

Section 5 Treatment and health service provision

Section 5: Experience of treatment

Discussions about Clinical Trials

- In this PEEK study, 64% of all participants (n=32) describe not being spoken to about clinical trials, seven participants brought up the topic with their doctor (14.00%) and the doctors of 11 participants brought up the topic (22.00%).

Participation in Clinical Trials

- Seven participants have taken part in a clinical trial (14.00%), and 33 participants have not taken part in a clinical trial would like if one was suitable for them (66.00%). Ten participants have not taken part and do not want to (20.00%)

Treatments experienced

- Participants were asked in the questionnaire to identify the treatments that they had experienced. most common treatments were Coenzyme Q10 (n=36, 72.00%), vitamins and supplements (n=32, 64.00%), followed by physical therapy (n=15, 30.00%), and diet (n=11, 22.00).
- Participants were asked to rate their quality of life on a scale of 1 to 7, while using each specific treatment (with 1 being 'Life was very distressing and 7 being 'Life was great'). Mean quality of life scores ranges from 3.34 to 4.33, that is, all quality of life scores were within the 'life was a little distressing' to 'Life was average' range. The treatment that scored the least impact on quality of life was speech therapy (mean score 4.33). All other treatments were in the 'Life was a little distressing' range (mean scores range 3.34 to 3.86).
- The treatments that had a mean effectiveness score of at least 3 (moderately effective) were respiratory therapy (average score 3.50), speech therapy (average score 3.33), and diet (average score 3.09). The remaining treatments scored had a mean effectiveness score of at least 2, that is in the somewhat effective range.
- Participants were asked in the structure interview to provide a description of mild side effects. The most common description of mild side effects were those that do not greatly impact activities of daily living (n=11, 22.00%). In relation to specific side effects that were considered to be mild, there were seven participants (14.00%) that described headaches, six participants (12.00%) that described gastrointestinal problems (diarrhoea and cramping) and five participants (10.00%) that described increased fatigue (and related irritability) as a mild side effect. There were also six participants that did not describe a mild side effect but talks about mitochondrial disease being part of everyday life (Particularly pain).
- In relation to sub-group variations, participants with high social functioning (40.00%) described mild side effects as those that do not greatly impact activities of daily living more frequently than the general population (22.00%).
- Participants were asked in the structure interview to provide a description of severe side effects. The most common description of severe side effects were those that limit daily activities for an extended period of time (n=19, 38.00%), seven participants (14.00%) described sever side effects as an effect requiring hospitalisation or medical attention/permanent damage, or a life threatening effect or inability to function. In relation to specific side effects that were considered severe, nine participants (18.00%) described severe fatigue, four participants (8.00%) described chronic headaches and four participants (8.00%) described loss of mobility or independence.
- In relation to sub-group variations, participants with a high school or trade education (15.38%), low physical function(25.00%) and low social functioning (26.67%) described severe side effects as effects limiting their daily activities for an extended period of time, less frequently than the general population (38.00%), while those with a university education (62.50%), high physical function (54.44%), high social functioning (55.00%), high general health (50.00%) and hearing impairment (50.00%) described this more frequently.

Adherence to medication

- Participants were asked in the online questionnaire if, in general, if they were good at taking medicine and sticking to it. The majority of participants were good at sticking to treatments all of the time (n=30, 60.00%) and the remaining were good at sticking to treatments most of the time (n=20, 40.00%). No participants felt they were never, rarely or sometimes good at sticking to treatments.
- Participants were also asked in the structured interview how long they stick with a therapy before they think it might not be working or give up on it. Close to half of all participants (n=24, 48.00%) describes using treatment for a period of one to three months before deciding if its working. The next most common theme was continuing a treatment indefinitely or as recommended by clinician/specialist (n=9, 18.00%) and there were six participants (12.00%) that described not trying new medications for mitochondrial disease and such not knowing how long they would continue a treatment.
- In relation to sub-group variations, participants from rural areas (30.00%) and participants with a hearing impairment (29.17%) reported continuing a treatment indefinitely or as recommended by clinician/specialist more frequently than the general population (18.00%). Participants with a hearing impairment (29.17%) reported using treatment for a period of one to three months before deciding if its working less frequently than the general population (48.00%), while those with high social functioning (60.00%) and high general health (59.09%) reported this more frequently.
- Participants were asked what needed to change for them to feel as though a treatment was working. The most common description was needing to feel more energetic, and increase in physical ability, to know a treatment is working (n=20, 40.00%). This was followed by needing to see improved symptoms by clinical measurement (test result) (n=13, 26.00%) and needing to generally feel better to know that a treatment is working (n=9, 13.00%). There were five participants (10.00%) that described needing to reduce pain to know a treatment is working and five participants (10.00%) needing to improve their quality of life to know a treatment is working.
- In relation to sub-group variations, participants from metropolitan areas (26.67%) and participants from high socio-economic areas (25.93%) reported needing to feel more energetic, and increase in physical ability, to know a treatment is working, less frequently than the general population (40.00%) while participants from rural areas (60.00%), participants from low socio-economic areas (56.52%). Participants with a hearing impairment (41.67%) reported improved symptoms by clinical measurement (test result) more frequently than the general population (26.00%). Participants with high physical functioning (31.82%) described needing to generally feel better to know that a treatment is working, more frequently than the general population (18.00%).

Complementary therapies

- Participants were asked whether they had used any complementary therapies. The most common therapies that were considered complementary and described by participants were vitamins, minerals and supplements (n=14, 28.00%) and allied health e.g. physiotherapy (including massage and hydrotherapy), speech therapy, occupational therapy (n=14, 14.00%). The next most frequent complementary therapies described were alternative medicine, e.g. osteopathy, acupuncture, chiropractor, Bowen therapy (n=12, 24.00%). There were also 11 participants (22.00%) that noted that they did not use any complementary therapies.

Service provision and affordability

- The main physician treating participants for mitochondrial disease were general practitioners (N=19, 38.00%), followed by neurologists (N=12, 24.00%) and mitochondrial specialists (N=11, 22.00%).
- Participants had access to a general practitioner (n=48, 96.00%), neurologist (n=43, 86.00%), mitochondrial specialist (n=29, 58.00%) and cardiologist (n=28, 56.00%) for the treatment of their mitochondrial disease.
- The majority of patients had private healthcare insurance (n=37, 74.00%), 29 (58.00%) participants were treated as public patients, 12 (24.00%) as private patients and 9 (18.00%) as equally public and private patients. The majority of participants were treated in the public hospital system (n=32, 64.00%).
- Almost half of participants have never missed medical appointments due to cost (n=24, 48.00%), and most have never been unable to afford prescription medications (n=34, 64.00%). Almost half of participants have found it somewhat to extremely difficult paying for basic needs due to their diagnosis with mitochondrial disease (n=24, 48.00%).

Changes to work status

- The work status for a number of participants changed due to their diagnosis with mitochondrial disease with about a quarter of participants reducing the number of hours worked (n=13, 26.00%), and 19 (38.00%) quitting their jobs.
- Of those that had a partner or carer, four carers/partners had to quit their job (23.53%), seven had to reduce the number of hours worked (41.18%), carers have had to take leave either with pay (n=2, 11.76%), or without pay (n=5, 29.41%).

Experience of respect during treatment

- Participants were asked if they felt they had been treated with respectfully throughout their treatment. Half of the participants felt that they had been treated respectfully with the exception of one or two occasions (n=25, 50.00%), 18 felt that they had been treated respectfully (36.00%) and seven felt they had not been treated respectfully (14.00%).

Clinical Trials

Discussions about Clinical Trials

In this PEEK study, 64% of all participants (n=32) describe not being spoken to about clinical trials, seven participants brought up the topic with their doctor (14.00%) and the doctors of 11 participants brought up the topic (22.00%).

Table 5.1: Discussions about clinical trials

Have you discussed clinical trials with your doctor?	N=50	Percentage of participants
I brought up the topic of clinical trials with my doctor for discussion	7	14.00
My doctor brought up the topic of clinical trials for discussion	11	22.00
No one has ever spoken to me about clinical trials	32	64.00

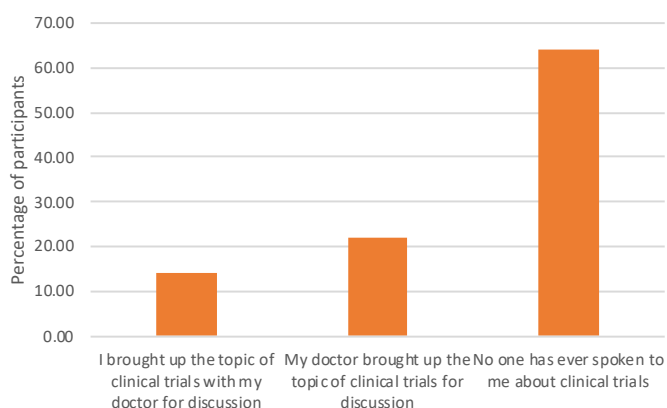


Figure 5.1: Discussions about clinical trials

Seven participants have taken part in a clinical trial (14.00%), and 33 participants have not taken part in a clinical trial would like if one was suitable for them (66.00%). Ten participants have not taken part and do not want to (20.00%).

Table 5.2: Participation in clinical trials

Participation in clinical trials	N=50	Percentage of participants
Have not participated in a clinical trial and do not want to	10	20.00
Have not participated in a clinical trial but would like to if there is one for me	33	66.00
Have participated in a clinical trial	7	14.00

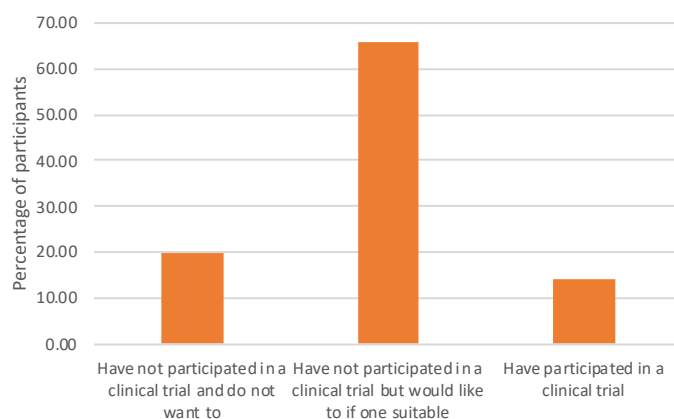


Figure 5.2: Participation in clinical trials

Treatments experienced

Participants were asked in the questionnaire to identify the treatments that they had experienced. most common treatments were Coenzyme Q10 (n=36, 72.00%) and Vitamins and supplements (n=32, 64.00%). This was followed by physical therapy (n=15, 30.00%), diet (n=11, 22.00%), speech therapy (n=9, 18.00%), and respiratory therapy (n=4, 8.00%).

