

Section 8

Quality of life

Section 8: Quality of life

Impact on quality of life

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Overall, there were 27 participants (51.92%) that described a negative impact on quality of life, 11 participants (21.15%) that described a minimal impact on quality of life, and six participants (11.54%) that described an overall positive impact on quality of life. There were four participants (7.69%) that reported no impact on quality of life, and the same number that reported a mix of positive and negative impact.

The most common themes in relation to a negative impact on quality of life were the emotional strain on family/change in dynamics of relationships with partners (n=16, 30.77%), family/change in dynamics of relationships with children (n=12, 23.08%), the mental and emotional impact (n=8, 15.38%), intimacy problems (n=5, 9.62%), and reduced social life (n=5, 9.62%). Other reasons for a negative impact on quality of life were from side effects or physical symptoms such as reduced physical activity (n=10, 19.23%), fatigue (n=7, 13.46%), and the impact of side effects from treatment (especially menopause) (n=5, 9.62%).

The most common theme in relation to a positive impact on quality of life was giving perspective on what is important (n=5, 9.62%).

Impact on mental health

In the structured interview, participants were asked if there had been an impact on their mental health. There were 50 participants (96.12%) who gave a description suggesting that overall there was some impact on their mental health and two participants (3.85%) who gave a description suggesting that overall there was no impact on mental health.

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common ways that participants reported managing their mental and emotional health was using mindfulness or meditation (n=25, 48.08%), physical exercise (n=19, 36.54%), and consulting a mental health professional (n=16, 30.77%). Other ways to maintain mental health were remaining social and enjoying hobbies (n=13, 25.00%), and the importance of family and friends (n=13, 25.00%). There were five participants (9.62%) that described no activities to maintain mental health.

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 ways that participants reported managing their health were by being physically active (n=25, 48.08%), and the importance of self-care (n=24, 46.15%). There were 16 participants (30.77%) that described understanding their limitations, ten participants (19.23%) that described the importance of complying with treatment, and eight participants (15.38%) that described maintaining a healthy diet. There were eight participants (15.38%) that described no activities to maintain health.

Experience of vulnerability

In the structured interview, participants were asked if there had been times that they felt vulnerable. There were 47 participants (90.38%) who gave a description suggesting that overall they had experiences of feeling vulnerable, and five participants (9.62%) who gave a description suggesting that overall they did not have feelings of being vulnerable.

In relation to when participants felt most vulnerable, the most common themes were feeling vulnerable during or after treatments (n=19, 36.54%), and feeling vulnerable during the diagnostic procedure (n=19, 36.54%). There were 11 participants (21.15%) that described feeling vulnerable because of interactions with their medical team, and eight participants (15.38%) described feeling vulnerable during the surgical procedure.

Methods to manage vulnerability

In the structured interview, participants described ways that they managed feelings of vulnerability. Participants described self-help, such as resilience, acceptance and staying positive to manage the feeling of vulnerability (n=16, 30.77%). Others described support from their nurse or treatment team (n=10, 19.23%), and support from their family and friends (n=8, 15.38%) to manage their vulnerability. There were five participants (9.62%), that were unsure of how to manage their vulnerability.

Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Overall, there were 13 participants (25.00%) that described no impact on relationships, and the same number that described a mix of positive and negative impacts on relationships. Other participants reported a positive impact on relationships (n=12, 23.08%), and a negative impact on relationships (n=9, 17.31%).

The most common themes in relation to having a positive impact on relationships were because of people being well-meaning and supportive (n=11, 21.15%), and from family relationships being strengthened (n=10, 19.23%). The most common theme in relation to having a negative impact on relationships were because of people not knowing what to say or do and withdrawing from relationships (n=16, 30.77%).

Burden on family

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Overall, there were 26 participants (50.00%) that felt there was an additional burden, and 26 participants (50.00%) that reported no additional burden.

The main reason that participant described their condition not being a burden in general was that they and remained independent and did not need any help (n=10, 19.23%). For participants that felt they were a burden on their family, the main reason was the extra household duties and responsibilities that their family must take on (n=14, 26.92%). There were six participants (9.62%) that described that the burden on their family was only temporary or during treatment .

