Section 8 Quality of life

Section 8: Experience of quality of life

Quality of life

- The most common impact on quality of life described by participants was poor mental health as a consequence of mitochondrial disease (n=19, 38.00%). There were also eight participants (16.00%) that noted poor mental health of family or friends (as carers) as a consequence of the disease. This was followed by a significant impact on family relationships and family dynamics (n=16, 32.00%) and withdrawing from activities with family and friends due to physical limitations (n=16, 32.00%). There were 13 participants (26.00%) that spoke about the need to access mental health services to maintain their quality of life, 12 participants (24.00%) that described that having days where physical limitations can be frustrating and eight participants (16.00%) that described limitations in travelling.
- In relation to sub-group variations, participants from metropolitan areas (26.67%) and participants with high physical function (27.27%) reported limitations of freedom to travel more frequently than the general population (16.00%), while participants from rural areas reported this less frequently (5.00%). Participants from rural areas (25.00%) described pleasure with maintaining hobbies and activities to overcome feelings of sadness or depression, more frequently than the general population (14.00%). Participants from low socio-economic areas (26.09%) and participants with a university degree (25.00%) described inability to participate in workforce to their level of expectation due to Mitochondrial disease, more frequently than the general population (14.00%). Participants with high school or trade education (34.62%) and those with high physical functioning (36.36%) reported having some days where physical limitations can be frustrating, more frequently than the general population (24.00%). Participants with high physical function (22.73%) reported little or no impact on family or friends' quality of life more frequently than the general population (12.00%).

Regular activities to maintain health

- The most common regular activity needed to maintain health reported by participants was having adequate rest to minimise fatigue (n=21, 42.00%). This was followed by having regular exercise (n=15, 30.00%) and eating a healthy/modified diet (n=10, 20.00%). There were seven participants (14.00%) that described taking prescription medication, six participants (12.00%) that considered taking supplements as an activity to maintain health and six participants (12.00%) that reported maintaining hobbies and activities in support of good mental health.
- In relation to sub-group variations, participants from low socio-economic areas (56.52%), those with high social function (60.00%) and low general health (57.14%) reported ensuring they have adequate rest to minimise fatigue, more frequently than the general population (42.00%). Participants with high physical function (50.00%) reported having regular exercise more frequently than the general population (30.00%) while those with low physical function (14.29%) and low general health (17.86%) reported this less frequently.

Impact on relationships

- The most common theme described by participants was a negative impact on personal relationships due to people withdrawing from relationships or not being able to understand (n=14, 28.00%) and this was followed by a negative impact on personal relationships due to social isolation (n=11, 22.00%). The next most common theme was a negative impact on personal relationships due to not being able to do all activities with family and friends (n=10, 20.00%). There were six participants (12.00%) that described a positive impact of strengthening relationships.
- In relation to sub-group variations, participants from low socio-economic areas (43.48%) and those with low social function (40.00%) reported a negative impact on personal relationships due to people withdrawing from relationships or not being able to understand, more frequently than the general population (28.00%), while those from high socio-economic areas (14.81) and high social function (10.00%) reported this less frequently. Participants from metropolitan areas (33.33%) and those with low emotional well-being (33.33%) reported a negative impact on personal relationships due to social isolation, more frequently than the general population (22.00%) while those from rural areas (10.00%) reported this less

frequently. Participants from low socio-economic areas (30.43%) described a negative impact on personal relationships due to not being able to do all activities with family and friends, more frequently than the general population (20.00%). Participants with high physical function (27.27%) and high social function (35.00%) described no impact on personal relationships more frequently than the general population (16.00%), while those with low social function described this less frequently.

- Participants were also asked if their condition caused any additional burden on their family. The most common theme was there was an additional burden on family, but the participant did not articulate a specific reason why there was a burden (n=13, 26.00%). The next most common theme was there was a burden due to needing help with transport and driving due to vision impairment (n=8, 16.00%), followed by participants describing that there was no additional burden, that it is just part of their life as they know it (n=7, 14.00%).
- In relation to sub-group variations, participants with a university education (37.50%), those with low physical function (39.29%) and those with low social function (33.33%) reported there being an additional burden (no additional information) more frequently than the general population (26.00%), while those with high physical function (9.09%) and those with high social function (15.00%) reported this less frequently.

Anxiety and 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, with a higher score denoting increased anxiety. Overall the entire cohort had a median total score of 34.10, which is a score in the middle of the scale.

Fear of progression – by general health

- There was no difference observed in the fear of progression total score between participants that had higher general health compared to those with lower general health.

Fear of progression – by physical functioning

- There was no difference observed in the fear of progression total score between participants that had higher physical functioning compared to those with lower physical functioning.

Fear of progression – by emotional well-being

- There was no difference observed in the fear of progression total score between participants that had higher emotional well-being compared to those with lower emotional well-being.

Fear of progression – by social functioning

- There was no difference observed in the fear of progression total score between participants that had higher social functioning compared to those with lower social functioning.

Fear of progression – by hearing problems

- There was no difference observed in the fear of progression total score between participants that had hearing problems compared to those with no hearing problems.

Fear of progression – by eye problems

- There was no difference observed in the fear of progression total score between participants that had eye problems compared to those with no eye problems.

Fear of progression – by hearing problems

- There was no difference observed in the fear of progression total score between participants that had hearing problems compared to those with no hearing problems.

Fear of progression – by location

- There was no difference observed in the fear of progression total score between participants that live in metropolitan areas and those that live in regional or rural areas.

Fear of progression – by level of education

- There was no difference observed in the fear of progression total score between participants with university qualifications and those with high school or trade certificates.

Fear of progression – by SEIFA

- There was no difference observed in the fear of progression total score between participants that live in an area with a higher SEIFA score and those that live in a lower SEIFA score.

Experience of quality of life

Participants were asked whether their condition has had an impact on their quality of life. The most common impact on quality of life described by participants was poor mental health as a consequence of mitochondrial disease (n=19, 38.00%). There were also eight participants (16.00%) that noted poor mental health of family or friends (as carers) as a consequence of the disease.

Participant describes poor mental health of patient as a consequence of the disease

Then there's also just a constant feeling in the back of my head that I'm being held down by this and held back a little bit. Sometimes it gets difficult. I feel a lot lower these days. Probably the worst thing is thinking that or knowing that it's going to get worse. It's never really going to get better unless some miracle treatment comes out but overall, quality of life is still very good. Participant 11

At first, in my head, it was devastating but not in my husband's head. I suffered gradually from depression. Do occasionally but I've got a really good therapist, who I still to talk to. That has made things better. It's really important that people with a disease have a therapist. Participant 12

It does affect my mental health. I feel restricted sometimes and I feel like people have to look after me a bit. I see a psychiatrist regularly and I take antidepressant medication. It's frustrating because sometimes I would like to be out and about doing more interesting things, but I need to stay home and be quiet. The times when I'm particularly tired and I just need to rest, those have a fairly depressing quality. Participant 43

This was followed by a significant impact on family relationships and family dynamics (n=16, 32.00%) and withdrawing from activities with family and friends due to physical limitations (n=16, 32.00%).

Participant describes a significant impact on family relationships and family dynamics

Well, the kids are always saying, "You don't come around and play with us anymore, Dad." Basically, family. I can't do that. I used to run around and play around with my other son and pass balls to him and kick. Participant 6

It impacts upon us 24/7. We always have to have back-up plans and think ahead to ensure that we are covered should something happen or change suddenly. My whole family is affected. Participant 30

Yes, I think it's affected everything. My relationship with my husband and with my children, really, really serious. Participant 34

Participant describes withdrawing from activities with family and friends due to physical limitations and the subsequent emotional response

For me, it's affected it terribly. My life stopped stopped….. I had to stop work then. I was studying. I was working in the pharmacy and studying to be a dispense tech. I just got so unreliable that I just had to quit. I don't even go out anymore. It's because I never know how I'm going to be. Obviously, if it's a wedding or something, I'll push through regardless of how I feel, but just to go the ball club or something on a Friday night for the raffles, I normally don't go. Because I can be fine when I leave home and half an hour after I get there, feel like absolute hell, so I just normally don't go. Participant 18

Sometimes, I wonder about those things because I really do have a huge problem with being in groups. I can't process language, group language. I've never been great. I've been able to do it and major part of my job was being able to do it. I don't mind that I don't do those things anymore. A lot of people think it's become pretty odd, I think, because I don't like gatherings or drinks or parties or whatever. I most certainly do family gatherings, and they're usually very big, but they don't de-stress me quite as much in that people will know that basically-- Well, I don't know if they know. That answer was slightly to the left of it, if you know what I mean. Participant 20

Social life is absolutely non-existent. I don't have the energy to do anything. I don't go out or I go out with a few friends once a week especially to a church meeting type of thing. I've got to get on till three until I'm pumped for feeding at night, it puts down me or anything else. It just stops everything, anything you wanted to do. You just don't have the energy to do anything. Participant 38

Massively. She lost all her friends having to move from school to home-schooling. It's created more anxiety around social interaction now because it was the wrong age to have to be taken out of school and stuff like that. Participant 49

There were 13 participants (26.00%) that spoke about the need to access mental health services to maintain their quality of life, 12 participants (24.00%) that described that having days where physical limitations can be frustrating and eight participants (16.00%) that described limitations in travelling.

