Section 4 Decision-making

Section 4: Experience of health professional communication

Conversations about treatments

- Participants were asked to describe the conversations they have had about mitochondrial disease treatment options. The most common treatments discussed were Coenzyme Q10 and ATP support (n=19, 38.00%). The next most common theme was that participants were told that there is no treatment for mitochondrial disease (n=16, 32.00%). Other themes included having no or little discussion about treatment options (n=9, 18.00%) and having discussions about lifestyle changes (diet, exercise etc.) (n=9, 18.00%).
- In relation to sub-group variations, participants with a university education (45.83%) reported being told that there were no treatments for mitochondrial disease, more frequently than the general population (32.00%)

Decision-making

- There were 16 participant (32.00%) that noted considering side effects, of which 10 participants noted a combination of both the benefits of the treatment as well as the side effects. The nest most common consideration was cost (n=9, 18.00%) followed by impact on lifestyle, including ability to work (n=6, 12.00%).
- In relation to sub-group variations, there were no participants from low socio-economic areas that reported considering the impact on their lifestyle (n=0, 0.00%) and there were no participants with high physical functioning (n=0, 0.00%) or high social functioning (n=0, 0.00%) that reported considering quality of life when making decisions about treatment.
- In the final question about decision-making, participants were asked whether they felt the way they made decisions had changed over time since they were diagnosed. Overall there were 26 participants (52.00%) that felt as though the way they make decisions has changed over time, while 20 participants (40.00%) felt that it had not changed.
- Where participants did feel as though the way they made decisions had changed, the most common reason for this was that they had become more informed (n=11, 22.00%) and that they consider quality of life more in the process of making treatment decisions (n=7, 14.00%).
- In relation to sub-group variations, participants from rural areas (25.00%) reported considering quality of life more frequently than the general population (14.00%).

Discussions about treatment

Participants were asked to describe the conversations they have had about mitochondrial disease treatment options. The most common treatments discussed were Coenzyme Q10 and ATP support (n=19, 38.00%).

Participant describes being told about supplements, such as Coenzyme Q10 and ATP support

Take CQ10 and, you know, don't do heavy exercise, and that was it. Yeah, so that was all that I ...There was no discussion about, you know, you can do this or have this done, or anything. Participant 15

I asked what could one do? And I was told that there was nothing. It was suggested that I take Magnesium Orotate, particularly the Orotate. Which I did. But at that point, there was nothing else. Subsequently Professor NAME and her team as medical scientists did develop ATP support. Which the recipe they gave to bioceuticals to compound the process. And it's now sold commercially. Participant 24

I remember they suggested when they were little, to go on this Coenzyme Q10, but it was just unaffordable back then. You were looking at $30 a bottle. Participant 44

The next most common theme was that participants were told that there is no treatment for mitochondrial disease (n=16, 32.00%).

Participant describes being told that they is no treatment for mitochondrial disease

He said there is no treatment and that it will probably, his initial words, just the CPEO part of it, he said, "It's probably not going to kill you, but it's going to become an inconvenience. You wouldn't be able to drive. You'll lose your license eventually", things like that. That there was no treatment…."There is no definitive treatment because everybody presents differently". There's no if I take it, this is going to slow it down, or take this, it's going to stop it. It's just basically roll with the punches. Very little for funding, don't expect a miracle cure. That was pretty well it. Participant 2

No treatments were offered to me in the early years, it was merely about the diagnosis. Later came attempts to treat individual symptoms…with varying degrees of success. I am generally the one who researches information and approaches my medical team about trying something. Participant 30

They basically told me that there was no treatment. They told me I could go on something called ATP Support, the bioceuticals. That's the only thing that I was offered. Participant 40

Other themes included having no or little discussion about treatment options (n=9, 18.00%) and having discussions about lifestyle changes (diet, exercise etc.) (n=9, 18.00%).

