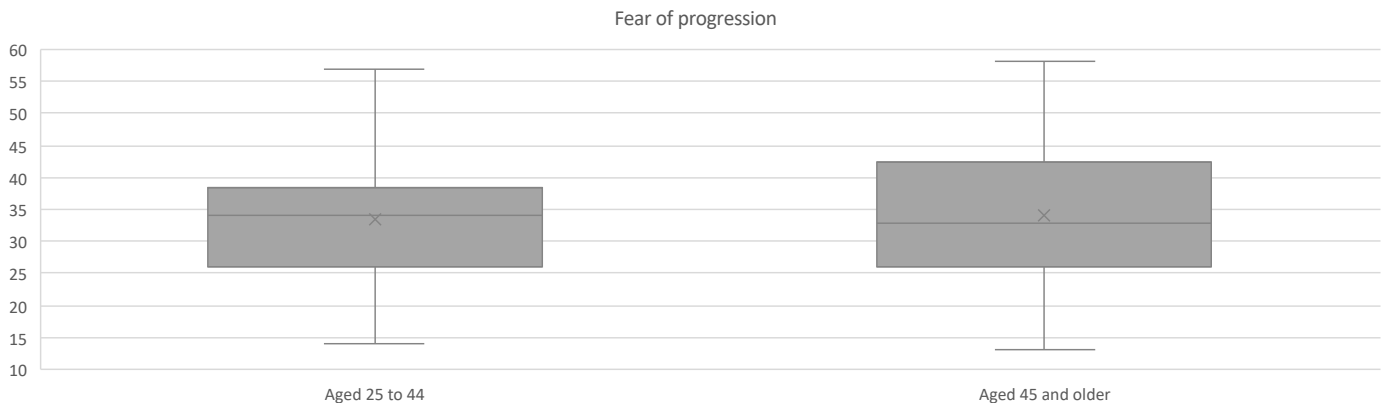


Figure 8.19: Boxplot of Fear of progression total score by age

Fear of progression by location

The **location** of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. Those living in regional or remote areas (n=15, 30.00%) were compared to those living in metropolitan areas (n=35, 70.00%).

Assumptions for normality and variance were met, a two-sample t-test was used.

No significant differences were observed between participants by **location** for any of the Fear of progression scales.

Table 8.34: Fear of progression total score by location summary statistics and one-way ANOVA

Fear of progression	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Total score	Regional or remote	15	30.00	34.73	10.01	0.43	48	0.6712
	Metropolitan	35	70.00	33.23	11.95			



Figure 8.20: Boxplot of Fear of progression total score by location

Fear of progression by socioeconomic advantage

Comparisons were made by **socioeconomic status**, using the Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a mid to low SEIFA score of 1-6, Mid to low status (n=25, 50.00%) compared to those with a

higher SEIFA score of 7-10, Higher status (n=25, 50.00%).

Assumptions for normality and variance were met, a two-sample t-test was used.

No significant differences were observed between participants by **socioeconomic advantage** for any of the Fear of progression scales.

Table 8.35: Fear of progression total score by socioeconomic advantage summary statistics and one-way ANOVA

Fear of progression	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Total score	Mid to low socioeconomic status	25	50.00	31.56	11.77	-1.33	48	0.1882
	Higher socioeconomic status	25	50.00	35.80	10.67			