Participant describes accessing mental health services to maintain high quality of life

In terms of taking care of my mental and emotional health, recently I've started to see a psychologist again, just to make sure that I have all the tools to ensure my wellbeing, my mental health, is kept as healthy as possible, given the current situation. I meditate, and I do things that relax me, but I also think, for my mental health, given my personality, I'm a social justice activist, so something that I'm passionate about actually helps improve my mental health. Participant 7

Again, over life it's been different times, but it certainly has affected my mental health severely, probably 15 years ago. Over quite a few years, or really 10 years, working with a psychologist and other healthcare professionals at times and also-- it was a psychiatrist as well at times on things, I'm working with my GP, we've addressed those mental health issues which are kind of separate to the mitochondrial disease. I guess once they're addressed then you can do a lot. Participant 13

I have no one to talk to so much about it. I now go to a counsellor once a month which is absolutely essential. That's what I do to keep sane, I go and see the counsellor. He had three changes of business, but it's totally understood when she goes into business that whenever she leaves she takes me with her. That's an understanding with her and her bosses that I go wherever she goes, because of having found someone I can talk to and who helps me keep sane, I stay with her. That's what I do. Participant 21

Participant describes having some days where physical limitations can be frustrating

Pretty telling question that one, isn't it? I try not to think about it. Like I said before, I get lactic acid build up very quickly in my legs or what feels like lactic acid in my legs very, very quickly, two flights of stairs. My office is on the second floor. When the lift aren't working, it's like, "Do I really have to do this?" You're constantly looking-- If I'm walking from one part of the city to the other, I'll try and walk the way that's the most flat even if it's a bit longer, so I don't have to walk up any hills because it's uncomfortable. The doctor at the LOCATION the other week when I was there said it was time to get back into the gym. I have got an issue with my shoulder at the moment that I'm getting some treatment on, and once that's fixed up I'll get back into the gym. I always have to psych myself up for that because I know that once I start I'm going to be in constant pain again because as I said before, in my past life when I've been body building and the like, you know you're going to do arms, back, chest and legs. Whatever you're doing, it'll hurt for a couple of days. but the next four or five days you going to do another part of your body, so it's not hurting for a few days by the time you on to the next one. I'm dreading the fact that whatever I do the pain may now last for five, six, seven, eight days, which means there's going to be no respite because by the time it starts feel better, I'm already on to that part body. That's an impact on my being. Participant 2

Okay. Probably two aspects. It stopped me doing some of the things that I love, as all the side effects from it, which is part of it, I guess. It's more the things that I haven't because of the mito. I can't play golf anymore, I'm too tired after nine rounds, and I love that. At least some of the things that you love, so it's like my sport, you know, seems like with the hearing loss that I stopped playing hockey. I can't walk long distances. The effect with the hearing loss has also affected my balance, especially at night. I'm in trouble walking at night, or just falling over, you know? That's ridiculous. Participant 15

I realize I can't work as much as what I used to. If I clean the whole house for a day, I need to rest, do nothing for the next one, two days to get my energy back. It's hard for me to get up early in the morning. I do have insomnia as well sometimes. Sometimes I'll sleep to ten o'clock, eleven o'clock. I just can't get up. I want to get up earlier, but I can't. I'll set the alarm early. I do get energy-less very easy. Participant 22

Every day is a challenge for NAME as far as he can't dress himself, toilet himself, feed himself, he needs to have assistance with that. He needs to get help getting into his wheelchair, I put him into the car and I him to school. I collect him daily, he needs assistance with showering every night. He needs help with day to day tasks, things that everybody just takes basically for granted that you do on your own. It's like having a toddler basically for NAME. Participant 50

In relation to sub-group variations, participants from metropolitan areas (26.67%) and participants with high physical function (27.27%) reported limitations of freedom to travel more frequently than the general population (16.00%), while participants from rural areas reported this less frequently (5.00%). Participants from rural areas (25.00%) described pleasure with maintaining hobbies and activities to overcome feelings of sadness or depression, more frequently than the general population (14.00%). Participants from low socio-economic areas (26.09%) and participants with a university degree (25.00%) described inability to participate in workforce to their level of expectation due to Mitochondrial disease, more frequently than the general population (14.00%).

Participants with high school or trade education (34.62%) and those with high physical functioning (36.36%) reported having some days where physical limitations can be frustrating, more frequently than the general population (24.00%). Participants with high physical function (22.73%) reported little or no impact on family or friends' quality of life more frequently than the general population (12.00%).

Table 8.1: Quality of life

Impact on quality of life	**All participants**		**Metropolitan**		**Rural**		**SEIFA (High)**		**SEIFA (Low)**	
	n=50	**%**	**n=30**	**%**	**n=20**	**%**	**n=27**	**%**	**n=23**	**%**
Participant describes poor mental health of patient as a consequence of the disease	19	38.00	11	36.67	8	40.00	10	37.04	9	39.13
Participant describes a significant impact on family relationships and family dynamics	16	32.00	10	33.33	7	35.00	10	37.04	7	30.43
Participant describes withdrawing from activities with family and friends due to physical limitations	16	32.00	10	33.33	6	30.00	8	29.63	8	34.78
Participant describes accessing mental health services to maintain high QOL	13	26.00	6	20.00	7	35.00	6	22.22	7	30.43
Participant describes having some days where physical limitations can be frustrating	12	24.00	9	30.00	4	20.00	6	22.22	7	30.43
Participant describes the limitations of freedom to travel	8	16.00	8	26.67	1	5.00	6	22.22	3	13.04
Participant describes poor mental health of family or friends as carers as a consequence of the disease	8	16.00	4	13.33	4	20.00	4	14.81	4	17.39
Participant describes pleasure with maintaining hobbies and activities to overcome feelings of sadness or depression	7	14.00	2	6.67	5	25.00	4	14.81	3	13.04
Participant describes inability to participate in workforce to their level of expectation due to Mitochondrial disease	7	14.00	4	13.33	4	20.00	2	7.41	6	26.09
Participant describes little or no impact for family or friends in relation to quality of life	6	12.00	5	16.67	1	5.00	3	11.11	3	13.04
Participant describes no real affect on quality of life of patient	5	10.00	2	6.67	3	15.00	3	11.11	2	8.70
Participant describes feelings of sadness and/or frustration with experiencing episodes of illness or injury	5	10.00	3	10.00	2	10.00	3	11.11	2	8.70

Impact on quality of life	**All participants**		**High school or trade**		**University**		**Hearing impairment**		**Eye or visual impairment**	
	n=50	**%**	**n=26**	**%**	**n=24**	**%**	**n=24**	**%**	**n=34**	**%**
Participant describes poor mental health of patient as a consequence of the disease	19	38.00	8	30.77	11	45.83	11	45.83	13	38.24
Participant describes a significant impact on family relationships and family dynamics	16	32.00	10	38.46	7	29.17	8	33.33	10	29.41
Participant describes withdrawing from activities with family and friends due to physical limitations	16	32.00	10	38.46	6	25.00	8	33.33	14	41.18
Participant describes accessing mental health services to maintain high QOL	13	26.00	5	19.23	8	33.33	7	29.17	7	20.59
Participant describes having some days where physical limitations can be frustrating	12	24.00	9	34.62	4	16.67	7	29.17	10	29.41
Participant describes the limitations of freedom to travel	8	16.00	5	19.23	4	16.67	4	16.67	6	17.65
Participant describes poor mental health of family or friends as carers as a consequence of the disease	8	16.00	4	15.38	4	16.67	5	20.83	6	17.65
Participant describes pleasure with maintaining hobbies and activities to overcome feelings of sadness or depression	7	14.00	5	19.23	2	8.33	4	16.67	5	14.71
Participant describes inability to participate in workforce to their level of expectation due to Mitochondrial disease	7	14.00	2	7.69	6	25.00	4	16.67	5	14.71
Participant describes little or no impact for family or friends in relation to quality of life	6	12.00	3	11.54	3	12.50	1	4.17	5	14.71
Participant describes no real affect on quality of life of patient	5	10.00	4	15.38	1	4.17	2	8.33	4	11.76
Participant describes feelings of sadness and/or frustration with experiencing episodes of illness or injury	5	10.00	2	7.69	3	12.50	1	4.17	3	8.82

