

Section 8

Quality of life

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Impact on quality of life

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Most commonly, the descriptions suggested that there was an overall negative impact on quality of life (57.58%), and a mix of positive and negative impact on quality of life (33.33%). This was followed by overall a minimal impact on quality of life (6.06%), and overall no impact on quality of life (3.03%).

The most common themes in relation to a negative impact on quality of life were emotional strain (including family/change in relationship dynamics) (45.45%), altering lifestyle to manage condition (including being immunocompromised) (21.21%), managing side effects and symptoms (21.21%), and reduced social interaction (21.21%). Other themes included, being unable to travel or having to adapt significantly in order to travel (15.15%), fatigue (12.12%), reduced capacity for physical activity or needing to slow down (12.12%), and that quality of life was reduced temporarily (12.12%).

Impact on mental health

In the structured interview, participants were asked if there had been an impact on their mental health. Most commonly, the descriptions suggested that overall, there was at least some impact on mental health (84.85%), and overall, there was no impact on mental health (12.12%).

Regular activities to maintain mental health

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common responses were mindfulness or meditation (30.30%), and the importance of physical exercise (24.24%). Other themes included coping strategies such as remaining social, lifestyle changes and hobbies (15.15%), the importance of family and friends in maintaining their mental health (15.15%), consulting a mental health professional (9.09%), and the importance of keeping busy (9.09%). There were 5 participants (15.15%) that described no activities to maintain mental health (15.15%).

Regular activities to maintain health

In the structured interview, participants were asked what were some of the things they needed to do everyday to maintain their health? The most common activities for general health were doing physical exercise or being physically active (36.36%), complying with treatment and management (21.21%), and self care e.g. more rest, accepting help, pacing (21.21%). Other themes included understanding their limitations (15.15%), maintaining a healthy diet (15.15%), mindfulness or meditation (12.12%), socialising with friends and/or family (9.09%), and maintaining a normal routine (9.09%).

Experience of vulnerability

In the structured interview, participants were asked if there had been times that they felt vulnerable. The most common responses were that they felt vulnerable during/after treatments (36.36%), and experiencing side effects from treatment or symptoms from condition (15.15%). Other themes included when having sensitive discussion (diagnosis, treatment decision) (12.12%), because of interactions with the medical team (12.12%), all the time (12.12%), and when feeling sick/unwell (9.09%).

Methods to manage vulnerability

In the structured interview, participants described ways that they managed feelings of vulnerability. The most common ways to manage vulnerability were using self-help methods (resilience, acceptance, staying positive) (15.15%), support from nurse or treatment team (9.09%), and getting support from family and friends (6.06%).

Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Most commonly, the descriptions suggested that overall, there was a negative impact on relationships (45.45%), and overall, there was a positive impact on relationships (27.27%). Other themes included overall, there was an impact on relationships that was both positive and negative (12.12%), and overall, there no impact on relationships (3.03%).

The most common themes in relation to having a negative impact on relationships were from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition (24.24%), and from people not knowing what to say or do and withdrawing from relationships (6.06 %).

The most common themes in relation to having a positive impact on relationships were from family relationships being strengthened (18.18%), and from people being well-meaning and supportive (18.18%).

Burden on family

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Most commonly, the descriptions suggested that overall, there was a burden on their family (75.76%), and overall, there was not a burden on their family (18.18%).

The main reason that participant described their condition being a burden were that the burden on family was temporary or only during treatment (27.27%), the mental/emotional strain placed on their family(21.21%), and the extra household duties and responsibilities that their family must take on (15.15%).

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. The most common descriptions were that overall, there was at least some cost burden (63.64%), and overall, there was no cost burden (33.33%).

Where participants described a cost burden associated with their condition, it was most commonly in relation to needing to take time off work (39.39%), the cost of treatments (including repeat scripts) (21.21%), and the cost of parking and travel to attend appointments (including accommodation) (18.18%). Other themes included a family member needing to take time off work (9.09%) and needing to access financial support from family or charities (9.09%).

Where participants described no cost burden associated with their condition, it was most commonly in relation to nearly everything was paid for through the public health system (45.45%), nearly everything was paid for through the private health system (12.12%), and the participant was able to afford all costs (12.12%).

Fear of progression

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

Impact on quality of life

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Most commonly, the descriptions suggested that there was an overall negative impact on quality of life (57.58%), and a mix of positive and negative impact on quality of life (33.33%). This was followed by overall a minimal impact on quality of life (6.06 %), and overall no impact on quality of life (3.03%).

The most common themes in relation to a negative impact on quality of life were emotional strain (including family/change in relationship dynamics) (45.45%), altering lifestyle to manage condition (including being immunocompromised) (21.21%), managing side effects and symptoms (21.21 %), and reduced social interaction (21.21%). Other themes included, being unable to travel or having to adapt significantly in order to travel (15.15%), fatigue (12.12%), reduced capacity for physical activity or needing to slow down (12.12%), and that quality of life was reduced temporarily (12.12%).

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

Not now, but I would say during the time of treatment, because I was very tired, I wanted to keep doing so much of everything that I had done prior to, but I couldn't keep up with my active children. I couldn't keep up with going out for dinners or going away on weekends. I was just too tired. When I'd go away, I'd have to take my medication with me or check my temperature. I couldn't eat certain foods. I tried not to let it get me down, but at times it would. I just used to think, "Well, it's only a short term thing. Hopefully everything goes well for long term gain." Over that period, that was very draining.
Participant 001_2023AUCRT

It affected the family, obviously, when I was diagnosed and being in hospital all the time. Now that I'm home, things are slowly returning back to normal. I'm at home most of the day and managing to do the daily activities and whatever, like cooking dinner and things like that, which I wasn't able to do before. Probably the worst for them is over, but I'm a bit concerned that I think they're a little bit overcautious at times about me being able to do things.
Participant 002_2023AUCRT

Not so much now, but certainly in the initial stages because nobody knew the, you know, the long term ramifications. So certainly that first couple of years was pretty, it's real tricky. And I had more very young grandchildren. They're all a little bit older now. Of course, I had more young grandchildren and I was helping out a bit with babysitting and all that sort of stuff. And so I couldn't do that anymore because for, you know, for quite a while that relationship was very... look, my kids are great, they're wonderful, but but it was hard on everyone, I mean, it was hard on my husband. It was hard on me. It was hard on a family.

Participant 020_2023AUCRT

During treatment and probably a couple years past the treatment, yes, it has affected my quality of life with what I've been able to do and to achieve with regards to work, my physical activity, socializing, things like that. About we had to give up everything that I was doing for three 3 1/2 years to maybe 4 1/2 years.

Participant 024_2023AUCRT

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

I guess in a way I thought maybe...my husband works a lot. I thought maybe after getting home, he took a little bit of time off but he still works a lot whereas it sort of made me reassess a little bit and I would like to spend a bit more time together but it's a bit difficult just having a business and everything. Yes, it's quality of life, my energy levels aren't like what they used to be. I guess spending a year doing nothing, it'll take a little while to get them back up to what they were. Other than that, yes, nothing else has changed too much since I've finished treatment.
Participant 005_2023AUCRT

Yeah, probably. It's it's getting better now. But obviously I felt when I've got three kids ... So it was very hard because that first year I spent more time in hospital than at home, so I felt like. I wasn't a very good mother to them and especially the youngest one. He had a lot of anxiety and depression and he's still sort of suffering from that. So I still feel that I feel guilty about that and I feel like that I haven't done the right. I never know that it's not my fault but and and just I guess with I feel I feel bad for like my husband and all my kids and my mom and dad and that how much how much worry and stress. Of course, even

though it's not my fault, but it's it's it's made me feel sort of bad. On the other hand then there's things like say now my husband is not that he was ever bad but he said I never realized how much I loved you until you almost died. So in a lot of ways I've brought it closer I guess so and it's he always made me feel like even when when I was. I had horrible hairy face because of steroids and no eyelash and eyebrows and just looked awful. He still made me feel good. So that's probably made things better. And yeah, I mean some friends and stuff. Obviously there's a lot of people I haven't seen as much or had as much to do with because because I was pretty well by the time I was past my danger neutropenic stage and COVID started so and I'm still immuno suppressed. I'm not vaccinated. So it makes you less social and like you can't sort of see as many people or you miss out or think on things a bit more and and then you feel like we'll probably some of your family's missing out on things because of that. Participant 006_2023AUCRT

It's certainly, I'm lucky enough to have both parents and they're in their mid 80s and I guess the anxiety that it it caused them. That in itself caused me more anxiety. Yeah, relationship with with my close friends have they were good, but they're really powerful....Relationships with all of the other people who are important in my life have been fantastic. Participant 009_2023AUCRT

Well, it's definitely affected mine because I can't do what I used to do. Yeah, like being active how I was and gone away and stuff like you just. I just can't do it anymore. I can't do stuff with my son like I used to. Like you'd go away for a week camping and stuff. That'd be a real struggle now. Yeah, like my wife and I were always really energetic, like we were traveling. And like there was, it would be nothing for us to walk 14 to 20 days today in a day to look at a National Park or whatever. And we did that all the time, like when we were traveling. And like we just can't do that now. I hear you, but I'm glad we got to do it before it

happened. Family were, they were really supportive, I think. How would you explain it? Some worries about about me, said it's my wife, but I think my wife now just accepts this is what we have to deal with now, you know, like she's pretty, she's pretty positive about everything. You know, like this is what we're going to do, and this is how it's going to happen. Participant 011_2023AUCRT

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

Not really. I thought. I haven't let it. Apart from when you have the transplants, Do you know what I mean? That's the only time, yeah. And so when you when I've been on chemo, I like I was on the last time I was on it for a couple of two years, I suppose. And I was doing it every Monday. I tried to lead as normal life as I could. Participant 025_2023AUCRT

To a point, COVID. I meant that I had advantages they didn't have. The immune system depletion that I have had with both stem cells and CAR T has limited what I do, but I've been really comfortable with it. I might say, but I don't go to pubs or footy matches or, and I probably wouldn't anyway. So I don't feel like I'm missing out. Participant 036_2023AUCRT

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

Look, I live on my own. I've lived on my own for 12, 13 years. I've got two daughters, I've got grandchildren. It hasn't affected any of those relationships. I've got some good friends who sort of bonded together around me and supported me and helped me, but not quality of life. I don't think that it has had a particular impact on me, simply because I'm get out there and do it and if it kills me, it kills me. Participant 008_2023AUCRT

Table 8.1: Impact on quality of life

Impact on quality of life	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7	%	n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Experience described suggests that there was an overall negative impact on quality of life	19	57.58	4	57.14	5	50.00	10	62.50	16	61.54	3	42.86	8	53.33	11	61.11
Experience described suggests that there was a mix of positive and negative impact on quality of life	11	33.33	3	42.86	4	40.00	4	25.00	9	34.62	2	28.57	5	33.33	6	33.33
Experience described suggests that there was overall a minimal impact on quality of life	2	6.06	0	0.00	1	10.00	1	6.25	1	3.85	1	14.29	2	13.33	0	0.00
Experience described suggests that there was overall no impact on quality of life	1	3.03	0	0.00	0	0.00	1	6.25	0	0.00	1	14.29	0	0.00	1	5.56

Impact on quality of life	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Experience described suggests that there was an overall negative impact on quality of life	19	57.58	10	52.63	9	64.29	8	57.14	11	57.89	9	64.29	10	52.63
Experience described suggests that there was a mix of positive and negative impact on quality of life	11	33.33	9	47.37	2	14.29	5	35.71	6	31.58	5	35.71	6	31.58
Experience described suggests that there was overall a minimal impact on quality of life	2	6.06	0	0.00	2	14.29	0	0.00	2	10.53	0	0.00	2	10.53
Experience described suggests that there was overall no impact on quality of life	1	3.03	0	0.00	1	7.14	1	7.14	0	0.00	0	0.00	1	5.26

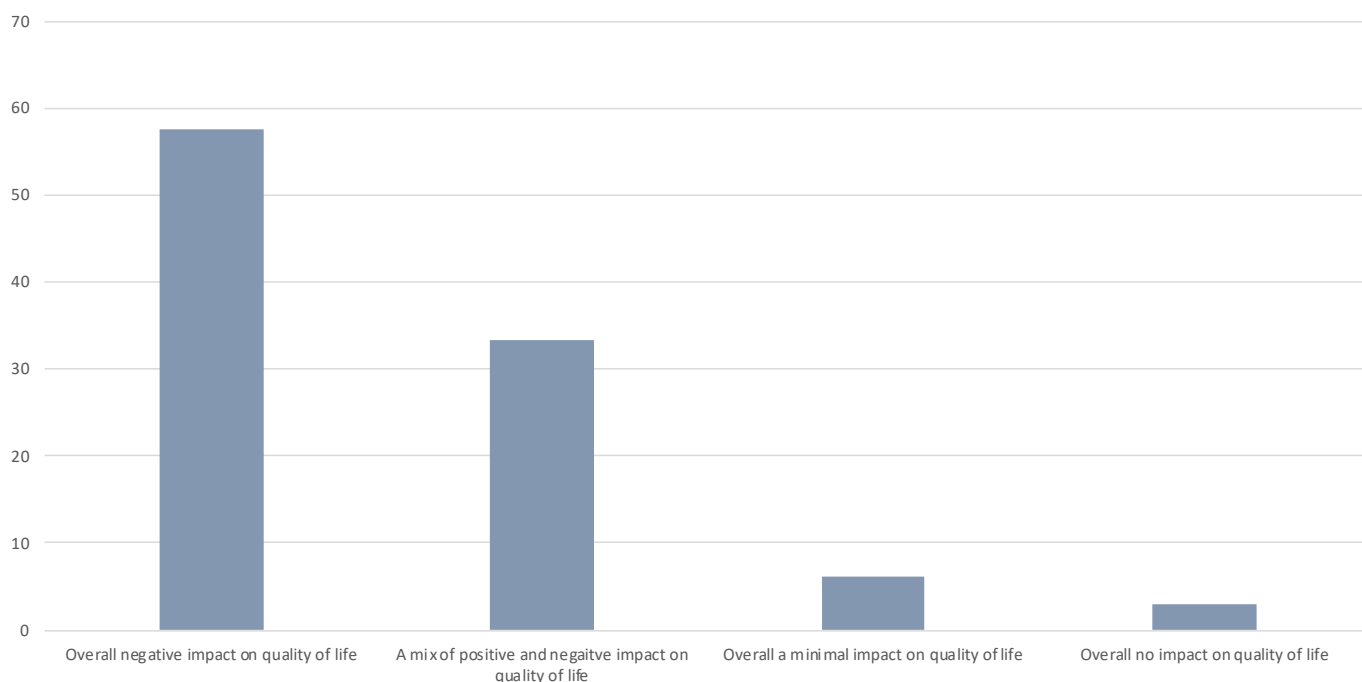


Figure 8.1: Impact on quality of life

Table 8.2: Impact quality of life – subgroup variations

Impact on quality of life	Reported less frequently	Reported more frequently
Experience described suggests that there was an overall negative impact on quality of life	CAR T-Cell therapy	-
Experience described suggests that there was a mix of positive and negative impact on quality of life	Aged 65 or older	Aged 25 to 64
Experience described suggests that there was overall no impact on quality of life	-	CAR T-Cell therapy

Table 8.3: Impact on quality of life (Reasons)

Impact on quality of life (reasons)	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7	%	n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes a negative impact on quality of life due to the emotional strain (including family/change in relationship dynamics)	15	45.45	5	71.43	3	30.00	7	43.75	14	53.85	1	14.29	8	53.33	7	38.89
Participant describes a negative impact on quality of life due to altering lifestyle to manage condition (including being immunocompromised)	7	21.21	2	28.57	3	30.00	2	12.50	3	11.54	4	57.14	5	33.33	2	11.11
Participant describes a negative impact on quality of life due to managing side effects and symptoms	7	21.21	2	28.57	0	0.00	5	31.25	6	23.08	1	14.29	3	20.00	4	22.22
Participant describes a negative impact on quality of life due to reduced social interaction	7	21.21	3	42.86	2	20.00	2	12.50	4	15.38	3	42.86	4	26.67	3	16.67
Participant describes a negative impact on quality of life due to being unable to travel/adapt significantly in order to travel	5	15.15	1	14.29	1	10.00	3	18.75	5	19.23	0	0.00	2	13.33	3	16.67
Participant describes a negative impact on quality of life without giving a reason	5	15.15	0	0.00	2	20.00	3	18.75	4	15.38	1	14.29	1	6.67	4	22.22
Participant describes a negative impact on quality of life due to fatigue	4	12.12	1	14.29	1	10.00	2	12.50	4	15.38	0	0.00	3	20.00	1	5.56
Participant describes a negative impact on quality of life due to reduced capacity for physical activity/need to slow down	4	12.12	2	28.57	1	10.00	1	6.25	4	15.38	0	0.00	1	6.67	3	16.67
Participant describes a negative impact on quality of life that was only temporary	4	12.12	3	42.86	0	0.00	1	6.25	4	15.38	0	0.00	2	13.33	2	11.11
Participant describes a positive impact on quality of life because it brings people together/highlights supportive relationships	9	27.27	3	42.86	3	30.00	3	18.75	7	26.92	2	28.57	4	26.67	5	27.78

