

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. Half of the participants descriptions suggested that there was an overall negative impact on quality of life (50.00%). Others described an overall a minimal impact on quality of life (16.67%), overall no impact on quality of life (16.67 %), and a mix of positive and negative impact on quality of life (8.33%).

The most common themes in relation to a negative impact on quality of life were emotional strain on self (41.67%), emotional strain (including family/change in relationship dynamics) (33.33%), and reduced social interaction (25.00 %). Other themes included managing side effects and symptoms (8.33%), and from stigma and discrimination (8.33%). The most common theme in relation to a positive impact on quality of life was that it brings people together/highlights supportive relationships (8.33%).

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 (83.33%), and overall, there was no impact on mental health(8.33%).

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 response was that they did not have any activities to maintain mental health (41.67%). Others described maintaining their mental health by consulting a mental health professional (16.67%), mindfulness and/or meditation (16.67 %), the importance of physical exercise (8.33%), the importance of family and friends in maintaining their mental health (8.33%), and importance of a healthy diet (8.33%).

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 complying with treatment/management (33.33%), and doing physical exercise/physically active (16.67%), Other themes included maintaining a healthy lifestyle (16.67%), maintaining a healthy diet (8.33%), socialising with friends and/or family (8.33%), and getting help with translating health information (8.33%).

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 during/after treatments (25.00%), all the time (16.67%), when having sensitive discussion (diagnosis, treatment decision) (16.67 %), and vulnerable because of feelings of stigma (16.67%). Other themes included feeling vulnerable waiting for results (8.33%), and because of interactions with the medical team (8.33%).

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 getting support from family and friends (8.33%). peer support (8.33 %) and taking charge of own health (8.33%).

Impact on relationships

Most commonly, the descriptions suggested that overall, there was a negative impact on relationships (41.67%), overall. Others described that there was no impact on relationships (16.67%), and overall, there was a positive impact on relationships (16.67 %).

The most common theme in relation to having a positive impact on relationships was from family relationships being strengthened (16.67%).

The most common themes in relation to having a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships (16.67%). This was followed by from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition (8.33 %), and from assigning blame for infection (8.33%).

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 a burden on their family (66.67%), overall, there was not a burden on their family(16.67%), and overall, there was not a burden on their family now but they anticipate this will change in the future (8.33 %).

The main reason that participant described their condition being a burden was that the burden on family was temporary or only during treatment (41.67%). Others described that their condition was a burden in general (25.00%) the mental/emotional strain placed on their family (16.67 %), and the extra financial assistance needed (8.33%).

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. Most commonly participants described that there was at least some cost burden (58.33%), and a third described that overall, there was no cost burden (33.33%).

Where participants described no cost burden associated with their condition, it was most commonly because nearly everything was paid for through the public health system (16.67%), nearly everything was paid for through the private health system (8.33%), and being able to afford all costs (8.33 %).

Where participants described a cost burden associated with their condition, it was most commonly in relation to the cost of treatments (including repeat scripts) (25.00%), needing to take time off work (16.67%), the cost of parking and travel to attend appointments (including accommodation) (8.33 %), and allied health care (8.33%).

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 range (median=3.00, IQR=3.50).

Fear of 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. Half of the participants descriptions suggested that there was an overall negative impact on quality of life (50.00%). Others described an overall a minimal impact on quality of life (16.67%), overall no impact on quality of life (16.67%), and a mix of positive and negative impact on quality of life (8.33%).

The most common themes in relation to a negative impact on quality of life were emotional strain on self (41.67%), emotional strain (including family/change in relationship dynamics) (33.33%), and reduced social interaction (25.00%). Other themes included managing side effects and symptoms (8.33%), and from stigma and discrimination (8.33%).

The most common theme in relation to a positive impact on quality of life was that it brings people together/highlights supportive relationships (8.33%).

Participant describes a negative impact on quality of life due to the emotional strain on self

But the only thing that I have is my mind. Every time I always think about it, I always think about it that when am I going to get sick? When am I going to get sick. So that is thought is always with me, but apart from that in my life is all good.

Participant 001_2023AUHDV

Participant describes a negative impact on quality of life due to the emotional strain (including family/change in relationship dynamics)

Well, they are just stopped as well. They are just stopped and they show a lot of concerns and it shows in the in their faces that they are worried about the situation all.

Participant 006_2023AUHDV

Participant describes a negative impact on quality of life due to reduced social interaction

Yeah, I it it actually affected affected my level of communication to the I saw outside world. I was shut down and didn't actually feel comfortable communicating anyone anymore. So I just felt shut down and turned off from all communications.

Participant 009_2023AUHDV

Yeah, that would be a big yes. Yep...I was left really in the dark about transmission pathways for the different types of hepatitis so I I wasn't I didn't have any understanding of how it was transmitted...and so I kind of I, you know, physically isolated myself from people and I didn't seek out physical contact. And yeah, so and then, you know, and then later found out that a lot of my assumptions there were incorrect. So yeah, it's had a big impact.

Participant 011_2023AUHDV

Participant describes a negative impact on quality of life from stigma and discrimination

Dealing with people who had stigma and discrimination against me. So yeah, I don't know.

Participant 010_2023AUHDV

Participant describes no impact on quality of life

No I I don't think that it's excluded me from anything that I wanted to do and you know I mean so I still travel like still get around I'm still mobile...my alcohol consumption's gone up and down and this is just an option that, well, I'm not actually drinking that much alcohol at the moment. So, but that's the only thing really.

Participant 007_2023AUHDV

Table 8.1: Impact on quality of life

Impact on quality of life	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Experience described suggests that there was an overall negative impact on quality of life	6	50.00	3	50.00	3	50.00	5	62.50	1	25.00	3	50.00	3	50.00	0	0.00	6	54.55	0	0.00	6	54.55
Experience described suggests that there was overall a minimal impact on quality of life	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18
Experience described suggests that there was overall no impact on quality of life	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	0	0.00	2	33.33	1	100.00	1	9.09	1	100.00	1	9.09
Experience described suggests that there was a mix of positive and negative impact on quality of life	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09

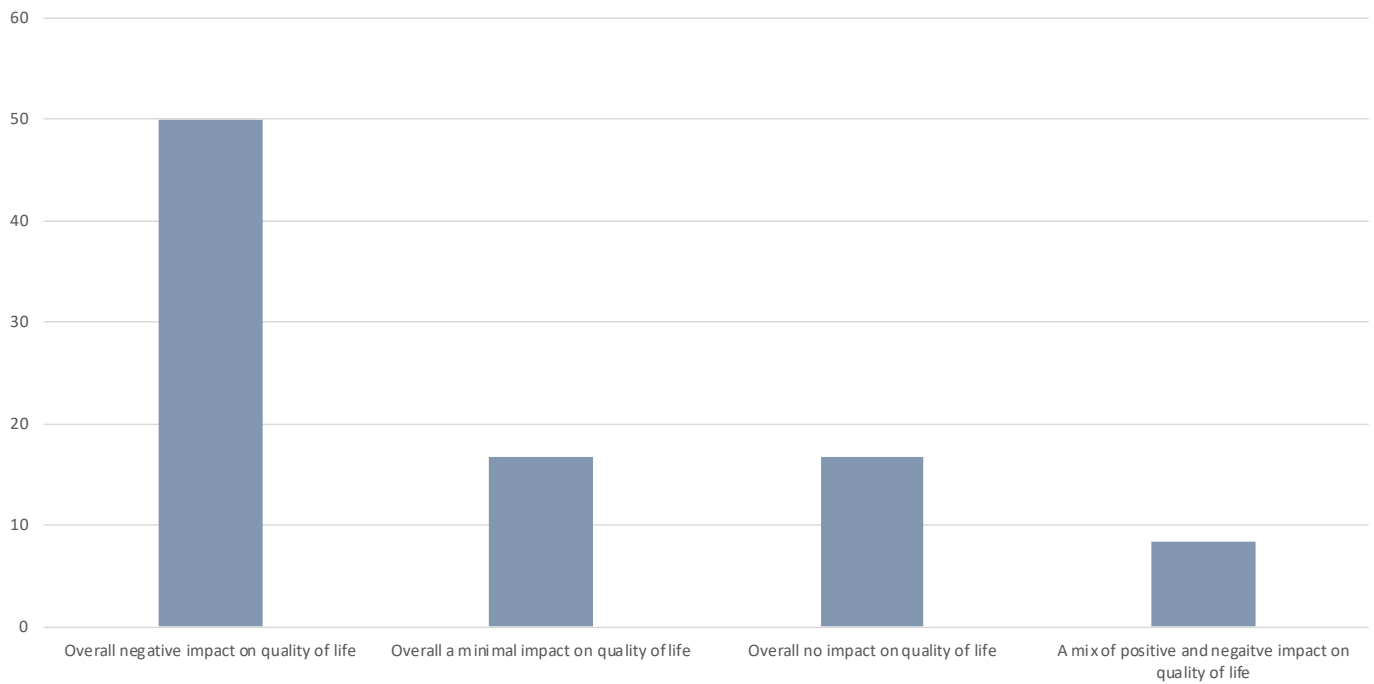


Figure 8.1: Impact on quality of life

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	Aged 45 and older	Aged 18 to 44

Table 8.3: Impact on quality of life (Reasons)

Impact on quality of life (reasons)	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes a negative impact on quality of life due to the emotional strain on self	5	41.67	2	33.33	3	50.00	4	50.00	1	25.00	3	50.00	2	33.33	0	0.00	5	45.45	0	0.00	5	45.45
Participant describes a negative impact on quality of life due to the emotional strain (including family/change in relationship dynamics)	4	33.33	3	50.00	1	16.67	3	37.50	1	25.00	2	33.33	2	33.33	0	0.00	4	36.36	0	0.00	4	36.36
Participant describes a negative impact on quality of life due to reduced social interaction	3	25.00	0	0.00	3	50.00	3	37.50	0	0.00	1	16.67	2	33.33	0	0.00	3	27.27	0	0.00	3	27.27
Participant describes a negative impact on quality of life due to managing side effects and symptoms	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes a negative impact on quality of life from stigma and discrimination	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes a positive impact on quality of life because it brings people together/highlights supportive relationships	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes a minimal impact on quality of life that has a general or temporary impact	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes no impact on quality of life	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	0	0.00	2	33.33	1	100.00	1	9.09	1	100.00	1	9.09
No particular comment	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09