Impact on quality of life	All participants		Physical function (High)		Physical function (Low)		Emotional well-being (High)		Emotional well-being (Low)	
	n=50	%	n=22	%	n=28	%	n=26	%	n=24	%
Participant describes poor mental health of patient as a consequence of the disease	19	38.00	6	27.27	13	46.43	11	42.31	8	33.33
Participant describes a significant impact on family relationships and family dynamics	16	32.00	6	27.27	11	39.29	7	26.92	10	41.67
Participant describes withdrawing from activities with family and friends due to physical limitations	16	32.00	7	31.82	9	32.14	10	38.46	6	25.00
Participant describes accessing mental health services to maintain high QOL	13	26.00	5	22.73	8	28.57	4	**15.38**	9	**37.50**
Participant describes having some days where physical limitations can be frustrating	12	24.00	8	**36.36**	5	17.86	6	23.08	7	29.17
Participant describes the limitations of freedom to travel	8	16.00	6	**27.27**	3	10.71	6	23.08	3	12.50
Participant describes poor mental health of family or friends as carers as a consequence of the disease	8	16.00	4	18.18	4	14.29	4	15.38	4	16.67
Participant describes pleasure with maintaining hobbies and activities to overcome feelings of sadness or depression	7	14.00	1	4.55	6	21.43	5	19.23	2	8.33
Participant describes inability to participate in workforce to their level of expectation due to Mitochondrial disease	7	14.00	4	18.18	4	14.29	3	11.54	5	20.83
Participant describes little or no impact for family or friends in relation to quality of life	6	12.00	5	**22.73**	1	3.57	4	15.38	2	8.33
Participant describes no real affect on quality of life of patient	5	10.00	3	13.64	2	7.14	4	15.38	1	4.17
Participant describes feelings of sadness and/or frustration with experiencing episodes of illness or injury	5	10.00	1	4.55	4	14.29	1	3.85	4	16.67

Impact on quality of life	All participants		Social functioning (High)		Social functioning (Low)		General health (High)		General health (Low)	
	n=50	%	n=20	%	n=30	%	n=22	%	n=28	%
Participant describes poor mental health of patient as a consequence of the disease	19	38.00	5	25.00	14	46.67	7	31.82	12	42.86
Participant describes a significant impact on family relationships and family dynamics	16	32.00	6	30.00	11	36.67	8	36.36	9	32.14
Participant describes withdrawing from activities with family and friends due to physical limitations	16	32.00	5	25.00	11	36.67	7	31.82	9	32.14
Participant describes accessing mental health services to maintain high QOL	13	26.00	4	20.00	9	30.00	3	13.64	10	35.71
Participant describes having some days where physical limitations can be frustrating	12	24.00	6	30.00	7	23.33	6	27.27	7	25.00
Participant describes the limitations of freedom to travel	8	16.00	5	25.00	4	13.33	5	22.73	4	14.29
Participant describes poor mental health of family or friends as carers as a consequence of the disease	8	16.00	3	15.00	5	16.67	5	22.73	3	10.71
Participant describes pleasure with maintaining hobbies and activities to overcome feelings of sadness or depression	7	14.00	3	15.00	4	13.33	3	13.64	4	14.29
Participant describes inability to participate in workforce to their level of expectation due to Mitochondrial disease	7	14.00	3	15.00	5	16.67	3	13.64	5	17.86
Participant describes little or no impact for family or friends in relation to quality of life	6	12.00	3	15.00	3	10.00	4	18.18	2	7.14
Participant describes no real affect on quality of life of patient	5	10.00	3	15.00	2	6.67	3	13.64	2	7.14
Participant describes feelings of sadness and/or frustration with experiencing episodes of illness or injury	5	10.00	0	0.00	5	16.67	2	9.09	3	10.71

Impact on quality of life	All participants		Under 18		24-44		45-54		55-64		65-74+	
	n=50	%	n=6	%	n=14	%	n=9	%	n=11	%	n=10	%
Participant describes poor mental health of patient as a consequence of the disease	19	38.00	2	33.33	9	64.29	1	11.11	4	36.36	3	30.00
Participant describes a significant impact on family relationships and family dynamics	16	32.00	3	50.00	3	21.43	2	22.22	5	45.45	4	40.00
Participant describes withdrawing from activities with family and friends due to physical limitations	16	32.00	2	33.33	2	14.29	2	22.22	7	63.64	3	30.00
Participant describes accessing mental health services to maintain high QOL	13	26.00	2	33.33	2	14.29	3	33.33	4	36.36	2	20.00
Participant describes having some days where physical limitations can be frustrating	12	24.00	2	33.33	3	21.43	5	55.56	1	9.09	2	20.00
Participant describes the limitations of freedom to travel	8	16.00	2	33.33	3	21.43	2	22.22	2	18.18	0	0.00
Participant describes poor mental health of family or friends as carers as a consequence of the disease	8	16.00	2	33.33	2	14.29	1	11.11	2	18.18	1	10.00
Participant describes pleasure with maintaining hobbies and activities to overcome feelings of sadness or depression	7	14.00	1	16.67	1	7.14	2	22.22	2	18.18	1	10.00
Participant describes inability to participate in workforce to their level of expectation due to Mitochondrial disease	7	14.00	1	16.67	3	21.43	0	0.00	4	36.36	0	0.00
Participant describes little or no impact for family or friends in relation to quality of life	6	12.00	0	0.00	2	14.29	1	11.11	1	9.09	2	20.00
Participant describes no real affect on quality of life of patient	5	10.00	1	16.67	2	14.29	0	0.00	1	9.09	1	10.00
Participant describes feelings of sadness and/or frustration with experiencing episodes of illness or injury	5	10.00	1	16.67	1	7.14	1	11.11	1	9.09	1	10.00

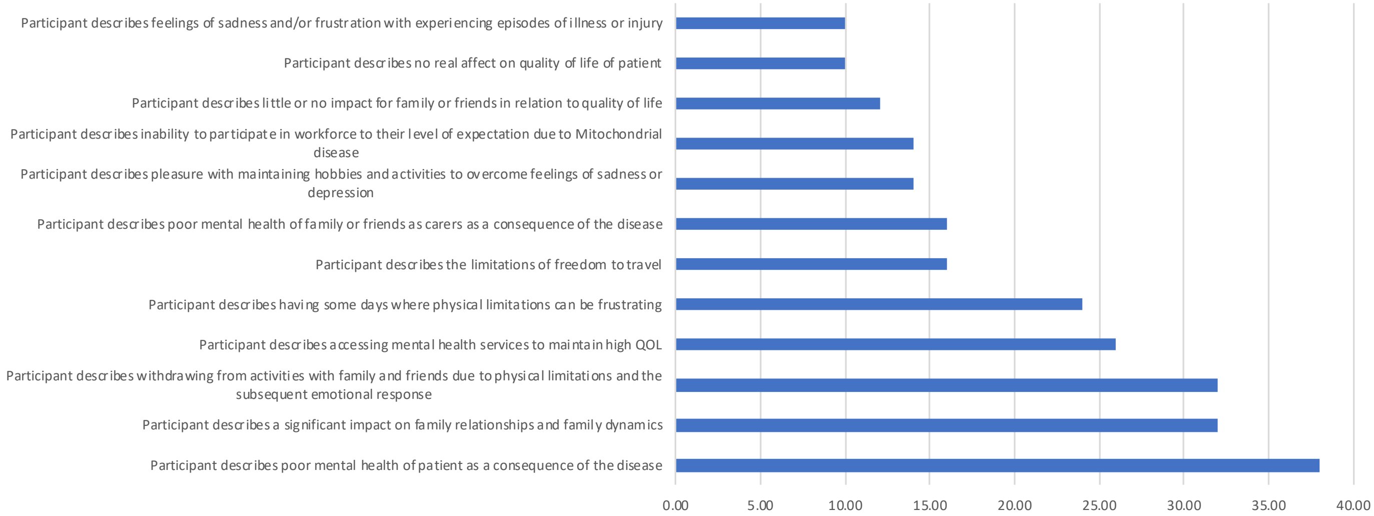

Figure 8.1: Quality of life (% of all participants)

Everyday activities to manage health

Participants were asked what some of the things are that they needed to do regularly to maintain their health. The most common regular activity needed to maintain health reported by participants was having adequate rest to minimise fatigue (n=21, 42.00%).