Impact on quality of life (reasons)	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes a negative impact on quality of life due to the emotional strain (including family/change in relationship dynamics)	15	45.45	10	52.63	5	35.71	4	28.57	11	57.89	4	28.57	11	57.89
Participant describes a negative impact on quality of life due to altering lifestyle to manage condition (including being immunocompromised)	7	21.21	4	21.05	3	21.43	0	0.00	7	36.84	1	7.14	6	31.58
Participant describes a negative impact on quality of life due to managing side effects and symptoms	7	21.21	4	21.05	3	21.43	1	7.14	6	31.58	0	0.00	7	36.84
Participant describes a negative impact on quality of life due to reduced social interaction	7	21.21	5	26.32	2	14.29	1	7.14	6	31.58	2	14.29	5	26.32
Participant describes a negative impact on quality of life due to being unable to travel/adapt significantly in order to travel	5	15.15	4	21.05	1	7.14	2	14.29	3	15.79	4	28.57	1	5.26
Participant describes a negative impact on quality of life without giving a reason	5	15.15	1	5.26	4	28.57	4	28.57	1	5.26	4	28.57	1	5.26
Participant describes a negative impact on quality of life due to fatigue	4	12.12	3	15.79	1	7.14	2	14.29	2	10.53	3	21.43	1	5.26
Participant describes a negative impact on quality of life due to reduced capacity for physical activity/need to slow down	4	12.12	3	15.79	1	7.14	2	14.29	2	10.53	3	21.43	1	5.26
Participant describes a negative impact on quality of life that was only temporary	4	12.12	3	15.79	1	7.14	1	7.14	3	15.79	2	14.29	2	10.53
Participant describes a positive impact on quality of life because it brings people together/highlights supportive relationships	9	27.27	7	36.84	2	14.29	4	28.57	5	26.32	4	28.57	5	26.32

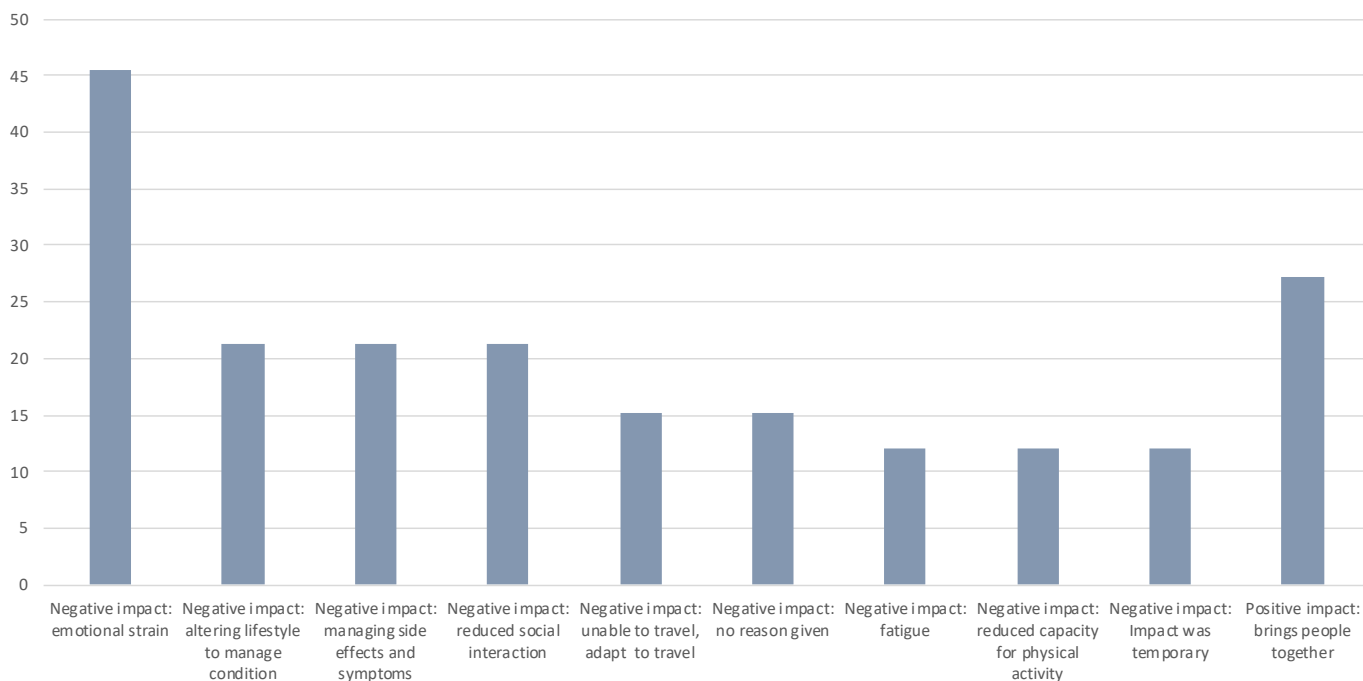


Figure 8.2: Impact on quality of life (Reasons)

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

Impact on quality of life (reasons)	Reported less frequently	Reported more frequently
Participant describes a negative impact on quality of life due to the emotional strain (including family/change in relationship dynamics)	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Regional or remote Mid to low status	B-cell acute lymphoblastic leukaemia (ALL) Metropolitan Higher status
Participant describes a negative impact on quality of life due to altering lifestyle to manage condition (including being immunocompromised)	Male Regional or remote Mid to low status	CAR T-Cell therapy Female Metropolitan Higher status
Participant describes a negative impact on quality of life due to managing side effects and symptoms	Diffuse Large B-Cell Lymphoma Regional or remote Mid to low status	Multiple Myeloma Metropolitan Higher status
Participant describes a negative impact on quality of life due to reduced social interaction	Regional or remote	B-cell acute lymphoblastic leukaemia (ALL) CAR T-Cell therapy Metropolitan
Participant describes a negative impact on quality of life due to being unable to travel/adapt significantly in order to travel	CAR T-Cell therapy	Mid to low status
Participant describes a negative impact on quality of life without giving a reason	B-cell acute lymphoblastic leukaemia (ALL)	Aged 65 or older Regional or remote Mid to low status
Participant describes a negative impact on quality of life due to fatigue	CAR T-Cell therapy	
Participant describes a negative impact on quality of life due to reduced capacity for physical activity/need to slow down	CAR T-Cell therapy	B-cell acute lymphoblastic leukaemia (ALL)
Participant describes a negative impact on quality of life that was only temporary	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy	B-cell acute lymphoblastic leukaemia (ALL)
Participant describes a positive impact on quality of life because it brings people together/highlights supportive relationships	Aged 65 or older	B-cell acute lymphoblastic leukaemia (ALL)

Impact on mental health

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

there was at least some impact on mental health (84.85%), and overall, there was no impact on mental health (12.12%).

Table 8.5: Impact on mental health

Impact on mental health	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7	%	n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Experience described suggests that overall, there was at least some impact on mental health	28	84.85	4	57.14	10	100.00	14	87.50	21	80.77	7	100.00	12	80.00	16	88.89
Experience described suggests that overall, there was no impact on mental health	4	12.12	2	28.57	0	0.00	2	12.50	4	15.38	0	0.00	2	13.33	2	11.11

Impact on mental health	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Experience described suggests that overall, there was at least some impact on mental health	28	84.85	16	84.21	12	85.71	13	92.86	15	78.95	12	85.71	16	84.21
Experience described suggests that overall, there was no impact on mental health	4	12.12	2	10.53	2	14.29	1	7.14	3	15.79	2	14.29	2	10.53

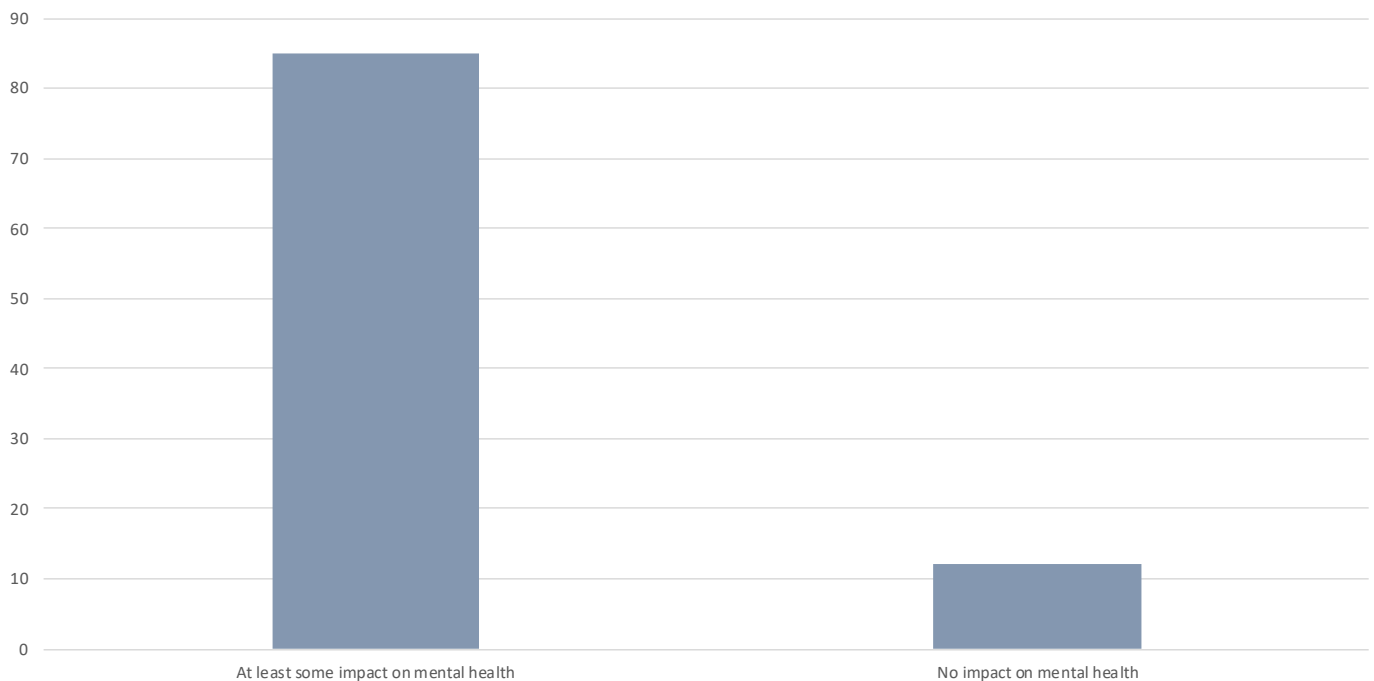


Figure 8.3: Impact on mental health

Table 8.6: Impact on mental health – subgroup variations

Impact on mental health	Reported less frequently	Reported more frequently
Experience described suggests that overall, there was at least some impact on mental health	B-cell acute lymphoblastic leukaemia (ALL)	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy
Experience described suggests that overall, there was no impact on mental health	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy	B-cell acute lymphoblastic leukaemia (ALL)

Regular activities to maintain mental health

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common responses were mindfulness or meditation (30.30%), and the importance of physical exercise (24.24%). Other themes included coping strategies such as remaining social, lifestyle changes and hobbies (15.15%), the

importance of family and friends in maintaining their mental health (15.15%), consulting a mental health professional (9.09%), and the importance of keeping busy (9.09%). There were 5 participants (15.15%) that described no activities to maintain mental health (15.15%).

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

Uncertainty is a big problem. I just tried to keep that under control, but I realize that's a problem now. My blood count started to drop. I thought I was cured, and getting into that level of the uncertainty again, I could feel myself going down a hole. I decided the best thing to do was do meditation. I'm doing a meditation course which I haven't started yet. I am starting on Friday.

Participant 003_2023AUCRT

Just sometimes if I find myself getting anxious, I've got coping techniques, breathing exercises, just learning my limits now compared to what they used to be.

Participant 005_2023AUCRT

No. I just keep thinking back to how I think I feel. Although, I don't ever feel sorry for myself, because I think I've got a positive outcome. I get to watch my two girls grow up, so that's all. I've won there so I don't really need anything else...I'm more of a positive person generally anyway.

Participant 001_2023AUCRT

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

Ride the bike. That sounds weird, but you can, you can solve it. And I bought a new puppy too. But yeah, yeah, you can solve the world's problems when you're out riding a bike.

Participant 022_2023AUCRT

I was involved with martial arts from a young age, so I was able to use that energy, I suppose, to focus on things. Yeah, that's about it. Really.

Participant 024_2023AUCRT

Participant describes coping strategies such as remaining social, lifestyle changes and hobbies to maintain their mental health

Yes. My mental health, I find I don't worry about stupid things anymore like I used to. I think I've calmed down that way. I still keep myself quite active mentally. I watch a lot of documentaries on TV, do a lot of word puzzles and whatever. Yes, I'm just taking each day as it comes just trying to get a little bit stronger just so I can start doing a little bit more.

Participant 002_2023AUCRT

We've got a little dog or more. You know, I take the dog out morning and afternoon or sometimes depending on my wife works four days a week. She can just walk walk to work. But so we're out with the dog, you know and there's so many dogs in the area. You know we live in a beautiful area. It's sort of like canal waterways and lovely walkways. So you when you go out, you know it's by heaps of dogs and the way dogs want to stop and then you you have a chat to people and I usually I'm in my mobility scooter and I don't have the dog on the lead. She just runs along beside me. She's very good. So people stop and have a chat and that's kind of therapeutic, you know. Well, at least I can get out and do that. Some people couldn't.

Participant 031_2023AUCRT

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

You know, I've never been a person to ring people up and chat on the phone and that sort of thing. I'm not terribly good at that when I can't see the person and I think I was just a good time for them or not. So but I've made a bit more of an effort with that. And also just contacting people, you know, sending a text, how are you going, blah, blah. And if they say, oh, can I come down and see you or can you come and meet me somewhere? I make an effort to do it...I hope now I'll make a bit more of an effort to keep in touch with people. It's really good to hear, yeah. You know, I think that's important. I just for my mental well-being. Otherwise it would be easy to be just come a bit isolated..

Participant 012_2023AUCRT

Oh, well, we see, see, see a lot of our children, our two married children down here, live within a walking distance for this. We moved out here to be near them and that's been wonderful. We were involved as participants of our grandchildren's sports, and there we go along to the soccer or basketball, which we enjoy. That's probably the biggest thing for mental health for both of us, because we're cut out a lot of other things. So the family's become a pivot for they're very good, the kids.

Participant 035_2023AUCRT

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

No, it doesn't have any effect now, not not now that I'm not having any treatment and I don't, I don't do anything now because there is no impact. But when there was, I don't, I don't think I did anything significant about it. I think I just, you know, put up with it.

Participant 014_2023AUCRT

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

Yeah, well I see the the psychologist and I do relaxation and she's also taught me a few techniques of how to manage things when they are when when you're getting anxious about about stuff. So that's very helpful and I also find I do I do a bit of exercise and yoga and that sort of thing to try and. I guess for relaxation, but also for us to make me feel like I'm doing something positive to contribute to my mental health. But yeah, it certainly does. I mean it's it's

always there. I don't know. I guess at one stage you feel better. But the last few days I felt a bit tired and my throat was a bit sore the other day and I thought, Oh no, this is just like when I got diagnosed. Am I having a relapse or where is? Most likely it's nothing, but normally most people, if they have a little minor thing happens, I wouldn't think anything of it. Whereas I tend to have to really draw myself back from not thinking the worst every time something happens. So yeah.

Participant 006_2023AUCRT

Participant describes the importance of keeping busy to maintain their mental health

OK, my mental the mental side of things seems OK. If I'm feeling lethargic and tired, then it's hard to keep the mental strong. So to me they seem to go hand in hand. So daily walking and getting on with doing things, yeah, it seems to me, and trying to get away now and again, it seems to be the most important thing for the mental health for me.