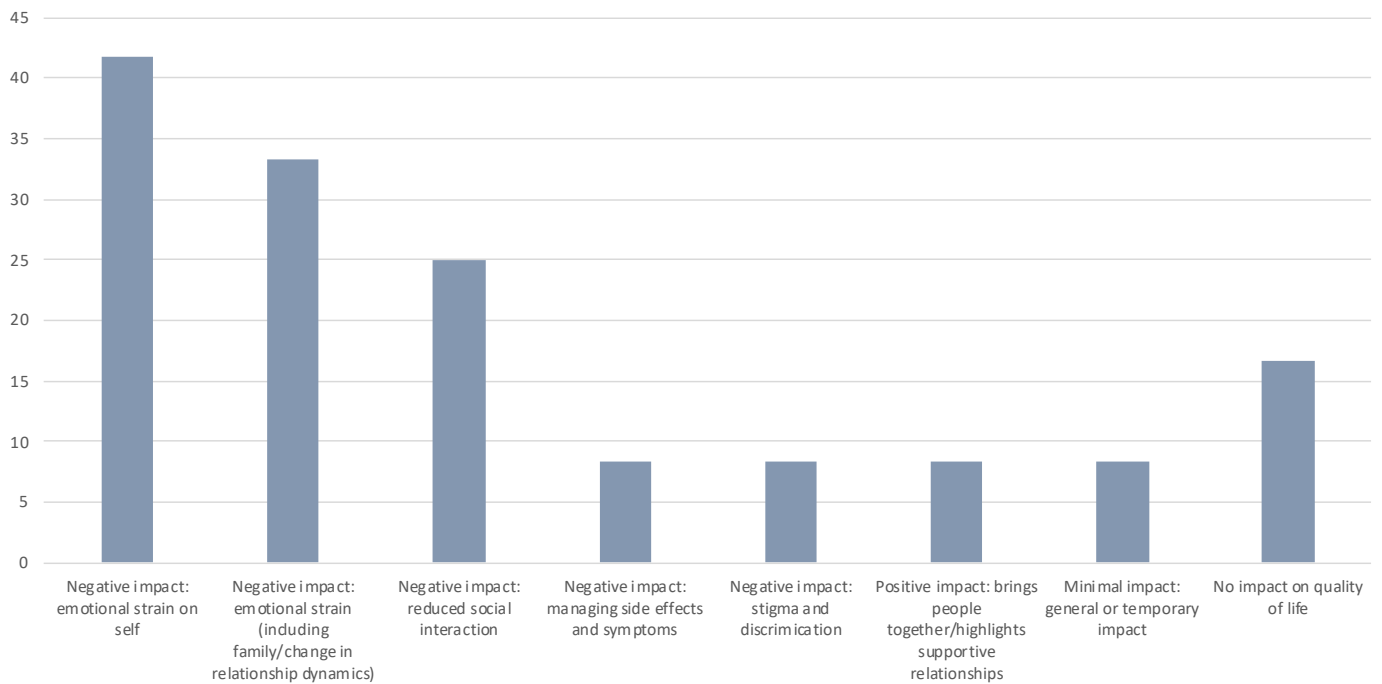


Figure 8.2: Impact on quality of life (Reasons)

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 on self	Aged 45 and older	-
Participant describes a negative impact on quality of life due to the emotional strain (including family/change in relationship dynamics)	Male	Female

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 (83.33%), and overall, there was no impact on mental health(8.33%).

Table 8.5: Impact on mental health

Impact on mental health	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Experience described suggests that overall, there was at least some impact on mental health	10	83.33	4	66.67	6	100.00	7	87.50	3	75.00	5	83.33	5	83.33	1	100.00	9	81.82	1	100.00	9	81.82
Experience described suggests that overall, there was no impact on mental health	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Other or mixed experience	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09

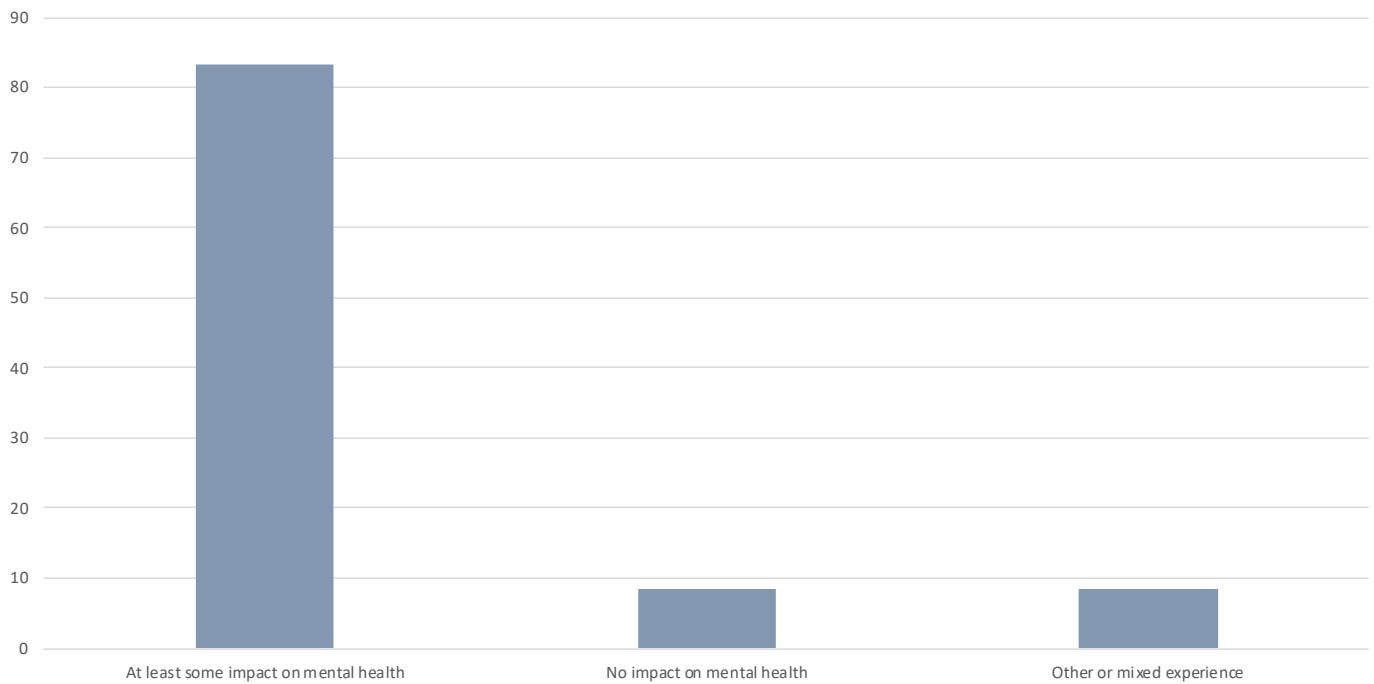


Figure 8.3: Impact on mental health

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	Female	Male

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 response was that they did not have any activities to maintain mental health (41.67%). Others described maintaining their mental health by consulting a mental health professional (16.67%), mindfulness and/or meditation (16.67%), the importance of physical exercise (8.33%), the importance of family and friends in maintaining their mental health (8.33%), and importance of a healthy diet (8.33%).

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

And I did visit the therapist and he actually told me about a few things that I should go through that would actually help me is stress.

Participant 009_2023AUHDV

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

Yeah, my, my mental health has been affected, that's for certain. And my emotions and everything has been affected. Yeah, I, I do certain activity once in a while, you know, to kind of, you know, soften the, the effects in my mental health, you know, let's say activity like yoga. And meditation, just to calm the calm the tension down.

Participant 006_2023AUHDV

Participant describes the importance of family and friends in maintaining their mental health to maintain their mental health

Yes, it did affect my mental and emotional health prior to treatment...I have a spiritual understanding that I live in the moment. I I am very connected with my family and with my close friends.

Participant 010_2023AUHDV

Table 8.7: Regular activities to maintain mental health

Regular activities to maintain mental health	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes no activities to maintain mental health to maintain their mental health	5	41.67	3	50.00	2	33.33	4	50.00	1	25.00	2	33.33	3	50.00	1	100.00	4	36.36	1	100.00	4	36.36
Participant describes consulting a mental health professional to maintain their mental health	2	16.67	1	16.67	1	16.67	2	25.00	0	0.00	0	0.00	2	33.33	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes mindfulness and/or meditation to maintain their mental health	2	16.67	0	0.00	2	33.33	1	12.50	1	25.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes the importance of physical exercise to maintain their mental health	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes the importance of family and friends in maintaining their mental health to maintain their mental health	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes the importance of a healthy diet to maintain their mental health	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
No Response	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18

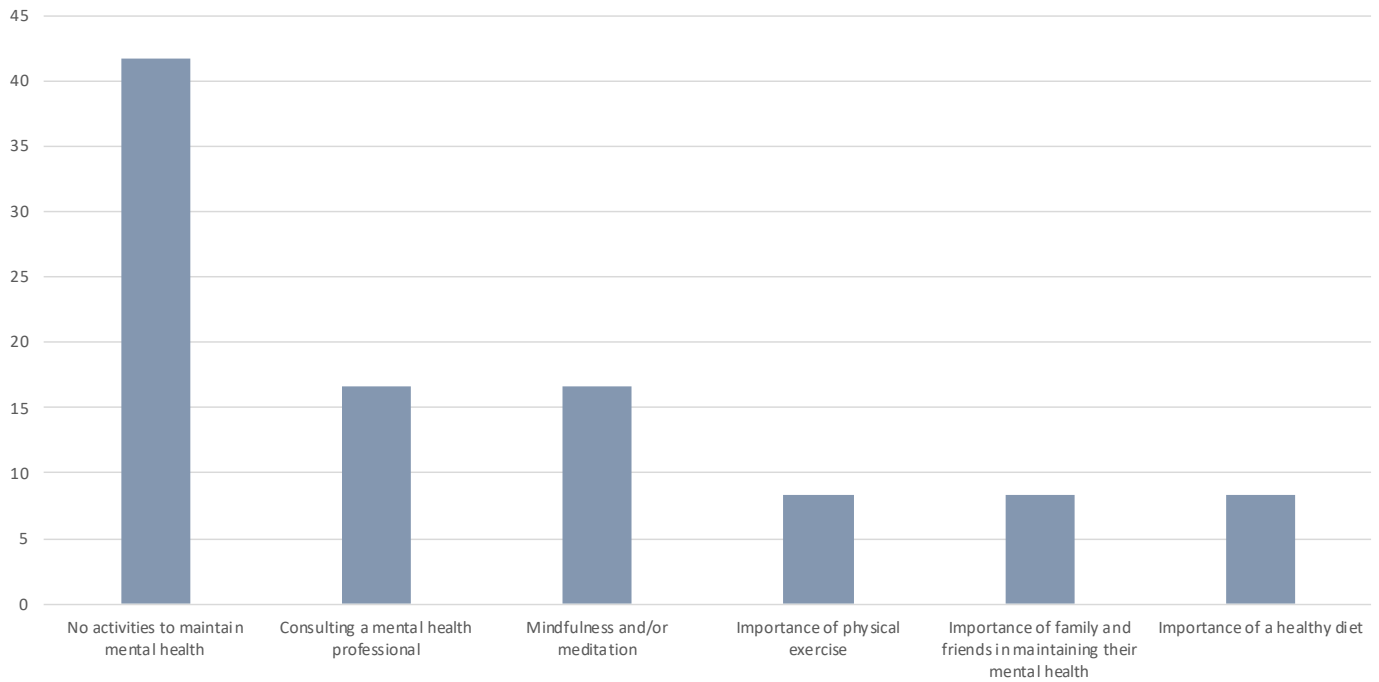


Figure 8.4: Regular activities to maintain mental health

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 no activities to maintain mental health to maintain their mental health	Aged 45 and older	-

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 complying with treatment/management (33.33%), and doing physical exercise/physically active (16.67%), Other themes included maintaining a healthy lifestyle (16.67%), maintaining a healthy diet (8.33%), socialising with friends and/or family (8.33%), and getting help with translating health information (8.33%).