Participants reports ensuring they have adequate rest to minimise fatigue

Sleep. [laughs] Sleep a lot, rest whenever I need to rest, go to chiro and masseuse monthly. Be flexible, in terms of how I might be social. If I need someone to come to me then I do that, if I need to take an afternoon nap in order to spend time with my friends, I'll do that. Participant 5

Come this time of the afternoon, where I normally am, I'll lay down for two hours. I don't sleep because I won't during the night, but I'll take time out to watch a bit of TV and catch up on a bit of paperwork and all that sort of stuff, regenerate. Participant 16

I've just got to stop. I've got to rest. As I said, if I'm walking, I've got to stop and really only long enough for the body to build a bit more energy again then I'll take off again. No, I don't think I do anything special for that. Participant 31

This was followed by having regular exercise (n=15, 30.00%) and eating a healthy/modified diet (n=10, 20.00%).

Participant reports completing regular exercise to increase energy levels

Diet, exercise has been incredibly important. Being more vigorous about exercise now than I probably was. I was doing the fair bit but really making sure that I keep up with this even if I don't want to. Diet and getting enough rest if I need to, being vigilant about that yes. Participant 3

I also try to do a bit of cardio every now and then because I noticed that after doing cardio something like consecutive few days after that, I feel like I have a bit more energy than usual. I try to keep the fitness up. Participant 11

Exercise. Mild exercise. Walking with my dog. Participant 20

I have to be meticulously doing stretches generally after coffee in the morning before I try and walk because of balance and muscles working it's really important for me. Participant 27

Participant describes eating a healthy and/or modified diet

I'm on a very strict diet. I've lost a huge number of teeth so I cannot chew things. It's a very soft-based diet. It has to be very soft-based anyway because I can't swallow properly because the muscles are all gone in my throat. It's very limited what I can do. Participant 12

Whether it's just taking time out, not doing housework for the day or making sure that I'm monitoring my blood sugar if I feel a bit out of it or making sure that I know what's going on whether it's because by inch in a level, whether it's because I haven't eaten properly. Just to try to make minimal changes and making sure I eat frequently, don't fast, make sure I get a regular sleep pattern. Just little things that I can do in a day, make sure I take medication. Participant 26

Trying to eat healthy, is also a little bit of a challenge. And yeah, that's about it. Participant 40

There were seven participants (14.00%) that described taking prescription medication, six participants (12.00%) that considered taking supplements as an activity to maintain health and six participants (12.00%) that reported maintaining hobbies and activities in support of good mental health.

Participant describes taking prescription medication on a daily basis

My body's completely changed because I have no muscle around my intestines. I constantly have to take very large amounts of laxatives being under a gastroenterologist who treats me like a paraplegic. Participant 12

Just little things that I can do in a day, make sure I take medication. Participant 26

Rest regularly, eat well, drink a lot, take medications, use an electric wheelchair to conserve energy, constantly monitor my health status...dysautonomia, epilepsy, dysphagia, etcetera. Participant 30

Participant describes taking supplements on a daily basis

CoQ10. Like I said that really helps with energy levels. Participant 11

Trying to have maybe some vitamins to help that regard. I guess that would be something that would help. Participant 29

It's basically just taking the medication and taking the vitamins to get me through the day, from day to day and trying to have enough sleep. (exercise) I don't exercise enough. [laughs]. Participant 35

Participant reports maintain hobbies and activities in support on good mental health

Eat chocolate. [chuckles] Totally, totally against all the rules, but it's something that helps keep me centred sane and totally needed. I also involved in a quilting club, a walking club. I need that distraction. My daughter quilt so it's something that we do in common. I don't know. It's just you've got to keep your mind away from disease. You can't live with disease all the time so do other things, keep your mind off it. Yes. I think that's it. Participant 21

I only do voluntary work so it's not like it's paid work or anything. It's just otherwise I'd go mad if I was at home by myself all the time. Participant 38

Also, she loves to study, so she's doing a Uni course and she's…I mean, that course is limited to doing two units, which she should be doing one because she's getting exhausted all the time. It's having that outward focus and living your life that way. So always having something that you're working towards that's really important. Participant 49

In relation to sub-group variations, participants from low socio-economic areas (56.52%), those with high social function (60.00%) and low general health (57.14%) reported ensuring they have adequate rest to minimise fatigue, more frequently than the general population (42.00%). Participants with high physical function (50.00%) reported having regular exercise more frequently than the general population (30.00%) while those with low physical function (14.29%) and low general health (17.86%) reported this less frequently.

Table 8.2: Everyday activities to manage health

Regular activities to maintain health	**All participants**		**Metropolitan**		**Rural**		**SEIFA (High)**		**SEIFA (Low)**	
	n=50	**%**	**n=30**	**%**	**n=20**	**%**	**n=27**	**%**	**n=23**	**%**
Participants reports ensuring they have adequate rest to minimise fatigue	**21**	42.00	13	43.33	9	45.00	9	33.33	13	**56.52**
Participant reports having regular exercise to increase energy levels	**15**	30.00	10	33.33	5	25.00	10	37.04	5	21.74
Participant describes eating a healthy and/or modified diet	**10**	20.00	6	20.00	4	20.00	6	22.22	4	17.39
Participant describes taking prescribed medication on a daily basis	**7**	14.00	3	10.00	4	20.00	3	11.11	4	17.39
Participant describes taking supplements on a daily basis	**6**	12.00	4	13.33	2	10.00	5	18.52	1	4.35
Participant reports maintaining hobbies and activities in support of good mental health	**6**	12.00	5	16.67	1	5.00	3	11.11	3	13.04
Participants reports no modification to behaviour or diet- just takes each day as it comes	**5**	10.00	2	6.67	3	15.00	2	7.41	3	13.04
Participant reports requiring home care or family providing care 24/7	**5**	10.00	4	13.33	1	5.00	3	11.11	2	8.70
Participant recommends minimising daily activities or using the spoon theory to accomplish all necessary requirements of a daily or weekly basis	**5**	10.00	3	10.00	2	10.00	3	11.11	2	8.70
Participant reports that monitoring health to ensure continuous good health	**5**	10.00	2	6.67	3	15.00	2	7.41	3	13.04
Participant reports maintaining a positive frame of mind	**4**	8.00	4	13.33	0	0.00	2	7.41	2	8.70

Regular activities to maintain health	**All participants**		**High school or trade**		**University**		**Hearing impairment**		**Eye or visual impairment**	
	n=50	**%**	**n=26**	**%**	**n=24**	**%**	**n=24**	**%**	**n=34**	**%**
Participants reports ensuring they have adequate rest to minimise fatigue	**21**	42.00	12	46.15	10	41.67	10	41.67	14	41.18
Participant reports having regular exercise to increase energy levels	**15**	30.00	6	23.08	9	37.50	9	37.50	9	26.47
Participant describes eating a healthy and/or modified diet	**10**	20.00	4	15.38	6	25.00	4	16.67	7	20.59
Participant describes taking prescribed medication on a daily basis	**7**	14.00	2	7.69	5	20.83	5	20.83	5	14.71
Participant describes taking supplements on a daily basis	**6**	12.00	4	15.38	2	8.33	4	16.67	4	11.76
Participant reports maintaining hobbies and activities in support of good mental health	**6**	12.00	4	15.38	2	8.33	3	12.50	4	11.76
Participants reports no modification to behaviour or diet- just takes each day as it comes	**5**	10.00	5	19.23	0	0.00	0	0.00	5	14.71
Participant reports requiring home care or family providing care 24/7	**5**	10.00	2	7.69	3	12.50	2	8.33	4	11.76
Participant recommends minimising daily activities or using the spoon theory to accomplish all necessary requirements of a daily or weekly basis	**5**	10.00	0	0.00	5	20.83	3	12.50	4	11.76
Participant reports that monitoring health to ensure continuous good health	**5**	10.00	2	7.69	3	12.50	3	12.50	4	11.76
Participant reports maintaining a positive frame of mind	**4**	8.00	2	7.69	2	8.33	3	12.50	3	8.82