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. There were 48 participants (92.31%) that described some cost burden and four participants (7.69%) that described no cost burden.

Where participants described a cost burden associated with their condition, it was most commonly in relation to the cost of treatments, including repeat scripts (n=43, 82.69%). Other cost burdens were in relation to taking time off work (n=24, 46.15%), the cost of specialist appointments (n=20, 38.46%), the cost of diagnostic tests and scans (n=20, 38.46%), family members needing to take time off work (n=7, 13.46%), and the cost of parking and travel to attend appointments, including accommodation (n=5, 9.62%). There were seven participants (13.46%) that described no cost burden and that nearly everything was paid for through the health system or private coverage.

Experience of anxiety related to disease progression

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

Impact on quality of life

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Overall, there were 27 participants (51.92%) that described a negative impact on quality of life, 11 participants (21.15%) that described a minimal impact on quality of life, and six participants (11.54%) that described an overall positive impact on quality of life. There were four participants (7.69%) that reported no impact on quality of life, and the same number that reported a mix of positive and negative impact.

The most common themes in relation to a negative impact on quality of life were the emotional strain on family/change in dynamics of relationships with partners (n=16, 30.77%), family/change in dynamics of relationships with children (n=12, 23.08%), the mental and emotional impact (n=8, 15.38%), intimacy problems (n=5, 9.62%), and reduced social life (n=5, 9.62%). Other reasons for a negative impact on quality of life were from side effects or physical symptoms such as reduced physical activity (n=10, 19.23%), fatigue (n=7, 13.46%), and the impact of side effects from treatment (especially menopause) (n=5, 9.62%).

The most common theme in relation to a positive impact on quality of life was giving perspective on what is important (n=5, 9.62%).

Participant describes positive impact on quality of life as the diagnosis helps you realise what is important (giving perspective)

I think you have a new-- When you say quality of life, you definitely have a different-- You see life through a different lens. I'm much more slower in some way, but I think much more slower and rightfully in a good way. Participant 021_2021AUHRP

I don't think it has. I think it actually-- This might seem really strange to you, but I think it's actually enhanced it because we've actually sat back and got a hell of a fright and thought, "You know what? There are more important things. Let's kick back, smell the roses, and nothing is-- the little things don't matter anymore." Participant 026_2021AUHRP

Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics (Partner)

My children are grown up, and it's just my husband and myself at home. I feel sorry for NAME because he's had to cope with my ups and downs and the pain that I've had. Other than that, no, I've tried to carry on as I normally would. Participant 012_2021AUHRP

Look, on the emotional side of things, that emotional strain, my husband is still struggling with that. He struggles physically with intimacy. He also struggles with the communication side of things. Just generally, if I get tired or if I have a conversation and halfway through the sentence, I forget what I'm talking about, or what that line of sentence is and such. Participant 031_2021AUHRP

I don't think so. I've probably done more since I've had breast cancer than I did before. I enjoy a lot more stuff. Participant 028_2021AUHRP

Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics (Children)

Yeah, I would say it has I think I no longer really trust my own body, you know, everyone just go through daily life just going or what does that ache and pain mean? Or what? You know, all that kind of thing. I think, you know, my kids were three and six at the time and they learned very quickly that mommy's get sick and sometimes mommies get very sick and I think that did affect especially my older boy who was six at the time he caught a few attachment issues for a good few years after that. And he's pretty good now at 17 but every now and again when we found out that I had to have hysterectomies, he was a bit freaked out about the whole thing because it had to work you know, cancer and that again, so here we go again. Participant 033_2021AUHRP

Initially, yes. I've got two daughters and a son, and they were obviously quite concerned and quite scared about what it meant to them, as well. I think the genetic testing that I had was able to put my daughters' minds at ease. If they think about birth control, or they think about any treatments, or they think about anything that they do, they now have to consider whether or not they should be having certain treatments given that my my cancer was so reactive to hormones, they need to make sure that they're aware of that, and they let their GPs know. Participant 037_2021AUHRP