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

*Basic took the treatment.
Participant 004_2023AUHDV*

No, no. Well, that's that's it. I mean I take, I'm probably taking about 10 pills a day now, so that's not too bad. But you know, apart from that, life just goes on and I mean pills in the morning, pills at night, that's it. It's no great drama. Participant 007_2023AUHDV

Participant describes no activities to maintain their general health

*No, no, I'm not doing anything because it's not treatable, so I don't even know what to do.
Participant 001_2023AUHDV*

Participant describes the importance of getting help with translating health information

*I think. Yeah, the only thing I do is try to translate for them I guess
Participant 003_2023AUHDV*

Table 8.9: Regular activities to maintain health

Regular activities to maintain general health	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes the importance of complying with treatment/management in maintaining their general health	4	33.33	1	16.67	3	50.00	3	37.50	1	25.00	1	16.67	3	50.00	1	100.00	3	27.27	1	100.00	3	27.27
Participant describes the importance of doing physical exercise/physically active in maintaining their general health	2	16.67	1	16.67	1	16.67	2	25.00	0	0.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes no activities to maintain their general health	2	16.67	2	33.33	0	0.00	2	25.00	0	0.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes the importance of maintaining a healthy lifestyle in maintaining their general health	2	16.67	0	0.00	2	33.33	1	12.50	1	25.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes the importance of maintaining a healthy diet in maintaining their general health	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes the importance of socialising with friends and/or family in maintaining their general health	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes the importance of getting help with translating health information	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
No particular comment	3	25.00	2	33.33	1	16.67	1	12.50	2	50.00	2	33.33	1	16.67	0	0.00	3	27.27	0	0.00	3	27.27

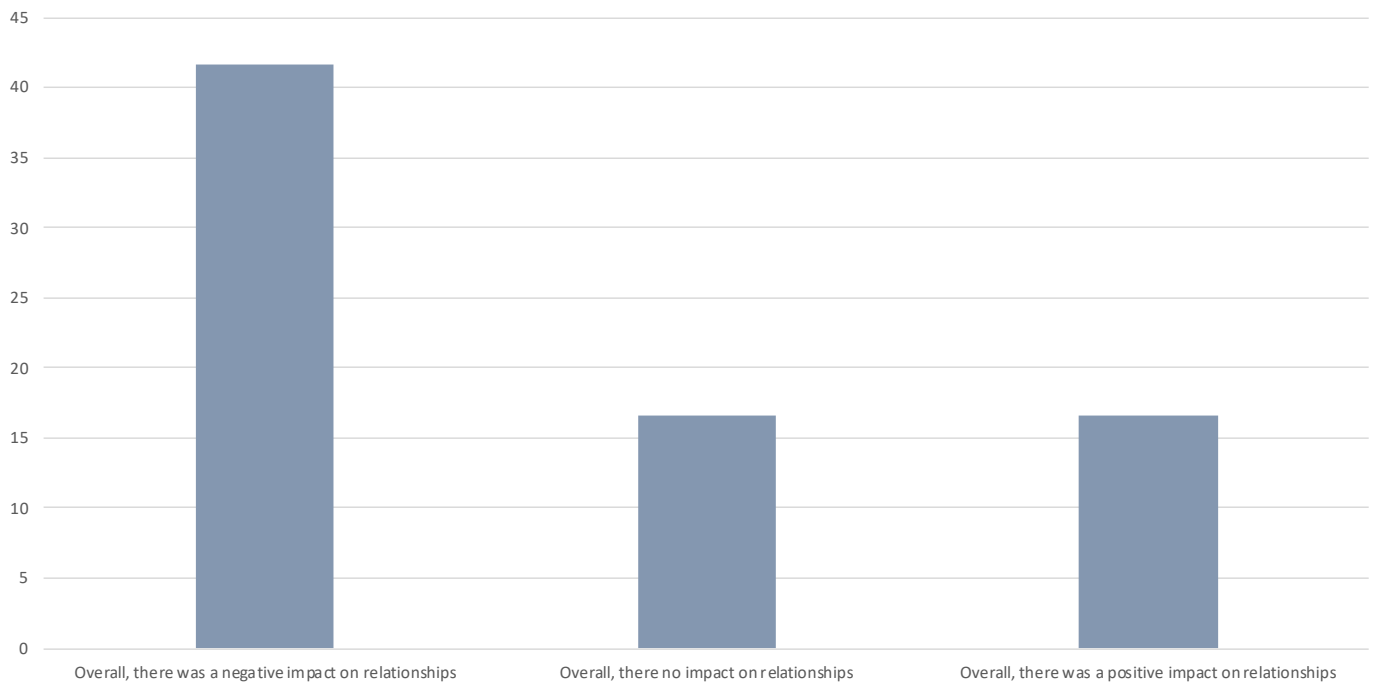


Figure 8.5: Regular activities to maintain health

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 complying with treatment/management in maintaining their general health	Female Trade or high school	Male University

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 during/after treatments (25.00%), all the time (16.67%), when having sensitive discussion (diagnosis, treatment decision) (16.67%), and vulnerable because of feelings of stigma (16.67%). Other themes included feeling vulnerable waiting for results (8.33%), and because of interactions with the medical team (8.33%).

Participant describes feeling vulnerable all the time

PARTICIPANT: *Um, yeah, most of the time. I, you know, I just feel. Tired of the situation. I just feel fed up. And yeah, sometimes, sometimes.*

INTERVIEWER: *And what what did you do to, you know, overcome this feeling?*

PARTICIPANT: *Well, I I just confide in my loved ones there. They kind of reassured me that it's just for the meantime, that I'll be fine. So it's just my loved one that helped me.*

Participant 006_2023AUHDV

Participant describes feeling vulnerable when having sensitive discussion (diagnosis, treatment decision)

OK, I actually felt vulnerable when I was scared and I didn't actually know what to do. I was really, really scared about hearing such information on such news. I was quite scared.

Participant 009_2023AUHDV

Participant describes feeling vulnerable because of feelings of stigma

Time all the time. I would say hepatitis has. That times kept me I felt as a prisoner from experiencing things and experiencing life. It just feels very shameful.

Participant 004_2023AUHDV

Participant describes feeling vulnerable while waiting for test results

Yeah, yeah, post post treatment there's. And I think this is true for the current treatments as well.

But there's this period of where you're waiting to find out results. So you might have an initial blood test that says you're negative...but you've still got there's

still a time, there's that window there where the thing can come back....and waiting for that and then waiting for the results.
Participant 011_2023AUHDV

Participant describes feeling vulnerable because of interactions with the medical team

Yeah, those two times where or maybe two or three times where the doctor and a couple of couple of

doctors and a couple of nurses were a bit judgmental about my past. So I just felt a bit vulnerable at that time, but I just spoke up so that was all good.
Participant 010_2023AUHDV

Participant describes that they did not feel vulnerable

I don't feel vulnerable.
Participant 005_2023AUHDV

Table 8.11: Experience of vulnerability

THEME	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes that overall, there was a negative impact on relationships	5	41.67	2	33.33	3	50.00	4	50.00	1	25.00	4	66.67	1	16.67	0	0.00	5	45.45	0	0.00	5	45.45
Participant describes that overall, there no impact on relationships	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	0	0.00	2	33.33	1	100.00	1	9.09	1	100.00	1	9.09
Participant describes that overall, there was a positive impact on relationships	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
No particular comment	3	25.00	2	33.33	1	16.67	2	25.00	1	25.00	1	16.67	2	33.33	0	0.00	3	27.27	0	0.00	3	27.27

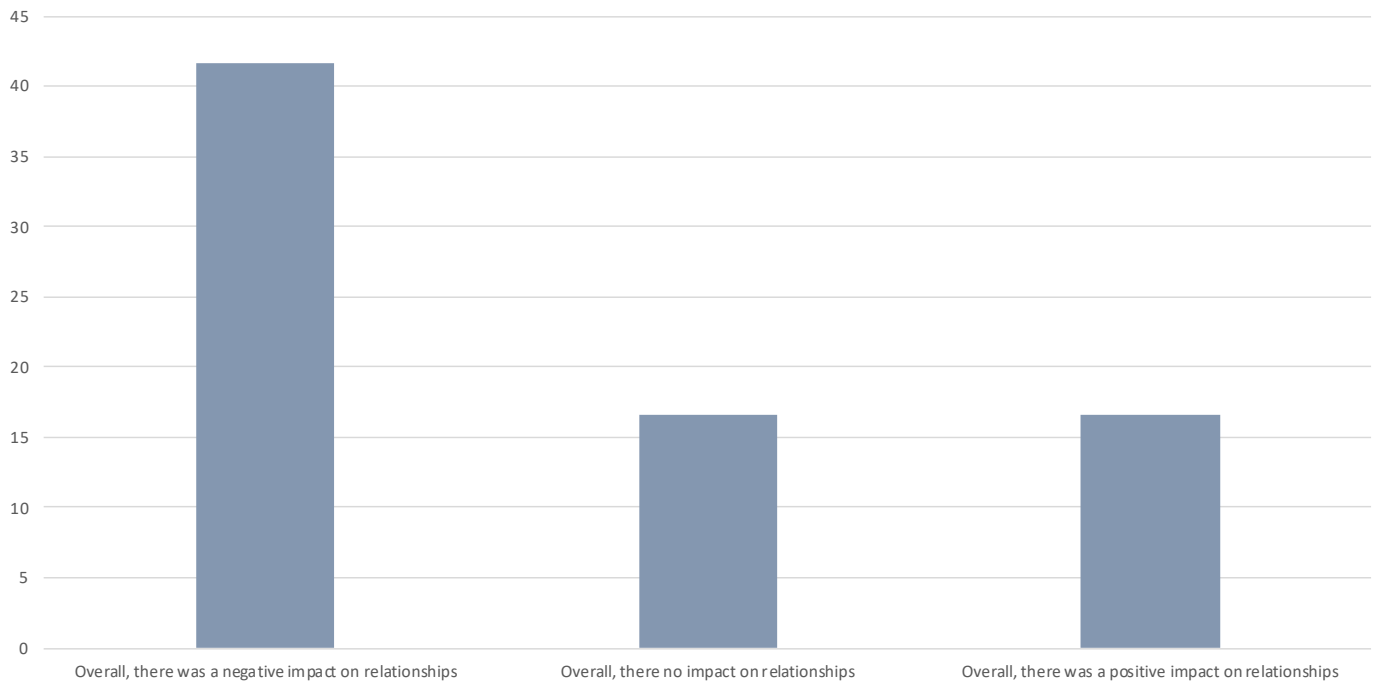


Figure 8.6: Experience of vulnerability

Table 8.12: Experience of vulnerability – subgroup variations

Experience of vulnerability	Reported less frequently	Reported more frequently
Participant describes that overall, there was a negative impact on relationships	Aged 45 and older University	Trade or high school

Table 8.13: Experience of vulnerability (details)