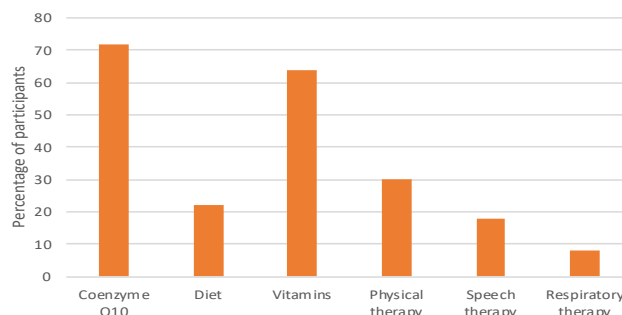


Figure 5.3: Treatments experienced (% of all participants)

Table 5.3: Treatments experienced

Treatment	N=50	Percent	Mean QOL score	Range (Worst QOL = 1, Best QOL = 7)	Mean effectiveness score	Range (Ineffective = 1, Very Effective = 5)
Coenzyme Q10	36	72.00	3.86	1-7	2.56	1-5
Diet	11	22.00	3.82	1-6	3.09	1-5
Vitamins	32	64.00	3.34	1-6	2.44	1-5
Physical therapy	15	30.00	3.60	1-6	2.80	1-5
Speech therapy	9	18.00	4.33	1-7	3.33	1-4
Respiratory therapy	4	8.00	3.75	1-5	3.50	1-4

As a follow-up question (within the questionnaire), participants were asked to rate their quality of life on a scale of 1 to 7, while using each specific treatment (with 1 being 'Life was very distressing and 7 being 'Life was great'). Mean quality of life scores ranges from 3.34 to 4.33, that is, all quality of life scores were with

the 'life was a little distressing' to 'Life was average' range. The treatment that scored the least impact on quality of life was speech therapy (mean score 4.33). All other treatments were in the 'Life was a little distressing' range (mean scores range 3.34 to 3.86).

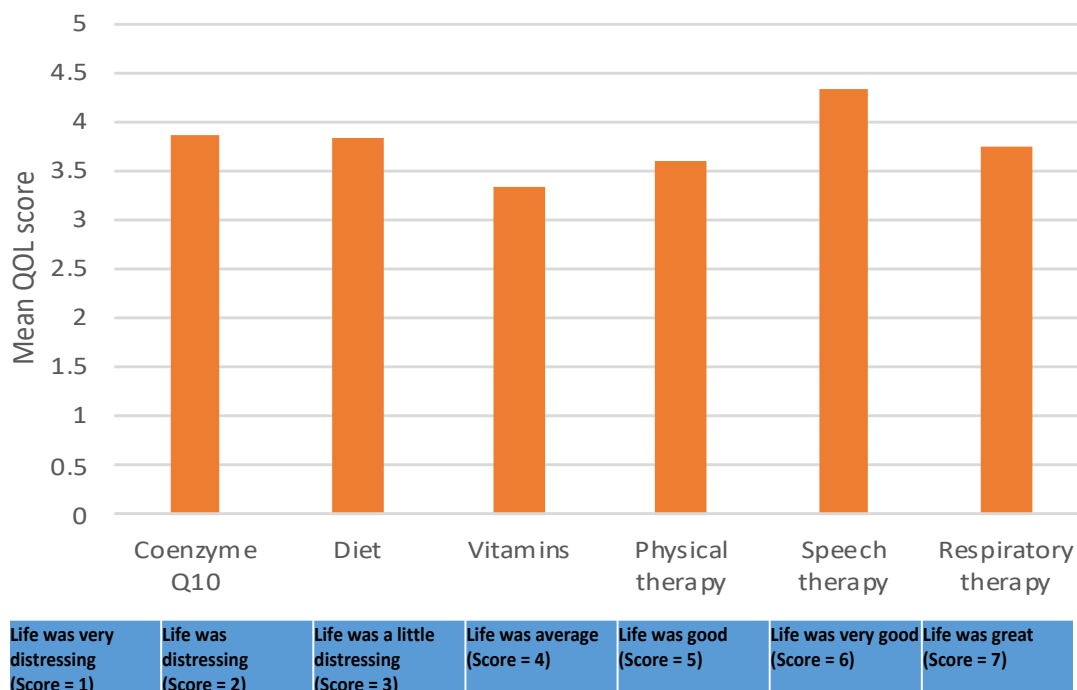


Figure 5.4: Treatments experienced and mean quality of life

A second follow-up question was asked in relation to how effective the participant felt the treatment was on a scale of 1 to 5 (with 1 being ineffective and 5 being very effective). The treatments that had a mean effectiveness score of at least 3 (moderately effective)

were respiratory therapy (average score 3.50), speech therapy (average score 3.33), and diet (average score 3.09). The remaining treatments scored had a mean effectiveness score of at least 2, that is in the somewhat effective range.

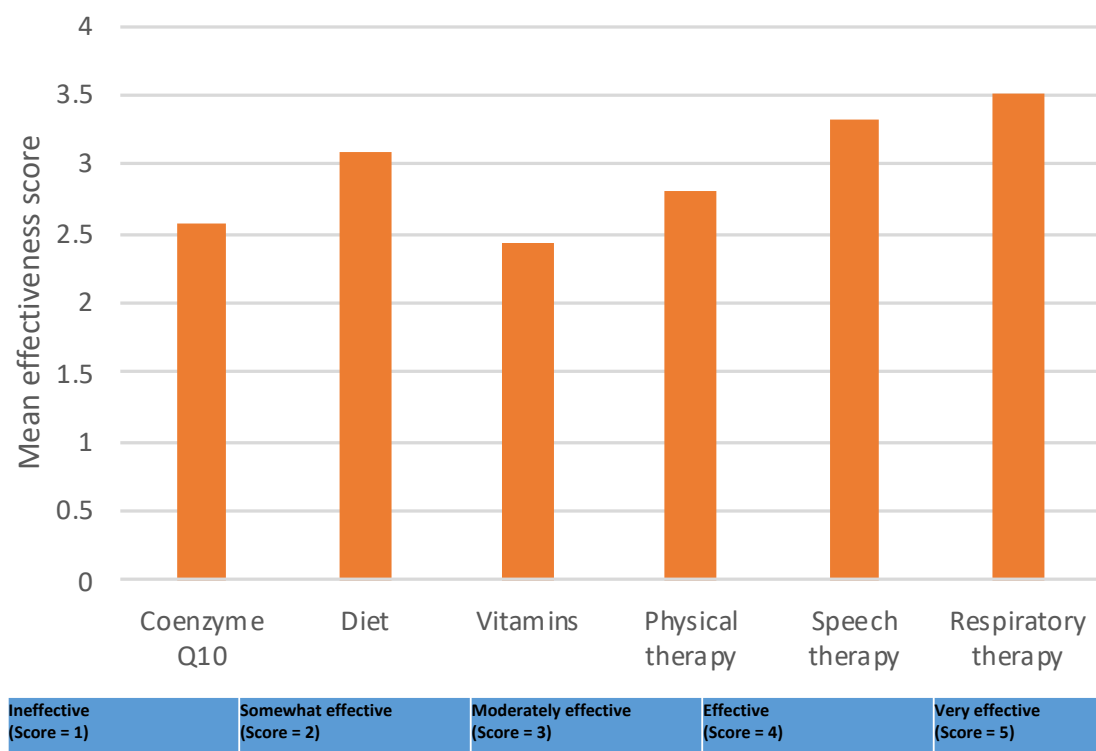


Figure 5.5: Treatments experienced and effectiveness

Side effects of treatment

Mild side effects

Participants were asked in the structure interview to provide a description of mild side effects. The most common description of mild side effects were those that do not greatly impact activities of daily living (n=11, 22.00%).

Participant describes mild side effects as those that do not greatly impact activities of daily living

Stuff that didn't impact on my day to day activities. Things that were potentially intermittent come and go. Something that you had to go through for a period of time but the benefit was that it did not stopping is that there'd be a benefit having gone through it I'd say. That's all mild to me. Participant 2

To me, probably mild side effects are ones that don't have any severe impact on your life and your lifestyle. It's like you can cope with it without making big alterations to what you can do and what you can't do,

and probably live, what I call a normal life. That's what I call mild side effect. Participant 15

Mild side effects I suppose would be a little bit annoying, but don't affect what you do in the day. Mild side effects, I would say would be a bit annoying, don't have an effect on your day to day activities. Participant 43

In relation to specific side effects that were considered to be mild, there were seven participants (14.00%) that described headaches, six participants (12.00%) that described gastrointestinal problems (diarrhoea and cramping) and five participants (10.00%) that described increased fatigue (and related irritability) as a mild side effect. There were also six participants that did not describe a mild side effect specifically but spoke about mitochondrial disease being part of everyday life (Particularly pain).

Participant does not describe a mild side effect but talks about mitochondrial disease being part of everyday life (Particularly pain)

I do sort of but I cope with it all. Yes, I just got to. I've got no choice. I get out of bed and I'm in agony every morning. I wait for the painkillers to kick in. Participant 18

In a scientific sense it's very difficult. I don't know how you would describe it. I don't have any factual measurement as such. I've always taken the attitude as nothing can be done about it. I've just got to press on and keep doing things. If you've got a cut finger, you put a band aid on it and get on with it. Participant 27

Mild side effects mean that I first deserve to get up in the day and just to do daily chores that I can handle, and that would be mild side effects. I'll have a rest in the afternoon, that's around half an hour nap. That gets me up and going for dinner time or watching television which I write that past that would be the mild side effects. Mild side effect is maybe just to say almost 100% pain relieving, it's if I would get pain in some of the muscle groups and not the others, and

that gives me a warning then to be careful. The main problem I will is I could be sitting where I'm sitting now and I could go just like you message if you would like to be entertained, and then sometimes I'm sitting down that then develops into a pain and a headache. If I'm walking around, of course, I could result in a fall, which I has happened quite a few. Then I use the pain just to give me balance into walking. That would be a mild side effect. Participant 23

In relation to sub-group variations, participants with high social functioning (40.00%) described mild side effects as those that do not greatly impact activities of daily living more frequently than the general population (22.00%).