Participant describes having little to no discussion about treatment options during diagnosis

Okay. I had a bit of a conversation with a geneticist too. They did not really say much. The geneticist only said it was very tentative. This is what some people are doing and sometimes it works for them. But for the most part, I don't think I really had a thorough conversation with any healthcare provider about the treatment. They said to look after yourself when you're there. There wasn't really much out there neither….So they said play it by ear essentially. If so get tests on every year and if something becomes debilitating then we'll treat that. Participant 11

…they gave us a little bit of information and explained that it would be the fatigue again, the headaches. Now, he's just finally….on the migraine headache to try and get rid of pain. There wasn't really much discussion about anything at the start. Participant 19

Nothing about treatment at all, just given painkillers. Participant 31

Participant describes having a discussion about lifestyle changes, e.g. diet and exercise

They totally suggested things like a diet, so metabolic diet. I was on that, which was going to help with your energy and stuff like that. I was on that for a while, but then when I got sick this time, that's when they said no, that diet wasn't actually good for me because the food I got to eat was a big part of that diet. I stopped that, use the same diet. Participant 1

He said, "There is no real treatment, except that it would be useful to get some exercise going, to keep things in a stable condition." That's about all I got. Participant 17

And they did say diet. We always had a dietician with us. They changed his diet up a little bit, and said, "He can't fast, he has to have regular food intake. Try and get this type of food into him, and also exercise." They also really put exercise at the forefront, and they also put early intervention. So we actually got a pretty good ... given that there's no treatment as such that they know is effective, we actually got a pretty....They did, they really did, and I think that's part of the reason he's done so well. Not ... I mean, for some reason he has done well, but I think that's also been a major factor. Participant 46

In relation to sub-group variations, participants with a university education (45.83%) reported being told that there were no treatments for mitochondrial disease, more frequently than the general population (32.00%)

Table 4.1: Conversations about treatment

Conversations about treatment	**All participants**		**Metropolitan**		**Rural**		**SEIFA (High)**		**SEIFA (Low)**	
	n=50	**%**	**n=30**	**%**	**n=20**	**%**	**n=27**	**%**	**n=23**	**%**
Participant describes being told about supplements, such as Coenzyme Q10 and ATP support	**19**	38.00	11	36.67	8	40.00	9	33.33	10	43.48
Participant describes being told that there is no treatment for mitochondrial disease	**16**	32.00	10	33.33	6	30.00	9	33.33	7	30.43
Participant describes having little to no discussion about treatment options during diagnosis	**9**	18.00	5	16.67	4	20.00	5	18.52	4	17.39
Participant describes having a discussion about lifestyle changes, e.g. diet and exercise	**9**	18.00	6	20.00	3	15.00	5	18.52	4	17.39

Conversations about 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 being told about supplements, such as Coenzyme Q10 and ATP support	**19**	38.00	11	42.31	8	33.33	9	37.50	15	44.12
Participant describes being told that there is no treatment for mitochondrial disease	**16**	32.00	5	19.23	11	**45.83**	10	41.67	10	29.41
Participant describes having little to no discussion about treatment options during diagnosis	**9**	18.00	5	19.23	4	16.67	3	12.50	5	14.71
Participant describes having a discussion about lifestyle changes, e.g. diet and exercise	**9**	18.00	4	15.38	5	20.83	3	12.50	7	20.59

Conversations about 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 being told about supplements, such as Coenzyme Q10 and ATP support	**19**	38.00	9	40.91	10	35.71	10	38.46	9	37.50
Participant describes being told that there is no treatment for mitochondrial disease	**16**	32.00	7	31.82	9	32.14	8	30.77	8	33.33
Participant describes having little to no discussion about treatment options during diagnosis	**9**	18.00	4	18.18	5	17.86	5	19.23	4	16.67
Participant describes having a discussion about lifestyle changes, e.g. diet and exercise	**9**	18.00	3	13.64	6	21.43	6	23.08	3	12.50