Experience of vulnerability (Details)	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes feeling vulnerable during/after treatments	3	25.00	0	0.00	3	50.00	1	12.50	2	50.00	2	33.33	1	16.67	1	100.00	2	18.18	1	100.00	2	18.18
Participant describes feeling vulnerable all the time	2	16.67	1	16.67	1	16.67	2	25.00	0	0.00	0	0.00	2	33.33	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes feeling vulnerable when having sensitive discussion (diagnosis, treatment decision)	2	16.67	0	0.00	2	33.33	1	12.50	1	25.00	0	0.00	2	33.33	1	100.00	1	9.09	1	100.00	1	9.09
Participant describes feeling vulnerable because of feelings of stigma	2	16.67	2	33.33	0	0.00	1	12.50	1	25.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes feeling vulnerable bwhile waiting for test results	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes feeling vulnerable because of interactions with the medical team	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes that they did not feel vulnerable	2	16.67	2	33.33	0	0.00	2	25.00	0	0.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Other/No response	2	16.67	1	16.67	1	16.67	2	25.00	0	0.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18

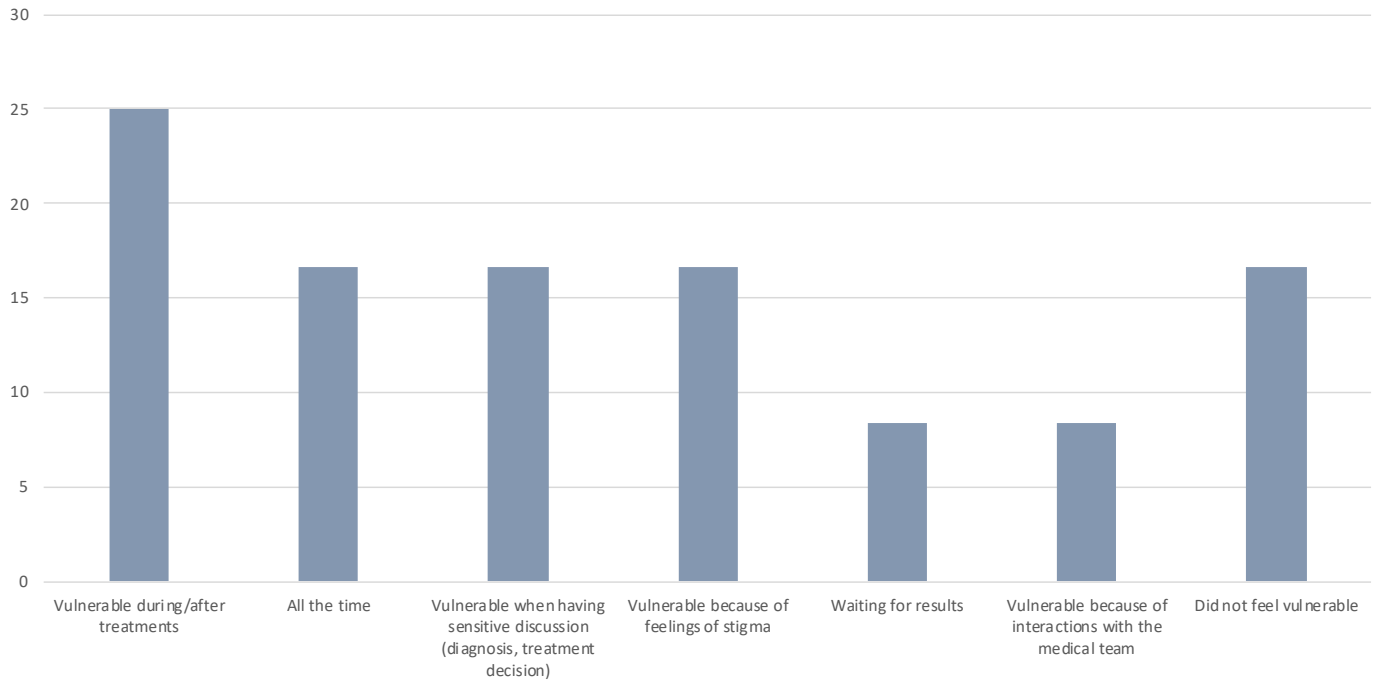


Figure 8.7: Experience of vulnerability (details)

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 getting support from family and friends (8.33%), peer support (8.33%), and taking charge of own health (8.33%).

Participant describes getting support from family and friends to manage the feeling of vulnerability

PARTICIPANT: *Um, yeah, most of the time. I, you know, I just feel. Tired of the situation. I just feel fed up. And yeah, sometimes, sometimes.*

INTERVIEWER: *And what what did you do to, you know, overcome this feeling?*

PARTICIPANT: *Well, I I just confide in my loved ones there. They kind of reassured me that it's just for the meantime, that I'll be fine. So it's just my loved one that helped me.*

Participant 006_2023AUHDV

Participant describes taking charge of their own health to manage the feeling of vulnerability

That's, that's what I can do. I can speak to other people, but, you know, I mean, I really have to take charge of my own health. I have to liaison with other people too. Participant 012_2023AUHDV

Table 8.14: Methods to manage vulnerability

Methods to manage vulnerability	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes Not applicable, no vulnerability	3	25.00	2	33.33	1	16.67	2	25.00	1	25.00	1	16.67	2	33.33	1	100.00	2	18.18	1	100.00	2	18.18
Participant describes getting support from family and friends to manage the feeling of vulnerability	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes peer support to manage the feeling of vulnerability	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes taking charge of their own health to manage the feeling of vulnerability	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Other/no response	6	50.00	3	50.00	3	50.00	5	62.50	1	25.00	3	50.00	3	50.00	0	0.00	6	54.55	0	0.00	6	54.55

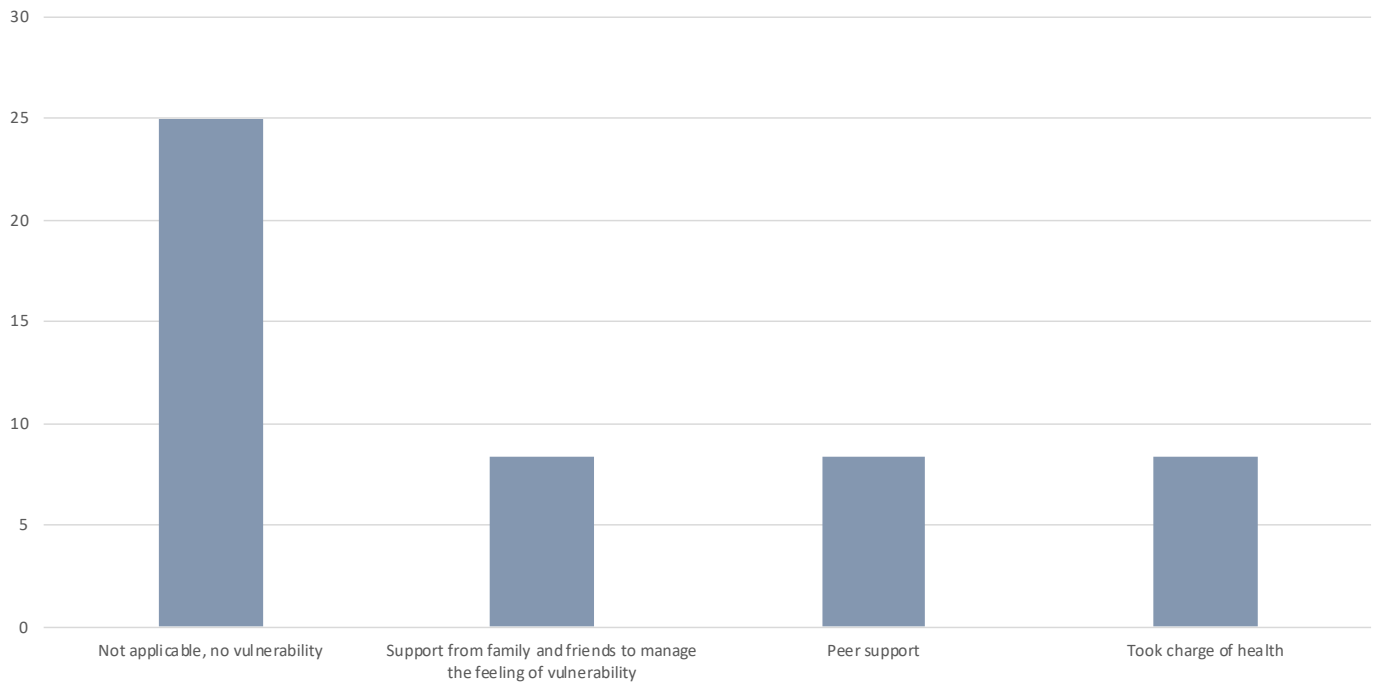


Figure 8.8: Methods to manage vulnerability

Impact on relationships

Most commonly, the descriptions suggested that overall, there was a negative impact on relationships (41.67%), overall. Others described that there was no impact on relationships (16.67%), and overall, there was a positive impact on relationships (16.67 %).

The most common theme in relation to having a positive impact on relationships was from family relationships being strengthened (16.67%).

The most common themes in relation to having a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships (16.67%). This was followed by from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition (8.33 %), and from assigning blame for infection (8.33%).

Participant describes a positive impact on relationships from family relationships being strengthened

PARTICIPANT: I'm. I'm not sure, but family, as I said, I think we become closer. Yeah, I care about them more.

Participant 003_2023AUHDV

I think it's actually empowered my personal relationships.

Participant 010_2023AUHDV

Participant describes a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships

Yes, yes. Especially with my friends. I wouldn't say the same about my family, but. With my friends, a lot of things have been, you know, affected and a lot of things have changed. I don't associate much and I

tend to shy away from certain activity, which I always engage with my friends, you know, like hanging out and taking drinks or drinking, and all these have been limited.