Participant 021_2023AUCRT

Table 8.7: Regular activities to maintain mental health

Regular activities to maintain mental health	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7	%	n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes the importance of doing physical exercise/physically active in maintaining their general health	12	36.36	2	28.57	4	40.00	6	37.50	10	38.46	2	28.57	5	33.33	7	38.89
Participant describes the importance of complying with treatment/management in maintaining their general health	7	21.21	2	28.57	0	0.00	5	31.25	6	23.08	1	14.29	3	20.00	4	22.22
Participant describes the importance of self care e.g. more rest, accepting help, pacing in maintaining their general health	7	21.21	0	0.00	3	30.00	4	25.00	5	19.23	2	28.57	4	26.67	3	16.67
Participant describes the importance of understanding their limitations in maintaining their general health	5	15.15	3	42.86	1	10.00	1	6.25	5	19.23	0	0.00	4	26.67	1	5.56
Participant describes the importance of maintaining a healthy diet in maintaining their general health	5	15.15	0	0.00	3	30.00	2	12.50	1	3.85	4	57.14	3	20.00	2	11.11
Participant describes the importance of mindfulness and/or meditation in maintaining their general health	4	12.12	1	14.29	1	10.00	2	12.50	2	7.69	2	28.57	2	13.33	2	11.11
Participant describes the importance of socialising with friends and/or family in maintaining their general health	3	9.09	0	0.00	1	10.00	2	12.50	2	7.69	1	14.29	2	13.33	1	5.56
Participant describes the importance of maintaining a normal routine in maintaining their general health	3	9.09	0	0.00	0	0.00	3	18.75	3	11.54	0	0.00	1	6.67	2	11.11
Regular activities to maintain mental health	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status			
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%		
Participant describes the importance of doing physical exercise/physically active in maintaining their general health	12	36.36	7	36.84	5	35.71	5	35.71	7	36.84	7	50.00	5	26.32		
Participant describes the importance of complying with treatment/management in maintaining their general health	7	21.21	2	10.53	5	35.71	3	21.43	4	21.05	3	21.43	4	21.05		
Participant describes the importance of self care e.g. more rest, accepting help, pacing in maintaining their general health	7	21.21	6	31.58	1	7.14	5	35.71	2	10.53	3	21.43	4	21.05		
Participant describes the importance of understanding their limitations in maintaining their general health	5	15.15	4	21.05	1	7.14	0	0.00	5	26.32	0	0.00	5	26.32		
Participant describes the importance of maintaining a healthy diet in maintaining their general health	5	15.15	3	15.79	2	14.29	1	7.14	4	21.05	1	7.14	4	21.05		
Participant describes the importance of mindfulness and/or meditation in maintaining their general health	4	12.12	2	10.53	2	14.29	3	21.43	1	5.26	1	7.14	3	15.79		
Participant describes the importance of socialising with friends and/or family in maintaining their general health	3	9.09	2	10.53	1	7.14	1	7.14	2	10.53	2	14.29	1	5.26		
Participant describes the importance of maintaining a normal routine in maintaining their general health	3	9.09	2	10.53	1	7.14	2	14.29	1	5.26	2	14.29	1	5.26		

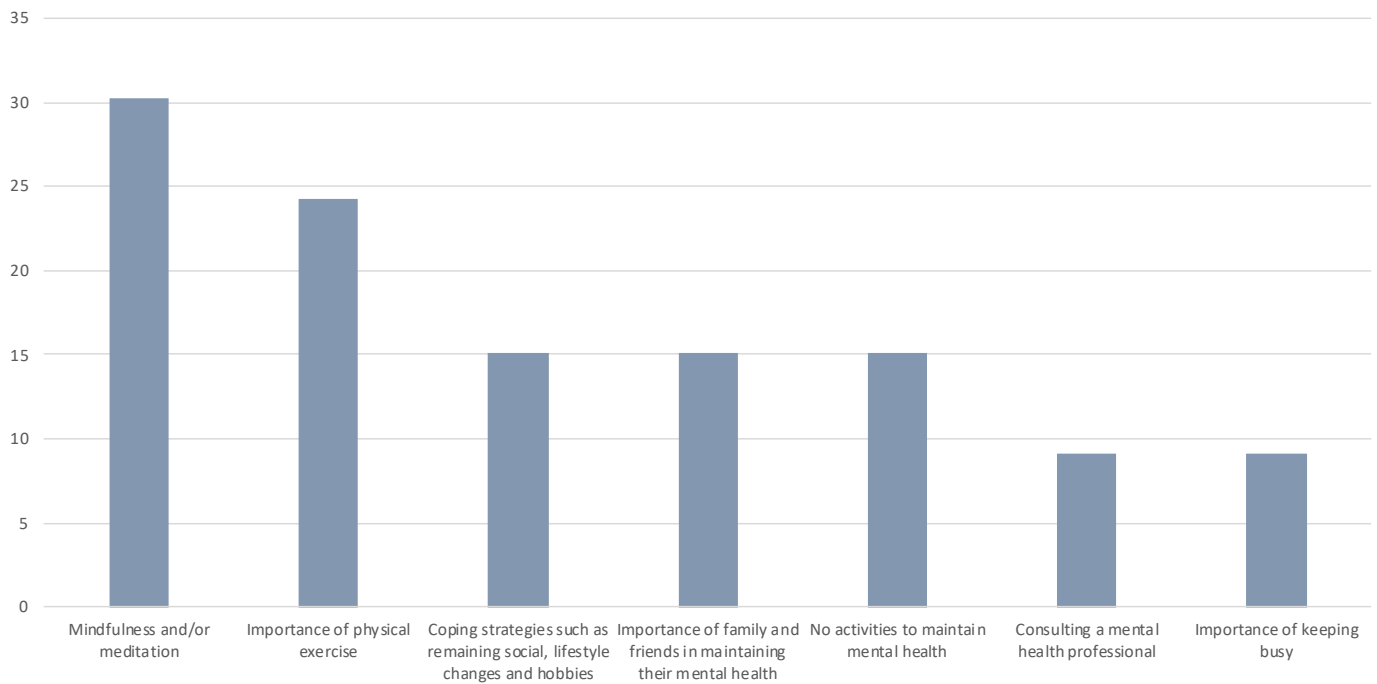


Figure 8.4: Regular activities to maintain mental health

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

Regular activities to maintain mental health	Reported less frequently	Reported more frequently
Participant describes mindfulness and/or meditation to maintain their mental health	Multiple Myeloma CAR T-Cell therapy Aged 65 or older	B-cell acute lymphoblastic leukaemia (ALL) Aged 25 to 64 Mid to low status
Participant describes coping strategies such as remaining social, lifestyle changes and hobbies to maintain their mental health	Diffuse Large B-Cell Lymphoma Regional or remote	Aged 65 or older Metropolitan
Participant describes the importance of family and friends in maintaining their mental health to maintain their mental health	B-cell acute lymphoblastic leukaemia (ALL) Regional or remote	CAR T-Cell therapy Aged 65 or older Metropolitan
Participant describes the importance of keeping busy to maintain their mental health	-	CAR T-Cell therapy

Regular activities to maintain health

In the structured interview, participants were asked what were some of the things they needed to do everyday to maintain their health? The most common activities for general health were doing physical exercise or being physically active (36.36%), complying with treatment and management (21.21%), and self care e.g. more rest, accepting help, pacing (21.21 %). Other themes included understanding their limitations (15.15%), maintaining a healthy diet (15.15%), mindfulness or meditation (12.12%), socialising with friends and/or family (9.09%), and maintaining a normal routine (9.09%).

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

I would say I'm somewhat back to normal. After I eased off the medication, which has been a year and a half now, I went back into the gym. It didn't take long. Once that medication went, it didn't take too long. Then just a little bit of different looking with my

face with the steroids and stuff like that. Once all that, everything slipped quite quickly into place, back to what I know is normal.

Participant 001_2023AUCRT

I found that I really need to exercise, so I've been doing laps. I've done laps in the pool. I try to do it every day, but it's probably usually about four times a week. Ride a bike. I found exercise is, it's really important actually.

Participant 003_2023AUCRT

That's a hard one...Like I force myself to do things at times when I don't want to. Like I try and exercise every day now and that was because of my knees and stuff. And I bought like a rower machine and a bike and I sort of do that every day religiously, you know, just to try and keep a little bit of a fitness up.

Participant 011_2023AUCRT

Well, you know, we've got this very good physiotherapy app, so doing that every day, most

days, you know, do exercises for balance as well as just core, you know, strength. And we try and we've got an exercise bike. So we either go on the exercise bike or so we actually live on the beach. We'll go for a walk along the beach, which is lovely. We must look and enjoy that. And I do, you know, light housework and light gardening, just to keep up my stamina.

Participant 035_2023AUCRT

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

The things that I need to do well, I have to stick to my medication. I have to make sure I have the blood tests when they do keep my doctor's appointments. They're the main things.

Participant 012_2023AUCRT

Well, take medication, keep exercising. I still have to be very aware of who I'm mixing with because I'm sorry, I am off immunosuppressants now, but I'm still, I don't have that immunity yet. I'm also, I haven't been vaccinated for, and I can't have for quite a while yet any of the live vaccines. So I have to be very aware of besides from COVID but I don't go near anyone who may have or be carrying chicken pox, measles, mumps or ruella anything like that. So you have to be a lot more careful. I'm a lot more limited in what you do and and I'll find even before COVID well I was wearing the mask so that was a a limiting thing and I'm just trying not to get too close to people sort of always if you're out somewhere and. You need to get to the other side of the park and there's a group of people there. You're always looking at ways to walk right away from people and not close to people. So yeah, so just things like that. Not not big, major things, I suppose.

Participant 006_2023AUCRT

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

I guess just getting enough sleep or just taking it easy if I'm stressed out or I'm tired.

Participant 005_2023AUCRT

Look after myself, know when I've got a rest, get more sleep than I used to have.

Participant 022_2023AUCRT

So we tried to do things to keep myself active and keep my mind active. And sometimes I struggle with things,

things that I could do probably in a day now takes a week to do sometimes. And a lot of that's just with the fact that I only have, you know, I just run out of puff and fatigue and I've got to go up and down in nap or something like that ... But we we can chip away and not find if I keep myself active you keep doing something we can keep on top of something we can do it.

Participant 027_2023AUCRT

Participant describes the importance of understanding their limitations in maintaining their general health

Basically, I tend to keep to myself. No, I don't keep to myself a lot, but I know what triggers me. I have a friend that's really overwhelming at times. She means well, but she's overwhelming, so I limit my exposure to that. I don't want to sit on the phone and talk for two hours. Even people in the family that I don't particularly want to associate with, I don't. I just try to keep my home life very peaceful and very quiet.

Participant 002_2023AUCRT

I think I've learned that I need to only do things in small doses, and I need a lot of rest because I still get really tired. Sometimes I'm great, I'm full of energy, then all of a sudden I'll just come to a halt. I used to be a real multi-tasker and do loads of things at once, but now I've learnt that I can't do that now

Participant 004_2023AUCRT

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

Diet. I walk 5 to 8 ks a day taking care of my bones, my teeth. I'm seeing a podiatrist for the first time today. I should have seen maybe 10 years ago. But yeah, thinking about and it's partly, I mean I'm nearly 70, so it's partly about age, but it's also and my daughters are 40 and point their finger and you have to do this and you have to do that. So it's encouraging and it's so there's not really anything else. I do, Except eat well. I haven't been on a diet in five years, haven't even thought about it's it's a different world.

Participant 036_2023AUCRT

Well, I eat well, but I'm not a, you know, I'm not a I'm not a sort of anal about it. I mean, I eat really well, but I'm happy to have a pizza or an ice cream or something here in there. Yeah. So you know, I I suppose it's 90% good, 10% not good.

Participant 019_2023AUCRT

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

Not to react to...how can I put this? Not to be so demanding of myself in terms of the time it takes me to do things, so allowing myself more time, allowing myself more rest and making sure I do two or three positive things in any given week.

Participant 009_2023AUCRT

I accept that I need to keep taking their medication. I've always maintained a fairly healthy diet and I continue to do so. I spend time each day just sitting and thinking and meditating, and the rest of the time I just get on with life.

Participant 008_2023AUCRT

Participant describes the importance of socialising with friends and/or family in maintaining their general health

Yeah. So I guess it's for me, I make sure I eat healthily, try and have a healthy diet because I don't feel like

eating at the moment. And yeah, and exercise. So yeah, if I can keep the good balance of those things and social contact, yeah, everything's doable then.

Participant 021_2023AUCRT

Participant describes the importance of maintaining a normal routine in maintaining their general health

I need to sleep, I need to exercise and move. I try, I try and walk. I walk every day. I try and do at least 10,000 plus steps. So I'm looking to walk at least 8 to 10K a day, which I I do generally and that does help. It helps with sleep. It helps with the your emotions and yeah, generally makes you feel good. So yeah, I I suppose I I enjoy still working. I have to admit that that that's the, you know, I had the choice to retire, but I prefer to work. I think that helps me, you know, socially and also helps me mentally. So I'm happy to do that. Generally I'm okay.

Participant 015_2023AUCRT

Table 8.9: Regular activities to maintain health

Regular activities to maintain general health	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7	%	n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes the importance of doing physical exercise/physically active in maintaining their general health	12	36.36	2	28.57	4	40.00	6	37.50	10	38.46	2	28.57	5	33.33	7	38.89
Participant describes the importance of complying with treatment/management in maintaining their general health	7	21.21	2	28.57	0	0.00	5	31.25	6	23.08	1	14.29	3	20.00	4	22.22
Participant describes the importance of self care e.g. more rest, accepting help, pacing in maintaining their general health	7	21.21	0	0.00	3	30.00	4	25.00	5	19.23	2	28.57	4	26.67	3	16.67
Participant describes the importance of understanding their limitations in maintaining their general health	5	15.15	3	42.86	1	10.00	1	6.25	5	19.23	0	0.00	4	26.67	1	5.56
Participant describes the importance of maintaining a healthy diet in maintaining their general health	5	15.15	0	0.00	3	30.00	2	12.50	1	3.85	4	57.14	3	20.00	2	11.11
Participant describes the importance of mindfulness and/or meditation in maintaining their general health	4	12.12	1	14.29	1	10.00	2	12.50	2	7.69	2	28.57	2	13.33	2	11.11
Participant describes the importance of socialising with friends and/or family in maintaining their general health	3	9.09	0	0.00	1	10.00	2	12.50	2	7.69	1	14.29	2	13.33	1	5.56
Participant describes the importance of maintaining a normal routine in maintaining their general health	3	9.09	0	0.00	0	0.00	3	18.75	3	11.54	0	0.00	1	6.67	2	11.11

Regular activities to maintain general health	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes the importance of doing physical exercise/physically active in maintaining their general health	12	36.36	7	36.84	5	35.71	5	35.71	7	36.84	7	50.00	5	26.32
Participant describes the importance of complying with treatment/management in maintaining their general health	7	21.21	2	10.53	5	35.71	3	21.43	4	21.05	3	21.43	4	21.05
Participant describes the importance of self care e.g. more rest, accepting help, pacing in maintaining their general health	7	21.21	6	31.58	1	7.14	5	35.71	2	10.53	3	21.43	4	21.05
Participant describes the importance of understanding their limitations in maintaining their general health	5	15.15	4	21.05	1	7.14	0	0.00	5	26.32	0	0.00	5	26.32
Participant describes the importance of maintaining a healthy diet in maintaining their general health	5	15.15	3	15.79	2	14.29	1	7.14	4	21.05	1	7.14	4	21.05
Participant describes the importance of mindfulness and/or meditation in maintaining their general health	4	12.12	2	10.53	2	14.29	3	21.43	1	5.26	1	7.14	3	15.79
Participant describes the importance of socialising with friends and/or family in maintaining their general health	3	9.09	2	10.53	1	7.14	1	7.14	2	10.53	2	14.29	1	5.26
Participant describes the importance of maintaining a normal routine in maintaining their general health	3	9.09	2	10.53	1	7.14	2	14.29	1	5.26	2	14.29	1	5.26