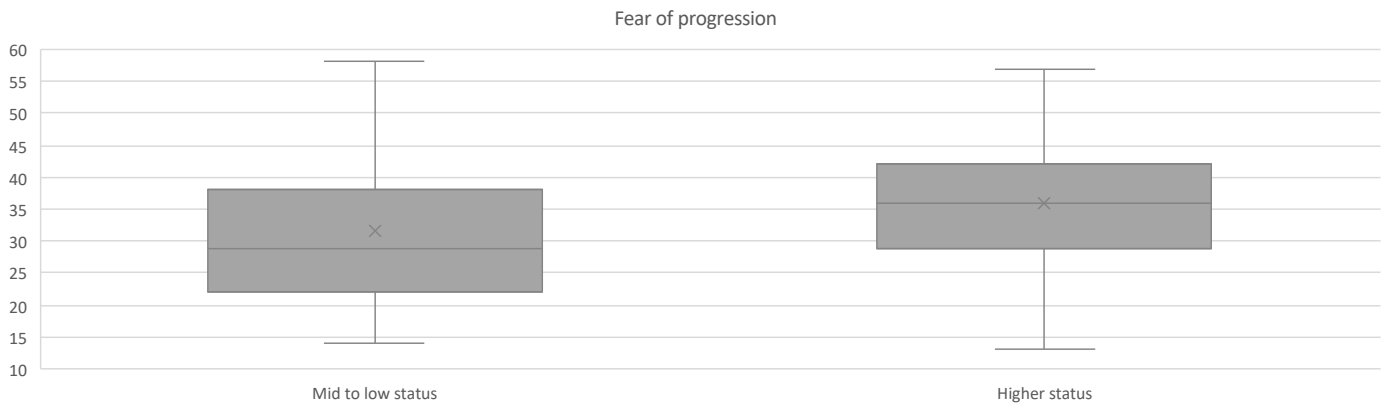


Figure 8.21: Boxplot of Fear of progression total score by socioeconomic advantage

Experience of anxiety related to disease progression

Fear of progression individual questions

On average, participants scored in the **“Never”** range for the following questions: “Anxious if not experiencing any side effects think it doesn’t work” (median=1.00, IQR=0.00).

On average, participants scored in the **“Seldom”** range for the following questions: “Is nervous prior to doctors appointments or periodic examinations” (median=2.00, IQR=1.75), “Afraid of pain” (median=2.00, IQR=1.75).

On average, participants scored in the **“Sometimes”** range for the following questions: “Becomes anxious thinking that disease may progress” (median=3.00, IQR=2.00), “Has concerns about reaching professional and/or personal goals because of illness:” (median=3.00, IQR=3.00), “When anxious, has physical symptoms such as a rapid heartbeat, stomach ache or

agitation” (median=2.50, IQR=2.00), “The possibility of relatives being diagnosed with this disease disturbs participant” (median=3.00, IQR=2.00), “Is disturbed that they may have to rely on strangers for activities of daily living” (median=2.50, IQR=2.75), “Worried that at some point in time will no longer be able to pursue hobbies because of illness” (median=3.00, IQR=2.00), “Afraid of severe medical treatments during the course of illness” (median=2.50, IQR=2.00), “Worried that treatment could damage their body” (median=3.00, IQR=2.75), “Worried about what will become of family if something should happen to participant” (median=3.00, IQR=2.00), “The thought that they might not be able to work due to illness disturbs participant” (median=3.00, IQR=3.50), “If a treatment and it is working well (limited side effects, no progression of disease), worry what will happen if treatment stopped” (median=3.00, IQR=1.75).

Table 8.36: Fear of progression individual questions

Fear of progression (n=50)	Mean	SD	Median	IQR	Average response
Becomes anxious thinking that disease may progress	2.88	1.30	3.00	2.00	Sometimes
Is nervous prior to doctors appointments or periodic examinations	2.56	1.30	2.00	1.75	Seldom
Afraid of pain	2.52	1.23	2.00	1.75	Seldom
Has concerns about reaching professional and/or personal goals because of illness:	3.06	1.54	3.00	3.00	Sometimes
When anxious, has physical symptoms such as a rapid heartbeat, stomach ache or agitation	2.72	1.23	2.50	2.00	Sometimes
The possibility of relatives being diagnosed with this disease disturbs participant	2.82	1.30	3.00	2.00	Sometimes
Is disturbed that they may have to rely on strangers for activities of daily living	2.54	1.49	2.50	2.75	Sometimes
Worried that at some point in time will no longer be able to pursue hobbies because of illness	3.08	1.28	3.00	2.00	Sometimes
Afraid of severe medical treatments during the course of illness	2.56	1.40	2.50	2.00	Sometimes
Worried that treatment could damage their body	2.82	1.42	3.00	2.75	Sometimes
Worried about what will become of family if something should happen to participant	3.04	1.37	3.00	2.00	Sometimes
The thought that they might not be able to work due to illness disturbs participant	3.02	1.57	3.00	3.50	Sometimes
If a treatment and it is working well (limited side effects, no progression of disease), worry what will happen if treatment stopped	2.62	1.23	3.00	1.75	Sometimes
Anxious if not experiencing any side effects think it doesn’t work	1.56	1.11	1.00	0.00	Never