Conversations about 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 being told about supplements, such as Coenzyme Q10 and ATP support	**19**	38.00	9	45.00	10	33.33	9	40.91	10	35.71
Participant describes being told that there is no treatment for mitochondrial disease	**16**	32.00	6	30.00	10	33.33	8	36.36	8	28.57
Participant describes having little to no discussion about treatment options during diagnosis	**9**	18.00	5	25.00	4	13.33	4	18.18	5	17.86
Participant describes having a discussion about lifestyle changes, e.g. diet and exercise	**9**	18.00	4	20.00	5	16.67	4	18.18	5	17.86

Conversations about 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 being told about supplements, such as Coenzyme Q10 and ATP support	**19**	38.00	5	83.33	4	28.57	2	22.22	5	45.45	3	30.00
Participant describes being told that there is no treatment for mitochondrial disease	**16**	32.00	0	0.00	2	14.29	5	55.56	6	54.55	3	30.00
Participant describes having little to no discussion about treatment options during diagnosis	**9**	18.00	0	0.00	5	35.71	1	11.11	1	9.09	2	20.00
Participant describes having a discussion about lifestyle changes, e.g. diet and exercise	**9**	18.00	2	33.33	2	14.29	1	11.11	2	18.18	2	20.00

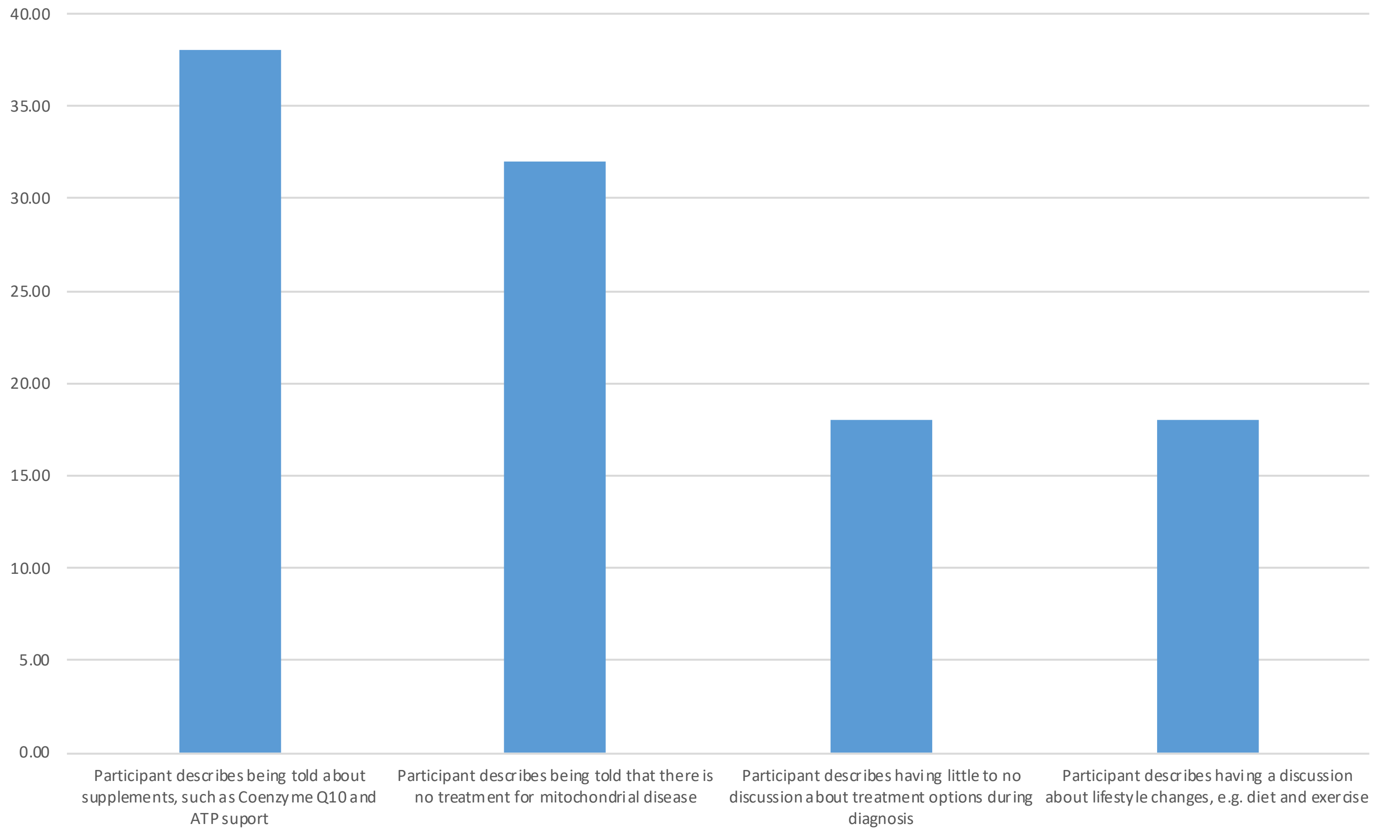

Figure 4.1: Conversations about treatment

Decision-making

What is considered when making decisions

Participants were asked about the things that they take into consideration when making decisions about treatment. There were 16 participant (32.00%) that noted considering side effects, of which 10 participants noted a combination of both the benefits of the treatment as well as the side effects.

Participant describes their main consideration as the side effects

Toxic. Like if it's adverse side effects. I do tend to ask the support groups, just joined a mitochondrial group on Facebook. And also, the United one, the one that's overseas, with the world group. Participant 18

More like how it will affect me long term and that's pretty much it really. How it will affect me personally like my health that kind of stuff really. Participant 38

Being aware of the medical aspects and medication and the contraindication with the condition. That's really important that doctors monitor that. I'm unaware of what could actually make this condition worse. Participant 42

Participant describes considering a combination of the benefits and side effects

The benefits, side effects. That'd be the two big things. What are the benefits going to be? Participant 2

What are the benefits? What are the negatives? If it's going to be…The benefit have to weigh out the negatives. Participant 8