Yes, I think it has. I think things have definitely changed and I think it definitely had an impact on my family but I think we're okay as well. We're getting through it, obviously, and, obviously, with COVID, it's made it a bit more difficult because I haven't been able to take the kids to the hospital. They haven't been able to visit me at any of them. They're dropping off. During lockdown and stuff for chemo, they weren't able to come in or they were able to visit me at the hospital when I had surgery. I think it has changed a lot for us, but I think we're also okay. Participant 042_2021AUHRP

Participant describes negative impact on quality of life as a result of reduced capacity for physical activity

I'm a single person. It hasn't really affected my family, but it has certainly affected the quality of my life, in terms of I was a very active person, bush-walking and kayaking. I am very limited in my ability to get back into that. It's affected that. I'd love to be out doing a lot more physical activities and things and I can't. I'm much reduced in that and I'm a lot more tired. I'm not back at work, so there is that aspect of purpose in life. I'm having to think about whether actually-- I'm left with a big choice of, "I'm I actually able to go back to work or should I retire and just try and enjoy the however many years that I have left?" There's certainly some big-- It certainly affected my outlook on life in terms of that and my life's pathway of where I'm going. Participant 047_2021AUHRP

Definitely. I try for it to not to. I've always been someone who's a bit of a weirdo. When it comes to exercise, I have low tolerance and stuff, I get sore easily. With all my chemo and the drugs that I've been on, I find it really hard. I went for a half and hour walk last night, it was so nice. I was nearly crippled by the time I got back. My legs were so sore. I'm so stiff in my joints. The last time when I was in bed, I was just in tears because my legs were in so much pain. Even during my chemo, probably up until the third

round, I was still on a treadmill. I was still able to go out, I was doing my exercises. Some days I'd feel the pain, but my body wasn't as sore. Now, all my joints are really bad. My bones ache really bad. I've obviously lost a lot of muscle strength. I'm finding it really hard to do any exercise. I've only just gone back to work the last three weeks and I'm only working two to three days a week and that's really physical. I'm just exhausted when I get home.

048_2021AUHRP

That's a tricky one. It's hard to just say yes or no. I feel my outlook has been better, I appreciate more. Quality of life through the different treatments has changed. When the trial was failing at the end of last year, quality of life was pretty poor. Xeloda wasn't fun because of the hand and foot, which really cut off or reduced my exercising opportunities because my feet were just really sensitive and hot and angry. I haven't been able to drive recently, so that's a bit tricky. Participant 051_2021AUHRP

Participant describes negative impact on quality of life as a result of the mental and emotional impact

I do think that, yes, it's affected my quality of life and certainly affects energy levels. I'm single, but I think in terms of affecting the family I know that they worry about me. Mom and Dad are early 90s, I wish that they didn't have to worry, but as parents, that's what you do. Now they've got two of us to worry about, having had breast cancer. Emotionally, yes, it's had an impact on quality of my mental health. Participant 023_2021AUHRP

I suppose there's still that element of vulnerability. Even though I've moved on, sometimes I go, "You've had cancer and cancer is a terminal illness. Whether I'm cancer free or not, it's irrelevant. At the end of the day, I have had a cancer diagnosis." That's the way I look at that. I don't dwell on it. I don't feel sorry for myself. I don't wallow. I don't whinge and whine but I've had cancer. Participant 027_2021AUHRP

Your temptation is just to brush it off and go, no. Given that I have lymphoedema, given that I have what I would say chronic low to moderate level pain, I do think that, yes, it's affected my quality of life and certainly affects energy levels. I'm single, but I think in terms of affecting the family I know that they worry about me. Mom and Dad are early 90s, I wish that they didn't have to worry, but as parents, that's what you do. Now they've got two of us to worry about, having had breast cancer. Emotionally, yes, it's had an impact on quality of my mental health. Participant 023_2021AUHRP

Participant describes negative impact on quality of life as a result of fatigue

I think in some aspects, yes. So far just going through treatment and not working. Then just being tired and also, just feeling soreness and things like that. We have tried to carry out things as much as we can, normally. I guess some of those aspects hasn't really changed things too much aside from just the fact that I do have it. Participant 052_2021AUHRP

Yeah, I still suffer from fatigue that affects my marriage as much as that the beginning he said he understood everything and he was quite careful with me and understood you know why I couldn't work as hard as I used to. But that changed and that would stand against me not being able to remember things and not being able to you know work seven days a week or whatever it was, caused quite a few problems. Participant 045_2021AUHRP