Regular activities to maintain health	**All participants**		**Physical function (High)**		**Physical function (Low)**		**Emotional well-being (High)**		**Emotional well-being (Low)**	
	n=50	**%**	**n=22**	**%**	**n=28**	**%**	**n=26**	**%**	**n=24**	**%**
Participants reports ensuring they have adequate rest to minimise fatigue	**21**	42.00	10	45.45	12	42.86	11	42.31	11	45.83
Participant reports having regular exercise to increase energy levels	**15**	30.00	11	**50.00**	4	**14.29**	10	38.46	5	20.83
Participant describes eating a healthy and/or modified diet	**10**	20.00	6	27.27	4	14.29	5	19.23	5	20.83
Participant describes taking prescribed medication on a daily basis	**7**	14.00	2	9.09	5	17.86	3	11.54	4	16.67
Participant describes taking supplements on a daily basis	**6**	12.00	4	18.18	2	7.14	4	15.38	2	8.33
Participant reports maintaining hobbies and activities in support of good mental health	**6**	12.00	2	9.09	4	14.29	4	15.38	2	8.33
Participants reports no modification to behaviour or diet- just takes each day as it comes	**5**	10.00	0	0.00	5	17.86	0	0.00	5	20.83
Participant reports requiring home care or family providing care 24/7	**5**	10.00	2	9.09	3	10.71	1	3.85	4	16.67
Participant recommends minimising daily activities or using the spoon theory to accomplish all necessary requirements of a daily or weekly basis	**5**	10.00	1	4.55	4	14.29	4	15.38	1	4.17
Participant reports that monitoring health to ensure continuous good health	**5**	10.00	1	4.55	4	14.29	3	11.54	2	8.33
Participant reports maintaining a positive frame of mind	**4**	8.00	3	13.64	1	3.57	2	7.69	2	8.33

Regular activities to maintain health	All participants		Social functioning (High)		Social functioning (Low)		General health (High)		General health (Low)	
	n=50	%	n=20	%	n=30	%	n=22	%	n=28	%
Participants reports ensuring they have adequate rest to minimise fatigue	**21**	42.00	12	**60.00**	10	33.33	6	27.27	16	**57.14**
Participant reports having regular exercise to increase energy levels	**15**	30.00	6	30.00	9	30.00	10	**45.45**	5	**17.86**
Participant describes eating a healthy and/or modified diet	**10**	20.00	5	25.00	5	16.67	4	18.18	6	21.43
Participant describes taking prescribed medication on a daily basis	**7**	14.00	1	5.00	6	20.00	1	4.55	6	21.43
Participant describes taking supplements on a daily basis	**6**	12.00	3	15.00	3	10.00	2	9.09	4	14.29
Participant reports maintaining hobbies and activities in support of good mental health	**6**	12.00	2	10.00	4	13.33	2	9.09	4	14.29
Participants reports no modification to behaviour or diet- just takes each day as it comes	**5**	10.00	0	0.00	5	16.67	0	0.00	5	17.86
Participant reports requiring home care or family providing care 24/7	**5**	10.00	1	5.00	4	13.33	2	9.09	3	10.71
Participant recommends minimising daily activities or using the spoon theory to accomplish all necessary requirements of a daily or weekly basis	**5**	10.00	2	10.00	3	10.00	1	4.55	4	14.29
Participant reports that monitoring health to ensure continuous good health	**5**	10.00	1	5.00	4	13.33	2	9.09	3	10.71
Participant reports maintaining a positive frame of mind	**4**	8.00	2	10.00	2	6.67	1	4.55	3	10.71

Regular activities to maintain health	All participants		Under 18		24-44		45-54		55-64		65-74+	
	n=50	%	n=6	%	n=14	%	n=9	%	n=11	%	n=10	%
Participants reports ensuring they have adequate rest to minimise fatigue	**21**	42.00	3	50.00	8	57.14	3	33.33	3	27.27	5	50.00
Participant reports completing regular exercise Participant reports having regular exercise to increase energy levels	**15**	30.00	2	33.33	5	35.71	1	11.11	4	36.36	3	30.00
Participant describes eating a healthy and/or modified diet	**10**	20.00	0	0.00	4	28.57	3	33.33	2	18.18	1	10.00
Participant describes taking prescribed medication on a daily basis	**7**	14.00	1	16.67	3	21.43	2	22.22	1	9.09	0	0.00
Participant describes taking supplements on a daily basis	**6**	12.00	1	16.67	2	14.29	1	11.11	1	9.09	1	10.00
Participant reports maintaining hobbies and activities in support of good mental health	**6**	12.00	1	16.67	2	14.29	1	11.11	1	9.09	1	10.00
Participants reports no modification to behaviour or diet- just takes each day as it comes	**5**	10.00	0	0.00	1	7.14	0	0.00	3	27.27	1	10.00
Participant reports requiring home care or family providing care 24/7	**5**	10.00	0	0.00	3	21.43	1	11.11	1	9.09	0	0.00
Participant recommends minimising daily activities or using the spoon theory to accomplish all necessary requirements of a daily or weekly basis	**5**	10.00	0	0.00	1	7.14	1	11.11	3	27.27	0	0.00
Participant reports that monitoring health to ensure continuous good health	**5**	10.00	2	33.33	3	21.43	0	0.00	0	0.00	0	0.00
Participant reports maintaining a positive frame of mind	**4**	8.00	0	0.00	1	7.14	2	22.22	1	9.09	0	0.00

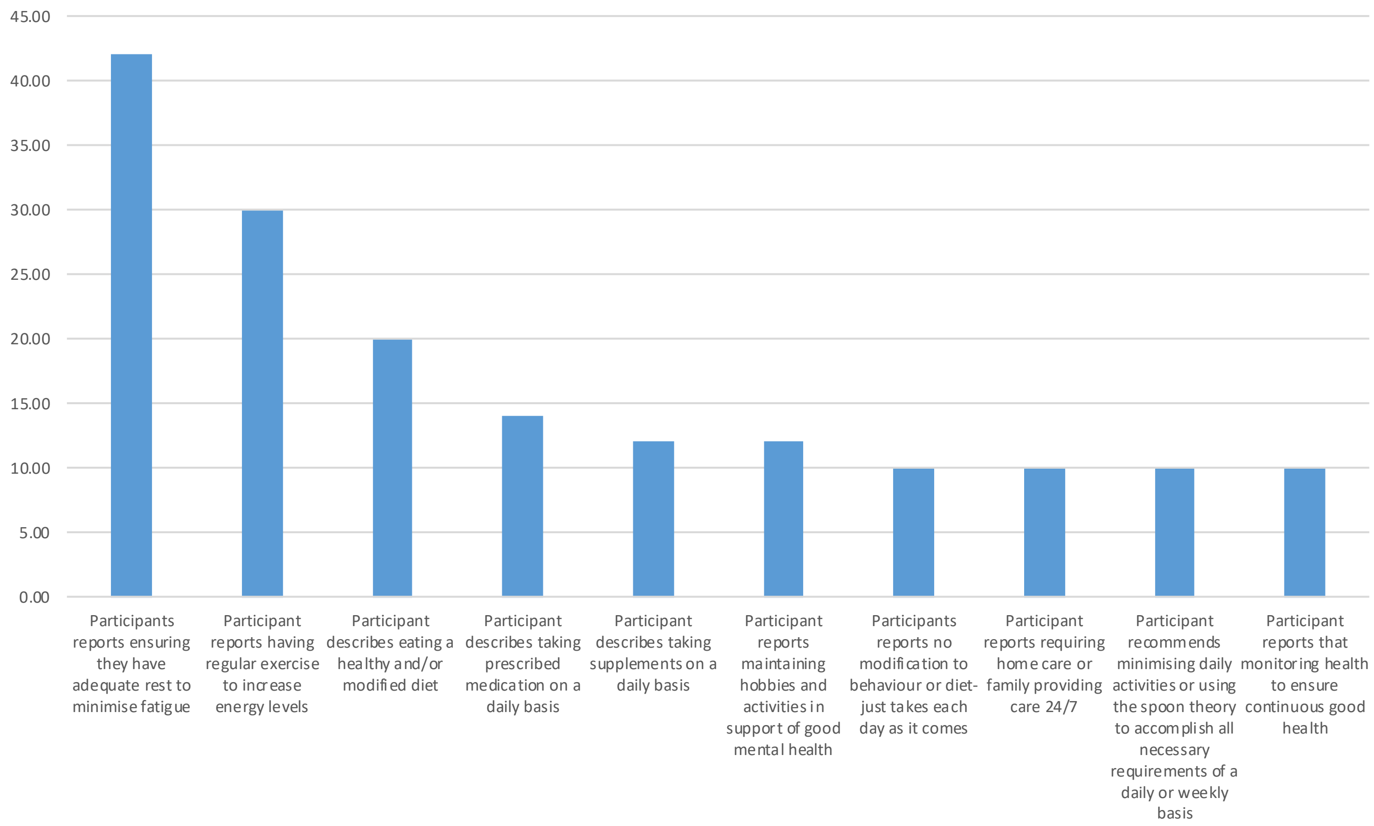

Figure 8.2: Everyday activities to manage health (% of all participants)

Impact on relationships with family and friends

Participants were asked whether having mitochondrial disease has had an impact on their relationships with family and friends. The most common theme described by participants was a negative impact on personal relationships due to people withdrawing from relationships or not being able to understand (n=14, 28.00%) and this was followed by a negative impact on personal relationships due to social isolation (n=11, 22.00%).