Participant 006_2023AUHDV

Table 8.15: Impact on relationships

Impact on relationships	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes that overall, there was a negative impact on relationships	5	41.67	2	33.33	3	50.00	4	50.00	1	25.00	4	66.67	1	16.67	0	0.00	5	45.45	0	0.00	5	45.45
Participant describes that overall, there no impact on relationships	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	0	0.00	2	33.33	1	100.00	1	9.09	1	100.00	1	9.09
Participant describes that overall, there was a positive impact on relationships	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
No particular comment	3	25.00	2	33.33	1	16.67	2	25.00	1	25.00	1	16.67	2	33.33	0	0.00	3	27.27	0	0.00	3	27.27

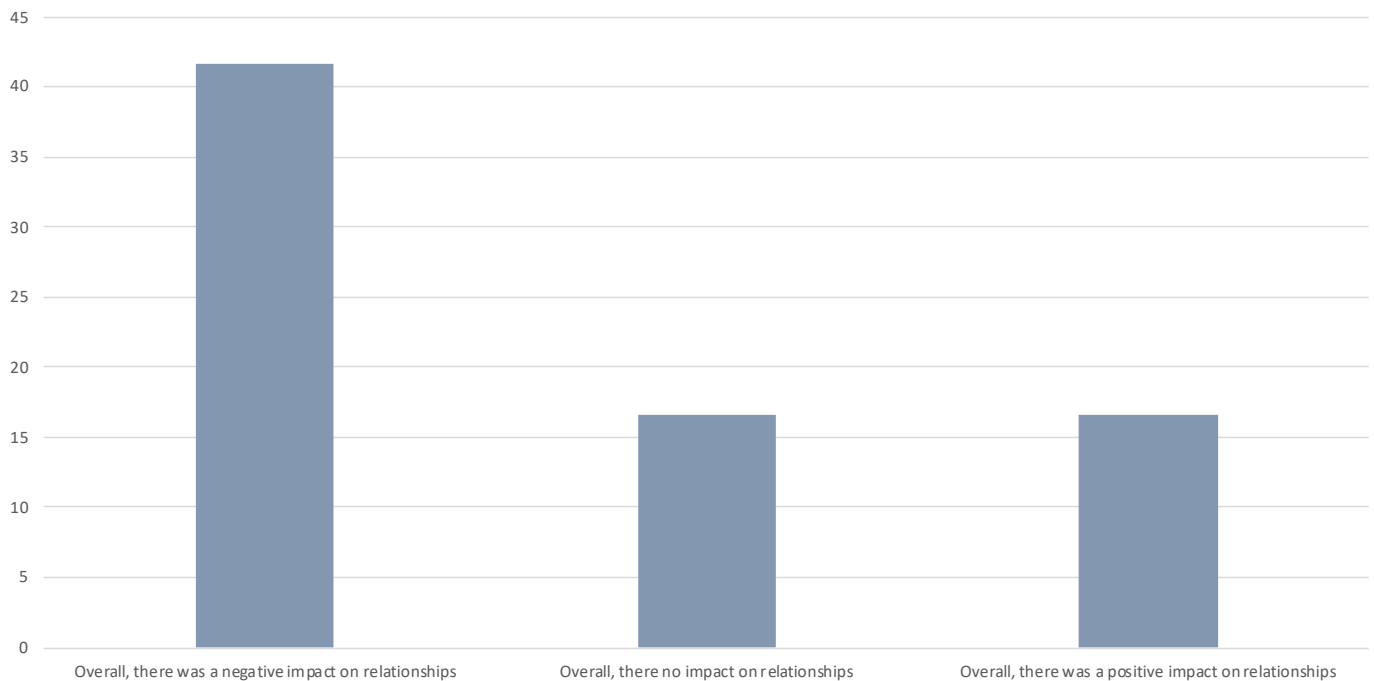


Figure 8.9: Impact on relationships

Table 8.16: Impact on relationships – subgroup variations

Impact on relationships	Reported less frequently		Reported more frequently	
	Aged 45 and older	University	Trade or high school	
Participant describes that overall, there was a negative impact on relationships				

Table 8.17: Impact on relationships (Reason for impact)

Impact on relationships (Reason for impact)	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes a positive impact on relationships from family relationships being strengthened	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships	2	16.67	0	0.00	2	33.33	2	25.00	0	0.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes a negative impact on relationships from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes a positive impact on relationships with family from assigning blame for infection	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
No impact/Not applicable	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	0	0.00	2	33.33	1	100.00	1	9.09	1	100.00	1	9.09
Other/No response	4	33.33	2	33.33	2	33.33	2	25.00	2	50.00	2	33.33	2	33.33	0	0.00	4	36.36	0	0.00	4	36.36

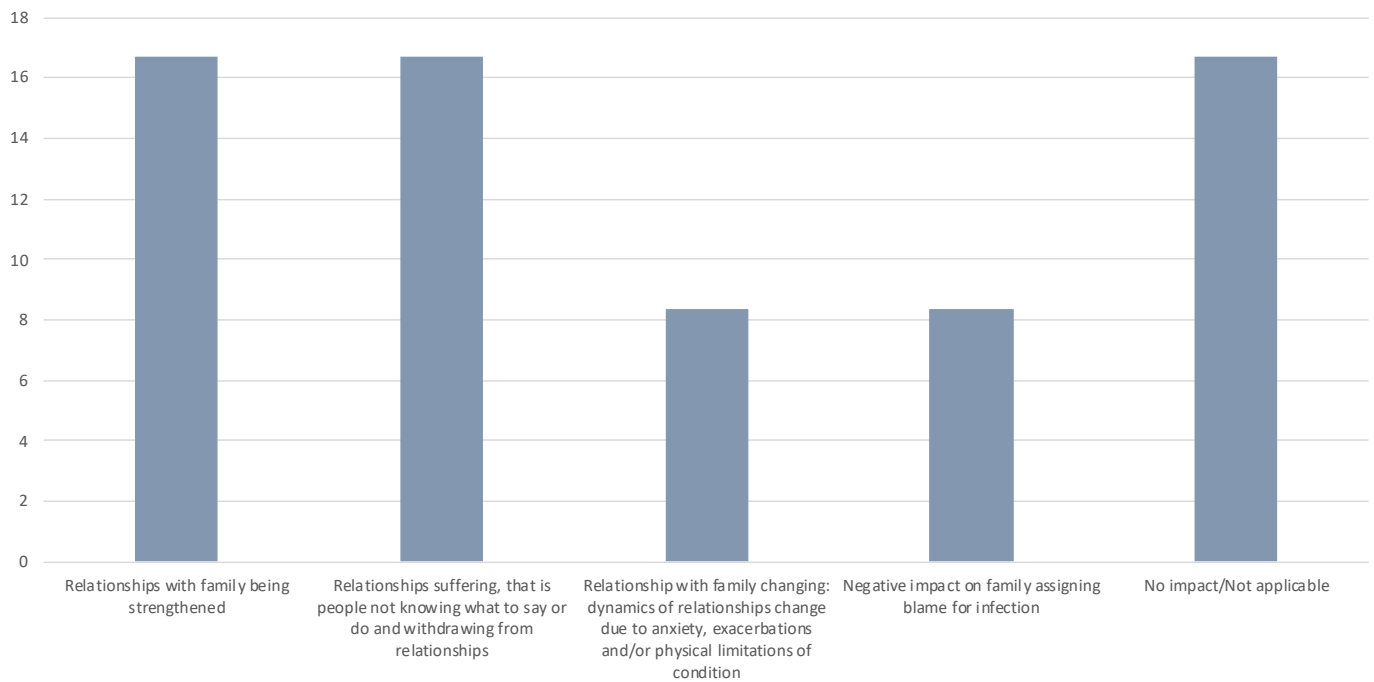


Figure 8.10: Impact on relationships

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 a burden on their family (66.67%), overall, there was not a burden on their family (16.67%), and overall, there was not a burden on their family now but they anticipate this will change in the future (8.33 %).

The main reason that participant described their condition being a burden was that the burden on family was temporary or only during treatment (41.67%). Others described that their condition was a burden in general (25.00%) the mental/emotional strain placed on their family (16.67 %), and the extra financial assistance needed (8.33%).

Participant describes that the burden on family was temporary

No, I think, you know, like I said when I was first finding out I had it and was diagnosed, it was a bit of an emotional burden on my daughter and while she was waiting for the results of her blood test to see if she'd been, you know, if she contracted the virus. So that was very emotional. Participant 010_2023AUHDV

Participant describes their condition being a burden in general (No specific examples) as a burden on their family

Yes, yes, definitely, definitely. Participant 006_2023AUHDV

Participant describes the mental/emotional strain placed on their family as a burden on their family

PARTICIPANT: It affected them, yeah. It affected them.

INTERVIEWER: Yeah, like how?

PARTICIPANT: Mentally.

Participant 001_2023AUHDV

Participant describes the extra financial assistance needed as a burden on their family

I think flowing on from yes I think it was and in terms of they gave me financial help. Yeah, So I'd say yes.

Participant 011_2023AUHDV

Table 8.18: Burden on family

Burden on family	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes that overall, there was a burden on their family	8	66.67	2	33.33	6	100.00	5	62.50	3	75.00	4	66.67	4	66.67	1	100.00	7	63.64	1	100.00	7	63.64
Participant describes that overall, there was not a burden on their family	2	16.67	2	33.33	0	0.00	2	25.00	0	0.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes that overall, there was not a burden on their family now but they anticipate this will change in the future	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
No particular comment	2	16.67	2	33.33	0	0.00	1	12.50	1	25.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18

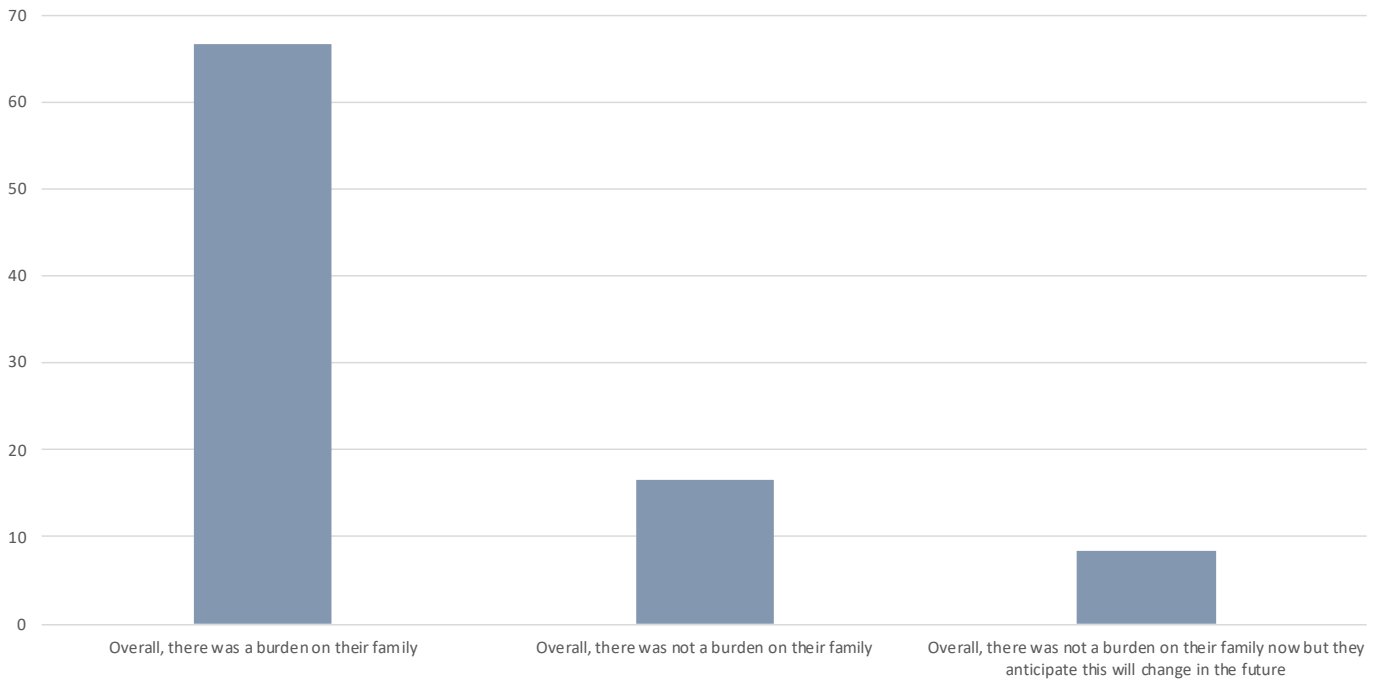


Figure 8.11: Burden on family

Table 8.19: Burden on family – subgroup variations

Burden on family	Reported less frequently		Reported more frequently	
Participant describes that overall, there was a burden on their family	Female		Male	