Table 5.4: Description of mild side effects

Description of mild side effects	All participants		Metropolitan		Rural		SEIFA (High)		SEIFA (Low)	
	n=50	%	n=30	%	n=20	%	n=27	%	n=23	%
Participant describes mild side effects as those that do not greatly impact activities of daily living	11	22.00	8	26.67	3	15.00	7	25.93	4	17.39
Participant describes mild side effects as headaches	7	14.00	4	13.33	3	15.00	3	11.11	4	17.39
Participant describes gastrointestinal problems (diarrhoea and cramping) as mild side effects	6	12.00	4	13.33	2	10.00	4	14.81	2	8.70
Participant does not describe a mild side effect but talks about mitochondrial disease being part of everyday life (Particularly pain)	6	12.00	4	13.33	2	10.00	4	14.81	2	8.70
Participant had not had any mild side effects and could not answer (N/A)	6	12.00	3	10.00	3	15.00	2	7.41	4	17.39
Participant describes mild side effects as something temporary, you can overcome in a short time period	5	10.00	4	13.33	1	5.00	3	11.11	2	8.70
Participant describes increased fatigue (and related irritability) as a mild side effect	5	10.00	4	13.33	1	5.00	4	14.81	1	4.35

Section 5

Description of mild side effects	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 mild side effects as those that do not greatly impact activities of daily living	11	22.00	5	19.23	6	25.00	3	12.50	8	23.53
Participant describes mild side effects as headaches	7	14.00	4	15.38	3	12.50	5	20.83	4	11.76
Participant describes gastrointestinal problems (diarrhoea and cramping) as mild side effects	6	12.00	4	15.38	2	8.33	3	12.50	4	11.76
Participant does not describe a mild side effect but talks about mitochondrial disease being part of everyday life (Particularly pain)	6	12.00	4	15.38	2	8.33	1	4.17	5	14.71
Participant had not had any mild side effects and could not answer (N/A)	6	12.00	4	15.38	2	8.33	3	12.50	5	14.71
Participant describes mild side effects as something temporary, you can overcome in a short time period	5	10.00	2	7.69	3	12.50	3	12.50	2	5.88
Participant describes increased fatigue (and related irritability) as a mild side effect	5	10.00	4	15.38	1	4.17	2	8.33	3	8.82

Description of mild side effects	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 mild side effects as those that do not greatly impact activities of daily living	11	22.00	6	27.27	5	17.86	8	30.77	3	12.50
Participant describes mild side effects as headaches	7	14.00	3	13.64	4	14.29	4	15.38	3	12.50
Participant describes gastrointestinal problems (diarrhoea and cramping) as mild side effects	6	12.00	1	4.55	5	17.86	4	15.38	2	8.33
Participant does not describe a mild side effect but talks about mitochondrial disease being part of everyday life (Particularly pain)	6	12.00	2	9.09	4	14.29	2	7.69	4	16.67
Participant had not had any mild side effects and could not answer (N/A)	6	12.00	2	9.09	4	14.29	3	11.54	3	12.50
Participant describes mild side effects as something temporary, you can overcome in a short time period	5	10.00	1	4.55	4	14.29	3	11.54	2	8.33
Participant describes increased fatigue (and related irritability) as a mild side effect	5	10.00	3	13.64	2	7.14	3	11.54	2	8.33

Description of mild side effects	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 mild side effects as those that do not greatly impact activities of daily living	11	22.00	8	40.00	3	10.00	7	31.82	4	14.29
Participant describes mild side effects as headaches	7	14.00	2	10.00	5	16.67	2	9.09	5	17.86
Participant describes gastrointestinal problems (diarrhoea and cramping) as mild side effects	6	12.00	1	5.00	5	16.67	2	9.09	4	14.29
Participant does not describe a mild side effect but talks about mitochondrial disease being part of everyday life (Particularly pain)	6	12.00	0	0.00	6	20.00	2	9.09	4	14.29
Participant had not had any mild side effects and could not answer (N/A)	6	12.00	2	10.00	4	13.33	3	13.64	3	10.71
Participant describes mild side effects as something temporary, you can overcome in a short time period	5	10.00	2	10.00	3	10.00	3	13.64	2	7.14
Participant describes increased fatigue (and related irritability) as a mild side effect	5	10.00	3	15.00	2	6.67	3	13.64	2	7.14

Description of mild side effects	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 mild side effects as those that do not greatly impact activities of daily living	11	22.00	2	33.33	2	14.29	5	55.56	1	9.09	1	10.00
Participant describes mild side effects as headaches	7	14.00	1	16.67	3	21.43	0	0.00	2	18.18	1	10.00
Participant describes gastrointestinal problems (diarrhoea and cramping) as mild side effects	6	12.00	2	33.33	4	28.57	0	0.00	0	0.00	0	0.00
Participant does not describe a mild side effect but talks about mitochondrial disease being part of everyday life (Particularly pain)	6	12.00	0	0.00	0	0.00	0	0.00	4	36.36	2	20.00
Participant had not had any mild side effects and could not answer (N/A)	6	12.00	1	16.67	1	7.14	1	11.11	1	9.09	2	20.00
Participant describes mild side effects as something temporary, you can overcome in a short time period	5	10.00	0	0.00	2	14.29	2	22.22	0	0.00	1	10.00
Participant describes increased fatigue (and related irritability) as a mild side effect	5	10.00	2	33.33	1	7.14	0	0.00	0	0.00	2	20.00

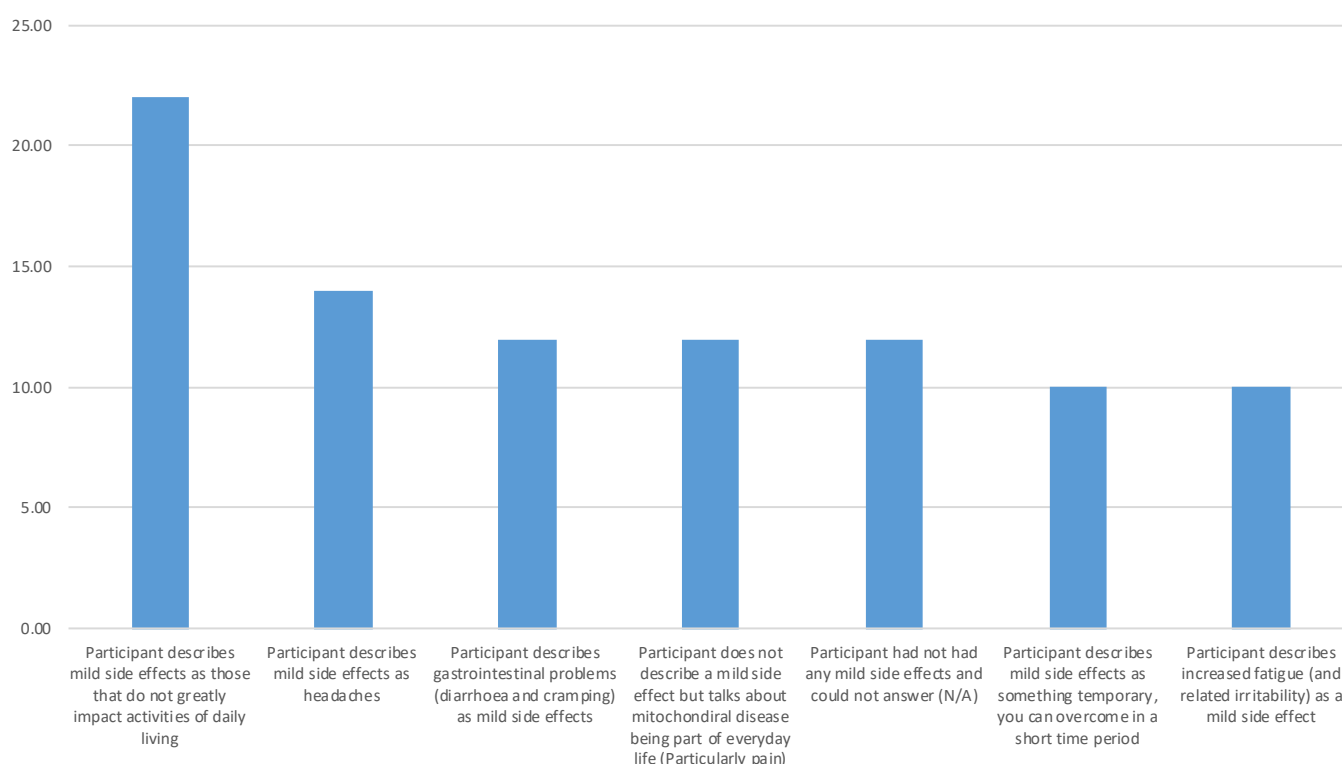


Figure 5.6: Description of severe side effects (% of all participants)

Severe side effects

Participants were asked in the structure interview to provide a description of severe side effects. The most common description of severe side effects were those that limit daily activities for an extended period of time (n=19, 38.00%), seven participants (14.00%) described severe side effects as an effect requiring hospitalisation or medical attention/permanent damage, or a life threatening effect or inability to function.

Participant describes severe side effects as effects limiting their daily activities (may be for an extended period of time).

Inability to perform daily tasks for an extended period. Inability to go to work, prolonged pain. Things that potentially stop me from being able to drive. Participant 2

It would be anything severe enough to stop me from doing my daily activities. Participant 13

Severe side effects make day to day activities hard, generally make me feel emotionally drained and physically tired. I usually will persist with what I'm doing for as long as I am able. Coping with daily activities is generally hard and usually means by the end you are drained of all resources. Participant 38

Participant describes severe side effects as an effect requiring hospitalisation or medical attention or permanent damage

Something, for me, that would be severe would be something that required hospital treatment, or something that severely impacted on my capacity to perform basic daily tasks like getting a meal, having a shower, or being able to be mobile. Participant 7

Severe side affect. Being given medication that have severe reaction to. Going into hospital and fasting and being put on a drip and become very lethargic. Participant 16

Severe side effects are ones that place me in bed or needing medical treatment which is frustrating as medical teams that don't understand the disease brush you off as though your overreacting. Participant 40

In relation to specific side effects that were considered severe, nine participants (18.00%) described severe fatigue, four participants (8.00%) described chronic headaches and four participants (8.00%) described loss of mobility or independence.