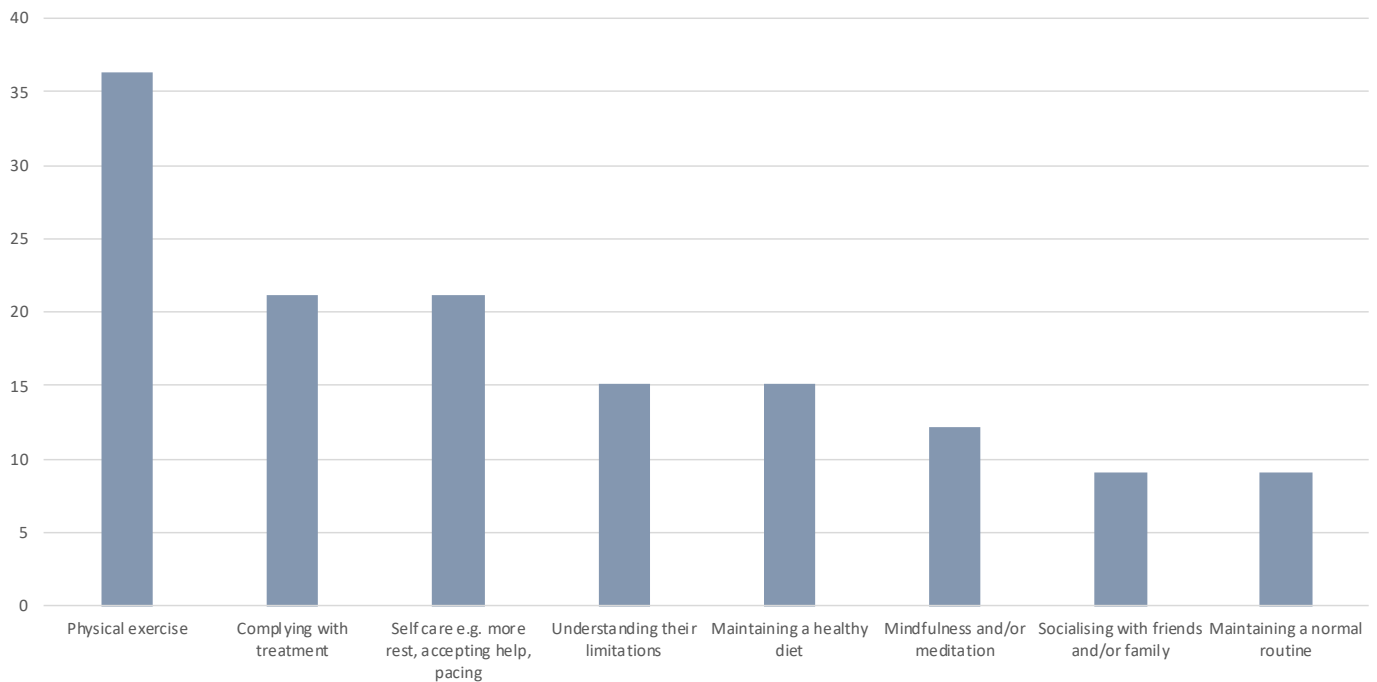


Figure 8.5: Regular activities to maintain health

Table 8.10: Regular activities to maintain health – subgroup variations

Regular activities to maintain general health	Reported less frequently	Reported more frequently
Participant describes the importance of doing physical exercise/physically active in maintaining their general health	Higher status	Mid to low status
Participant describes the importance of complying with treatment/management in maintaining their general health	Diffuse Large B-Cell Lymphoma Aged 25 to 64	Multiple Myeloma Aged 65 or older
Participant describes the importance of self care e.g. more rest, accepting help, pacing in maintaining their general health	B-cell acute lymphoblastic leukaemia (ALL) Aged 65 or older Metropolitan	Aged 25 to 64 Regional or remote
Participant describes the importance of understanding their limitations in maintaining their general health	CAR T-Cell therapy Regional or remote Mid to low status	B-cell acute lymphoblastic leukaemia (ALL) Female Metropolitan Higher status
Participant describes the importance of maintaining a healthy diet in maintaining their general health	B-cell acute lymphoblastic leukaemia (ALL) No CAR T-Cell therapy	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy
Participant describes the importance of mindfulness and/or meditation in maintaining their general health	-	CAR T-Cell therapy

Experience of vulnerability

In the structured interview, participants were asked if there had been times that they felt vulnerable. The most common responses were that they felt vulnerable during/after treatments (36.36%), and experiencing side effects from treatment or symptoms from condition (15.15%). Other themes included when having sensitive discussion (diagnosis, treatment decision) (12.12%), because of interactions with the medical team (12.12%), all the time (12.12%), and when feeling sick/unwell (9.09%).

Participant describes feeling vulnerable during/after treatments

Most of the time was undergoing for chemotherapy because it's just the unknown of what's going to be happening next week or the next month or how you're

feeling. Because when you're if you're getting basically smashed by all these drugs so you don't know how quickly like if you have a cold, you can say oh we're going to recover in a week. But when you're having this chemo for three years, you go, well, how long is this going to affect me for? So it's just the unknown place that's the. The bit that you're frightened on. Well, not frightened, but you just wanna know more information than no one can really tell you.¶

Participant 024_2023AUCRT

Yeah, I did when I was on the dexamethasone. I've I felt well, I just felt bad in every way and I you know for part of the thalidomide time too with the rash I was, which by the way, I'd forgotten about until I was reminded by my wife who's sitting in the next room.

But I felt I felt pretty bad then too. But, but yeah, they were in, when you look back over for pretty brief periods in that time.

Participant 014_2023AUCRT

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

Yes. At one stage my blood sugar levels went high and I ended up in casualty. And that that was scary because both things were happening. So I was new to having blood sugar problems and certainly new to lymphoma and the combination of the two was a bit much, yeah. But that that only happened once.

Participant 009_2023AUCRT

When I was going through the stage where I didn't have any immunity, I felt really ill and I was, I have to admit, when I was on medication, I had a lot of hallucinations and just some weird, weird thoughts and no concentration. I couldn't watch anything on television. I was just just uncomfortable, a lot of pain. I spoke to at times you think, oh, you know, if I'm going to die, I'm going to die kind of feeling. But things did improve.

Participant 015_2023AUCRT

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

That's an interesting question. I mean in the beginning, possibly you know, but only because there's so much to take in and you know you, you feel. It's hard to say, but you feel pissed off, I suppose you know. Why me? Why? Why? Why me? Why? Yeah. What have I done to deserve this? And and so you sort of feel feel pretty bad. But you know, since I've been coming two years now since I was diagnosed, almost coming up early September, it was so early September is when I was first diagnosed. So now you only have to look around every day that I'm in hospital and there's always someone worse off than you are. So that's my sort of philosophy on, on feeling to say, you know, what could be worse or we could be living in America and where I mean, I'd use my private health insurance, but Even so, Medicare is fantastic and a lot of people, you know, a lot of people don't have that. If you live in America, there's no Medicare. You'd hate to be in that situation.

Participant 031_2023AUCRT

I remember that that moment when they said that chemotherapy didn't work and I still didn't know what the what's next that was that was that that moment that that was kind of reality check. Yeah, but but then they said, you know, for that CAR T and all the stuff.

Participant 034_2023AUCRT

Participant describes feeling vulnerable because of interactions with the medical team

Like I know when I was in the the HOSPITAL getting chems and my specialist, that first specialist, the oncologist was away for the weekend and they had a part time one. And I come in and I said, he said to me, I said ohh, the lymphoma is in my heart and he said 'no it's not you don't like you don't get lymphoma in the heart', and I said, well, I have. And he said no you haven't, no you haven't. And just walked away. And I thought he didn't know. And then I asked my specialist said, yeah, well, here's the PET scans, yeah, he didn't know what he was talking about and you lose a bit of confidence.

Participant 011_2023AUCRT

I think that time when I was in, when I went to have the stem cell transplant, I had to be admitted to hospital, on a public holiday and they didn't have a bed for me. So I had to go and stay at the cancer accommodation in CITY and it was like being on a parallel universe because it was a public holiday. Practically everything was closed. There was no nothing to eat there and and I just turned on the television and watched one movie after another after another must have watched about 8 movies in a row. And I felt like I was in and out of space. And a friend went out and got me some food and I had to be at the hospital the next day at 10:00 o'clock to be admitted and I went there, I was there at 10:00 o'clock. I sat in the waiting room there till 6:00 o'clock that night and finally someone brought me some dinner, which I ate there and then about 7:00 o'clock, I got admitted to the room that I was to be in. So that I guess that time I felt the most vulnerable because it was kind of all out of my control. I just had to go with it.

Participant 012_2023AUCRT

As I said, there was one doctor that that probably should think about the words he chooses when he's talking to his patients is probably, makes you feel a bit despondent. I suppose there's once I went out there not not in tears but but teary eyed is probably the right word because I'd had a great response from a treatment and I thought, ohh, this is really good. I'm

doing really, really well. And then for some reason he just saw it in his way to say, 'well look yeah, but there's no you sugar coating this it's it's going to get you'. I said what you mean. He said, well you said it's going to get you. He said you have this condition and there is no cure. And then after that I felt really I was quite devastated and and it actually shocked me a little bit and I it's just stuff like that which I know he's he no he's not right but he could be right. But I just sometimes you don't need it shoved in your face. Like we we live with cancer and a lot of people with cancer don't have much hope. But to hang on to a little bit of it is something that keeps us ticking. Even if it keeps us ticking for another six months it's better than giving up. So to tell us that, you know it's going to get you is sort of took the wind out of my sails a little bit and you know, I had to talk it out with my wife just I was quite upset about it. And then I did raise it with him and he apologized, but he did, he said, well, this, you know, I said his explanation was, you know, I don't want to give you false hope. And I said I understand that. And I said, you don't have to give me no hope so. Yeah, so stuff like that, just it's sometimes doctors just need to be a little bit empathetic in their wording that they use, that was all.

Participant 019_2023AUCRT

Participant describes feeling vulnerable all the time

I think from the date of my diagnosis until now, I continue to feel vulnerable. In different ways I am vulnerable.

Participant 016_2023AUCRT

I am. Most of the time, yes. When there is no, I don't know when. But yeah, most of the time I'm not. I'm very vulnerable, yeah.

Participant 017_2023AUCRT

Yeah. Every day, yeah. Yep.

Participant 027_2023AUCRT

Participant describes feeling vulnerable when feeling sick/unwell

Like you're lying in hospital, really, really sick. As sick as you can get. It's not great, but you know, there's always something, there was always something to find some joy in, to look forward to, to get you out of it.

Participant 022_2023AUCRT

Table 8.11: Experience of vulnerability

Experience of vulnerability	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7	%	n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes feeling vulnerable during/after treatments	12	36.36	2	28.57	2	20.00	8	50.00	10	38.46	2	28.57	4	26.67	8	44.44
Participant describes feeling vulnerable experiencing side effects from treatment or symptoms from condition	5	15.15	0	0.00	1	10.00	4	25.00	3	11.54	2	28.57	1	6.67	4	22.22
Participant describes feeling vulnerable when having sensitive discussion (diagnosis, treatment decision)	4	12.12	0	0.00	2	20.00	2	12.50	2	7.69	2	28.57	1	6.67	3	16.67
Participant describes feeling vulnerable because of interactions with the medical team	4	12.12	0	0.00	1	10.00	3	18.75	4	15.38	0	0.00	1	6.67	3	16.67
Participant describes feeling vulnerable all the time	4	12.12	1	14.29	0	0.00	3	18.75	3	11.54	1	14.29	1	6.67	3	16.67
Participant describes feeling vulnerable when feeling sick/unwell	3	9.09	0	0.00	1	10.00	2	12.50	2	7.69	1	14.29	1	6.67	2	11.11

Experience of vulnerability	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes feeling vulnerable during/after treatments	12	36.36	5	26.32	7	50.00	5	35.71	7	36.84	4	28.57	8	42.11
Participant describes feeling vulnerable experiencing side effects from treatment or symptoms from condition	5	15.15	2	10.53	3	21.43	2	14.29	3	15.79	1	7.14	4	21.05
Participant describes feeling vulnerable when having sensitive discussion (diagnosis, treatment decision)	4	12.12	2	10.53	2	14.29	1	7.14	3	15.79	1	7.14	3	15.79
Participant describes feeling vulnerable because of interactions with the medical team	4	12.12	2	10.53	2	14.29	2	14.29	2	10.53	3	21.43	1	5.26
Participant describes feeling vulnerable all the time	4	12.12	3	15.79	1	7.14	3	21.43	1	5.26	2	14.29	2	10.53
Participant describes feeling vulnerable when feeling sick/unwell	3	9.09	2	10.53	1	7.14	1	7.14	2	10.53	1	7.14	2	10.53

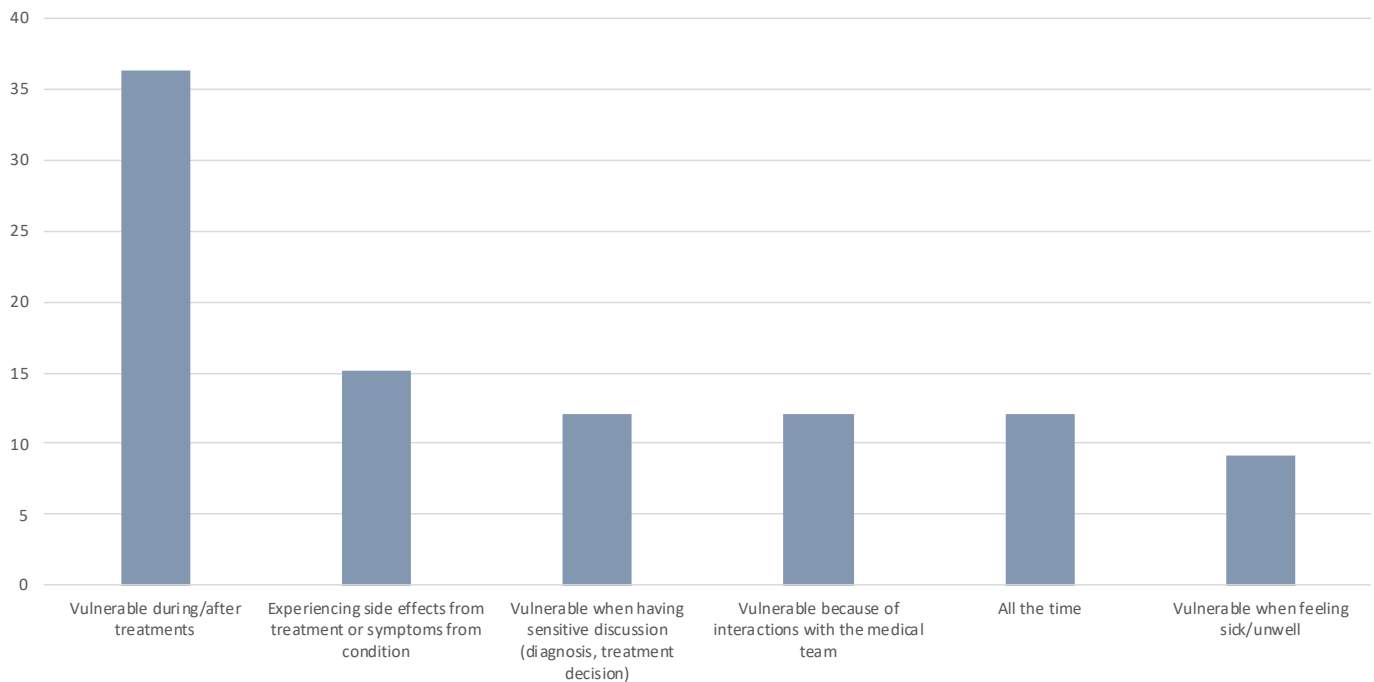


Figure 8.6: Experience of vulnerability

Table 8.12: Experience of vulnerability – subgroup variations

Experience of vulnerability	Reported less frequently	Reported more frequently
Participant describes feeling vulnerable during/after treatments	Diffuse Large B-Cell Lymphoma Aged 25 to 64	Multiple Myeloma Aged 65 or older
Participant describes feeling vulnerable experiencing side effects from treatment or symptoms from condition	B-cell acute lymphoblastic leukaemia (ALL)	CAR T-Cell therapy
Participant describes feeling vulnerable when having sensitive discussion (diagnosis, treatment decision)	B-cell acute lymphoblastic leukaemia (ALL)	CAR T-Cell therapy
Participant describes feeling vulnerable because of interactions with the medical team	B-cell acute lymphoblastic leukaemia (ALL) CAR T-Cell therapy	
Participant describes feeling vulnerable all the time	Diffuse Large B-Cell Lymphoma	

Methods to manage vulnerability

In the structured interview, participants described ways that they managed feelings of vulnerability. The most common ways to manage vulnerability were using self-help methods (resilience, acceptance, staying positive) (15.15%), support from nurse or treatment team (9.09%), and getting support from family and friends (6.06 %).

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

I think the only defense that I have is meditation and exercise and probably physical activities that I do and I do something related to my 5 senses. It distracts me if I'm doing a little bit of gardening or I'm working on my car or doing. These are the moments that I totally forget about what's going on. And after four hours, five hours...all of a sudden you come back to the reality that, oh, I've been sick.

Participant 017_2023AUCRT

Participant describes support from nurse or treatment team to manage the feeling of vulnerability

I was in a ward with a lot of other people. We talked to other people and to talk to health professionals.

Participant 020_2023AUCRT

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

Well, I had a few friends that came and helped, which was good and yeah, a few of them have stayed with me and they help with transport and everything and food and everything. So yeah, that was, that was good. I should say. I always have my son was there as well and he was ok but he didn't understand possibly.