Participant describes a negative impact on personal relationships due to people withdrawing from relationships or not being able to understand

The relationship I was in when I was diagnosed which was a four year relationship, it wasn't a short term one. He left. I was diagnosed…he walked out Christmas eve. Couldn't deal with it. The poor fellow. Participant 18

Yes, probably with my friends because it's hard to explain it because I look all right, and I don't think they see that I'm really tired. I've probably lost a few friends. Especially at uni when I went to uni and that because there was no real diagnosis and I was tired and sick and couldn't really do the things I was doing. They were like, "Why aren't you doing those things?" Participant 19

Definitely. Yes, I think my sisters particularly don't really want to know about it, and I think they think I'm just making a mountain out of a molehill kind of thing. I suppose I'm fortunate that, in a way, I've just accepted the way I was, but they don't understand what it's like to be left behind and all that sort of stuff always. I did manage to get two of them to come with me to a genetic counselling appointment that I had once. That was very helpful really for me just for them to be convinced that, yes, this is a real thing, and something we should all know about, so it's good. I think it's really frustrating for my husband, but he's quiet. He tries to be understanding and he does a lot of practical things that are helpful... Participant 34

Participant describes a negative impact on personal relationships due to social isolation

Unfortunately, I think so, but not in any intentional way like no one's…I think it's just hard because you have less time when you've got Mitochondrial disease, you need to have so much rest. Relationships that were built on going out to dinner just can't…It's hard to sustain anything like that anymore. Participant 5

Absolutely. I have no friends, as I cannot predictably leave the house and people feel uncomfortable being around me. Participant 30

Definitely, yes. He doesn't have close friends. He's never had anyone ask him over for a play date. He doesn't have little buddies apart from kids that are at school. His best friend is his dog that we got eight, nine months ago. Participant 50

The next most common theme was a negative impact on personal relationships due to not being able to do all activities with family and friends (n=10, 20.00%).

Participant describes a negative impact on personal relationships due to not being able to do all activities with family and friends

Yes, from time to time…I've been trying to come up with a plan medication-wise, and the family have said to me that when I'm on some of those…We don't know which ones they were because I was trying a myriad of them, but they said there was periods there when I was a grumpy ass. Soon as I got off it, went back to being my normal self, so that sort of impacted on them. Knocked down for a walk with my missis with the dog in the afternoon, that's impacted on her. They'd be periods where your family wants to do something that might involve a bit of walking and stuff like that, and I'll make up an excuse…no not an excuse. I'll come up with something else to do that means that I have to participate in that just to avoid the pain that comes with walking those distances and things. Next time I'm playing golf forget about playing a round of golf and walking there. Then if you've got to be in a buggy you will forget about it. Participant 2

Yes. My husband worries about me and these things, but we obviously don't do bush walking, we live on a farm and I can't do the stuff with him that he'd like us to do, we haven't had children, that's the biggest. When I was first diagnosed I didn't know what it was or how it would be transmitted, so I chose not to have children because I didn't want to transmit something that I didn't know what I was going to be transmitting. The worry for people, I think they worry. Participant 3

Yes, because I can't do the things they do. My family, they think there's nothing wrong with me, I'm just putting it all on. Old age, some said to me, "It's just old age dad." Participant 42

There were six participants (12.00%) that described a positive impact of strengthening relationships.

Participant describes a positive impact of strengthening relationships

In a lot of ways it's brought me a lot closer to a lot of other people. I have a friend who has got a very different chronic illness to me, but we share a lot of the same frustrations. In some ways, it's brought me closer to other people. Participant 5

Now, I've got a lovely fellow I see. He's just gorgeous. He seems to deal with it. I think he deals with it better than I do. He's a bit of a rock for me actually. [Interviewer: That's wonderful] It is. It is because I'd given up. [laughs] I just thought this was going to be it. Participant 18

Yeah, it's actually quite … it's really lovely to see…seeing that a little bit more as he gets older but he's got some lovely school friends. There are some lovely, little mother hens he's had over the years. He's had that right through since preschool, actually. He's a lovable child and of course, the fact that he is wheelchair bound means that you have some beautiful little things. They just want to fuss over him and there's this one little girl, NAME at school. They've gone through an intervention together and they just have a really, very beautiful connection but in saying that I'm being told that nine-minute school that the kids in his class. He's in a support class of eight children and they fight as to who's going to sit next to NAME. It's really, very, very special…It's really lovely to see and know about. Participant 45

In relation to sub-group variations, participants from low socio-economic areas (43.48%) and those with low social function (40.00%) reported a negative impact on personal relationships due to people withdrawing from relationships or not being able to understand, more frequently than the general population (28.00%), while those from high socio-economic areas (14.81) and high social function (10.00%) reported this less frequently. Participants from metropolitan areas (33.33%) and those with low emotional well-being (33.33%) reported a negative impact on personal relationships due to social isolation, more frequently than the general population (22.00%) while those from rural areas (10.00%) reported this less frequently. Participants from low socio-economic areas (30.43%) described a negative impact on personal relationships due to not being able to do all activities with family and friends, more frequently than the general population (20.00%). Participants with high physical function (27.27%) and high social function (35.00%) described no impact on personal relationships more frequently than the general population (16.00%), while those with low social function described this less frequently.

Table 8.3: Impact on relationships

Impact on relationships	**All participants**		**Metropolitan**		**Rural**		**SEIFA (High)**		**SEIFA (Low)**	
	n=50	**%**	**n=30**	**%**	**n=20**	**%**	**n=27**	**%**	**n=23**	**%**
Participant describes a negative impact on personal relationships due to people withdrawing from relationships or not being able to understand	**14**	28.00	7	23.33	7	35.00	4	**14.81**	10	**43.48**
Participant describes a negative impact on personal relationships due to social isolation	**11**	22.00	10	**33.33**	2	**10.00**	7	25.93	5	21.74
Participant describes a negative impact on personal relationships due to not being able to do all activities with family and friends	**10**	20.00	5	16.67	5	25.00	3	11.11	7	**30.43**
Participant describes no impact on personal relationships (No specific reason)	**8**	16.00	6	20.00	2	10.00	6	22.22	2	8.70
Participant describes a positive impact of strengthening relationships	**6**	12.00	3	10.00	3	15.00	4	14.81	2	8.70
Participant describes impact on personal relationships (No specific reason)	**5**	10.00	4	13.33	1	5.00	3	11.11	2	8.70
Participant describes a negative impact of personal relationships due to communication problems (associated with hearing loss)	**5**	10.00	3	10.00	2	10.00	2	7.41	3	13.04

Impact on relationships	**All participants**		**High school or trade**		**University**		**Hearing impairment**		**Eye or visual impairment**	
	n=50	**%**	**n=26**	**%**	**n=24**	**%**	**n=24**	**%**	**n=34**	**%**
Participant describes a negative impact on personal relationships due to people withdrawing from relationships or not being able to understand	**14**	28.00	8	30.77	6	25.00	8	33.33	11	32.35
Participant describes a negative impact on personal relationships due to social isolation	**11**	22.00	6	23.08	6	25.00	3	12.50	8	23.53
Participant describes a negative impact on personal relationships due to not being able to do all activities with family and friends	**10**	20.00	5	19.23	5	20.83	5	20.83	8	23.53
Participant describes no impact on personal relationships (No specific reason)	**8**	16.00	6	23.08	2	8.33	3	12.50	5	14.71
Participant describes a positive impact of strengthening relationships	**6**	12.00	5	19.23	1	4.17	3	12.50	5	14.71
Participant describes impact on personal relationships (No specific reason)	**5**	10.00	2	7.69	3	12.50	1	4.17	1	2.94
Participant describes a negative impact of personal relationships due to communication problems (associated with hearing loss)	**5**	10.00	4	15.38	1	4.17	3	12.50	5	14.71