Side effects mainly. Always check them out to see whether it's worth going through, that's all, nothing else. If they suggested something, you try to see if it helped. I always took a course of it or maybe two courses, that was it then if it wasn't doing any good, I wouldn't take it anymore. Participant 10

I would definitely be looking at how risky is something and whether it's worth the risk or not. Well, I'm not sure what the benefits would be if it helped. The risk, benefits, that's really. Participant 25

The nest most common consideration was cost (n=9, 18.00%) followed by impact on lifestyle, including ability to work (n=6, 12.00%).

Participant describes considering the impact on their lifestyle, including work

Obviously there's ramifications of it in terms of my lifestyle, because I live alone. That's the biggest one. Otherwise, I'm prepared to try anything. Participant 19

A second part will be, you know, I'm working full-time, so what effect that will have on me in my work life. They're the probably two considerations that I would have. Participant 21

Oh yes. Also like how it impacts my daily routine, like how long it takes. That's a lot to take into consideration. Participant 45

In relation to sub-group variations, there were no participants from low socio-economic areas that reported considering the impact on their lifestyle (n=0, 0.00%) and there were no participants with high physical functioning (n=0, 0.00%) or high social functioning (n=0, 0.00%) that reported considering quality of life when making decisions about treatment.

Table 4.2: Considerations when making decisions

Considerations when making decisions about treatment	All participants		Metropolitan		Rural		SEIFA (High)		SEIFA (Low)	
	n=50	%	n=30	%	n=20	%	n=27	%	n=23	%
Participant describes considering a combination of the benefits and side effects	10	20.00	5	16.67	5	25.00	4	14.81	6	26.09
Participant describes their main consideration as the side effects	6	12.00	5	16.67	1	5.00	4	14.81	2	8.70
Participant describes their main consideration as the evidence to support the use of the treatment (Efficacy)	10	20.00	5	16.67	5	25.00	5	18.52	5	21.74
Participant describes their main consideration as the cost of the treatment	9	18.00	7	23.33	2	10.00	5	18.52	4	17.39
Participant describes considering the impact on their lifestyle, including work	6	12.00	5	16.67	1	5.00	6	22.22	0	0.00
Participant describes taking the advice from the specialist with no specific considerations	5	10.00	4	13.33	1	5.00	3	11.11	2	8.70
Participant describes considering their quality of life when deciding on a treatment	5	10.00	2	6.67	3	15.00	2	7.41	3	13.04