Participant describes severe side effects as loss of mobility or independence

The severe problems are the progression so that it is easy to fall over, Getting out of breath easily, difficulty walking with a walker, getting worse, pain in head where hair falling out, sometimes incontinent which makes going out, especially early in the morning, difficult. Participant 14

Severe side effects may include sudden muscle weakness in my legs, which prevents me from doing anything in the day and brings about anxiety and paranoia that I am getting worse. Having a combination of muscle fatigue, impaired hearing and reduced energy can bring about depression and thinking that my body will not recover. Participant 26

Mobility limitations requiring aids. All Myopathic weakness and developing disability including curvature of the spine and deformity and weakness in joints leading to all sorts more problems Aspiration causing pneumonias and inability to communicate via voice . Participant 49

In relation to sub-group variations, participants with a high school or trade education (15.38%), low physical function(25.00%) and low social functioning (26.67%) described severe side effects as effects limiting their daily activities for an extended period of time, less frequently than the general population (38.00%), while those with a university education (62.50%), high physical function (54.44%), high social functioning (55.00%), high general health (50.00%) and hearing impairment (50.00%) described this more frequently.

Table 5.5: Description of severe side effects

Description of severe side effects	All participants		Metropolitan		Rural		SEIFA (High)		SEIFA (Low)	
	n=50	%	n=30	%	n=20	%	n=27	%	n=23	%
Participant describes severe side effects as effects limiting their daily activities for an extended period of time	19	38.00	11	36.67	8	40.00	9	33.33	10	43.48
Participant describes severe side effects as severe fatigue	9	18.00	4	13.33	5	25.00	5	18.52	4	17.39
Participant describes severe side effects as an effect requiring hospitalisation or medical attention/permanent damage, or a life threatening effect or inability to function	7	14.00	5	16.67	2	10.00	4	14.81	3	13.04
Participant describes severe side effects as chronic headaches	4	8.00	2	6.67	2	10.00	2	7.41	2	8.70
Participant describes severe side effects as loss of mobility or independence	4	8.00	1	3.33	3	15.00	2	7.41	2	8.70
Participant describes severe side effects as diarrhoea or nausea that affects the whole body	3	6.00	1	3.33	2	10.00	1	3.70	2	8.70
Participant describes severe side effects as cardiovascular issues such as shortness of breath and irregular heart rhythm	3	6.00	1	3.33	2	10.00	1	3.70	2	8.70

Description of severe side effects	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 severe side effects as effects limiting their daily activities for an extended period of time	19	38.00	4	15.38	15	62.50	12	50.00	11	32.35
Participant describes severe side effects as severe fatigue	9	18.00	4	15.38	5	20.83	4	16.67	7	20.59
Participant describes severe side effects as an effect requiring hospitalisation or medical attention/permanent damage, or a life threatening effect or inability to function	7	14.00	4	15.38	3	12.50	5	20.83	3	8.82
Participant describes severe side effects as chronic headaches	4	8.00	3	11.54	1	4.17	2	8.33	3	8.82
Participant describes severe side effects as loss of mobility or independence	4	8.00	2	7.69	2	8.33	1	4.17	3	8.82
Participant describes severe side effects as diarrhoea or nausea that affects the whole body	3	6.00	3	11.54	0	0.00	1	4.17	3	8.82
Participant describes severe side effects as cardiovascular issues such as shortness of breath and irregular heart rhythm	3	6.00	3	11.54	0	0.00	0	0.00	3	8.82

Description of severe side effects	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 severe side effects as effects limiting their daily activities for an extended period of time	19	38.00	12	54.55	7	25.00	11	42.31	8	33.33
Participant describes severe side effects as severe fatigue	9	18.00	5	22.73	4	14.29	5	19.23	4	16.67
Participant describes severe side effects as an effect requiring hospitalisation or medical attention/permanent damage, or a life threatening effect or inability to function	7	14.00	1	4.55	6	21.43	3	11.54	4	16.67
Participant describes severe side effects as chronic headaches	4	8.00	2	9.09	2	7.14	1	3.85	3	12.50
Participant describes severe side effects as loss of mobility or independence	4	8.00	0	0.00	4	14.29	2	7.69	2	8.33
Participant describes severe side effects as diarrhoea or nausea that affects the whole body	3	6.00	0	0.00	3	10.71	1	3.85	2	8.33
Participant describes severe side effects as cardiovascular issues such as shortness of breath and irregular heart rhythm	3	6.00	1	4.55	2	7.14	2	7.69	1	4.17

Description of severe side effects	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 severe side effects as effects limiting their daily activities for an extended period of time	19	38.00	11	55.00	8	26.67	11	50.00	8	28.57
Participant describes severe side effects as severe fatigue	9	18.00	5	25.00	4	13.33	5	22.73	4	14.29
Participant describes severe side effects as an effect requiring hospitalisation or medical attention/permanent damage, or a life threatening effect or inability to function	7	14.00	1	5.00	6	20.00	0	0.00	7	25.00
Participant describes severe side effects as chronic headaches	4	8.00	2	10.00	2	6.67	0	0.00	4	14.29
Participant describes severe side effects as loss of mobility or independence	4	8.00	1	5.00	3	10.00	2	9.09	2	7.14
Participant describes severe side effects as diarrhoea or nausea that affects the whole body	3	6.00	1	5.00	2	6.67	1	4.55	2	7.14
Participant describes severe side effects as cardiovascular issues such as shortness of breath and irregular heart rhythm	3	6.00	1	5.00	2	6.67	2	9.09	1	3.57

Description of severe side effects	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 severe side effects as effects limiting their daily activities for an extended period of time	19	38.00	1	16.67	7	50.00	5	55.56	3	27.27	3	30.00
Participant describes severe side effects as severe fatigue	9	18.00	1	16.67	2	14.29	1	11.11	4	36.36	1	10.00
Participant describes severe side effects as an effect requiring hospitalisation or medical attention/permanent damage, or a life threatening effect or inability to function	7	14.00	1	16.67	3	21.43	1	11.11	1	9.09	1	10.00
Participant describes severe side effects as chronic headaches	4	8.00	0	0.00	1	7.14	1	11.11	1	9.09	1	10.00
Participant describes severe side effects as loss of mobility or independence	4	8.00	1	16.67	1	7.14	0	0.00	1	9.09	1	10.00
Participant describes severe side effects as diarrhoea or nausea that affects the whole body	3	6.00	0	0.00	1	7.14	1	11.11	0	0.00	1	10.00
Participant describes severe side effects as cardiovascular issues such as shortness of breath and irregular heart rhythm	3	6.00	1	16.67	1	7.14	0	0.00	1	9.09	0	0.00

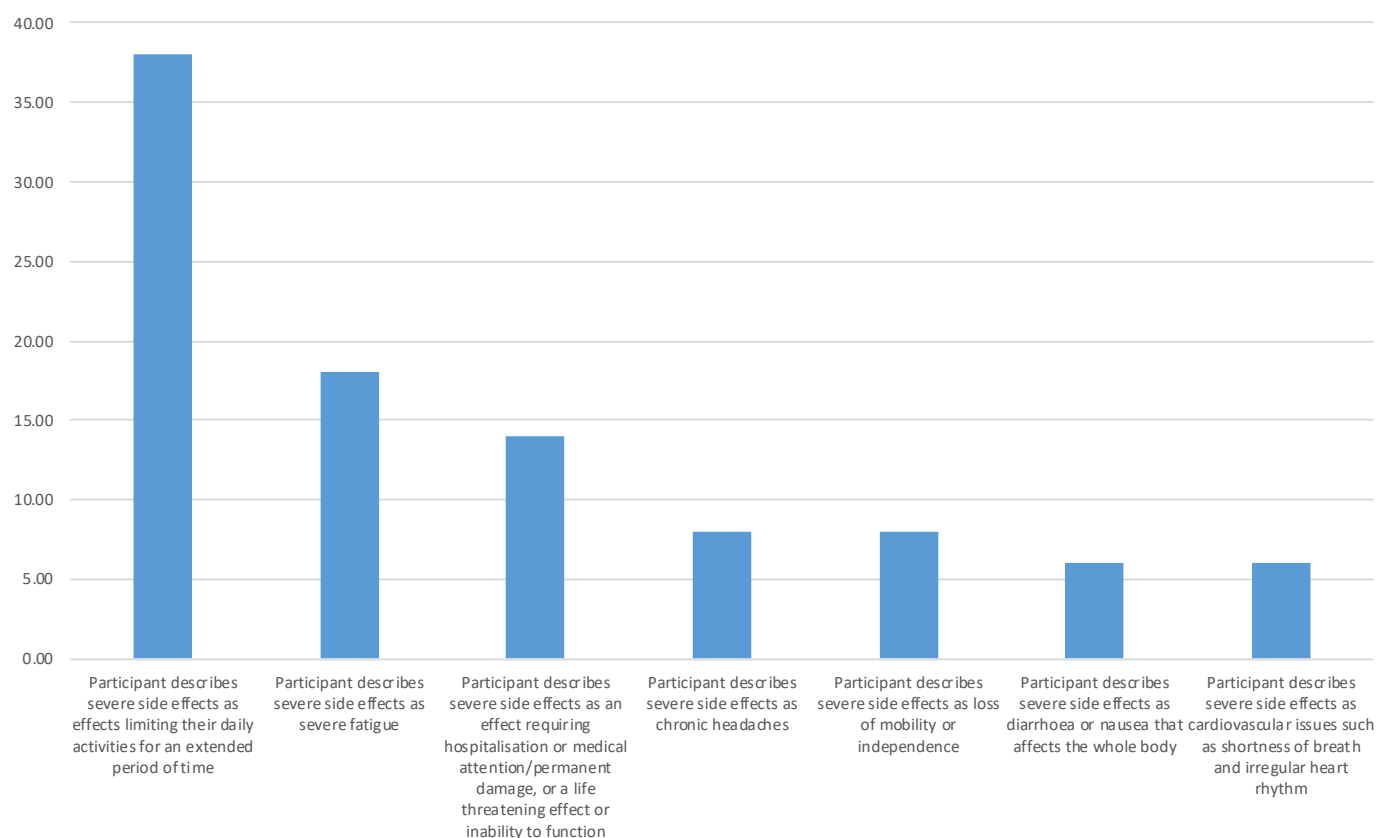


Figure 5.7: Description of severe side effects (% of all participants)

Adherence to medications

Participants were asked in the online questionnaire, if in general, if they were good at taking medicine and sticking to it. The majority of participants were good at sticking to treatments all of the time (n=30, 60.00%) and the remaining were good at sticking to treatments most of the time (n=20, 40.00%). No participants felt they were never, rarely or sometimes good at sticking to treatments.