Participant 015_2023AUCRT

Table 8.13: Methods to manage vulnerability

Methods to manage vulnerability	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7	%	n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes using self-help methods (resilience, acceptance, staying positive) to manage the feeling of vulnerability	5	15.15	0	0.00	2	20.00	3	18.75	3	11.54	2	28.57	1	6.67	4	22.22
Participant describes support from nurse or treatment team to manage the feeling of vulnerability	3	9.09	0	0.00	1	10.00	2	12.50	2	7.69	1	14.29	2	13.33	1	5.56
Participant describes getting support from family and friends to manage the feeling of vulnerability	2	6.06	0	0.00	0	0.00	2	12.50	2	7.69	0	0.00	0	0.00	2	11.11

Methods to manage vulnerability	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes using self-help methods (resilience, acceptance, staying positive) to manage the feeling of vulnerability	5	15.15	3	15.79	2	14.29	2	14.29	3	15.79	3	21.43	2	10.53
Participant describes support from nurse or treatment team to manage the feeling of vulnerability	3	9.09	1	5.26	2	14.29	1	7.14	2	10.53	0	0.00	3	15.79
Participant describes getting support from family and friends to manage the feeling of vulnerability	2	6.06	2	10.53	0	0.00	1	7.14	1	5.26	1	7.14	1	5.26

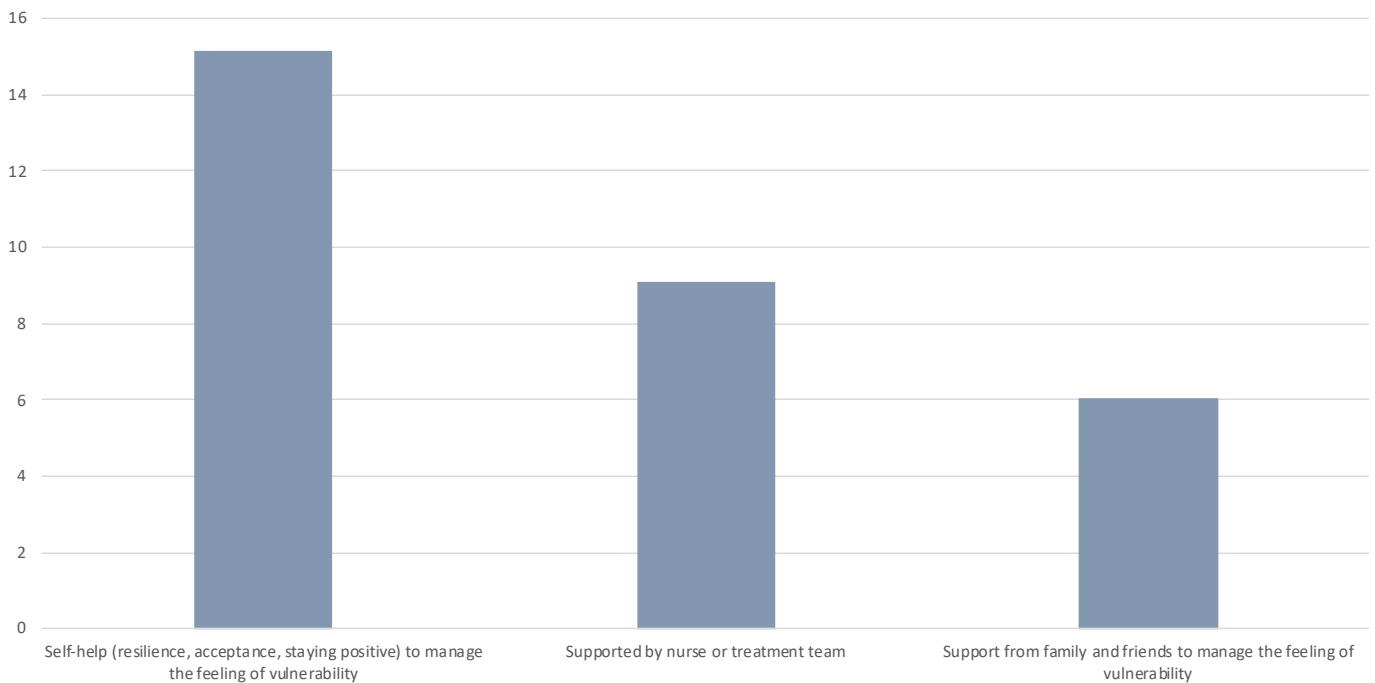


Figure 8.7: Methods to manage vulnerability

Table 8.14: Methods to manage vulnerability– subgroup variations

Methods to manage vulnerability	Reported less frequently	Reported more frequently
Participant describes using self-help methods (resilience, acceptance, staying positive) to manage the feeling of vulnerability	B-cell acute lymphoblastic leukaemia (ALL)	Multiple Myeloma Aged 65 or older

Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Most commonly, the descriptions suggested that overall, there was a negative impact on relationships (45.45%), and overall, there was a positive impact on relationships (27.27%). Other themes included overall, there was an impact on relationships that was both positive and negative (12.12%), and overall, there no impact on relationships (3.03%).

The most common themes in relation to having a negative impact on relationships were from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition (24.24%), and from people not knowing what to say or do and withdrawing from relationships (6.06 %).

The most common themes in relation to having a positive impact on relationships were from family relationships being strengthened (18.18%), and from people being well-meaning and supportive (18.18%).

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

No, but it was hard sometimes with some friends that live very close by. I felt over that period of that 10 months, my life was just going to the hospital every day. That was a bit like Groundhog Day every day. You could see them going off doing what they wanted. Only a few friends, not all of them but a couple of them, probably distanced our friendship because of that, because I was away for that long period. I guess like anything, if you don't associate with someone for 10 or 11 months.

Participant 001_2023AUCRT

We don't see a lot of friends as much as we used to. Yeah, I mean we'll have, we'll have friends perhaps maximum of four in our home, but we we're active churchgoers and so we don't go into that environment. We have to live stream church services. So there are a lot of friends that we haven't seen face to face.

Participant 013_2023AUCRT

It does, yes. So we changed my whole plans of life and I don't get to get too much social time with my friends anymore because of the fatigue and the timing that I'm considering for my bedtime and so yeah, I'm a different person to what I used to be. Yeah, but I guess, yeah, life is like that makes you to be a different person every now and then.

Participant 017_2023AUCRT

Yeah, the biggest thing it takes from you, and I think probably all cancers probably do, that is your confidence. When I was diagnosed, I generally thought I was bulletproof and I actually probably generally believed I hadn't been to a heart doctor at all in any sort, GP for whatever, for probably five or six years. I just don't go like it was just I never got sick or never got cold, never got anything. And so I just bulletproofly went about life in an arrogant way, that sort of thing. But it it's just the way I did. So I was actually quite confident. And you know, we're obviously socialized with friends a lot and we, you know, for no reason just live life as you do with good friends and good family. But when once I was diagnosed, it was like, just tread warily to, you know, what your body can do. And with that came this sort of lack of bulletproofness. And so I was always, so I withdrew in a little bit. I don't like coming out of my shell as much as I used to. So I my friendships haven't deteriorated. But I used to be probably more outgoing

than I was. But now I'm more conservative and withdrawn because it's sort of safe.

Participant 019_2023AUCRT

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

No, everyone was really supportive. Really, really supportive at the time. It was actually wonderful the support that I got like emotional support from people wishing me well and cards and little gifts and things like that, so that was good.

Participant 004_2023AUCRT

Not really. I mean, I have to say my friends have been very supportive. My, my, sorry, there's an airplane just passing now, so I just come outside. I'll just wait for that pass. That's Qantas.... Sorry, Sorry. My friends have been very good, very supportive. My my children have been very good. My daughter only lives about 5 minutes away from me. She we're in regular contact. So then I had a PET scan that is, I think it is. And that showed up I had lesions in my neck, in my spine, in my shoulder, and in my sternum and clavicle okay. But anyway I'm good I'm I'm good in that regard....

Participant 015_2023AUCRT

I don't think so. They, my siblings worry like crazy and some of our friends do worry, no matter how I try to assure them not to. So it's that's nice. Sometimes it's it's too much. But the attention.... I keep saying I'm not going to die, I'm not going to die. I'll let you know if I'm going to die....So yeah, it's it's nice that that they care so much.

Participant 036_2023AUCRT

It's actually it's made a bit of a I guess I never used to be home, you know, I'd always be working, you know, and I guess now I'm always at home so. But I guess my wife and I bonded actually, better. Well, I say better, but you know, we, I suppose I listened to her more than I ever did. Which probably from the man saying that it probably that's a bit that's just my thoughts there, whereas I probably didn't listen to him much before.

Participant 031_2023AUCRT

In the sense we've become closer, I think, which is lovely, you know, grandchildren will take me by the arm or help me down steps, you know, automatically. I love you, Pop. It's beautiful, really. So we're very close. We always have been close, but that's been enhanced. It's I'm aware that it's not easy for NAME because she's had to give up a lot, but we do enjoy

being with each other and you know, we'll go out to lunch or whatever.

Participant 035_2023AUCRT

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

Not so much family I feel very cared about. It's with friends. It has two reasons. One, COVID, you know, I just don't do the social thing as much as I used to. I probably could start to. I don't have the energy and

there's kind of probably friendships that I had. I just don't have the energy to engage. I'm really, really selective now about who I give my energy to. Where I was once, I'm very generous person and that I really has kind of I just can't do that. And so if people can't accept that change in me, well, they have. That's kind of how it is now. So there's probably a few friendships that are slowly fizzling and dying that, you know, my energy is primarily for my family. You know, my children, my family, my partner and a few close friends. And then after that we see what happens.

Participant 016_2023AUCRT

Table 8.15: Impact on relationships

Impact on relationships	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7	%	n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes that overall, there was a negative impact on relationships	15	45.45	4	57.14	4	40.00	7	43.75	12	46.15	3	42.86	5	33.33	10	55.56
Participant describes that overall, there was a positive impact on relationships	9	27.27	1	14.29	4	40.00	4	25.00	7	26.92	2	28.57	5	33.33	4	22.22
Participant describes that overall, there was an impact on relationships that was both positive and negative	4	12.12	2	28.57	1	10.00	1	6.25	3	11.54	1	14.29	3	20.00	1	5.56
Participant describes that overall, there no impact on relationships	1	3.03	0	0.00	0	0.00	1	6.25	1	3.85	0	0.00	1	6.67	0	0.00
No particular comment	4	12.12	0	0.00	1	10.00	3	18.75	3	11.54	1	14.29	1	6.67	3	16.67

Impact on relationships	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes that overall, there was a negative impact on relationships	15	45.45	9	47.37	6	42.86	8	57.14	7	36.84	10	71.43	5	26.32
Participant describes that overall, there was a positive impact on relationships	9	27.27	5	26.32	4	28.57	3	21.43	6	31.58	3	21.43	6	31.58
Participant describes that overall, there was an impact on relationships that was both positive and negative	4	12.12	4	21.05	0	0.00	2	14.29	2	10.53	0	0.00	4	21.05
Participant describes that overall, there no impact on relationships	1	3.03	0	0.00	1	7.14	0	0.00	1	5.26	0	0.00	1	5.26
No particular comment	4	12.12	1	5.26	3	21.43	1	7.14	3	15.79	1	7.14	3	15.79

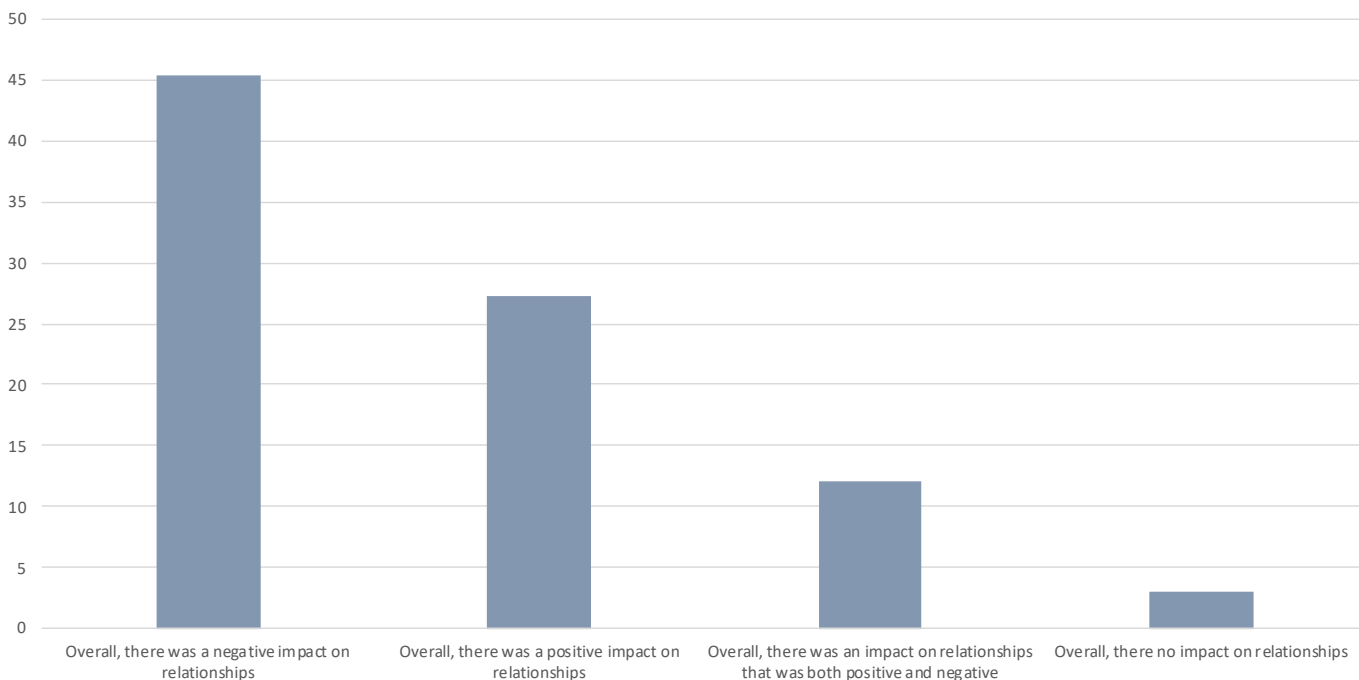


Figure 8.8: Impact on relationships

Table 8.16: Impact on relationships – subgroup variations

Impact on relationships	Reported less frequently	Reported more frequently
Participant describes that overall, there was a negative impact on relationships	Female Higher status	B-cell acute lymphoblastic leukaemia (ALL) Male Regional or remote Mid to low status
Participant describes that overall, there was a positive impact on relationships	B-cell acute lymphoblastic leukaemia (ALL)	Diffuse Large B-Cell Lymphoma
Participant describes that overall, there was an impact on relationships that was both positive and negative	Aged 65 or older Mid to low status	B-cell acute lymphoblastic leukaemia (ALL)

Table 8.17: Impact on relationships (Reason for impact)

Impact on relationships (Reason for impact)	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7	%	n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes a negative impact on relationships from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition	8	24.24	3	42.86	1	10.00	4	25.00	7	26.92	1	14.29	3	20.00	5	27.78
Participant describes a negative impact on relationships in general (no specifics articulated)	7	21.21	1	14.29	3	30.00	3	18.75	6	23.08	1	14.29	3	20.00	4	22.22
Participant describes a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships	2	6.06	1	14.29	1	10.00	0	0.00	1	3.85	1	14.29	1	6.67	1	5.56
Participant describes a positive impact on relationships from family relationships being strengthened	6	18.18	2	28.57	2	20.00	2	12.50	5	19.23	1	14.29	3	20.00	3	16.67
Participant describes a positive impact on relationships from people being well-meaning and supportive	6	18.18	1	14.29	3	30.00	2	12.50	5	19.23	1	14.29	4	26.67	2	11.11
Participant describes a positive impact on relationships in general (no specifics described)	2	6.06	0	0.00	1	10.00	1	6.25	1	3.85	1	14.29	1	6.67	1	5.56

Impact on relationships (Reason for impact)	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes a negative impact on relationships from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition	8	24.24	6	31.58	2	14.29	2	14.29	6	31.58	3	21.43	5	26.32
Participant describes a negative impact on relationships in general (no specifics articulated)	7	21.21	5	26.32	2	14.29	6	42.86	1	5.26	5	35.71	2	10.53
Participant describes a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships	2	6.06	1	5.26	1	7.14	1	7.14	1	5.26	1	7.14	1	5.26
Participant describes a positive impact on relationships from family relationships being strengthened	6	18.18	4	21.05	2	14.29	2	14.29	4	21.05	2	14.29	4	21.05
Participant describes a positive impact on relationships from people being well-meaning and supportive	6	18.18	4	21.05	2	14.29	2	14.29	4	21.05	2	14.29	4	21.05
Participant describes a positive impact on relationships in general (no specifics described)	2	6.06	2	10.53	0	0.00	2	14.29	0	0.00	0	0.00	2	10.53