It has definitely affected relationships. I have dropped some friends due to the cancer diagnosis. I believe they just didn't know to deal with it or cope. I've also made some very good friends through the whole process. I did attempt going back to work a couple of times because my workplace did keep my job open for a while a little bit back prior to COVID for about four months. Then, when COVID happened, I went on move again due to my lung nodules. I just got back again earlier this year for another four months, but just on the fatigue, everything's got overwhelming. It has definitely affected our income, our ability to work, and losing our family home. Participant 049_2021AUHRP

Participant describes negative impact on quality of life as a result of intimacy problems

No. Probably intimacy with my husband it has because it puts you into menopause, but no, not with my children or anything. No. Participant 006_2021AUHRP

Yes, it's probably affected the quality of my life because I have a little bit of restriction from pain, and definitely it's reduced my quality of life with the hormone blockers, but not dramatically. It hasn't really affected my relationship apart from the intimate side of it, [chuckles] because of the hormone blockers, they tend to do lots of things to your body. I've got a very wonderful partner, very supportive partner. I'm incredibly lucky that way too. Participant 017_2021AUHRP

On the physical side of things, because of the hormone blockers and all of those sorts of things, it severely impacted my intimate side of things with my husband. It's very difficult because just things don't work the way that they used to, and that's not to say that we don't have a good relationship. We do, but the physical side of our relationship has been severely impacted. Participant 018_2021AUHRP

Well, hugely, hugely, yes. As I mentioned before, it's my shoulders I've had problems with my shoulders, so it's impacted me there. I can't even do my brow up, I can't go swimming on the beach because I've had a mastectomy, so I haven't got a site. Yes, I could probably go and buy swimming prosthesis but I haven't done that yet but whereas before I used to go down the beach, no problem. I can't do that at the moment not until I get a swimming prosthesis, so that's impacted on me. I don't feel-- I used to be a really happy-go-lucky out there, bright and bubbly person, I think I've lost a bit of that. I'm a little bit more contained, serious and concerned about-- even though I try not to think about it, I do think, I wonder whether I still got a long future or how it often comes up in your head. You think, "Has it all gone or will it come back?" Participant 035_2021AUHRP

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

Yeah, I don't want to go out anymore, really. I don't really like to go out. I do, because I have to go to work and that's my outlet. And I put on my face and do it. And the husband probably, don't know why he sticks around, but he does. So yeah, that I feel bad about that. Participant 041_2021AUHRP

Yes, it has. In some ways, it's given me an understanding of what my quality of life is but it does affect, yes, what I can do and what I can't do. I'm making decisions about what to do, I don't have the confidence to say, "I can go out and go and meet friends and do a day's music festival for instance, or something like that." Therefore it affects my quality of life with my family because we don't do all that, all things that we might ordinarily do with my husband, so yes. Participant 043_2021AUHRP

Well, yes, it's affected my quality of life, because the treatment has reduced my ability to do things, enjoy things, be social, work in the office. It's reduced me to staying at home where it's safe, especially, because of COVID. I don't want to catch COVID while I'm having cancer treatment. It has impacted me a lot in that sense, that I don't get to go out and enjoy myself as much because, A, I don't have the energy, and, B, it's not safe. Participant 044_2021AUHRP

Participant describes negative impact on quality of life as a result of side effects of treatment (menopause in particular)

It has affected my quality of life. One, getting around with vaginal atrophy is not a big fun. The medication, when I had the medication in the morning, I feel quite yuck for about an hour or so. I think it does make me feel harder and I think this hardness comes from insomnia so, yes, I don't have nearly the energy. I was

always on the dose. I don't have that energy that I used to have. Some days, it's a bit unpredictable to plan ahead because I think, "I'll do this tomorrow," and then tomorrow comes and not feeling well, so, "I'm not going to do this." Yes, I've had in terms of my family. Participant 004_2021AUHRP

The scars have healed, should be a beautiful job on the scars. The tamoxifen, it's medical-induced menopause. I'm not quite at menopause yet. I just turned 50. This is going to be something that you go through and I recognize that it will change my sexual life and I just have to deal with that. Participant 007_2021AUHRP