Table 5.6: Participants ability to stick with treatments

Participant very good at sticking to taking medicine	N=50	Percentage of participants
Never	0	0.00
Rarely	0	0.00
Sometimes	0	0.00
Most of the time	20	40.00
All of the time	30	60.00

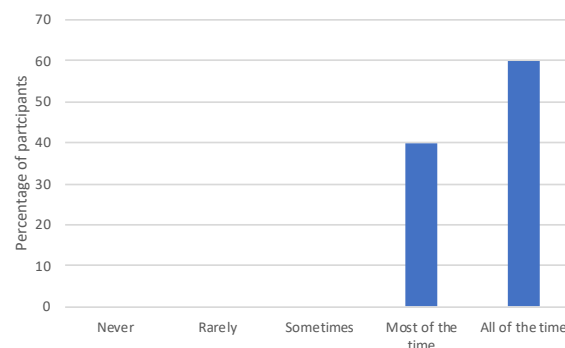


Figure 5.8: Participants ability to stick with treatments

Participants were also asked in the structured interview how long they stick with a therapy before they think it might not be working or give up on it. Close to half of all participants (n=24, 48.00%) describes using treatment for a period of one to three months before deciding if its working.

Participant describes continuing a treatment indefinitely or as recommended by clinician

It would depend on the outcome, the benefits. If somebody said this one stick with all these terrible side effects for six months because we know at the end it will all be good, then I'll stick with it. Participant 3

I always keep doing it unless the doctors tell me otherwise. Participant 9

I'd actually persevere with it for as long as ... I mean, you're right to say I'm looking to the future with this one because we have really experienced that sort of chance but I guess an example if I'm to look back to the concoctions that he's on, I just ... as long as I know that something can't give him any hurt, like be harmful to him I always continue on with it. Participant 45

The next most common theme was continuing a treatment indefinitely or as recommended by clinician/specialist (n=9, 18.00%) and there were six participants (12.00%) that described not trying new medications for mitochondrial disease and such not knowing how long they would continue a treatment.

Participant describes continuing a treatment indefinitely or as recommended by clinician

It would depend on the outcome, the benefits. If somebody said this one stick with all these terrible side effects for six months because we know at the end it will all be good, then I'll stick with it. Participant 3

I always keep doing it unless the doctors tell me otherwise. Participant 9

I'd actually persevere with it for as long as ... I mean, you're right to say I'm looking to the future with this one because we have really experienced that sort of chance but I guess an example if I'm to look back to the concoctions that he's on, I just ... as long as I know that something can't give him any hurt, like be harmful to him I always continue on with it. Participant 45

Participant describes not trying new medications for mitochondrial disease and such not knowing how long they would continue a treatment

I haven't really. Nothing new has been tried since 2012. Like when Neurontin and Lyrica and the other one didn't work, they started on the Oxycontin. It went up to increments and down. They weren't doing anything. They were but I was finding by about 10...11 in the morning that the extreme pain has started to creep back in. I normally have two Panadeine for around that time now. But that's it. My medication hasn't increased now in three years, I've been on the same dose. Participant 18

I don't. It's not applicable for me because I've never had treatments for mito. Generally, as a person, I'm very good at sticking at things and making decisions

about where I should go, especially on things like, mental, I don't know what you call them, states. Participant 20

I haven't tried any other medication. Everything else has been supplements. Participant 24

In relation to sub-group variations, participants from rural areas (30.00%) and participants with a hearing impairment (29.17%) reported continuing a treatment indefinitely or as recommended by clinician/specialist more frequently than the general population (18.00%). Participants with a hearing impairment (29.17%) reported using treatment for a period of one to three months before deciding if its working less frequently than the general population (48.00%), while those with high social functioning (60.00%) and high general health (59.09%) reported this more frequently.

Table 5.7: How long patients stick to a therapy

Adherence to treatment	All participants		Metropolitan		Rural		SEIFA (High)		SEIFA (Low)	
	n=50	%	n=30	%	n=20	%	n=27	%	n=23	%
Participant describes using treatment for a period of one to three months before deciding if its working	24	48.00	15	50.00	9	45.00	11	40.74	13	56.52
Participant describes continuing a treatment indefinitely or as recommended by clinician/specialist	9	18.00	3	10.00	6	30.00	5	18.52	4	17.39
Participant describes not trying new medications for mitochondrial disease and such not knowing how long they would continue a treatment	6	12.00	5	16.67	1	5.00	5	18.52	1	4.35
Participant describes the time period varying depending on what the treatment is, however if it is causing severe discomfort then they would cease	4	8.00	4	13.33	0	0.00	3	11.11	1	4.35
Participant describes continuing a treatment indefinitely unless there is a severe reaction	2	4.00	1	3.33	1	5.00	2	7.41	0	0.00

Adherence to treatment	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 using treatment for a period of one to three months before deciding if its working	24	48.00	13	50.00	11	45.83	7	29.17	18	52.94
Participant describes continuing a treatment indefinitely or as recommended by clinician/specialist	9	18.00	3	11.54	6	25.00	7	29.17	7	20.59
Participant describes not trying new medications for mitochondrial disease and such not knowing how long they would continue a treatment	6	12.00	3	11.54	3	12.50	3	12.50	4	11.76
Participant describes the time period varying depending on what the treatment is, however if it is causing severe discomfort then they would cease	4	8.00	3	11.54	1	4.17	2	8.33	2	5.88
Participant describes continuing a treatment indefinitely unless there is a severe reaction	2	4.00	1	3.85	1	4.17	2	8.33	1	2.94

Adherence to treatment	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 using treatment for a period of one to three months before deciding if its working	24	48.00	10	45.45	14	50.00	15	57.69	9	37.50
Participant describes continuing a treatment indefinitely or as recommended by clinician/specialist	9	18.00	6	27.27	3	10.71	6	23.08	3	12.50
Participant describes not trying new medications for mitochondrial disease and such not knowing how long they would continue a treatment	6	12.00	2	9.09	4	14.29	3	11.54	3	12.50
Participant describes the time period varying depending on what the treatment is, however if it is causing severe discomfort then they would cease	4	8.00	2	9.09	2	7.14	1	3.85	3	12.50
Participant describes continuing a treatment indefinitely unless there is a severe reaction	2	4.00	2	9.09	0	0.00	1	3.85	1	4.17

Adherence to treatment	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 using treatment for a period of one to three months before deciding if its working	24	48.00	12	60.00	12	40.00	13	59.09	11	39.29
Participant describes continuing a treatment indefinitely or as recommended by clinician/specialist	9	18.00	5	25.00	4	13.33	5	22.73	4	14.29
Participant describes not trying new medications for mitochondrial disease and such not knowing how long they would continue a treatment	6	12.00	2	10.00	4	13.33	2	9.09	4	14.29
Participant describes the time period varying depending on what the treatment is, however if it is causing severe discomfort then they would cease	4	8.00	0	0.00	4	13.33	1	4.55	3	10.71
Participant describes continuing a treatment indefinitely unless there is a severe reaction	2	4.00	2	10.00	0	0.00	1	4.55	1	3.57

Adherence to treatment	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 using treatment for a period of one to three months before deciding if its working	24	48.00	3	50.00	7	50.00	4	44.44	5	45.45	5	50.00
Participant describes continuing a treatment indefinitely or as recommended by clinician/specialist	9	18.00	1	16.67	4	28.57	2	22.22	1	9.09	1	10.00
Participant describes not trying new medications for mitochondrial disease and such not knowing how long they would continue a treatment	6	12.00	0	0.00	1	7.14	1	11.11	3	27.27	1	10.00
Participant describes the time period varying depending on what the treatment is, however if it is causing severe discomfort then they would cease	4	8.00	2	33.33	1	7.14	0	0.00	0	0.00	1	10.00
Participant describes continuing a treatment indefinitely unless there is a severe reaction	2	4.00	0	0.00	0	0.00	0	0.00	1	9.09	1	10.00

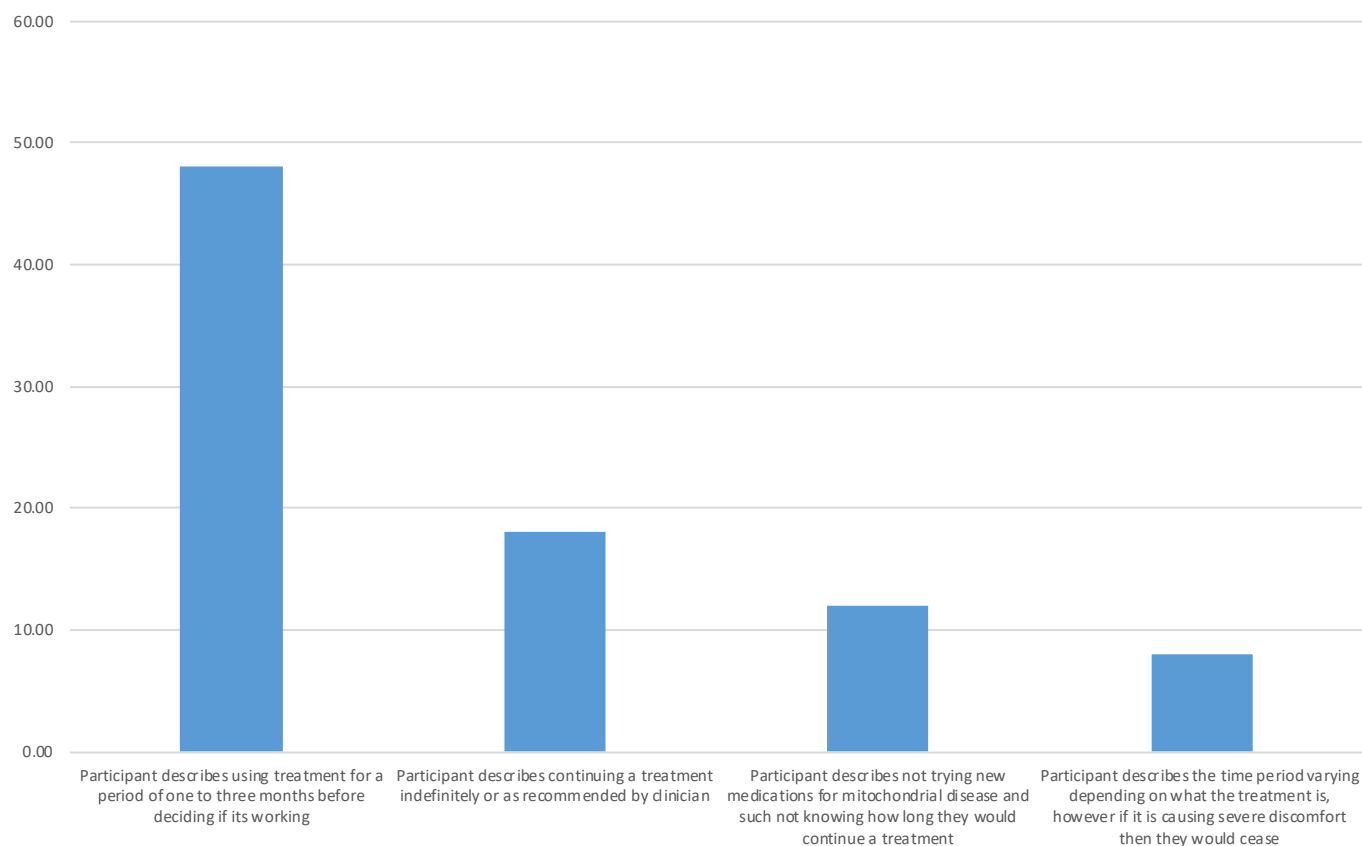


Figure 5.9: How long patients stick to a therapy (% of all participants)

Impact of treatment

Participants were asked what needed to change for them to feel as though a treatment was working. The most common description was needing to feel more energetic, and increase in physical ability, to know a treatment is working (n=20, 40.00%).