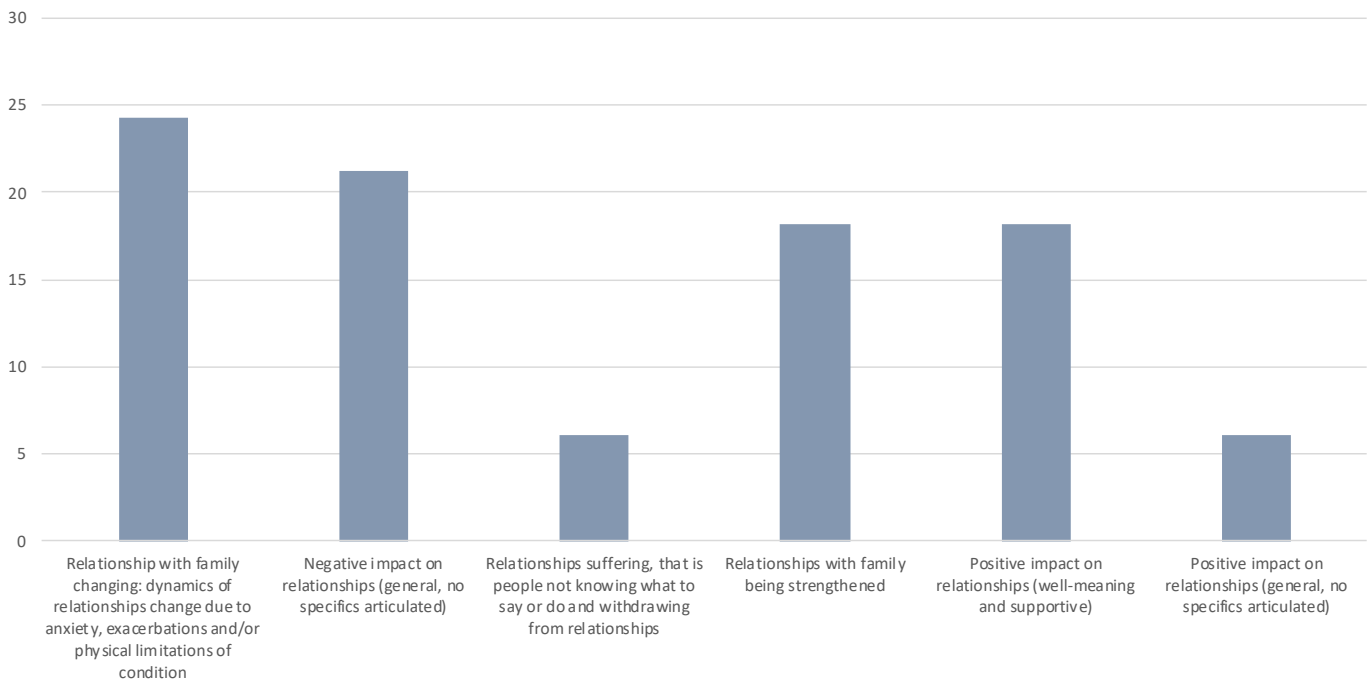


Figure 8.9: Impact on relationships

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

Impact on relationships (Reason for impact)	Reported less frequently	Reported more frequently
Participant describes a negative impact on relationships from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition	Diffuse Large B-Cell Lymphoma	B-cell acute lymphoblastic leukaemia (ALL)
Participant describes a negative impact on relationships in general (no specifics articulated)	Metropolitan Higher status	Regional or remote Mid to low status
Participant describes a positive impact on relationships from family relationships being strengthened	-	B-cell acute lymphoblastic leukaemia (ALL)
Participant describes a positive impact on relationships from people being well-meaning and supportive	-	Diffuse Large B-Cell Lymphoma

Burden on family

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Most commonly, the descriptions suggested that overall, there was a burden on their family (75.76%), and overall, there was not a burden on their family (18.18%).

The main reason that participant described their condition being a burden were that the burden on family was temporary or only during treatment (27.27%), the mental/emotional strain placed on their family(21.21%), and the extra household duties and responsibilities that their family must take on (15.15%).

Participant describes that the burden on family was temporary or only during treatment

Well, probably not not as much now as it was. I mean it definitely was when I was was really unwell because they had to do everything. Now it's more just I suppose they've got that extra burden of they've just got to make sure that they don't get me sick or. That sort of thing, just just being more careful with with those things. So I have to remind them and I have to make sure and say okay, yeah, well, yes, we know we've been vaccinated for chicken pox, but they could still get it slightly and pass it on to me. So I have to be very aware of that. But I'm not a burden now in that, yeah, I cook, I cook, I cook the meals, I clean the house. I go with my husband for his appointment. So I do whatever. So I'm I'm sort of almost almost normal, just with just the fact that I'm more tired and have to be a bit more cautious with stuff.

Participant 006_2023AUCRT

No, not really. There's been that obviously when there's you know that when there's treatment and different levels of pain and that's the stuff, there's there is an extra requirement in terms of perhaps help that one needs. And because I'm by myself, you know I need to rely on the NAME. My son is always helpful for that. But nothing, Nothing too great.

Participant 023_2023AUCRT

Well, it was certainly before, but not anymore.

Participant 014_2023AUCRT

Not at this stage, no. Earlier in the earlier days, yeah, yeah. Possibly yes.

Participant 020_2023AUCRT

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

Well, I suppose as far as them stress wise, you know worrying about the if you know you're going to survive that that that would be a burden to them and that's something I don't want for them. But yeah, that that's the only area and yeah it's I suppose it's just how they feel about how you're feeling or what's going to happen to you. It's more of the problem.

Participant 015_2023AUCRT

Not care and assistance. It's more my, if I had to worry, it's my worry that they worry too much about me. That's it, you know. But other than that, no no.

Participant 018_2023AUCRT

No, not really. The burden is mental stress in a way, because my wife worries about me and my daughter worries about me and they carry that and they she annoys me. Like if I'd groaned or something, I was standing up and I'd just groaned. They go, 'You all right?' You know, I'll go for my take my bike rides on a Saturday morning and sometimes I come back looking a bit worse away, just sweated too much or the wind was too much. My eyes and they go, oh, you OK? You OK? You feeling alright? Take it easy, don't rush. Yeah. And it's like now with my cold I wanna train, but I can't because I've been there. And no, you should be just taking it easy. Just rest, you know. All this sort of stuff so it causes a lot of mental anguish rather than anything else, that's all.

Participant 019_2023AUCRT

No, not now. At the time, it was my husband was the one who looked after me, so he was the one that did it all, but he did it without any complaint. He wanted to, but it was stressful for him, very stressful.

Participant 004_2023AUCRT

Participant describes the extra household duties and responsibilities that their family must take on as a burden on their family

Yeah, yeah, I think it is. I don't think that 14 year old boys should have to, you know. You know, my kids kind of pick up and just clean the house, which in one way is every mom's dream, but in another way, that's not what they should be doing, you know? Yeah. So, no, I do. I think they feel very responsible for me and my children. Yeah.

Participant 016_2023AUCRT

Well, yes and no. Yes. My partner, my husband has been amazing. He's been the right arm and he's had he's a very fit. Healthy man generally, but he's a couple of things where I've had to look after him. But in the main he's been the store because CAR T needs you have to have someone attend with you for 30 days. Everything, everything. And he hates hospitals so he happily did that. Well, happily might be going too far, but we worked. He did it without an issue and that was great. That was and. Yeah, he's always been there, brings me everything, you know, when I was in for stem cells, he'd bring me before lunch and dinner and no matter what I'd ordered I'd say to him, I'll bring this, bring that and he would bring it and I'm just going to blow my nose through. He, he just has been fantastic in that way. So I've been very fortunate.

Participant 036_2023AUCRT

Initially yes, like when mum took the year off to look after me, because she really, really enjoys her job, but now not so much only because I'm fortunate, there's no longer any treatment required or anything and the just the every three months going back to LOCATION for checkup biopsies.

Participant 005_2023AUCRT

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

Well, not on my family because they're not here. But you know, I, for instance, I've got all my financial affairs in order and I've had the advanced care directives done and I've had the, the will done and I've had them, you know, authorized to make decisions for me. And also the, you know, giving them access to my financial accounts and things like that. So that if I do need to ask them to do things, that it's all set up and they're ready to do that.

Participant 012_2023AUCRT

Yeah. No. So far we are managing, you know, it would be in in that life, so say for instance, you know, going for camping you know holidays and just last night you know my husband just said that he already booked this one for March next year. You know that they go for holidays. So we we tried to you know of course outside of season where there are no school holidays you know those you know grey nomads you know just moving the quiet times you know to those you know places. So that that works for us. It's not.

Participant 034_2023AUCRT

Table 8.19: Burden on family

Burden on family	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7	%	n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes that overall, there was a burden on their family	25	75.76	4	57.14	9	90.00	12	75.00	19	73.08	6	85.71	12	80.00	13	72.22
Participant describes that overall, there was not a burden on their family	6	18.18	2	28.57	1	10.00	3	18.75	5	19.23	1	14.29	3	20.00	3	16.67
No particular comment	2	6.06	1	14.29	0	0.00	1	6.25	2	7.69	0	0.00	0	0.00	2	11.11

Burden on family	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes that overall, there was a burden on their family	25	75.76	15	78.95	10	71.43	12	85.71	13	68.42	10	71.43	15	78.95
Participant describes that overall, there was not a burden on their family	6	18.18	3	15.79	3	21.43	1	7.14	5	26.32	3	21.43	3	15.79
No particular comment	2	6.06	1	5.26	1	7.14	1	7.14	1	5.26	1	7.14	1	5.26

Figure 8.10: Burden on family

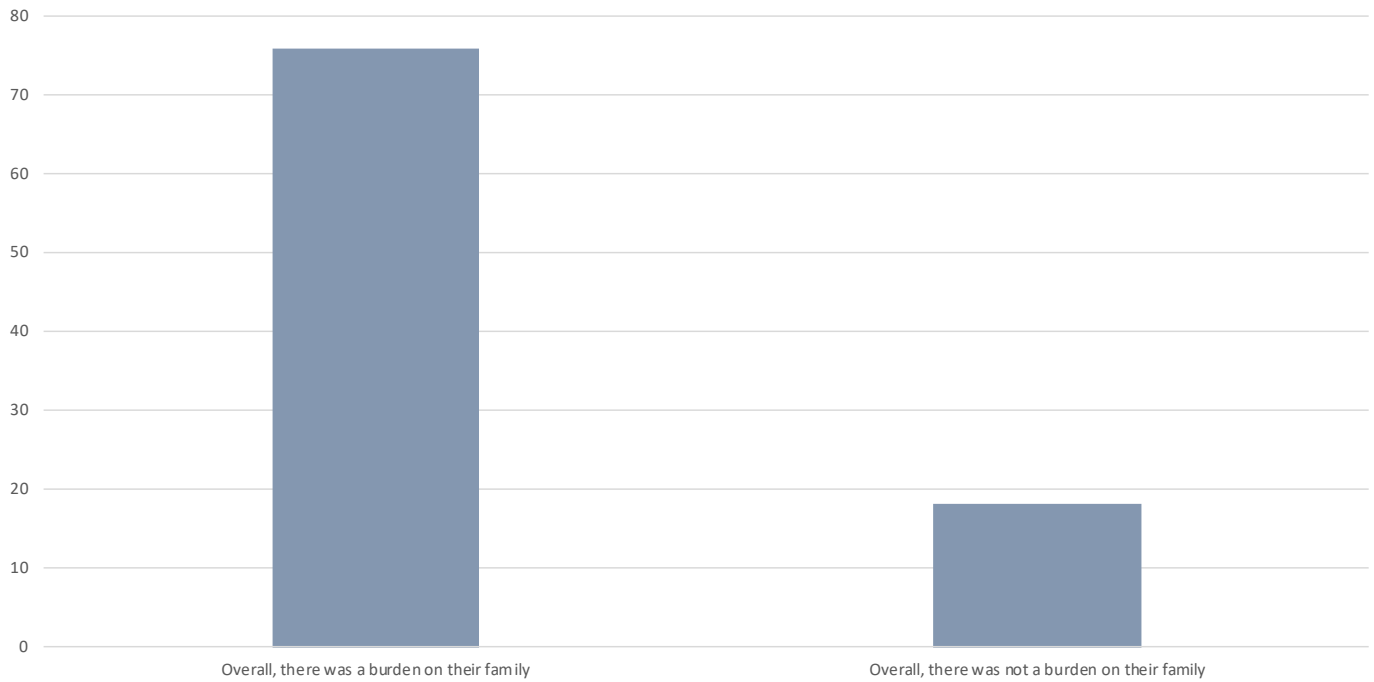


Table 8.20: Burden on family – subgroup variations

Burden on family	Reported less frequently	Reported more frequently
Participant describes that overall, there was a burden on their family	B-cell acute lymphoblastic leukaemia (ALL)	Diffuse Large B-Cell Lymphoma
Participant describes that overall, there was not a burden on their family	Regional or remote	B-cell acute lymphoblastic leukaemia (ALL)

Table 8.21: Burden on family (description)

Burden on family (description)	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7	%	n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes that the burden on family was temporary or only during treatment	9	27.27	2	28.57	4	40.00	3	18.75	7	26.92	2	28.57	6	40.00	3	16.67
Participant describes the mental/emotional strain placed on their family as a burden on their family	7	21.21	0	0.00	3	30.00	4	25.00	7	26.92	0	0.00	3	20.00	4	22.22
Participant describes the extra household duties and responsibilities that their family must take on as a burden on their family	5	15.15	1	14.29	3	30.00	1	6.25	3	11.54	2	28.57	4	26.67	1	5.56
Participant describes their condition being a burden in general (No specific examples) as a burden on their family	5	15.15	1	14.29	2	20.00	2	12.50	4	15.38	1	14.29	2	13.33	3	16.67
Participant describes their condition not being a burden in general (No specific examples) as a burden on their family	5	15.15	2	28.57	0	0.00	3	18.75	4	15.38	1	14.29	1	6.67	4	22.22

Burden on family (description)	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes that the burden on family was temporary or only during treatment	9	27.27	5	26.32	4	28.57	4	28.57	5	26.32	3	21.43	6	31.58
Participant describes the mental/emotional strain placed on their family as a burden on their family	7	21.21	4	21.05	3	21.43	3	21.43	4	21.05	3	21.43	4	21.05
Participant describes the extra household duties and responsibilities that their family must take on as a burden on their family	5	15.15	3	15.79	2	14.29	1	7.14	4	21.05	1	7.14	4	21.05
Participant describes their condition being a burden in general (No specific examples) as a burden on their family	5	15.15	5	26.32	0	0.00	3	21.43	2	10.53	3	21.43	2	10.53
Participant describes their condition not being a burden in general (No specific examples) as a burden on their family	5	15.15	2	10.53	3	21.43	2	14.29	3	15.79	2	14.29	3	15.79

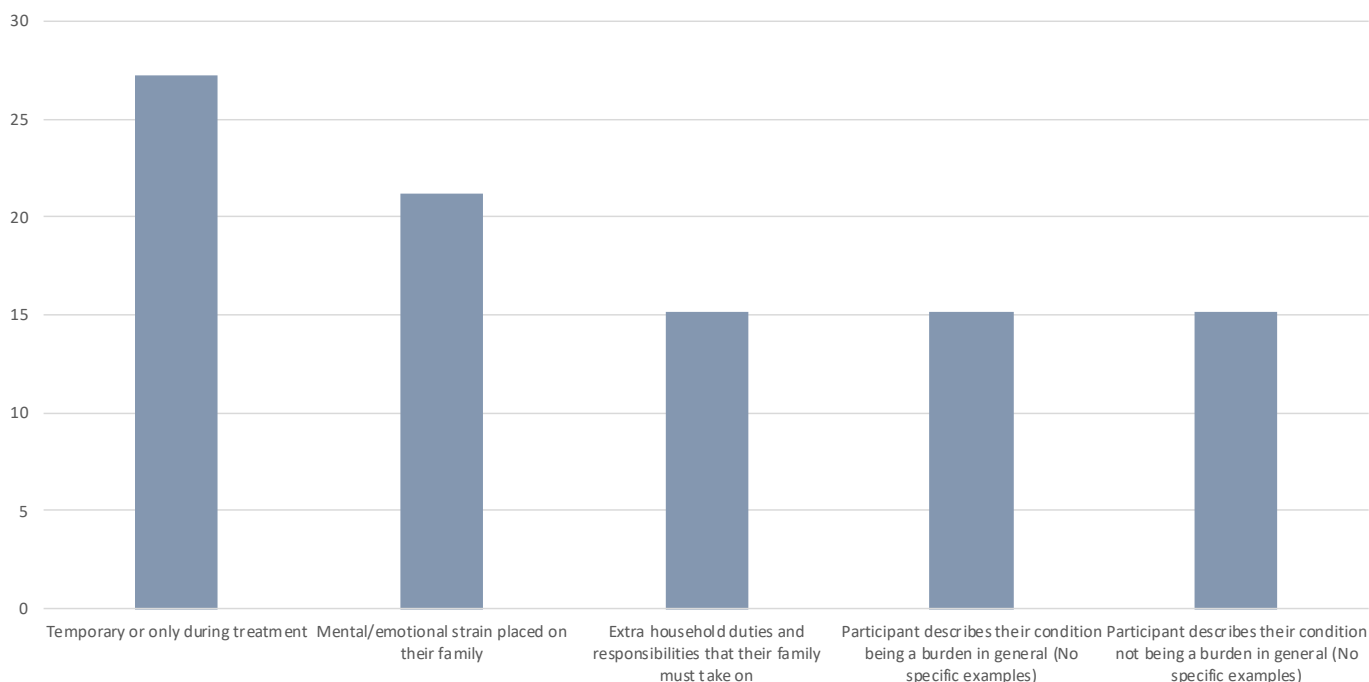


Figure 8.11: Burden on family (description)

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

Burden on family (description)	Reported less frequently	Reported more frequently
Participant describes that the burden on family was temporary or only during treatment	Male	Diffuse Large B-Cell Lymphoma Female
Participant describes the mental/emotional strain placed on their family as a burden on their family	B-cell acute lymphoblastic leukaemia (ALL) CAR T-Cell therapy	-
Participant describes the extra household duties and responsibilities that their family must take on as a burden on their family	-	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Female
Participant describes their condition being a burden in general (No specific examples) as a burden on their family	Aged 65 or older	Aged 25 to 64
Participant describes their condition not being a burden in general (No specific examples) as a burden on their family	Diffuse Large B-Cell Lymphoma	B-cell acute lymphoblastic leukaemia (ALL)

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. The most common descriptions were that overall, there was at least some cost burden (63.64%), and overall, there was no cost burden (33.33%).