Impact on relationships	**All participants**		**Physical function (High)**		**Physical function (Low)**		**Emotional well-being (High)**		**Emotional well-being (Low)**	
	n=50	**%**	**n=22**	**%**	**n=28**	**%**	**n=26**	**%**	**n=24**	**%**
Participant describes a negative impact on personal relationships due to people withdrawing from relationships or not being able to understand	**14**	28.00	7	31.82	7	25.00	5	19.23	9	37.50
Participant describes a negative impact on personal relationships due to social isolation	**11**	22.00	4	18.18	8	28.57	4	15.38	8	**33.33**
Participant describes a negative impact on personal relationships due to not being able to do all activities with family and friends	**10**	20.00	4	18.18	6	21.43	5	19.23	5	20.83
Participant describes no impact on personal relationships (No specific reason)	**8**	16.00	6	**27.27**	2	7.14	6	23.08	2	8.33
Participant describes a positive impact of strengthening relationships	**6**	12.00	2	9.09	4	14.29	2	7.69	4	16.67
Participant describes impact on personal relationships (No specific reason)	**5**	10.00	2	9.09	3	10.71	4	15.38	1	4.17
Participant describes a negative impact of personal relationships due to communication problems (associated with hearing loss)	**5**	10.00	3	13.64	2	7.14	2	7.69	3	12.50

Impact on relationships	**All participants**		**Social functioning (High)**		**Social functioning (Low)**		**General health (High)**		**General health (Low)**	
	n=50	**%**	**n=20**	**%**	**n=30**	**%**	**n=22**	**%**	**n=28**	**%**
Participant describes a negative impact on personal relationships due to people withdrawing from relationships or not being able to understand	**14**	28.00	2	**10.00**	12	**40.00**	5	22.73	9	32.14
Participant describes a negative impact on personal relationships due to social isolation	**11**	22.00	3	15.00	9	30.00	4	18.18	8	28.57
Participant describes a negative impact on personal relationships due to not being able to do all activities with family and friends	**10**	20.00	5	25.00	5	16.67	4	18.18	6	21.43
Participant describes no impact on personal relationships (No specific reason)	**8**	16.00	7	**35.00**	1	**3.33**	5	22.73	3	10.71
Participant describes a positive impact of strengthening relationships	**6**	12.00	2	10.00	4	13.33	0	0.00	6	21.43
Participant describes impact on personal relationships (No specific reason)	**5**	10.00	4	20.00	1	3.33	3	13.64	2	7.14
Participant describes a negative impact of personal relationships due to communication problems (associated with hearing loss)	**5**	10.00	2	10.00	3	10.00	3	13.64	2	7.14

Impact on relationships	**All participants**		**Under 18**		**24-44**		**45-54**		**55-64**		**65-74+**	
	n=50	**%**	**n=6**	**%**	**n=14**	**%**	**n=9**	**%**	**n=11**	**%**	**n=10**	**%**
Participant describes a negative impact on personal relationships due to people withdrawing from relationships or not being able to understand	**14**	28.00	1	16.67	5	35.71	2	22.22	4	36.36	2	20.00
Participant describes a negative impact on personal relationships due to social isolation	**11**	22.00	3	50.00	4	28.57	0	0.00	3	27.27	2	20.00
Participant describes a negative impact on personal relationships due to not being able to do all activities with family and friends	**10**	20.00	1	16.67	3	21.43	3	33.33	1	9.09	2	20.00
Participant describes no impact on personal relationships (No specific reason)	**8**	16.00	0	0.00	2	14.29	2	22.22	1	9.09	3	30.00
Participant describes a positive impact of strengthening relationships	**6**	12.00	1	16.67	3	21.43	0	0.00	2	18.18	0	0.00
Participant describes impact on personal relationships (No specific reason)	**5**	10.00	1	16.67	1	7.14	2	22.22	0	0.00	1	10.00
Participant describes a negative impact of personal relationships due to communication problems (associated with hearing loss)	**5**	10.00	0	0.00	2	14.29	1	11.11	0	0.00	2	20.00

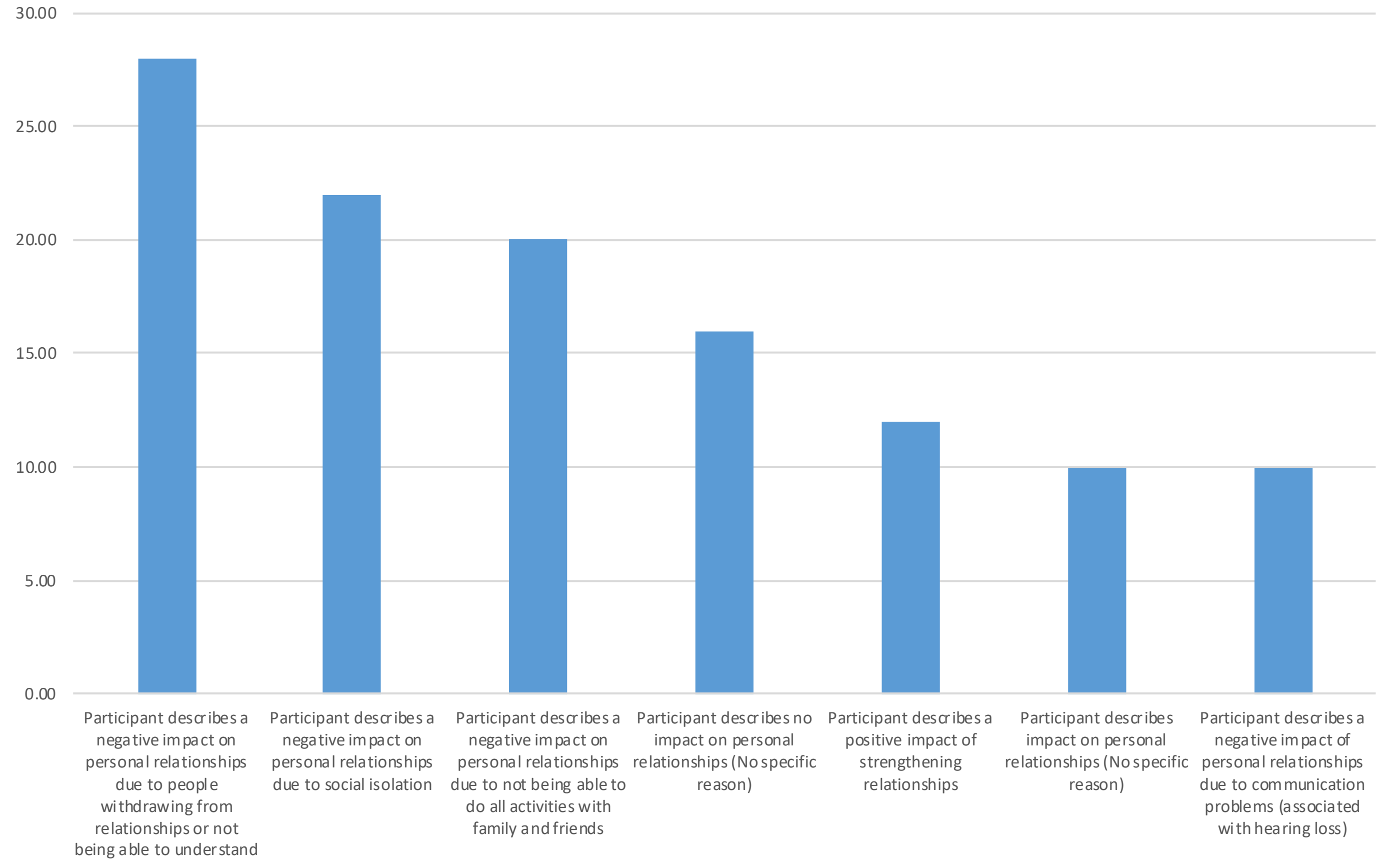

Figure 8.3: Impact on relationships (% of all participants)

Experience of anxiety related to disease 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, with a higher score denoting increased anxiety. Summary statistics for the entire cohort are displayed alongside the possible range of the scale in Table 8.4. Overall the entire cohort had a mean total score of 34.10, which is a score in the middle of the scale.

Boxplots of Fear of Progression Total Score (FOPTS) by disease stage, metastatic status, location, and education status are displayed in Figures 8.5 to 8.13.

Comparisons of FOPTS have been made based on general health (Figure 8.5), physical functioning (Figure 8.6), emotional well-being (Figure 8.7), social functioning, (Figures 8.8), hearing problems (Figure 8.9), eye problems (Figure 8.10), location (Figure 8.11), education (Figure 8.12), and SEIFA (Figure 8.13).

Comparisons were made by a two-sample t-test was used when assumptions for normality and variance were met (Table 8.5), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 8.6).

There were no statistically significant differences between any of the subgroups for FOPTS.

In addition to the fear of progression questionnaire, participants were asked if they become anxious if they did not experience side effects of treatment as it makes them feel that the treatment is not working. The majority of participants never (n=28, 56.00%), seldom (n=5, 10.00%), sometimes (n=12, 24.00%), often (n=3, 6.00%) and very often (n=3, 6.00%).