Considerations when making decisions about 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 considering a combination of the benefits and side effects	10	20.00	7	26.92	3	12.50	5	20.83	7	20.59
Participant describes their main consideration as the side effects	6	12.00	2	7.69	4	16.67	4	16.67	3	8.82
Participant describes their main consideration as the evidence to support the use of the treatment (Efficacy)	10	20.00	3	11.54	7	29.17	6	25.00	6	17.65
Participant describes their main consideration as the cost of the treatment	9	18.00	5	19.23	4	16.67	4	16.67	7	20.59
Participant describes considering the impact on their lifestyle, including work	6	12.00	4	15.38	2	8.33	3	12.50	4	11.76
Participant describes taking the advice from the specialist with no specific considerations	5	10.00	3	11.54	2	8.33	2	8.33	4	11.76
Participant describes considering their quality of life when deciding on a treatment	5	10.00	2	7.69	3	12.50	3	12.50	2	5.88

Considerations when making decisions about 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 considering a combination of the benefits and side effects	10	20.00	4	18.18	6	21.43	5	19.23	5	20.83
Participant describes their main consideration as the side effects	6	12.00	2	9.09	4	14.29	5	19.23	1	4.17
Participant describes their main consideration as the evidence to support the use of the treatment (Efficacy)	10	20.00	5	22.73	5	17.86	6	23.08	4	16.67
Participant describes their main consideration as the cost of the treatment	9	18.00	2	9.09	7	25.00	6	23.08	3	12.50
Participant describes considering the impact on their lifestyle, including work	6	12.00	3	13.64	3	10.71	4	15.38	2	8.33
Participant describes taking the advice from the specialist with no specific considerations	5	10.00	3	13.64	2	7.14	1	3.85	4	16.67
Participant describes considering their quality of life when deciding on a treatment	5	10.00	0	0.00	5	17.86	2	7.69	3	12.50

Considerations when making decisions about 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 considering a combination of the benefits and side effects	10	20.00	4	20.00	6	20.00	5	22.73	5	17.86
Participant describes their main consideration as the side effects	6	12.00	3	15.00	3	10.00	1	4.55	5	17.86
Participant describes their main consideration as the evidence to support the use of the treatment (Efficacy)	10	20.00	4	20.00	6	20.00	3	13.64	7	25.00
Participant describes their main consideration as the cost of the treatment	9	18.00	4	20.00	5	16.67	2	9.09	7	25.00
Participant describes considering the impact on their lifestyle, including work	6	12.00	3	15.00	3	10.00	2	9.09	4	14.29
Participant describes taking the advice from the specialist with no specific considerations	5	10.00	2	10.00	3	10.00	2	9.09	3	10.71
Participant describes considering their quality of life when deciding on a treatment	5	10.00	0	0.00	5	16.67	1	4.55	4	14.29

Considerations when making decisions about 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 considering a combination of the benefits and side effects	10	20.00	3	50.00	4	28.57	1	11.11	1	9.09	1	10.00
Participant describes their main consideration as the side effects	6	12.00	1	16.67	4	28.57	1	11.11	0	0.00	0	0.00
Participant describes their main consideration as the evidence to support the use of the treatment (Efficacy)	10	20.00	1	16.67	4	28.57	1	11.11	3	27.27	1	10.00
Participant describes their main consideration as the cost of the treatment	9	18.00	2	33.33	4	28.57	1	11.11	1	9.09	1	10.00
Participant describes considering the impact on their lifestyle, including work	6	12.00	1	16.67	0	0.00	1	11.11	2	18.18	2	20.00
Participant describes taking the advice from the specialist with no specific considerations	5	10.00	0	0.00	1	7.14	1	11.11	2	18.18	1	10.00
Participant describes considering their quality of life when deciding on a treatment	5	10.00	1	16.67	2	14.29	0	0.00	1	9.09	1	10.00