Table 8.20: Burden on family (description)

Burden on family (Description)	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes that the burden on family was temporary or only during treatment	5	41.67	2	33.33	3	50.00	2	25.00	3	75.00	3	50.00	2	33.33	1	100.00	4	36.36	1	100.00	4	36.36
Participant describes their condition being a burden in general (No specific examples) as a burden on their family	3	25.00	1	16.67	2	33.33	3	37.50	0	0.00	1	16.67	2	33.33	0	0.00	3	27.27	0	0.00	3	27.27
Participant describes the mental/emotional strain placed on their family as a burden on their family	2	16.67	2	33.33	0	0.00	1	12.50	1	25.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes the extra financial assistance needed as a burden on their family	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes not telling anyone about their condition and are not a burden on their family	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Other/No response	2	16.67	2	33.33	0	0.00	1	12.50	1	25.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18

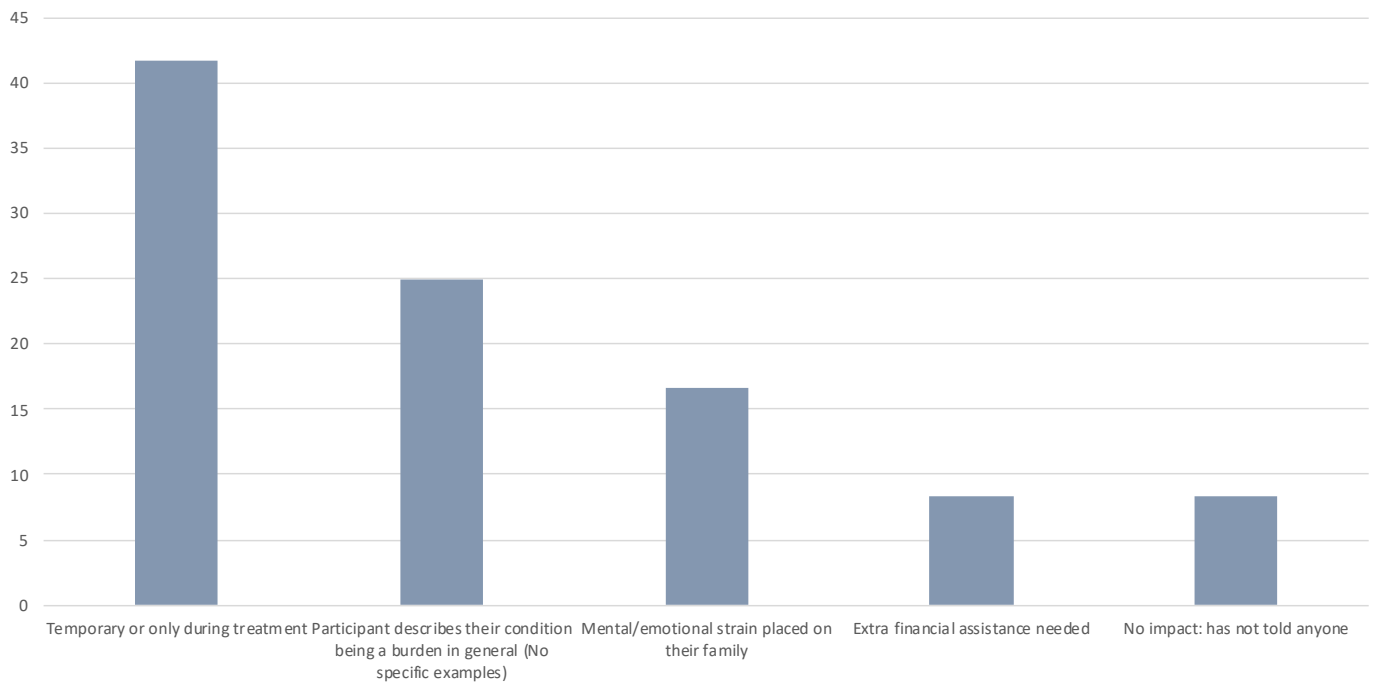


Figure 8.12: Burden on family (description)

Table 8.21: Burden on family (description)– subgroup variations

Burden on family (Description)	Reported less frequently	Reported more frequently
Participant describes that the burden on family was temporary or only during treatment	Aged 18 to 44	Aged 45 and older

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. Most commonly participants described that there was at least some cost burden (58.33%), and a third described that overall, there was no cost burden (33.33%).

Where participants described no cost burden associated with their condition, it was most commonly because nearly everything was paid for through the public health system (16.67%), nearly everything was paid for through the private health system (8.33%), and being able to afford all costs (8.33 %).

Where participants described a cost burden associated with their condition, it was most commonly in relation to the cost of treatments (including repeat scripts) (25.00%), needing to take time off work (16.67%), the cost of parking and travel to attend appointments (including accommodation) (8.33 %), and allied health care (8.33%).

Participant describes no cost burden and that nearly everything was paid for through the public health system

PARTICIPANT: Most of my costs have been looked after by the PBS and that I'm very fortunate.

Participant describes no cost burden and that nearly everything was paid for through the private health system

I can consider the cost actually was I've got I've got a private health for everything is just covered, so I've never encountered any cost like out of pocket so far. Participant 001_2023AUHDV

Participant describes cost of treatments (including repeat scripts)

I would say my medication costs and it's been around the \$40 mark every two months for all that I have to cover, all the conditions...I would say psychology costs of how it's impacted me. Participant 004_2023AUHDV

Table 8.22: Cost considerations

Cost considerations	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes that overall, there was at least some cost burden	7	58.33	3	50.00	4	66.67	5	62.50	2	50.00	3	50.00	4	66.67	1	100.00	6	54.55	1	100.00	6	54.55
Participant describes that overall, there was no cost burden	4	33.33	3	50.00	1	16.67	2	25.00	2	50.00	3	50.00	1	16.67	0	0.00	4	36.36	0	0.00	4	36.36
Other/No response	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09

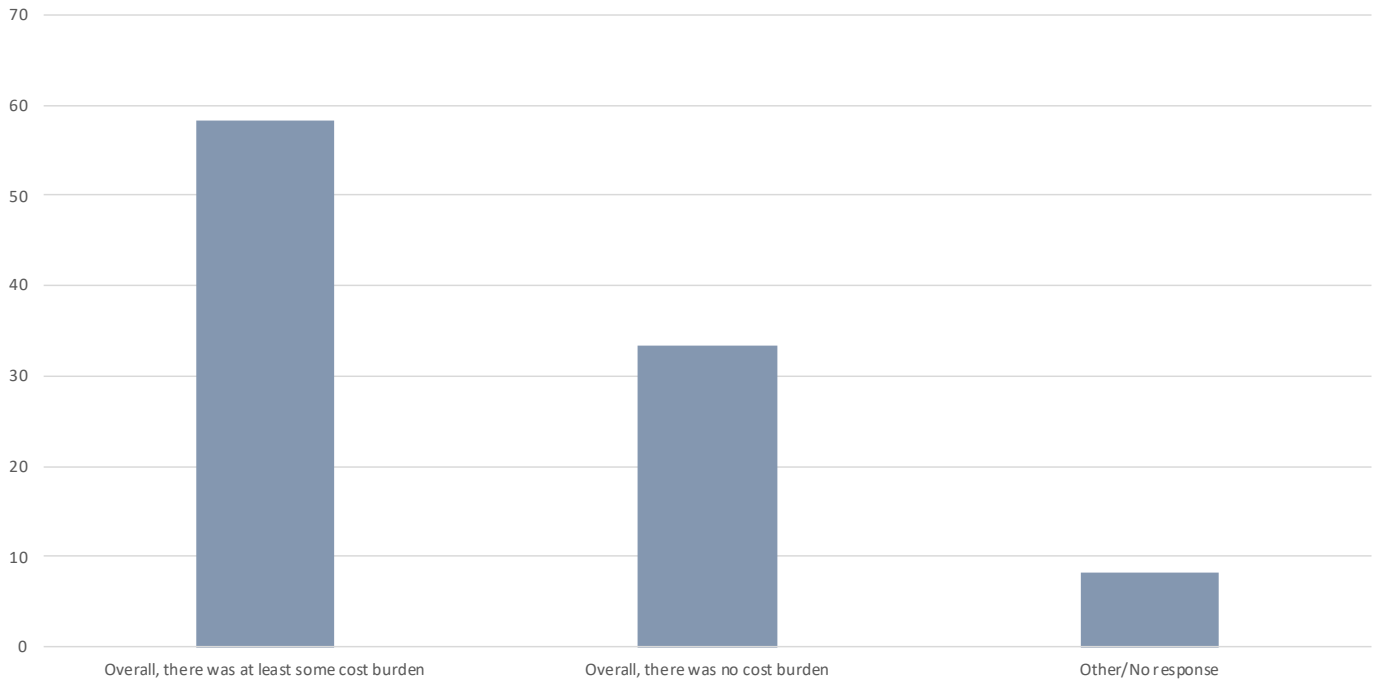


Figure 8.13: Cost considerations

Table 8.23: Cost considerations – subgroup variations

Cost considerations	Reported less frequently	Reported more frequently
Participant describes that overall, there was no cost burden	Male University	Female Aged 45 and older Trade or high school

Table 8.24: Cost considerations (Reasons for cost)

Cost considerations (reasons for costs)	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes no cost burden and that nearly everything was paid for through the public health system	2	16.67	0	0.00	2	33.33	1	12.50	1	25.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes no cost burden and that nearly everything was paid for through the private health system	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes no cost burden as participant was able to afford all costs	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes cost burden without giving a reason	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes cost of treatments (including repeat scripts)	3	25.00	1	16.67	2	33.33	2	25.00	1	25.00	0	0.00	3	50.00	1	100.00	2	18.18	1	100.00	2	18.18
Participant describes cost burden in relation to needing to take time off work	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes cost of parking and travel to attend appointments (including accommodation)	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	0	0.00	1	16.67	1	100.00	0	0.00	1	100.00	0	0.00
Participant describes cost burden in needing to access financial support from family or charities	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Cost burden in relation to allied health care	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes no cost burden without giving a reason	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09