Table 8.4: Fear of Progression Total Score

	Mean*	SD	Median	IQR	Possible range
FOPTS	34.10	8.09	34.00	4	12-60

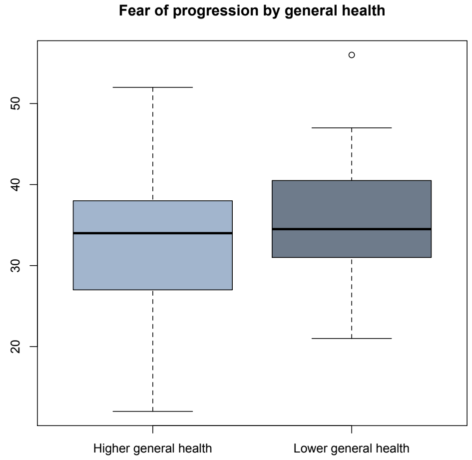

Figure 8.5: Boxplot of FOPTS by general health

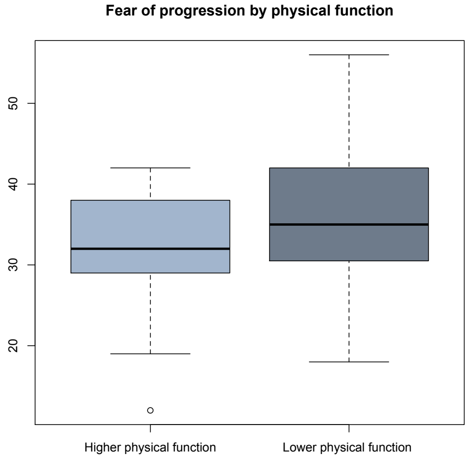

Figure 8.6: Boxplot of of FOPTS by physical functioning

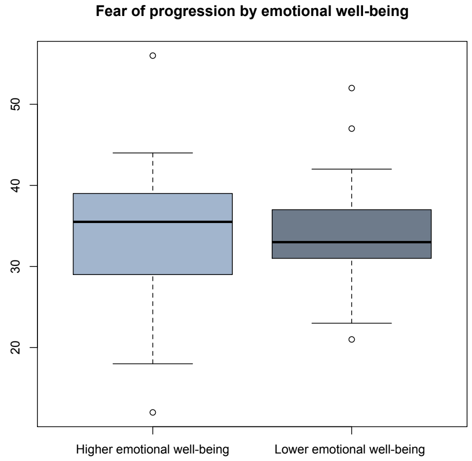

Figure 8.7: Boxplot of FOPTS by emotional well-being

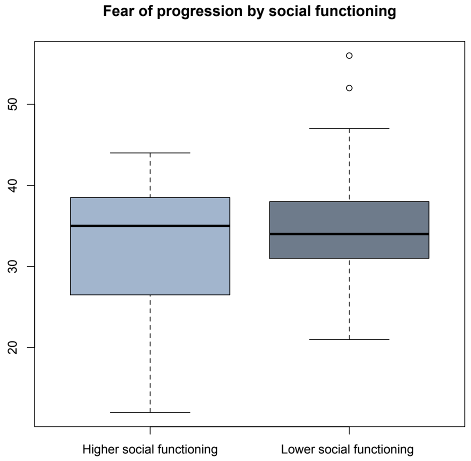

Figure 8.8: Boxplot of FOPTS by social functioning

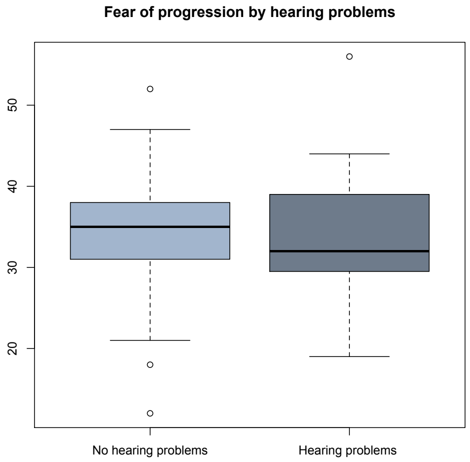

Figure 8.9: Boxplot of FOPTS by hearing problems

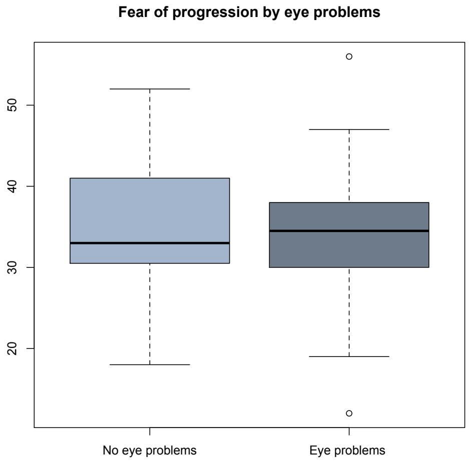

Figure 8.10: Boxplot of of FOPTS by eye problems

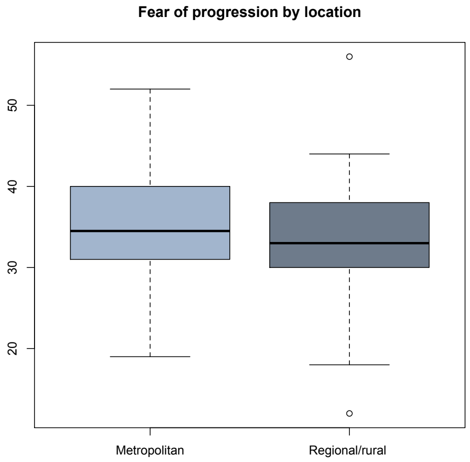

Figure 8.11: Boxplot of FOPTS by location

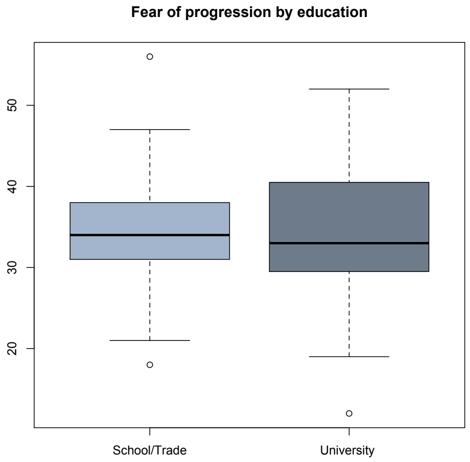

Figure 8.12: Boxplot of FOPTS by education

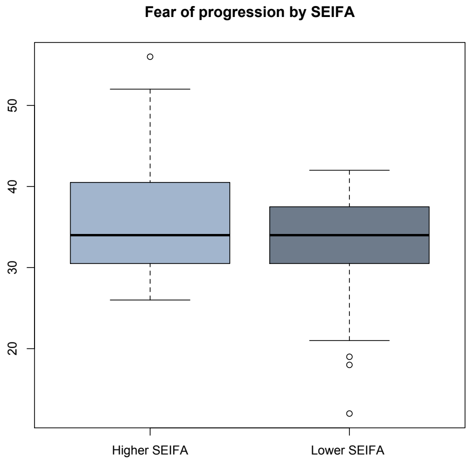

Figure 8.13: Boxplot of FOPTS by SEIFA

Table 8.5: Summary statistics and two sample t-test FOPTS

FOPTS by subgroups	Groups	Count	Mean	SD	t	dF	P
General health	Higher general health	2	32.36	9.17	-1.36	48	0.1812
	Lower general health	28	35.46	7.00			
Emotional well-being	Higher emotional well-being	26	33.85	9.32	-0.23	48	0.8201
	Lower emotional well-being	24	34.38	6.69			
Hearing problems	No hearing problems	26	34.42	8.40	0.29	48	0.7722
	Hearing problems	24	33.75	7.90			
Eye problems	No eye problems	26	34.69	7.80	0.35	48	0.7285
	Eye problems	34	33.82	8.32			
Location	Metropolitan	30	35.00	6.94	0.96	48	0.3405
	Regional/rural	20	32.75	9.60			
Education	School/Trade	26	34.35	7.60	0.22	48	0.8254
	University	24	33.83	8.74			

Table 8.6: Summary statistics Wilcoxon rank sum test with continuity correction of FOPTS

FOPTS by subgroups	Groups	Count	Median	IQR	W	P
Physical functioning	Higher physical functioning	22	32.00	8.00	248.00	0.2439
	Lower physical functioning	28	35.00	11.25		
Social functioning	Higher social functioning	20	35.00	11.50	274.00	0.6129
	Lower social functioning	30	34.00	6.50		
SEIFA	Higher SEIFA	27	34.00	10.00	363.50	0.3058
	Lower SEIFA	23	34.00	7.00		