Where participants described a cost burden associated with their condition, it was most commonly in relation to needing to take time off work (39.39%), the cost of treatments (including repeat scripts) (21.21%), and the cost of parking and travel to attend appointments (including accommodation) (18.18 %). Other themes included a family member needing to take time off work (9.09%) and needing to access financial support from family or charities (9.09%).

Where participants described no cost burden associated with their condition, it was most commonly in relation to nearly everything was paid for through the public health system (45.45%), nearly everything was paid for through the private health system

(12.12%), and the participant was able to afford all costs (12.12 %).

Cost burden in relation to needing to take time off work

I haven't really incurred many costs at all. Some of the medications are little bit pricey, but given the big picture, they're only one \$40, \$50. My big thing for me is that I've had to leave work. It's just that sense of independence, that's all, but no other costs really that have been of a worry.

Participant 002_2023AUCRT

Pretty limited actually, because I have private health and a private hospital. You pay the first 250 each year and then medications, vaccinations, those things on paid as you go. So pretty minimal and but if I didn't have fabulous superannuation and investments and a

good job and you know I think I've said in the thing I probably lost two years of two to three years of income that I would have had, I probably would have retired 2020, that was my plan. End of 2020 I would have retired. So 18/19/20. That's a fair chunk.
Participant 036_2023AUCRT

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

OK. The only cost that I've had to bear is really for medications, and I never quite reached the whatever the limit is which reduced. The cost of medication, so that that that was sort of like a regular cost that that I did feel particularly as interest rates have gone up. So I was, I was getting a little anxious about that.
Participant 009_2023AUCRT

Cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)

It's expensive, very expensive. Even though we had private health and we had so much support from the Leukemia Foundation or just wonderful. Yeah, it's really expensive. It's all the little things, you know, that just added, like for instance, like park in your car to go to appointments, you travel to appointments, your medications.
Participant 011_2023AUCRT

Cost burden in relation to a family member needing to take time off work

My mum did take the year off of work because to stay at the leukemia village, I needed a carer. So my husband could keep working, mum took the year off to look after me. I just helped, I paid the groceries and helped mum out with bills and that. Mum's not in a great financial spot but my husband and I are quite comfortable. He has a business and we both work full time so yes, we definitely didn't suffer in the way that some other people do so we were quite fortunate.
Participant 005_2023AUCRT

Cost burden in needing to access financial support

But the biggest cost is your time off work because ultimately we dipped into my super I think for the 12 to 18 months that from diagnosis to the stem cells transplant and beyond. And my wife, she did work part time but when I was in depths of heavy treatment she would take time off work. So unfortunately I had good friends that supported us in ways but also we

dipped into my super stuff like that just to get us through financially. We took to recover it away because you know we borrowed a bit of money off mum and dad and sit the Super and stuff like that. So but we got there and you know and then we just sort of paid mum and dad back and retopped up the Super. But it's it's taken a while, like it's probably taking the whole 12 years, so.
Participant 019_2023AUCRT

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

It's been entirely amazing. I really have a big appreciation of the Australian medical system, really. I didn't pay anything. That was many many months, many persons, and the only money I've paid is when I've come back into a regional area. Then it's glaringly obvious that the regional areas don't get the same support as the city hospitals in things like scans or blood tests or any of that sort of stuff. Luckily, that's all I've needed down here. I've had to pay for that. Whereas if I was in the city, I wouldn't have to pay for any of that.
Participant 003_2023AUCRT

Across well, really the only cost that I've had because I've been, well I was I've been traded in the public health system. We we did use our private health cover for the...I said the hospital gets the money from Bupa, but I haven't had any private appointments or private hospital thing. So the only cost that I've found has been the the medication when you come home. So and that is quite expensive and when I first came out of the hospital until I got to the safety net, it was probably \$500 a month or something....So yeah, so, so, so really the the cost of just being medication.
Participant 006_2023AUCRT

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

No, well I didn't have to have any time off work because I had retired by the time I was diagnosed and and I don't have any family members here. So nobody has had to take, you know, time off to do anything with me And the cost. I've got the top medical benefits and I've never queried any expenses or anything.
Participant 012_2023AUCRT

No cost burden as participant was able to afford all costs

It didn't really cost anything. I think you know we got reimbursed some money for fuel and stuff when we were traveling back on. My wife was traveling to and from LOCATION, from up here and they they helped her with accommodation that was cheap and near the hospital and and and and and fuel and stuff like that.

We would have been out of pocket a little bit, but it was nothing we really noticed and I had savings that could cover all that.

Participant 010_2023AUCRT

I guess we're fortunate enough that that we have sufficient. So there's no financial issues, pressures at all. Participant 013_2023AUCRT

Table 8.23: Cost considerations

Cost considerations	All participants		B-cell acute lymphoblastic leukaemia (ALL) n=7	Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male		
	n=33	%		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%	
Participant describes that overall, there was at least some cost burden	21	63.64	5	71.43	7	70.00	9	56.25	18	69.23	3	42.86	11	73.33	10	55.56
Participant describes that overall, there was no cost burden	11	33.33	1	14.29	3	30.00	7	43.75	7	26.92	4	57.14	4	26.67	7	38.89
Other/No response	1	3.03	1	14.29	0	0.00	0	0.00	1	3.85	0	0.00	0	0.00	1	5.56

Cost considerations	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes that overall, there was at least some cost burden	21	63.64	16	84.21	5	35.71	9	64.29	12	63.16	8	57.14	13	68.42
Participant describes that overall, there was no cost burden	11	33.33	2	10.53	9	64.29	4	28.57	7	36.84	5	35.71	6	31.58
Other/No response	1	3.03	1	5.26	0	0.00	1	7.14	0	0.00	1	7.14	0	0.00

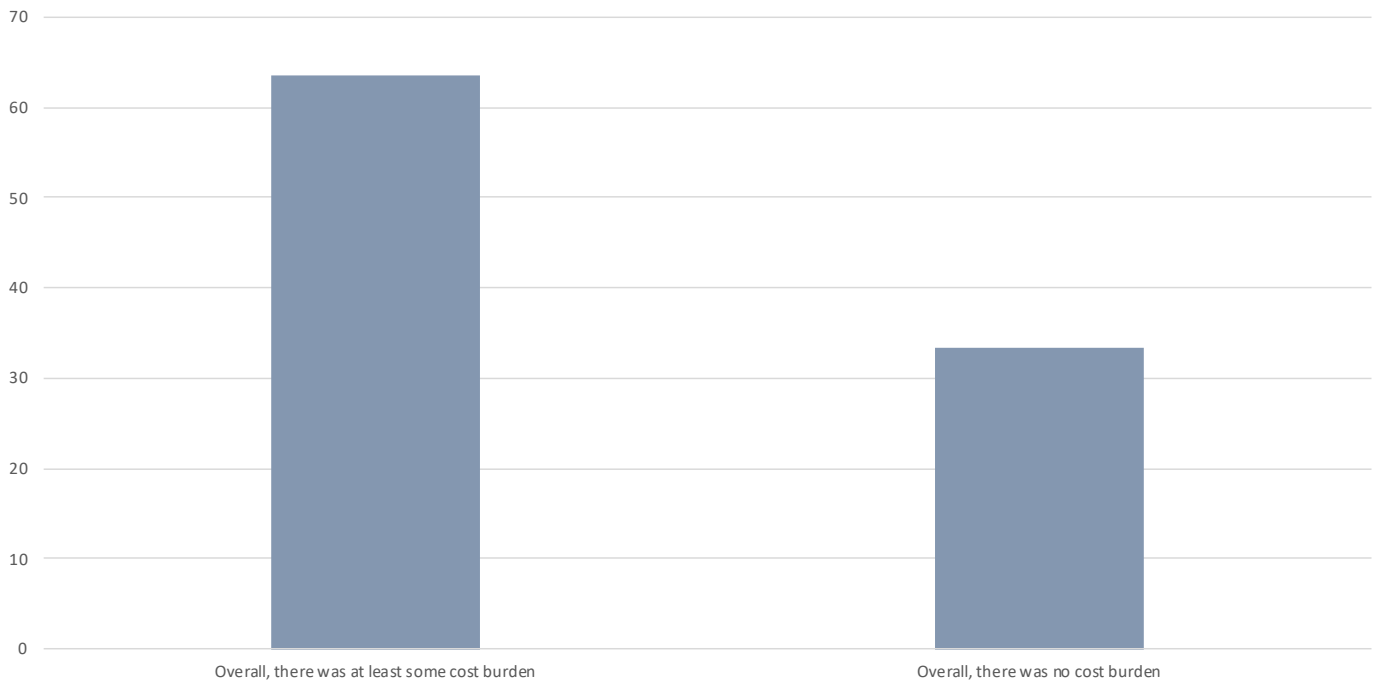


Figure 8.12: Cost considerations

Table 8.24: Cost considerations – subgroup variations

Cost considerations	Reported less frequently	Reported more frequently
Participant describes that overall, there was at least some cost burden	CAR T-Cell therapy Aged 65 or older	Aged 25 to 64
Participant describes that overall, there was no cost burden	B-cell acute lymphoblastic leukaemia (ALL) Aged 25 to 64	Multiple Myeloma CAR T-Cell therapy Aged 65 or older

Table 8.25: Cost considerations (Reasons for cost)

Cost considerations (reasons for costs)	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7	%	n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Cost burden in relation to needing to take time off work	13	39.39	5	71.43	4	40.00	4	25.00	11	42.31	2	28.57	9	60.00	4	22.22
Cost burden in relation to the cost of treatments (including repeat scripts)	7	21.21	2	28.57	2	20.00	3	18.75	6	23.08	1	14.29	3	20.00	4	22.22
Cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	6	18.18	3	42.86	2	20.00	1	6.25	6	23.08	0	0.00	2	13.33	4	22.22
Cost burden in relation to a family member needing to take time off work	3	9.09	1	14.29	1	10.00	1	6.25	3	11.54	0	0.00	1	6.67	2	11.11
Cost burden in needing to access financial support from family or charities	3	9.09	1	14.29	1	10.00	1	6.25	3	11.54	0	0.00	1	6.67	2	11.11
No cost burden and that nearly everything was paid for through the public health system	15	45.45	2	28.57	5	50.00	8	50.00	13	50.00	2	28.57	6	40.00	9	50.00
No cost burden and that nearly everything was paid for through the private health system	4	12.12	0	0.00	2	20.00	2	12.50	2	7.69	2	28.57	3	20.00	1	5.56
No cost burden as participant was able to afford all costs	4	12.12	0	0.00	1	10.00	3	18.75	2	7.69	2	28.57	0	0.00	4	22.22

Cost considerations (reasons for costs)	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Cost burden in relation to needing to take time off work	13	39.39	10	52.63	3	21.43	3	21.43	10	52.63	4	28.57	9	47.37
Cost burden in relation to the cost of treatments (including repeat scripts)	7	21.21	6	31.58	1	7.14	4	28.57	3	15.79	3	21.43	4	21.05
Cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	6	18.18	5	26.32	1	7.14	3	21.43	3	15.79	4	28.57	2	10.53
Cost burden in relation to a family member needing to take time off work	3	9.09	3	15.79	0	0.00	2	14.29	1	5.26	2	14.29	1	5.26
Cost burden in needing to access financial support from family or charities	3	9.09	3	15.79	0	0.00	2	14.29	1	5.26	2	14.29	1	5.26
No cost burden and that nearly everything was paid for through the public health system	15	45.45	7	36.84	8	57.14	8	57.14	7	36.84	6	42.86	9	47.37
No cost burden and that nearly everything was paid for through the private health system	4	12.12	1	5.26	3	21.43	0	0.00	4	21.05	1	7.14	3	15.79
No cost burden as participant was able to afford all costs	4	12.12	0	0.00	4	28.57	2	14.29	2	10.53	1	7.14	3	15.79

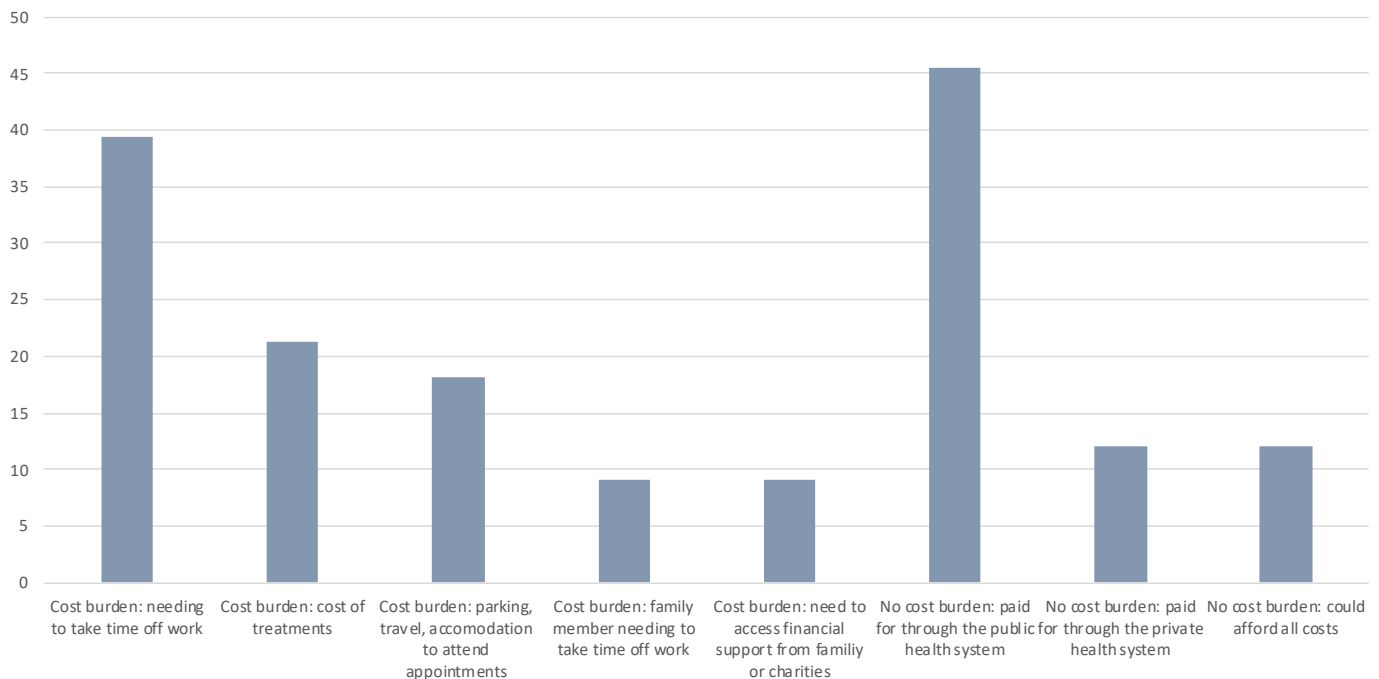


Figure 8.13: Cost considerations (Reasons for cost)

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

Cost considerations (reasons for costs)	Reported less frequently	Reported more frequently
Cost burden in relation to needing to take time off work	Multiple Myeloma CAR T-Cell therapy Male Aged 65 or older Regional or remote	B-cell acute lymphoblastic leukaemia (ALL) Female Aged 25 to 64 Metropolitan
Cost burden in relation to the cost of treatments (including repeat scripts)	Mid to low status Aged 65 or older	Aged 25 to 64
Cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	Multiple Myeloma CAR T-Cell therapy Aged 65 or older	B-cell acute lymphoblastic leukaemia (ALL) Mid to low status
No cost burden and that nearly everything was paid for through the public health system	B-cell acute lymphoblastic leukaemia (ALL) CAR T-Cell therapy	Aged 65 or older Regional or remote
No cost burden and that nearly everything was paid for through the private health system	B-cell acute lymphoblastic leukaemia (ALL) Regional or remote	CAR T-Cell therapy
No cost burden as participant was able to afford all costs	B-cell acute lymphoblastic leukaemia (ALL) Female Aged 25 to 64	CAR T-Cell therapy Male Aged 65 or older

Experience of anxiety related to disease progression

Fear of progression

The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their conditions. The Fear of Progression questionnaire comprises a total score, between 12 and 60, with a higher score denoting increased anxiety. Summary statistics for the entire cohort are displayed in the table below. The overall scores for the cohort were in the second lowest quintile for Fear of progression: Total score (mean=30.82, SD=11.27), indicating low levels of anxiety

Comparisons of Care co-ordination have been made based on blood cancer type, CAR T-cell therapy, gender, age, location and socioeconomic status.