It hasn't affected the quality of life of my family. No, the only thing is this business now, whinging about my knees, the joints. Other than that, really, no. Participant 022_2021AUHRP

Table 8.1: Impact on quality of life

Impact on quality of life	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes an overall negative impact on quality of life	27	51.92	7	36.84	13	61.90	7	58.33	14	48.28	13	56.52	12	63.16	15	45.45
Participant describes an overall minimal impact on quality of life	11	21.15	6	31.58	3	14.29	2	16.67	8	27.59	3	13.04	3	15.79	8	24.24
Participant describes an overall positive impact on quality of life	6	11.54	2	10.53	1	4.76	3	25.00	2	6.90	4	17.39	2	10.53	4	12.12
Participant describes no impact on quality of life	4	7.69	1	5.26	3	14.29	0	0.00	3	10.34	1	4.35	1	5.26	3	9.09
Participant describes a mix of positive and negative impact on quality of life	4	7.69	3	15.79	1	4.76	0	0.00	2	6.90	2	8.70	1	5.26	3	9.09

Impact on quality of life	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes an overall negative impact on quality of life	27	51.92	6	60.00	9	56.25	12	46.15	7	63.64	20	48.78	10	55.56	17	50.00
Participant describes an overall minimal impact on quality of life	11	21.15	3	30.00	4	25.00	4	15.38	1	9.09	10	24.39	3	16.67	8	23.53
Participant describes an overall positive impact on quality of life	6	11.54	1	10.00	0	0.00	5	19.23	1	9.09	5	12.20	0	0.00	6	17.65
Participant describes no impact on quality of life	4	7.69	0	0.00	1	6.25	3	11.54	1	9.09	3	7.32	1	5.56	3	8.82
Participant describes a mix of positive and negative impact on quality of life	4	7.69	0	0.00	2	12.50	2	7.69	1	9.09	3	7.32	4	22.22	0	0.00