Participant describes needing to feel more energetic, and increase in physical ability, to know a treatment is working

Well, changing my energy levels and fatigue level. That is a big benefit to me. I'd also walk long distances. All I can do at present is walking the pool, which I was doing, and a bit of therapy. Walking unaided down the street, when I walk about 15 meters and I would need a rest, whatever. (An improvement of that would mean it has improved?) Yes, and get up stairs, too. That would be a big benefit. I used to get up the stairs using my hands on the armrest, can't do that now. Participant 6

If I felt better. [chuckles] If I wasn't so bloody tired all the time. Participant 10

I would hope that I have more energy. I think that's the first thing, it's just to feel like I've got more energy in me and be able to do things. I guess that's the main thing because that's where it all falls apart. Just being able to get through the day without feeling really tired and exhausted, being able to just get home and do things longer but yes, it's the energy factor I think for me, I'm looking for. Participant 26

My energy levels would be one thing. The biggest...I'd like to be able to not be so tired...We went back to school and within about 10 minutes of being there, I thought I hadn't been on holidays at all. I spent one day doing some gardening at home and it took me about three weeks to get over the fact that I've done that. Participant 38

This was followed by needing to see improved symptoms by clinical measurement (test result) (n=13, 26.00%) and needing to generally feel better to know that a treatment is working (n=9, 13.00%).

Participant describes improved symptoms by clinical measurement (test result)

I suppose, I would usually have the blood test, definitely. If I feel a lot better, then that's a good thing. Now I'm just taking the tablets I told you, Q10. Participant 1

Everything is got to have a benefit. If it's not working, if it's not getting a result whether that be something that can be measured by way of blood tests or

whether it's a feeling of not feeling right on it, get off it. It's not working. Participant 2

When they review it and ask me how it's gone. "Yes, that's good. I haven't had an episode for so and so." Participant 29

Participant describes needing to generally feel better to know that a treatment is working

Anything that could improve how you feel and, you know, reduce the lactic acidosis. Anything that you actually feel ... Health. Health is, of course, you know, in long term, you know? Participant 15

Normally energy. My mood will change so I'll either feel happy or better. I can just feel a difference within. I know it sounds stupid but I know when I don't have my antidepressant I feel more grumpy and Mum's like, "You only haven't had it for one day." I'm like, "I just feel it." Participant 26

Well, I guess, I have had some improvement in energy and in general, like just every day like sleep and I look better and I generally feel better. Participant 47

There were five participants (10.00%) that described needing to reduce pain to know a treatment is working and five participants (10.00%) needing to improve their quality of life to know a treatment is working.

Participant describes needing to reduce pain to know a treatment is working

The extreme soreness. I don't know how to explain it, but I'm so sore to touch. If the grandchildren grab me on the arm or something, and they are only little, if they do, oh goodness. It sends me through the roof. Just so sore. Participant 18

That would be dropping the level of pain, or the pain might seem to go well. Participant 23

To be without chronic pain, chronic fatigue is a big part of it, to be without those two things as much as possible. Participant 35

Participant describes needing to improve their quality of life to know a treatment is working

My quality of life, so my capacity to perhaps have increased mobility, better finer motor skills. Participant 7

I will continue with a treatment when I can see a measurable reduction in symptoms and/or improvement in a quality of life symptom. Participant 30

I guess the quality of life. Just the fact that she doesn't crash as often or she has more energy. She can function, she can think without being so distressed because she gets brain fog and fatigue. Participant 49

In relation to sub-group variations, participants from metropolitan areas (26.67%) and participants from high socio-economic areas (25.93%) reported needing to feel more energetic, and increase in physical ability, to know a treatment is working, less frequently than the general population (40.00%) while participants from rural areas (60.00%), participants from low socio-economic areas (56.52%). Participants with a hearing

impairment (41.67%) reported improved symptoms by clinical measurement (test result) more frequently than the general population (26.00%). Participants with high physical functioning (31.82%) described needing to generally feel better to know that a treatment is working, more frequently than the general population (18.00%).

Table 5.8: What needs to change to know a treatment has worked

What needs to change to feel like treatment is effective	All participants		Metropolitan		Rural		SEIFA (High)		SEIFA (Low)	
	n=50	%	n=30	%	n=20	%	n=27	%	n=23	%
Participant describes needing to feel more energetic, and increase in physical ability, to know a treatment is working	20	40.00	8	26.67	12	60.00	7	25.93	13	56.52
Participant describes improved symptoms by clinical measurement (test result)	13	26.00	9	30.00	4	20.00	9	33.33	4	17.39
Participant describes needing to generally feel better to know that a treatment is working	9	18.00	7	23.33	2	10.00	6	22.22	3	13.04
Participant describes needing to reduce pain to know a treatment is working	5	10.00	1	3.33	4	20.00	1	3.70	4	17.39
Participant describes needing to improve their quality of life to know a treatment is working	5	10.00	3	10.00	2	10.00	3	11.11	2	8.70

What needs to change to feel like treatment is effective	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 needing to feel more energetic, and increase in physical ability, to know a treatment is working	20	40.00	10	38.46	10	41.67	8	33.33	17	50.00
Participant describes improved symptoms by clinical measurement (test result)	13	26.00	5	19.23	8	33.33	10	41.67	6	17.65
Participant describes needing to generally feel better to know that a treatment is working	9	18.00	5	19.23	4	16.67	4	16.67	7	20.59
Participant describes needing to reduce pain to know a treatment is working	5	10.00	3	11.54	2	8.33	3	12.50	2	5.88
Participant describes needing to improve their quality of life to know a treatment is working	5	10.00	2	7.69	3	12.50	3	12.50	2	5.88

What needs to change to feel like treatment is effective	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 needing to feel more energetic, and increase in physical ability, to know a treatment is working	20	40.00	7	31.82	13	46.43	12	46.15	8	33.33
Participant describes improved symptoms by clinical measurement (test result)	13	26.00	7	31.82	6	21.43	9	34.62	4	16.67
Participant describes needing to generally feel better to know that a treatment is working	9	18.00	7	31.82	2	7.14	7	26.92	2	8.33
Participant describes needing to reduce pain to know a treatment is working	5	10.00	3	13.64	2	7.14	1	3.85	4	16.67
Participant describes needing to improve their quality of life to know a treatment is working	5	10.00	0	0.00	5	17.86	2	7.69	3	12.50

What needs to change to feel like treatment is effective	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 needing to feel more energetic, and increase in physical ability, to know a treatment is working	20	40.00	10	50.00	10	33.33	7	31.82	13	46.43
Participant describes improved symptoms by clinical measurement (test result)	13	26.00	6	30.00	7	23.33	6	27.27	7	25.00
Participant describes needing to generally feel better to know that a treatment is working	9	18.00	5	25.00	4	13.33	4	18.18	5	17.86
Participant describes needing to reduce pain to know a treatment is working	5	10.00	1	5.00	4	13.33	2	9.09	3	10.71
Participant describes needing to improve their quality of life to know a treatment is working	5	10.00	0	0.00	5	16.67	1	4.55	4	14.29

What needs to change to feel like treatment is effective	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 needing to feel more energetic, and increase in physical ability, to know a treatment is working	20	40.00	3	50.00	5	35.71	5	55.56	4	36.36	3	30.00
Participant describes improved symptoms by clinical measurement (test result)	13	26.00	0	0.00	3	21.43	5	55.56	3	27.27	2	20.00
Participant describes needing to generally feel better to know that a treatment is working	9	18.00	2	33.33	4	28.57	2	22.22	1	9.09	0	0.00
Participant describes needing to reduce pain to know a treatment is working	5	10.00	0	0.00	1	7.14	1	11.11	1	9.09	2	20.00
Participant describes needing to improve their quality of life to know a treatment is working	5	10.00	1	16.67	3	21.43	0	0.00	1	9.09	0	0.00