*Normal distribution use mean and SD as measure of central tendency

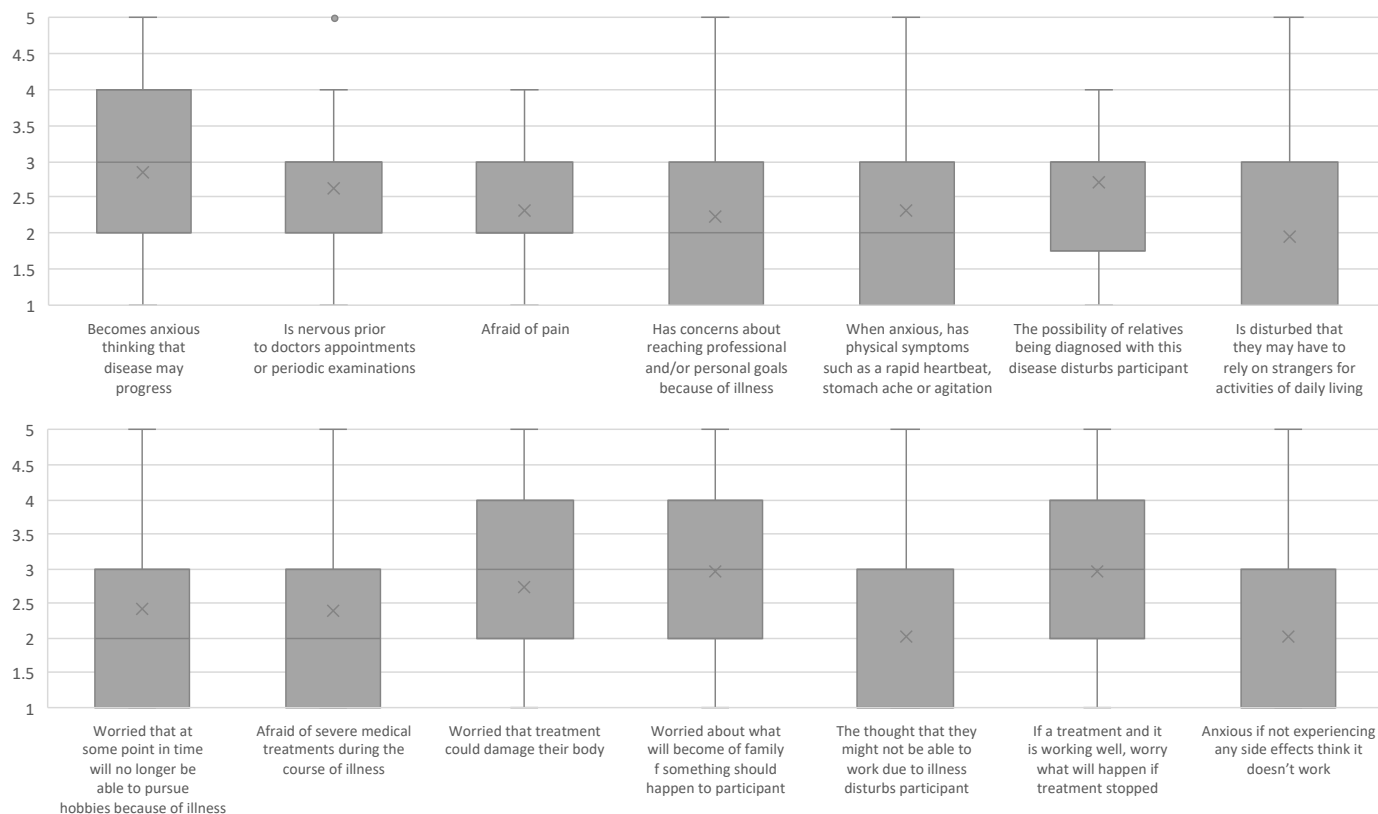


Figure 8.22: Fear of progression individual questions