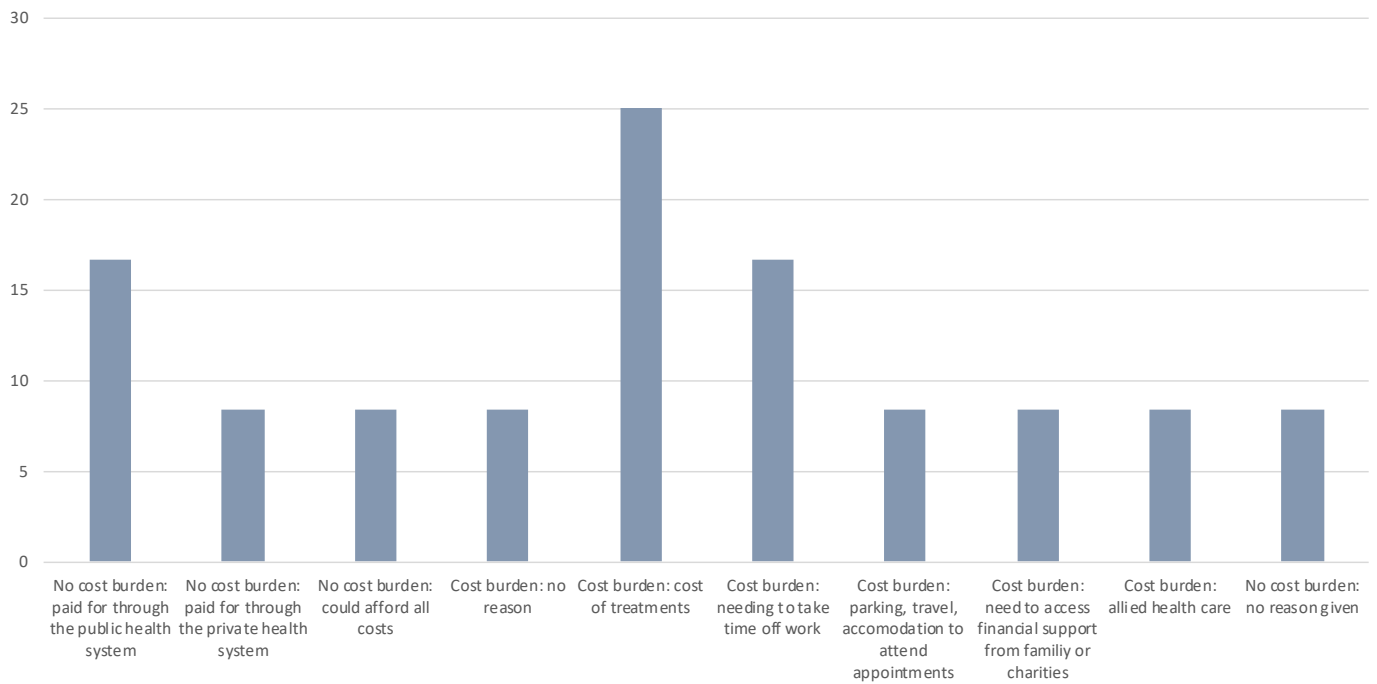


Figure 8.14: Cost considerations (Reasons for cost)

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 range (median=3.00, IQR=3.50).

Table 8.25: Overall impact of condition on quality of life

Impact of condition on quality of life	Number (n=14)	Percent
1 Life is/was very distressing	2	14.29
2 Life is/was distressing	3	21.43
3 Life is/was a little distressing	3	21.43
4 Life is/was average	2	14.29
5 Life is/was good	0	0.00
6 Life is/was very good	4	28.57
7 Life is/was great	0	0.00

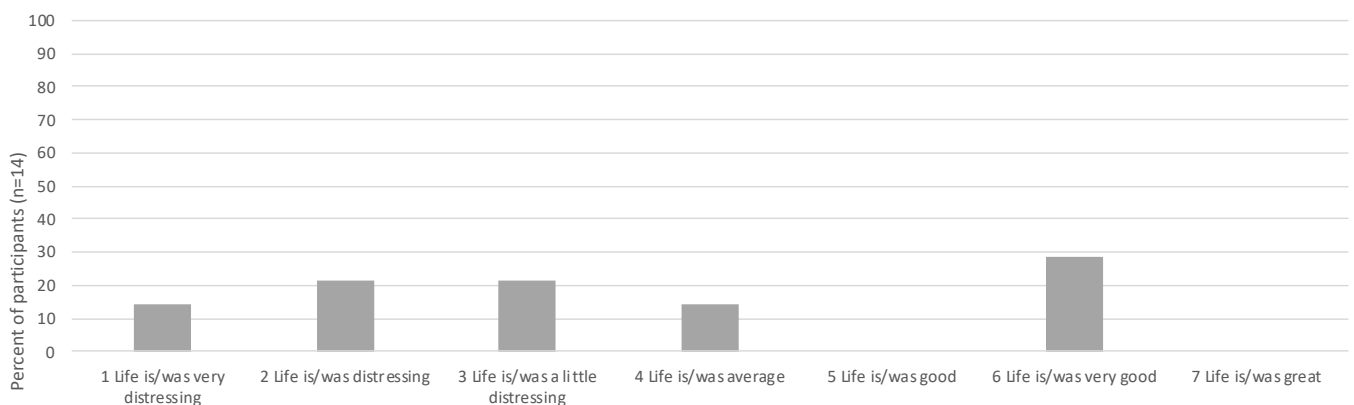


Figure 8.15: Overall impact of condition on quality of life

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. Summary statistics for the entire cohort are displayed in Table 8.26. The overall scores for the cohort were in the highest quintile for Fear of progression: Total score (mean=33.15, SD=13.28) indicating moderate levels of anxiety

Comparisons of Care coordination have been made based on gender, age, education, location and socioeconomic status (Tables 8.27 to 8.31 Figures 8.16to 8.18).

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 8.26: Fear of progression summary statistics

Fear of progression (n=13)	Mean	SD	Median	IQR	Possible range	Quintile
Total score*	33.15	13.28	34.00	21.00	12 to 60	3

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

Fear of progression by gender

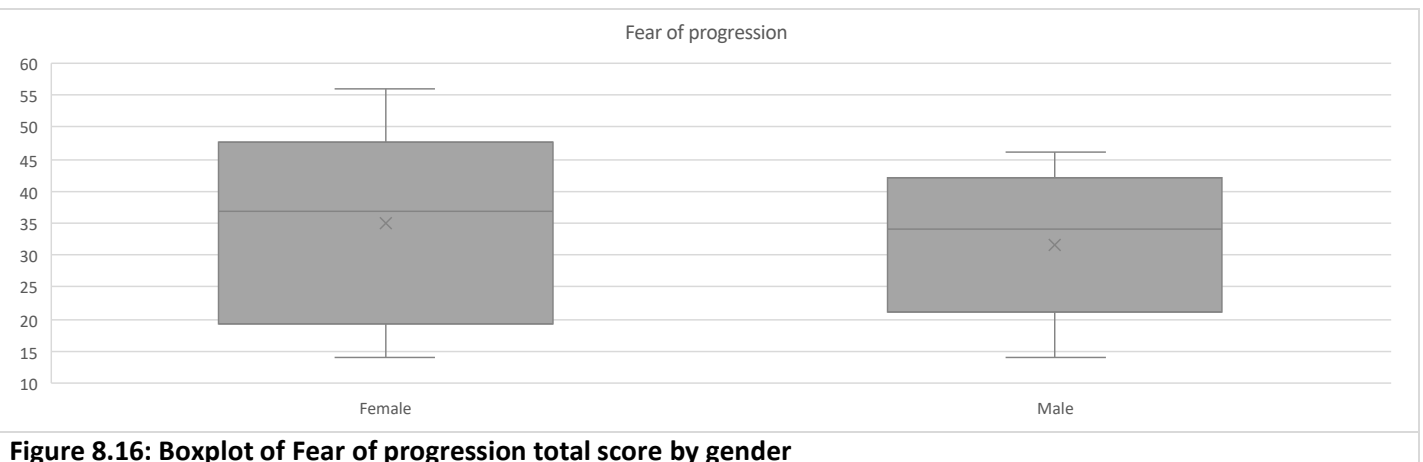
Comparisons were made by Gender, there were 6 female participants (46.15%), and 7 male participants (53.85%).

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 8.27).

Table 8.27: Fear of progression total score by gender summary statistics and T-test

Fear of progression	Group	Number (n=13)	Percent	Mean	SD	T	dF	p-value
Total score	Female	6	46.15	35.00	15.72	0.45	11	0.6626
	Male	7	53.85	31.57	11.84			



Fear of progression by age

Participants were grouped according to age, with comparisons made between participants aged under 44 (n=7, 53.85%), and participants aged 45 and older (n=6, 46.15%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.28).

A two sample t-test indicated that the mean score for the Fear of progression Total score scale [t(11) = 2.51, p = 0.0289] was significantly higher for participants in the Aged 18 to 44 subgroup (Mean = 40.29, SD = 9.91)

compared to participants in the Aged 45 and older subgroup (Mean = 24.83, SD = 12.29.)

The **Fear of Progression** questionnaire measures the level of anxiety people experience in relation to their conditions. On average, participants in the Aged 18 to 44 subgroup scored higher than participants in the Aged 45 and older subgroup. This indicates that participants in the Aged 18 to 44 subgroup had moderate levels of anxiety, and participants in the Aged 45 and older subgroup had low levels of anxiety.

Table 8.28: Fear of progression total score by age summary statistics and T-test

Fear of progression	Group	Number (n=13)	Percent	Mean	SD	T	dF	p-value
Total score	Aged 18 to 44	7	53.85	40.29	9.91	2.51	11	0.0289*
	Aged 45 and older	6	46.15	24.83	12.29			

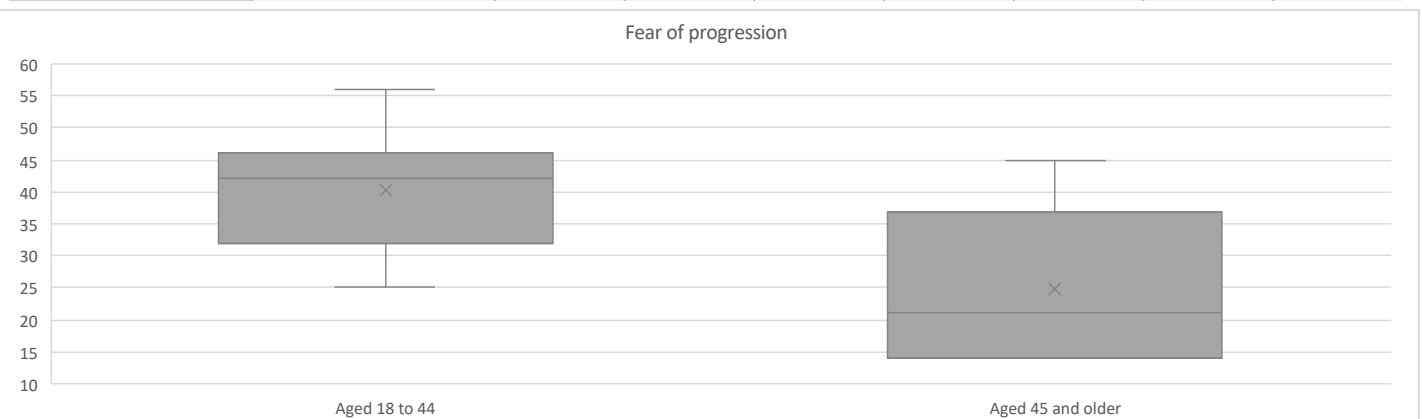


Figure 8.17: Boxplot of Fear of progression total score by age

Fear of progression by education

Comparisons were made by education status, between those with trade or high school qualifications, Trade or high school (n=5, 38.46%), and those with a university qualification, University (n=8, 64.54%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.29).