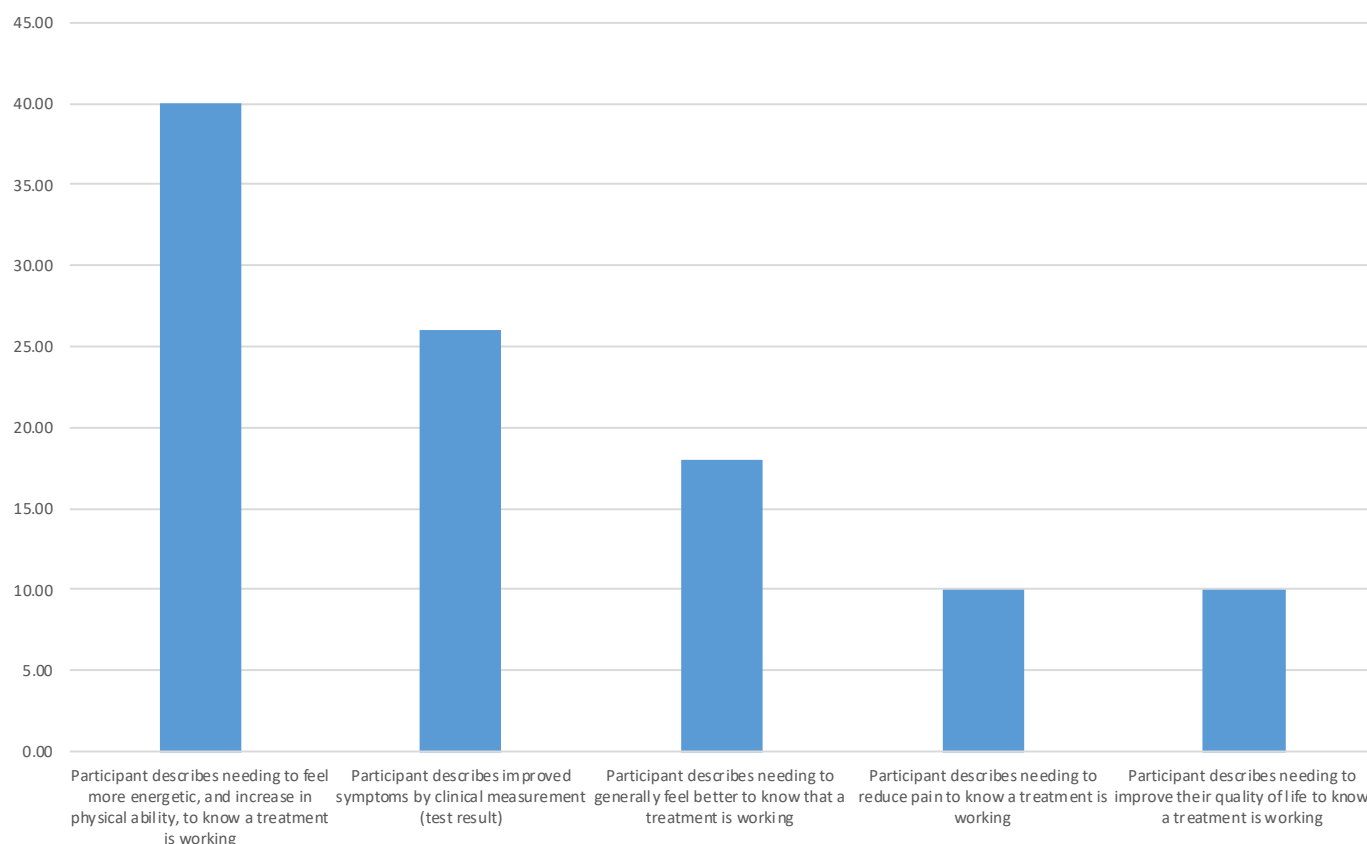


Figure 5.10: What needs to change to know a treatment has worked

Use of complementary therapies

Participants were asked whether they had used any complementary therapies. The most common therapies that were considered complementary and described by participants were vitamins, minerals and supplements (n=14, 28.00%) and allied health e.g. physiotherapy (including massage and hydrotherapy), speech therapy, occupational therapy (n=14, 14.00%).

Participant describes taking vitamin, mineral and various supplements

Yes. I've taken magnesium tablets from time to time in the hope that that'll make me feel better. [laughs] They don't really work very well, though. They may sometimes though. No, not really. Participant 10

I tried creatine. I was told creatine helps. Folic acid as well. There are few studies on folic acid. I had like a sort of cocktail going on for a while. Creatine, folic acid, CoQ10 and L-carnitine. That was about it. Participant 11

I'm just trialling some turmeric. I know it's not proven or anything, but I thought I'd ... I don't go back to my Rheumatologist until July, so I'm hoping if I tried turmeric daily, and it makes any difference I'd be able to say to him, "I don't like your choices, I'll stick with the turmeric for a while." But ask me that at the end of July. Participant 36

Participant describes having a form of allied health e.g. physiotherapy (including massage and hydrotherapy), speech therapy, occupational therapy

I did do physio for a bit. Then that wasn't really helping in the sense that I wasn't getting any pain relief from that because I did get a lot of muscle pain. Participant 1

I gave massage a go but my massage therapist was honest with me and said that I had no muscle left, and that massage wasn't going to work for me. Participant 12

I tried all sorts of things to get rid of the migraines and also physiotherapy but perhaps, the physiotherapy

wasn't exactly targeted to the muscles. I'm looking at starting physiotherapy for that to maintain my muscle strength. Participant 26

Right. Yes. Massages, I find helpful because I get a lot of muscle soreness and sore neck and shoulders and things like that. I do find that it just gives you a general feeling of well being, but also it just reduces the discomfort. Yes, I do find that good. Participant 34

The next most frequent complementary therapies described were alternative medicine, e.g. osteopathy, acupuncture, chiropractor, Bowen therapy (n=12, 24.00%).

Participant describes having a form of alternative medicine, e.g. osteopathy, acupuncture, chiropractor, Bowen therapy

I have a lot of osteopath appointments and she tries to alter my migraines and fix through soft manipulation on my head and on my back. Participant 19

Yes, because I initially had headaches or migraines. Something around the time that I lost my hearing but again, I'm not 100% sure that it's related but I think it is. I tried acupuncture for that. Participant 26

All we've ever used for her was chiropractic. That was good at the times that we used it. It was good. We're reluctant to because we don't have anyone to help us assess her at the moment and her muscles and bones have worsened quite a lot. The chiropractors and everyone said that they'd be happy to work with someone that can be guided. Even they notice the difference. Participant 49

There were also 11 participants (22.00%) that noted that they did not use any complementary therapies.

Table 5.9: Use of complementary therapies

Use of complementary therapies	All participants		Metropolitan		Rural		SEIFA (High)		SEIFA (Low)	
	n=50	%	n=30	%	n=20	%	n=27	%	n=23	%
Participant describes taking vitamin, mineral and various supplements	14	28.00	7	23.33	7	35.00	9	33.33	5	21.74
Participant describes having a form of allied health e.g. physiotherapy (including massage and hydrotherapy), speech therapy, occupational therapy	14	28.00	9	30.00	5	25.00	7	25.93	7	30.43
Participant describes having a form of alternative medicine, e.g. osteopathy, acupuncture, chiropractor, Bowen therapy	12	24.00	7	23.33	5	25.00	5	18.52	7	30.43
Participant describes not trying any complementary medicines	11	22.00	8	26.67	3	15.00	7	25.93	4	17.39

Use of complementary therapies	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 taking vitamin, mineral and various supplements	14	28.00	8	30.77	6	25.00	5	20.83	9	26.47
Participant describes having a form of allied health e.g. physiotherapy (including massage and hydrotherapy), speech therapy, occupational therapy	14	28.00	6	23.08	8	33.33	6	25.00	12	35.29
Participant describes having a form of alternative medicine, e.g. osteopathy, acupuncture, chiropractor, Bowen therapy	12	24.00	6	23.08	6	25.00	6	25.00	9	26.47
Participant describes not trying any complementary medicines	11	22.00	5	19.23	6	25.00	6	25.00	6	17.65

Use of complementary therapies	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 taking vitamin, mineral and various supplements	14	28.00	5	22.73	9	32.14	9	34.62	5	20.83
Participant describes having a form of allied health e.g. physiotherapy (including massage and hydrotherapy), speech therapy, occupational therapy	14	28.00	5	22.73	9	32.14	7	26.92	7	29.17
Participant describes having a form of alternative medicine, e.g. osteopathy, acupuncture, chiropractor, Bowen therapy	12	24.00	7	31.82	5	17.86	6	23.08	6	25.00
Participant describes not trying any complementary medicines	11	22.00	5	22.73	6	21.43	5	19.23	6	25.00

Use of complementary therapies	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 taking vitamin, mineral and various supplements	14	28.00	5	25.00	9	30.00	7	31.82	7	25.00
Participant describes having a form of allied health e.g. physiotherapy (including massage and hydrotherapy), speech therapy, occupational therapy	14	28.00	7	35.00	7	23.33	4	18.18	10	35.71
Participant describes having a form of alternative medicine, e.g. osteopathy, acupuncture, chiropractor, Bowen therapy	12	24.00	5	25.00	7	23.33	6	27.27	6	21.43
Participant describes not trying any complementary medicines	11	22.00	4	20.00	7	23.33	6	27.27	5	17.86

Use of complementary therapies	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 taking vitamin, mineral and various supplements	14	28.00	2	33.33	4	28.57	0	0.00	5	45.45	3	30.00
Participant describes having a form of allied health e.g. physiotherapy (including massage and hydrotherapy), speech therapy, occupational therapy	14	28.00	2	33.33	6	42.86	2	22.22	2	18.18	2	20.00
Participant describes having a form of alternative medicine, e.g. osteopathy, acupuncture, chiropractor, Bowen therapy	12	24.00	3	50.00	4	28.57	1	11.11	1	9.09	3	30.00
Participant describes not trying any complementary medicines	11	22.00	1	16.67	1	7.14	4	44.44	2	18.18	3	30.00