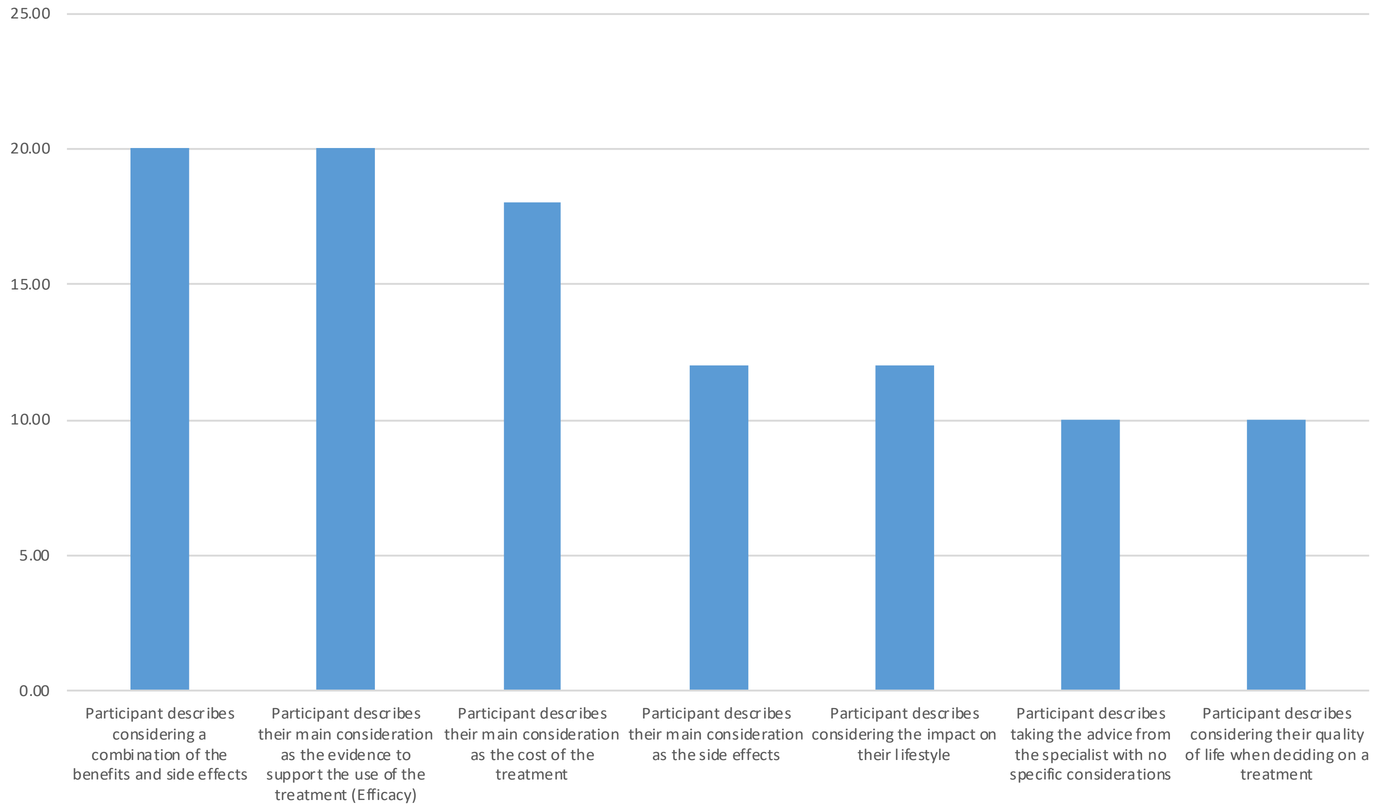

Figure 4.2: Considerations when making decisions

Changes in decision-making

In the final question about decision-making, participants were asked whether they felt the way they made decisions had changed over time since they were diagnosed. Overall there were 26 participants (52.00%) that felt as though the way they make decisions has changed over time, while 20 participants (40.00%) felt that it had not changed.