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

Table 8.27: Fear of progression summary statistics

Fear of progression (n=34)	Mean	SD	Median	IQR	Possible range	Quintile
Total score	30.82	11.27	28.50	18.00	12 to 60	2

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

Fear of progression by blood cancer type

Comparisons were made by type of blood cancer. There were 8 participants (23.53%) with B-cell acute lymphoblastic leukemia (ALL), 10 participants (29.41%) with Diffuse Large B-Cell Lymphoma, and 16 participants (47.06%) with Multiple Myeloma.

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal.

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

Table 8.28: Fear of progression total score by blood cancer type summary statistics and one-way ANOVA

Fear of progression	Group	Number (n=34)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Total score	B-cell acute lymphoblastic leukemia (ALL)	8	23.53	36.88	8.82	Between groups	496.00	2.00	248.10	2.08	0.1420
	Diffuse Large B-Cell Lymphoma	10	29.41	31.60	10.30	Within groups	3696.00	31.00	119.20		
	Multiple Myeloma	16	47.06	27.31	12.10	Total	4192.00	33.00	367.30		

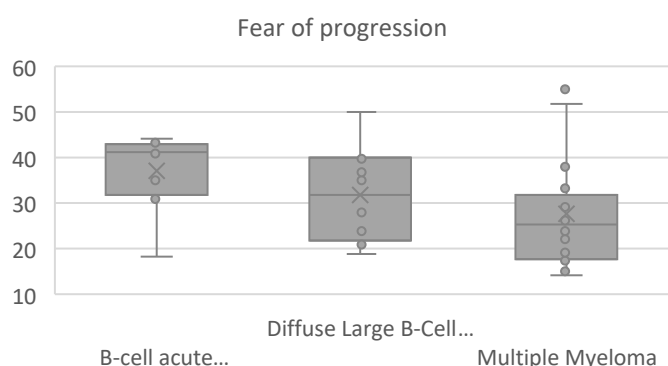


Figure 8.14: Boxplot of Fear of progression total score by blood cancer type

Fear of progression by CAR T-cell therapy

Comparisons were made by CAR T-cell therapy there were 27 participants (79.41%) that had treatment with Car T-cell therapy and, 7 participants (20.59%) that did not .

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

No significant differences were observed between participants by **CAR T-cell therapy** for any of the Fear of progression scales

Table 8.29: Fear of progression total score by CAR T-cell therapy summary statistics and T-test

Fear of progression	Group	Number (n=34)	Percent	Mean	SD	T	dF	p-value
Total score	No	27	79.41	32.22	11.01	131.00	0.1250	0.1584
	Yes	7	20.59	25.43	11.44			

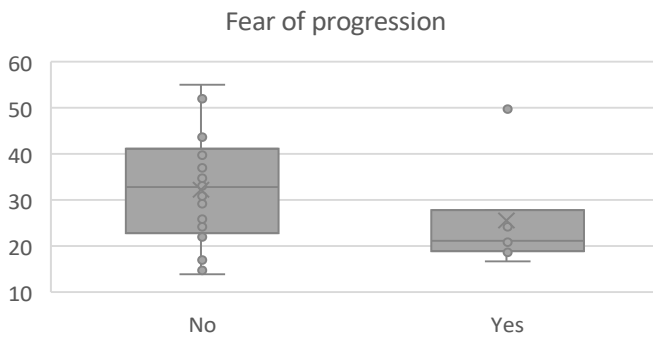


Figure 8.15: Boxplot of Fear of progression total score by CAR T-cell therapy

Fear of progression by gender

Comparisons were made by gender, there were 16 female participants (47.06%), and 18 male participants (52.94%).

Assumptions for normality and variance for a two-sample t-test were not met, a Wilcoxon rank sum test with continuity correction was used.

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

Table 8.30: Fear of progression total score by gender summary statistics and Wilcoxon test

Fear of progression	Group	Number (n=34)	Percent	Median	IQR	W	p-value
Total score	Female	16	47.06	35.00	12.75	190.00	0.1162
	Male	18	52.94	23.50	18.25		

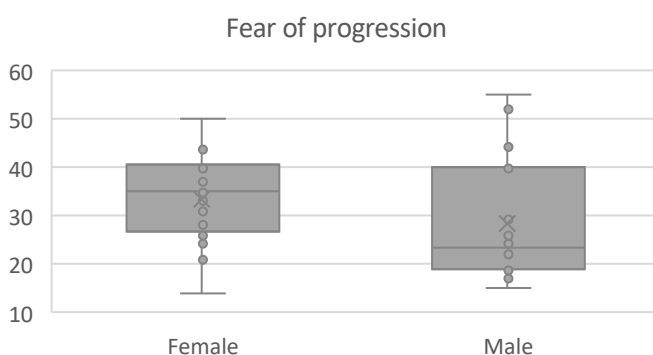


Figure 8.16: Boxplot of Fear of progression total score by gender

Fear of progression by age

Participants were grouped according to age, with comparisons made between participants aged 25 to 64 (n=20, 58.82%), and participants aged 65 and older (n=14, 41.18%).

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

A two sample t-test indicated that the mean score for the Fear of progression Total score scale [t(32) = 3.34 ,

p = 0.0021] was significantly higher for participants in the Aged 25 to 64 subgroup (Mean = 35.55, SD = 10.51) compared to participants in the Aged 65 and older (Mean = 24.07, SD = 8.81.)

conditions. On average, participants in the Aged 25 to 64 subgroup scored higher than participants in the Aged 65 and older. This indicates that participants in the Aged 25 to 64 subgroup had moderate levels of anxiety, and participants in the Aged 65 and older had low levels of anxiety.

The **Fear of Progression** questionnaire measures the level of anxiety people experience in relation to their

Table 8.31: Fear of progression total score by age summary statistics and T-test

Fear of progression	Group	Number (n=34)	Percent	Mean	SD	T	dF	p-value
Total score	Aged 25 to 64	20	58.82	35.55	10.51	3.34	32.00	0.0021*
	Aged 65 and older	14	41.18	24.07	8.81			

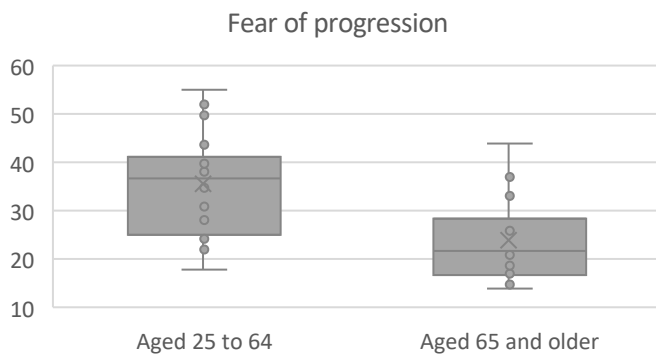


Figure 8.17: Boxplot of Fear of progression total score by age

Fear of progression by location

The location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. Those living in regional/rural areas (n=15, 44.12%) were compared to those living in a major city (n=19, 55.88%).

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

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

Table 8.32: Fear of progression total score by location summary statistics and T-test

Fear of progression	Group	Number (n=34)	Percent	Mean	SD	T	dF	p-value
Total score	Metropolitan	15	44.12	32.20	12.10	0.63	32.00	0.5352
	Regional or remote	19	55.88	29.74	10.78			

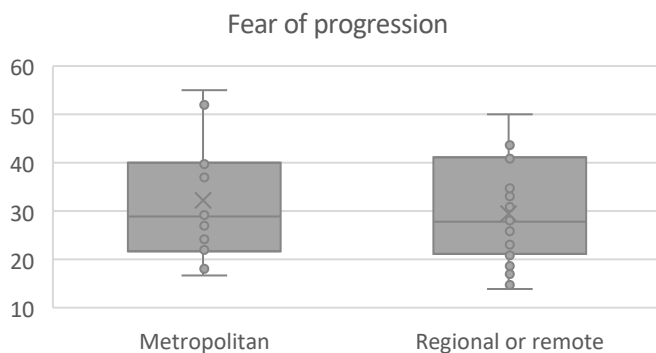


Figure 8.18: Boxplot of Fear of progression total score by location

Fear of progression by socioeconomic status

Comparisons were made by socioeconomic status, using the Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a mid to low SEIFA score of 1-6 (n=15, 44.12%) compared to those with a higher SEIFA score of 7-10 (n=19, 55.88%).

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

A two sample t-test indicated that the mean score for the Fear of progression Total score scale [t(32) = 2.38, p = 0.0236] was significantly higher for participants in

the Higher advantage subgroup (Mean = 35.67, SD = 11.76) compared to participants in the Mid to low advantage subgroup (Mean = 27.00, SD = 9.50).

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

Table 8.33: Fear of progression total score by socioeconomic status summary statistics and T-test

Fear of progression	Group	Number (n=34)	Percent	Mean	SD	T	dF	p-value
Total score	Higher advantage	15	44.12	35.67	11.76	2.38	32.00	0.0236*
	Mid to low advantage	19	55.88	27.00	9.50			

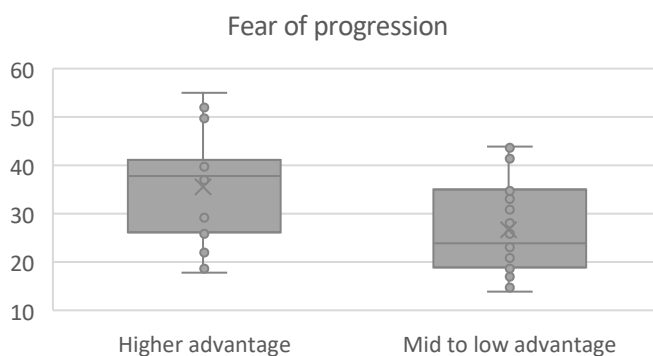


Figure 8.19: Boxplot of Fear of progression total score by socioeconomic status

Anxiety about treatment

Fear of progression individual questions

An overview of responses to individual fear of progression questions is given in the table below.

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

On average, participants scored in the “Seldom” range for the following questions: “Is nervous prior to doctors appointments or periodic examinations” (median=2.00, IQR=1.50), “Afraid of pain” (median=2.25, IQR=1.00), “The possibility of relatives being diagnosed with this disease disturbs participant”

(median=2.00, IQR=1.75), “Is disturbed that they may have to rely on strangers for activities of daily living” (median=2.00, IQR=2.00), “Worried that at some point in time will no longer be able to pursue hobbies because of illness” (median=2.00, IQR=2.38), “Afraid of severe medical treatments during the course of illness” (median=2.25, IQR=2.88), “The thought that they might not be able to work due to illness disturbs participant” (median=2.00, IQR=2.75), “If a treatment and it is working well (limited side effects, no progression of disease), worry what will happen if treatment stopped” (median=2.00, IQR=2.00).

On average, participants scored in the “Sometimes” range for the following questions: “Becomes anxious thinking that disease may progress” (median=3.00,

IQR=2.00), “Has concerns about reaching professional and/or personal goals because of illness:” (median=3.00, IQR=2.00), “When anxious, has physical symptoms such as a rapid heartbeat, stomach ache or agitation” (median=3.00, IQR=3.00), “Worried that

treatment could damage their body” (median=3.00, IQR=1.88), “Worried about what will become of family if something should happen to participant” (median=3.00, IQR=2.00).

Table 8.34: Fear of progression individual questions

Fear of progression (n=34)	Mean	SD	Median	IQR	Average response
Becomes anxious thinking that disease may progress	2.99	1.16	3.00	2.00	Sometimes
Is nervous prior to doctors appointments or periodic examinations	2.65	1.33	2.00	1.50	Seldom
Afraid of pain	2.60	1.20	2.25	1.00	Seldom
Has concerns about reaching professional and/or personal goals because of illness:	2.79	1.33	3.00	2.00	Sometimes
When anxious, has physical symptoms such as a rapid heartbeat, stomach ache or agitation	2.65	1.33	3.00	3.00	Sometimes
The possibility of relatives being diagnosed with this disease disturbs participant	1.93	1.02	2.00	1.75	Seldom
Is disturbed that they may have to rely on strangers for activities of daily living	2.16	1.16	2.00	2.00	Seldom
Worried that at some point in time will no longer be able to pursue hobbies because of illness	2.49	1.30	2.00	2.38	Seldom
Afraid of severe medical treatments during the course of illness	2.49	1.35	2.25	2.88	Seldom
Worried that treatment could damage their body	2.82	1.25	3.00	1.88	Sometimes
Worried about what will become of family if something should happen to participant	2.76	1.31	3.00	2.00	Sometimes
The thought that they might not be able to work due to illness disturbs participant	2.50	1.42	2.00	2.75	Seldom
If a treatment and it is working well (limited side effects, no progression of disease), worry what will happen if treatment stopped	2.09	1.20	2.00	2.00	Seldom
Anxious if not experiencing any side effects think it doesn't work	1.46	0.68	1.00	1.00	Never

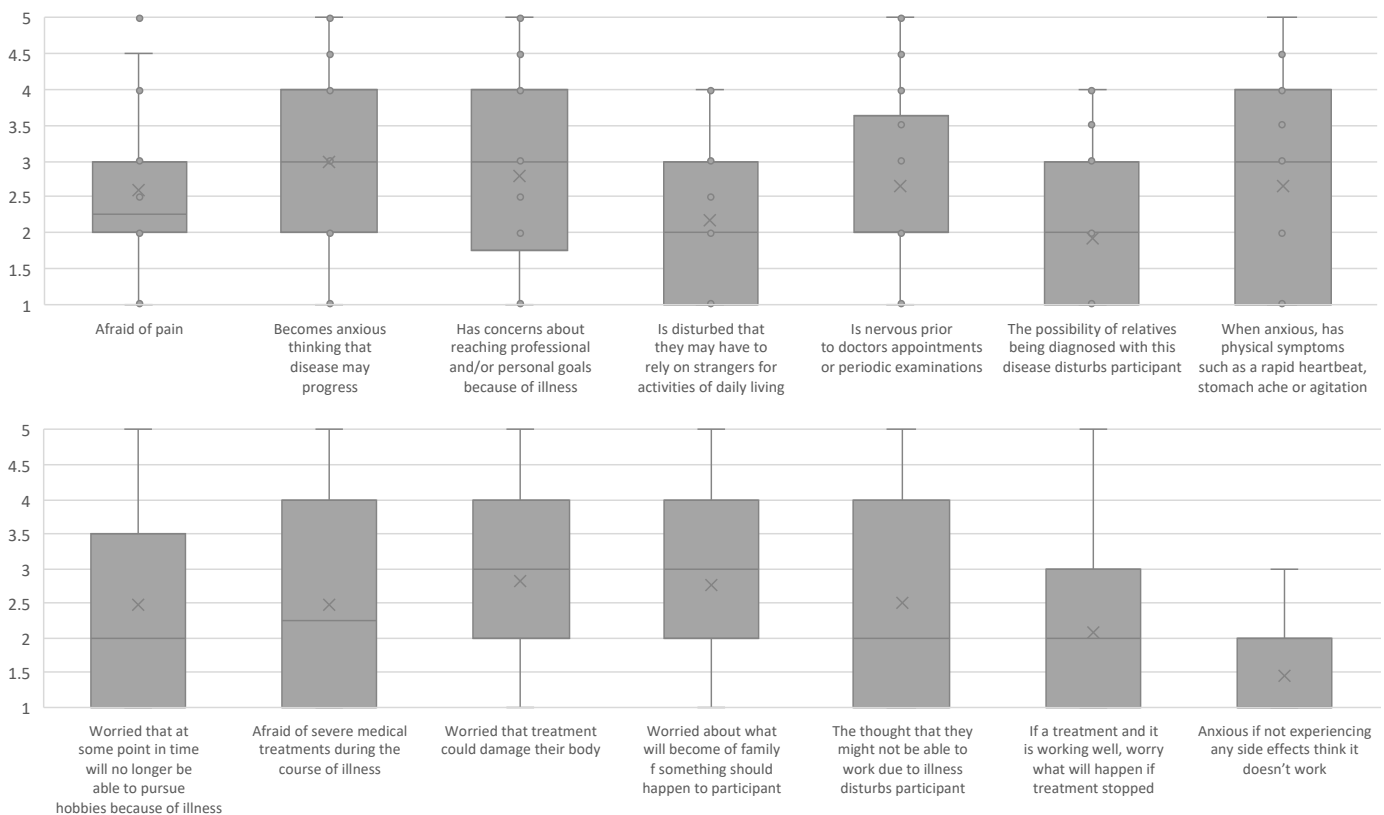


Figure 8.20: Fear of progression individual questions