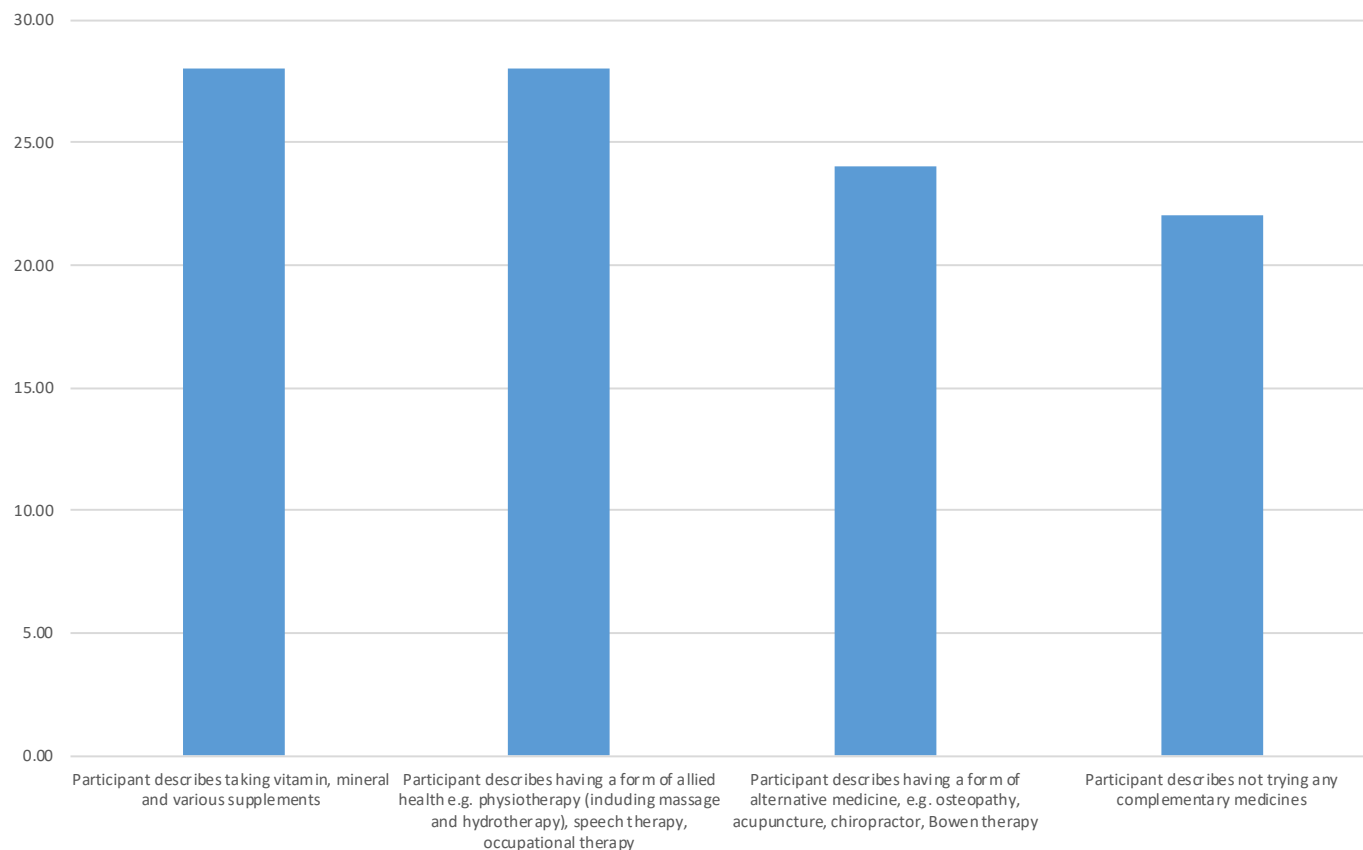


Figure 5.11: Use of complementary therapies (% of all participants)

Service provision and affordability

Details about the healthcare system, where participants were treated for mitochondrial disease and financial implications from treatment are listed in Tables 5.10 to 5.12.

The main physician treating participants for mitochondrial disease were general practitioners (N=19, 38.00%), followed by neurologists (N=12, 24.00%) and mitochondrial specialists (N=11, 22.00%).

Participants had access to a general practitioner (n=48, 96.00%), neurologist (n=43, 86.00%), mitochondrial specialist (n=29, 58.00%) and cardiologist (n=28, 56.00%) for the treatment of their mitochondrial disease.

The majority of patients had private healthcare insurance (n=37, 74.00%), 29 (58.00%) participants were treated as public patients, 12 (24.00%) as private

patients and 9 (18.00%) as equally public and private patients. The majority of participants were treated in the public hospital system (n=32, 64.00%).

Almost half of participants have never missed medical appointments due to cost (n=24, 48.00%), and most have never been unable to afford prescription medications (n=34, 64.00%). Almost half of participants have found it somewhat to extremely difficult paying for basic needs due to their diagnosis with mitochondrial disease (n=24, 48.00%).

The work status for a number of participants changed due to their diagnosis with mitochondrial disease with about a quarter of participants reducing the number of hours worked (n=13, 26.00%), and 19 (38.00%) quitting their jobs (Table 5.12). Of those that had a partner or carer, four carers/partners had to quit their job (23.53%), seven had to reduce the number of hours worked (41.18%), carers have had to take leave either with pay (n=2, 11.76%), or without pay (n=5, 29.41%).

Table 5.10: Provider of treatment

Health professional	N=50	Percent
General practitioner	19	38.00
Neurologist	12	24.00
Mitochondrial specialist	11	22.00
Geneticist	2	4.00
Metabolic Medicine	2	4.00
Endocrinologist	1	2.00
Functional medicine specialist	1	2.00
neuro-ophthalmologist	1	2.00
Not currently receiving treatment or management	1	2.00

Table 5.11: Access to health services

Access to health professionals	N=50	%
General Practitioner	48	96.00
Neurologist	43	86.00
Mitochondrial specialist	29	58.00
Cardiologist/Heart specialist	28	56.00
Gastroenterologist/Digestive system specialist	25	50.00
Physiotherapy	25	50.00
Dietitian	24	48.00
Geneticist	23	46.00
Counselling or psychological support	19	38.00
Occupational therapy	17	34.00
Registered Nurse	17	34.00
Endocrinologist/diabetes,hormone, thyroid specialist	14	28.00
Psychiatrist	13	26.00
Respiratory physician	12	24.00
Genetic counsellor	11	22.00
Nephrologist/Kidney specialist	9	18.00
Ophthalmologist	8	16.00
Paediatrician	8	16.00
Hepatologist/Liver specialist	4	8.00
Audiologist	3	6.00
Pain Specialist	2	4.00
Chiro and myotherapy	1	2.00
Dentist	1	2.00
ENT	1	2.00
Gynaecologist	1	2.00
Neuro-ophthalmologist	1	2.00
Orthopaedics	1	2.00
Rheumatologist	1	2.00
Sexual health physician	1	2.00
Social Worker	1	2.00

Table 5.12: Service provision and affordability

		N=50	Percent
Private health insurance	Yes	37	74.00
	No	13	26.00
Treated as public or private patient	Equally public and private	9	18.00
	Private	12	24.00
	Public	29	58.00
Primary hospital system treated in	Both public and private	10	20.00
	Private	8	16.00
	Public	32	64.00
Had to delay or cancel healthcare appointments due to affordability	Never	24	48.00
	Rarely	9	18.00
	Sometimes	13	26.00
	Often	3	6.00
	Very often	1	2.00
Unable to fill prescription due to cost	Never	34	68.00
	Rarely	9	18.00
	Sometimes	7	14.00
	Often	0	
	Very often	0	
Difficult to pay for basic needs as a result of mitochondrial disease diagnosis	Not at all difficult	19	38.00
	Slightly difficult	7	14.00
	Somewhat difficult	12	24.00
	Moderately difficult	8	16.00
	Extremely difficult	4	8.00
Change in employment due to mitochondrial disease (can choose more than one option)	I have accessed my Superannuation early due to my mitochondrial disease	6	12.00
	I have had to quit my job	19	38.00
	I have reduced the number of hours that I work	13	26.00
	I have taken leave from work with pay	4	8.00
	I have taken leave from work without pay	3	6.00
	I was retired or did not have a job when I was diagnosed with mitochondrial disease	13	26.00
	My work status has not changed since I was diagnosed with mitochondrial disease	10	20.00
Change in carer job status (can choose more than one option) (N=34)	My partner/main carer/other carer had to quit their job	4	23.53
	My partner/main carer/other carer reduced the number of hours that they work	7	41.18
	My partner/main carer/other carer took leave from work without pay	5	29.41
	My partner/main carer/other carer was retired or did not have a job	7	41.12
	My partner/main carer/other carer took leave from work with pay	2	11.76
	The employment status of my partner/main carer/other carer status has not changed	14	41.18
	I do not have a partner or other carer	16	

Monthly out of pocket expenses

Participants were asked what their monthly spend was on mitochondrial disease, four participants had no expenses (8.89%), 10 (22.22%) spent less than \$100, 17 (37.78%) spent more than \$100 but less than \$500, three (6.69%) spent between \$501 and \$1000 per month, and 11 (24.44%) spent more than \$1000 per month.

Table 5.13: Approximate monthly spend on mitochondrial disease

Monthly expenses (n=45)	N=	Percentage of participants
\$0	4	8.89
\$1 - \$100	10	22.22
\$101 - \$500	17	37.78
\$501-\$1000	3	6.69
>\$1000	11	24.44

Participants were then asked if their monthly spend due to mitochondrial disease was a significant burden, 20 participants found it to be extremely or moderately significant (40.00%), 20 participants found it somewhat or slightly significant (40.00%) and ten found not significant at all (20.00%).

Table 5.14: Burden of monthly spend on mitochondrial disease

Cost of monthly treatment a significant burden	N=50	Percent
Extremely significant	14	12.00
Moderately significant	6	16.00
Somewhat significant	16	10.00
Slightly significant	4	12.00
Not at all significant	10	50.00

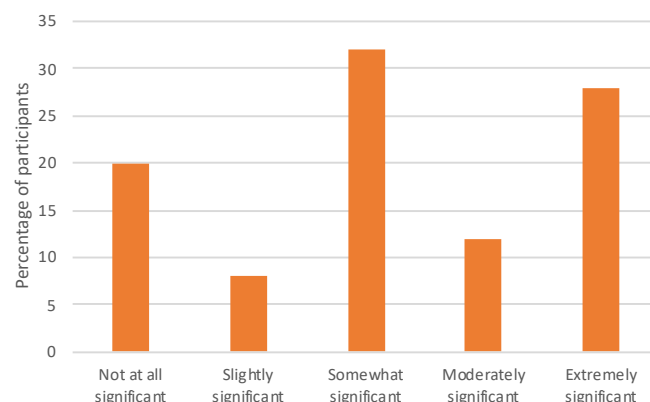


Figure 5.12: Burden of monthly spend on mitochondrial disease

Experience of respect during treatment

Participants were asked if they felt they had been treated with respectfully throughout their treatment. Half of the participants felt that they had been treated respectfully with the exception of one or two occasions (n=25, 50.00%), 18 felt that they had been treated respectfully (36.00%) and seven felt they had not been treated respectfully (14.00%).

Table 5.15: Participant feels that they have been treated respectfully throughout treatment

Have you been treated respectfully throughout your experience?	n=50	Percentage of participants
No	7	14.00
Yes	18	36.00
Yes, with the exception of one or two occasions	25	50.00

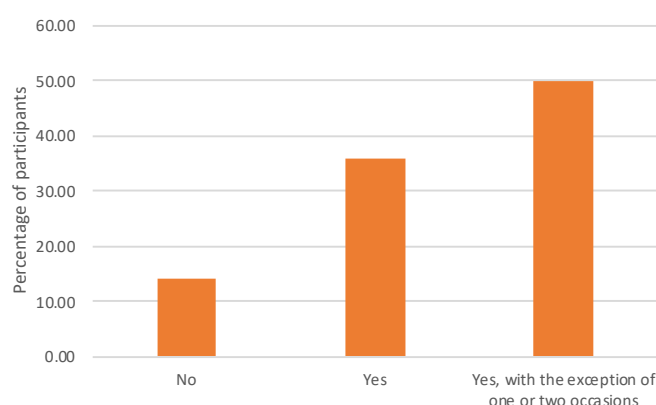


Figure 5.13: Participant feels that they have been treated respectfully throughout treatment