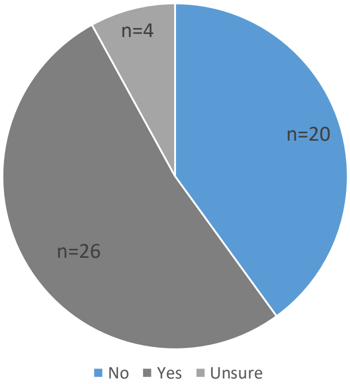

Figure 4.3: Changes in decision-making

Where participants did feel as though the way they made decisions had changed, the most common reason for this was that they had become more informed (n=11, 22.00%) and that they consider quality of life more in the process of making treatment decisions (n=7, 14.00%):

Participant describes decision-making changing as they have become more informed

It probably has because I'm a bit more informed now. When they talk about having the bone marrow transfusion and they talk about that sort of thing I understand. Whereas at first I probably wouldn't have gotten what they were really on about. Participant 6

No, it probably has changed. I'd say it probably has changed because I've got a little bit more knowledge but trying to find a local doctor really is very hard. Participant 12

Most changed over time. Initially, I probably looked at anything, grabbed onto anything that might be a treatment and might have possible benefits. Over time, I've become someone who definitely looks at the science base to it and the evidence base to it. Participant 34

Participant describes decision-making changing as they consider quality of life more

No. Yeah, I can see that if it dragged on for 10 years that I'd get to the point where I'd say, "Look I just can't go backwards and forwards to see them all the time. I'm not going to do it anymore." Participant 7

No, it's definitely changed. It changes all the time anyway through your life. I think your priorities change quite a lot in life. When you have a diagnosis like this where you're unsure of if you can get any assistance or if anything is ever going to get better or change. It's just prioritizing, what's important, what makes you happy, what keeps the family running. Participant 28

My decisions now are much more informed than when I was first diagnosed – then we were looking for the "magic bullet". Now my choices are based around quality of life treatments. Participant 32

In relation to sub-group variations, participants from rural areas (25.00%) reported considering quality of life more frequently than the general population (14.00%).

Table 4.3: Decision-making over time

Does decision-making change over time?	All participants		Metropolitan		Rural		SEIFA (High)		SEIFA (Low)	
	n=50	%	n=30	%	n=20	%	n=27	%	n=23	%
Participant describes decision-making changing as they have become more informed	11	22.00	5	16.67	6	30.00	5	18.52	6	26.09
Participant describes decision-making changing as they consider quality of life more	7	14.00	2	6.67	5	25.00	2	7.41	5	21.74
Participant describes decision-making not changing as they have not been given any treatment options	5	10.00	3	10.00	2	10.00	2	7.41	3	13.04

Does decision-making change over time?	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 decision-making changing as they have become more informed	11	22.00	5	19.23	6	25.00	5	20.83	8	23.53
Participant describes decision-making changing as they consider quality of life more	7	14.00	3	11.54	4	16.67	5	20.83	5	14.71
Participant describes decision-making not changing as they have not been given any treatment options	5	10.00	3	11.54	2	8.33	3	12.50	5	14.71

Does decision-making change over time?	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 decision-making changing as they have become more informed	11	22.00	7	31.82	4	14.29	4	15.38	7	29.17
Participant describes decision-making changing as they consider quality of life more	7	14.00	1	4.55	6	21.43	3	11.54	4	16.67
Participant describes decision-making not changing as they have not been given any treatment options	5	10.00	3	13.64	2	7.14	2	7.69	3	12.50

Does decision-making change over time?	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 decision-making changing as they have become more informed	11	22.00	6	30.00	5	16.67	3	13.64	8	28.57
Participant describes decision-making changing as they consider quality of life more	7	14.00	1	5.00	6	20.00	3	13.64	4	14.29
Participant describes decision-making not changing as they have not been given any treatment options	5	10.00	2	10.00	3	10.00	3	13.64	2	7.14