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

Table 8.29: Fear of progression total score by education statistics and T-test

Fear of progression	Group	Number (n=13)	Percent	Mean	SD	T	dF	p-value
Total score	Trade or high school	5	38.46	30.00	16.23	-0.66	11	0.5222
	University	8	61.54	35.13	11.84			

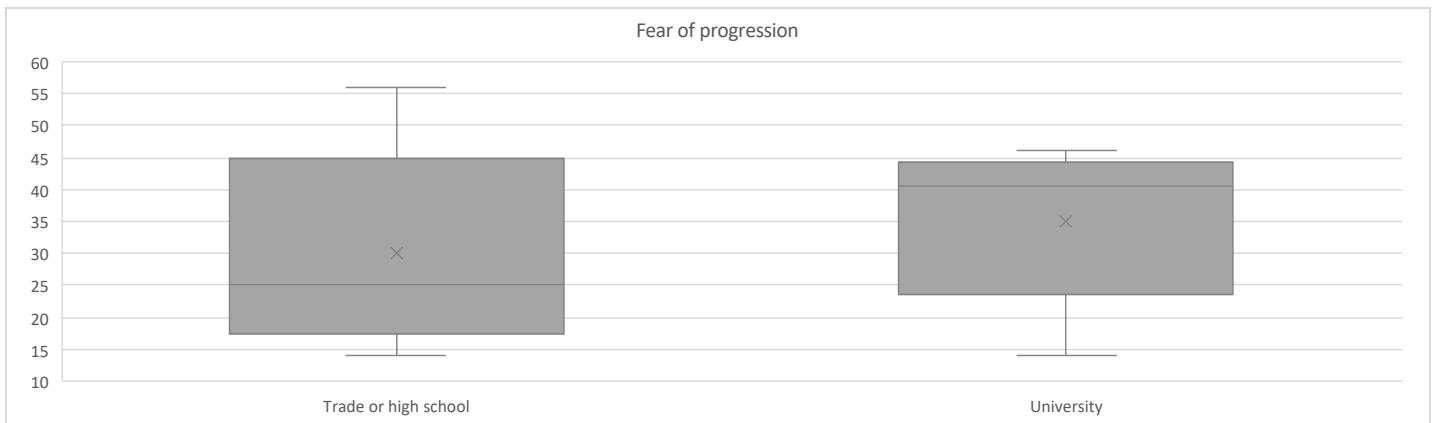


Figure 8.18: Boxplot of Fear of progression total score by education

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/rural areas, Regional or remote (n=3, 23.08%) were compared to

those living in a major city, Metropolitan (n=10, 76.92%).

There were too few participants in the regional and remote subgroup to make comparison. Summary statistics are displayed in Table 8.30.

Table 8.30: Fear of progression total score by location summary statistics

Fear of progression	Group	Number (n=13)	Percent	Mean	SD	Median	IQR
Total score	Rural or remote	3	23.08	18.67	4.04	21.00	3.50
	Metropolitan	10	76.92	37.50	11.85	40.50	11.75

Fear of progression by socioeconomic status

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=2, 15.38%) compared to those with a higher SEIFA score of 7-10, Higher status (n=11, 84.62%).

There were too few participants in the mid to low status subgroup to make comparison. Summary statistics are displayed in Table 8.31.

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

Table 8.31: Fear of progression total score by socioeconomic status summary statistics

Fear of progression	Group	Number (n=13)	Percent	Mean	SD	Median	IQR
Total score	Mid to low	2	15.38	17.50	4.95	17.50	3.50
	Higher	11	84.62	36.00	12.30	39.00	15.00

Experience of anxiety related to disease progression

Fear of progression individual questions

The average scores of the individual fear of progression questions are presented in Table 8.32 below.

On average, participants scored in the “Seldom” range for the following questions: “Is disturbed that they may have to rely on strangers for activities of daily living” (mean=2.38, SD=1.39), “If a treatment and it is working well (limited side effects, no progression of disease), worry what will happen if treatment stopped” (median=2.00, IQR=2.00), “Anxious if not experiencing any side effects think it doesn’t work” (median=2.00, IQR=2.00).

On average, participants scored in the “Sometimes” range for the following questions: “Becomes anxious thinking that disease may progress” (mean=3.15, SD=1.52), “Is nervous prior to doctors appointments or

periodic examinations” (median=3.00, IQR=3.00), “Afraid of pain” (mean=2.85, SD=1.41), “Has concerns about reaching professional and/or personal goals because of illness:” (mean=2.62, SD=1.39), “When anxious, has physical symptoms such as a rapid heartbeat, stomach ache or agitation” (median=3.00, IQR=3.00), “The possibility of relatives being diagnosed with this disease disturbs participant” (mean=2.54, SD=1.33), “Worried that at some point in time will no longer be able to pursue hobbies because of illness” (mean=3.00, SD=1.53), “Afraid of severe medical treatments during the course of illness” (mean=2.77, SD=1.30), “Worried that treatment could damage their body” (mean=2.92, SD=1.32), “Worried about what will become of family if something should happen to participant” (mean=2.77, SD=1.54), “The thought that they might not be able to work due to illness disturbs participant” (mean=2.85, SD=1.52).

Table 8.32: Fear of progression individual questions

Fear of progression (n=13)	Mean	SD	Median	IQR	Average response
Becomes anxious thinking that disease may progress	3.15	1.52	3.00	3.00	Sometimes
Is nervous prior to doctors appointments or periodic examinations	2.62	1.66	3.00	3.00	Sometimes
Afraid of pain	2.85	1.41	3.00	2.00	Sometimes
Has concerns about reaching professional and/or personal goals because of illness:	2.62	1.39	3.00	3.00	Sometimes
When anxious, has physical symptoms such as a rapid heartbeat, stomach ache or agitation	2.69	1.55	3.00	3.00	Sometimes
The possibility of relatives being diagnosed with this disease disturbs participant	2.54	1.33	3.00	2.00	Sometimes
Is disturbed that they may have to rely on strangers for activities of daily living	2.38	1.39	2.00	2.00	Seldom
Worried that at some point in time will no longer be able to pursue hobbies because of illness	3.00	1.53	3.00	2.00	Sometimes
Afraid of severe medical treatments during the course of illness	2.77	1.30	3.00	1.00	Sometimes
Worried that treatment could damage their body	2.92	1.32	3.00	2.00	Sometimes
Worried about what will become of family if something should happen to participant	2.77	1.54	3.00	3.00	Sometimes
The thought that they might not be able to work due to illness disturbs participant	2.85	1.52	3.00	3.00	Sometimes
If a treatment and it is working well (limited side effects, no progression of disease), worry what will happen if treatment stopped	2.23	1.30	2.00	2.00	Seldom
Anxious if not experiencing any side effects think it doesn't work	2.23	1.36	2.00	2.00	Seldom

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

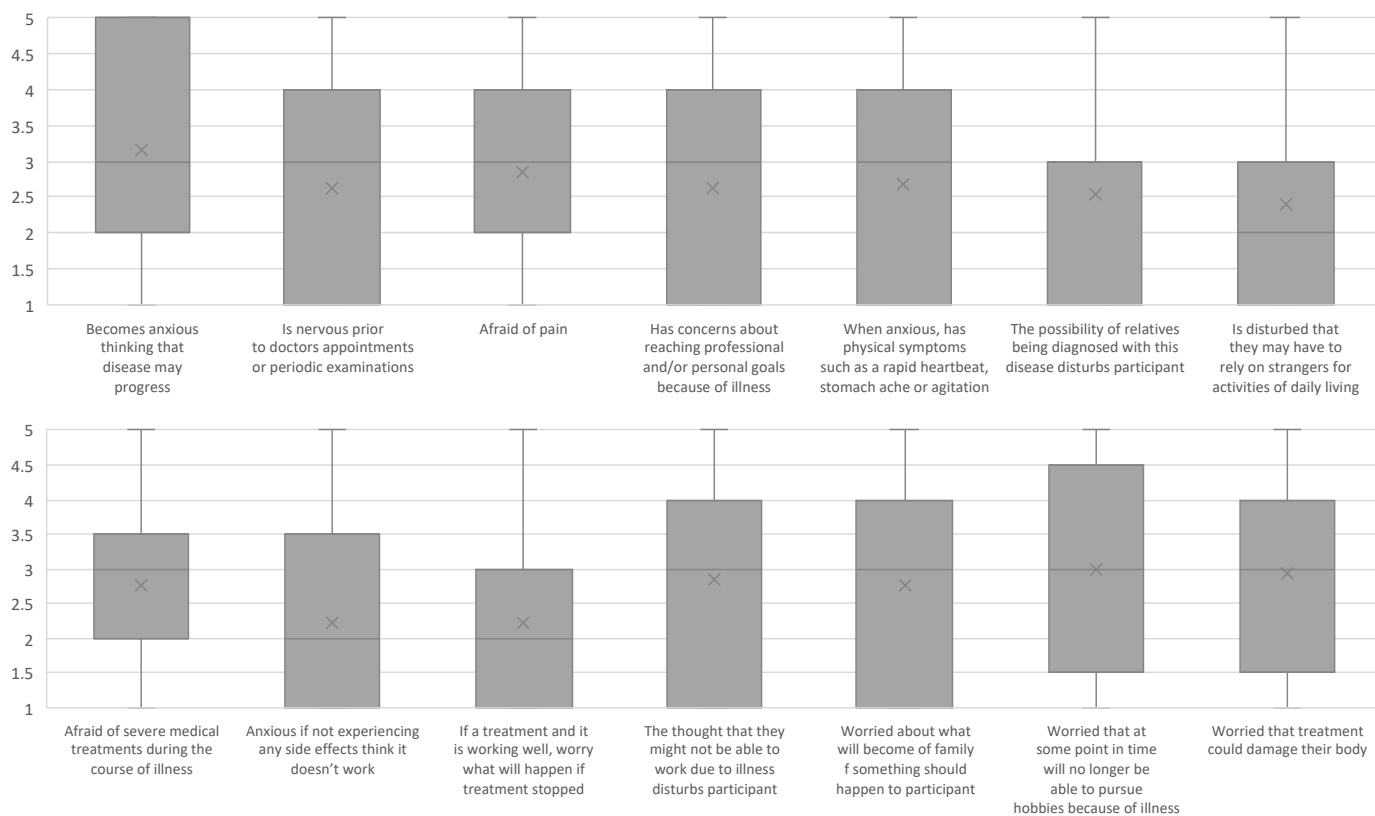


Figure 8.19: Fear of progression individual questions

Seldom worried about

- “Is disturbed that they may have to rely on strangers for activities of daily living”
- “If a treatment and it is working well (limited side effects, no progression of disease), worry what will happen if treatment stopped”
- “Anxious if not experiencing any side effects think it doesn’t work”

Sometimes worried about

- “Becomes anxious thinking that disease may progress”
- “Is nervous prior to doctors appointments or periodic examinations”
- “Afraid of pain”
- “Has concerns about reaching professional and/or personal goals because of illness:”
- “When anxious, has physical symptoms such as a rapid heartbeat, stomach ache or agitation”
- “The possibility of relatives being diagnosed with this disease disturbs participant”
- “Worried that at some point in time will no longer be able to pursue hobbies because of illness”
- “Afraid of severe medical treatments during the course of illness”
- “Worried that treatment could damage their body”
- “Worried about what will become of family if something should happen to participant”
- “The thought that they might not be able to work due to illness disturbs participant”