Does decision-making change over time?	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 decision-making changing as they have become more informed	11	22.00	1	16.67	2	14.29	5	55.56	3	27.27	0	0.00
Participant describes decision-making changing as they consider quality of life more	7	14.00	1	16.67	2	14.29	0	0.00	3	27.27	1	10.00
Participant describes decision-making not changing as they have not been given any treatment options	5	10.00	0	0.00	3	21.43	1	11.11	1	9.09	0	0.00

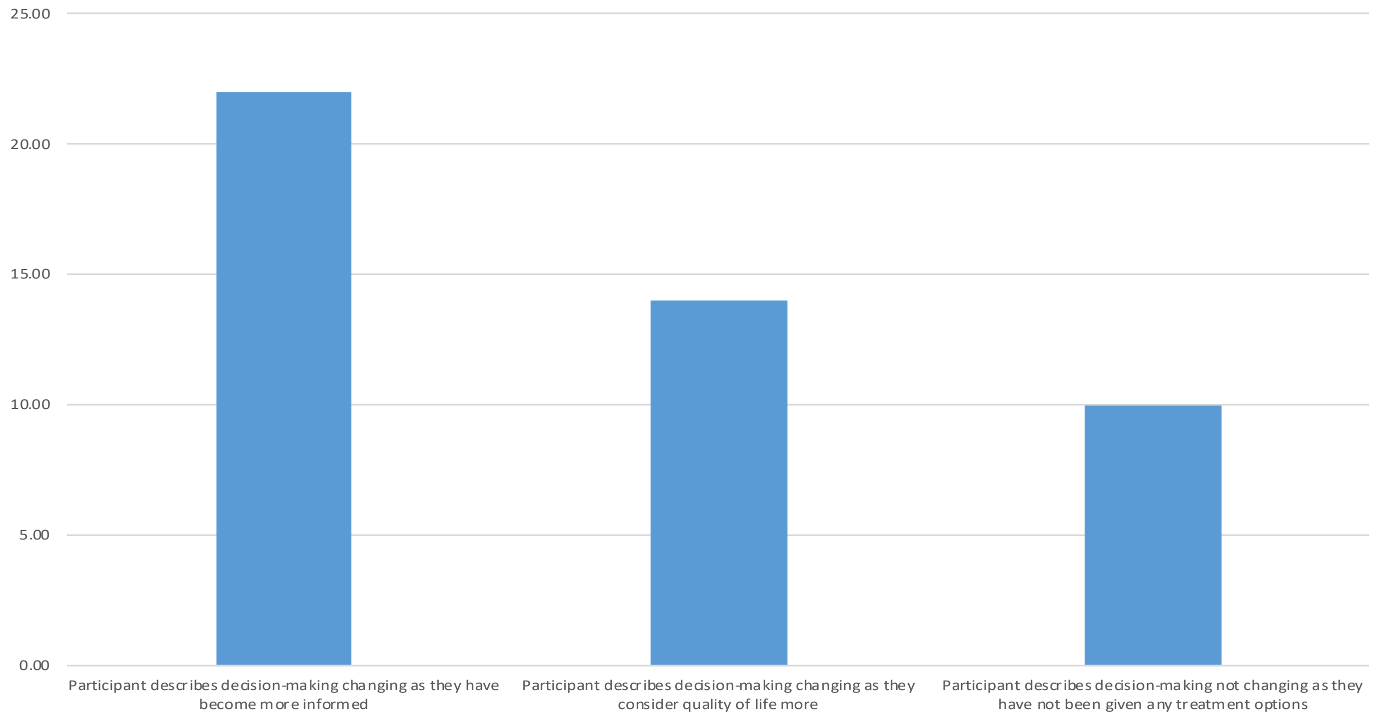

Figure 4.4: Decision-making over time