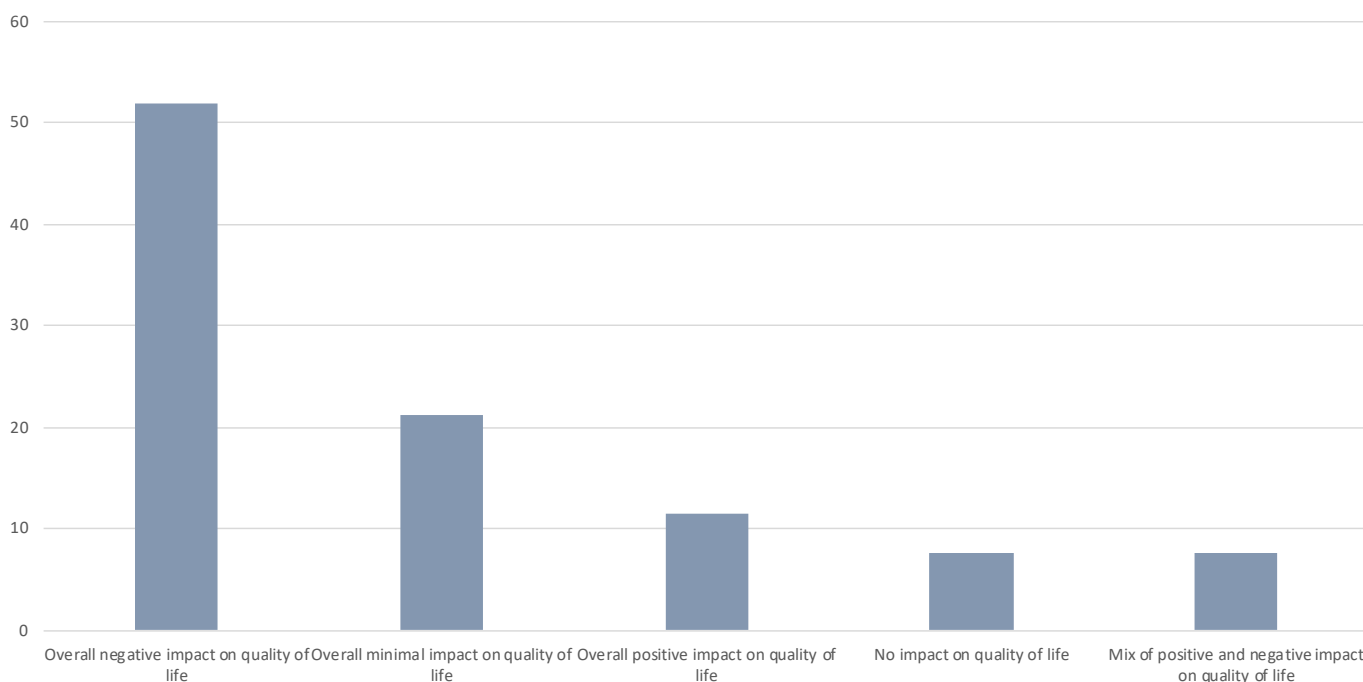


Figure 8.1: Impact on quality of life

Table 8.2: Impact quality of life – subgroup variations

Impact on quality of life	Reported less frequently	Reported more frequently
Participant describes an overall negative impact on quality of life	Stage 0 and I	Trade or high school Regional or remote
Participant describes an overall minimal impact on quality of life	Regional or remote	Stage 0 and I
Participant describes an overall positive impact on quality of life	Diagnosed in 2017 to 2019 Mid to low status	Stage III and IV
Participant describes a mix of positive and negative impact on quality of life	-	Mid to low status

Table 8.3: Impact on quality of life (Reasons)

Impact on quality of life (Reasons)	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes positive impact on quality of life as the diagnosis helps you realise what is important (giving perspective)	5	9.62	3	15.79	0	0.00	2	16.67	1	3.45	4	17.39	2	10.53	3	9.09
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics (Partner)	16	30.77	5	26.32	8	38.10	3	25.00	6	20.69	10	43.48	7	36.84	9	27.27
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics (Children)	12	23.08	3	15.79	6	28.57	3	25.00	5	17.24	7	30.43	7	36.84	5	15.15
Participant describes negative impact on quality of life as a result of reduced capacity for physical activity	10	19.23	5	26.32	4	19.05	1	8.33	4	13.79	6	26.09	5	26.32	5	15.15
Participant describes negative impact on quality of life as a result of the mental and emotional impact	8	15.38	4	21.05	4	19.05	0	0.00	3	10.34	5	21.74	4	21.05	4	12.12
Participant describes negative impact on quality of life as a result of fatigue	7	13.46	2	10.53	4	19.05	1	8.33	2	6.90	5	21.74	3	15.79	4	12.12
Participant describes negative impact on quality of life as a result of intimacy problems	5	9.62	2	10.53	3	14.29	0	0.00	1	3.45	4	17.39	5	26.32	0	0.00
Participant describes negative impact on quality of life due to reduced social interaction	5	9.62	2	10.53	1	4.76	2	16.67	3	10.34	2	8.70	1	5.26	4	12.12
Participant describes negative impact on quality of life as a result of side effects of treatment (menopause in particular)	5	9.62	2	10.53	2	9.52	1	8.33	4	13.79	1	4.35	2	10.53	3	9.09

Impact on quality of life (Reasons)	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes positive impact on quality of life as the diagnosis helps you realise what is important (giving perspective)	5	9.62	0	0.00	1	6.25	4	15.38	1	9.09	4	9.76	2	11.11	3	8.82
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics (Partner)	16	30.77	2	20.00	7	43.75	7	26.92	4	36.36	12	29.27	6	33.33	10	29.41
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics (Children)	12	23.08	3	30.00	5	31.25	4	15.38	4	36.36	8	19.51	7	38.89	5	14.71
Participant describes negative impact on quality of life as a result of reduced capacity for physical activity	10	19.23	4	40.00	2	12.50	4	15.38	5	45.45	5	12.20	8	44.44	2	5.88
Participant describes negative impact on quality of life as a result of the mental and emotional impact	8	15.38	2	20.00	1	6.25	5	19.23	2	18.18	6	14.63	2	11.11	6	17.65
Participant describes negative impact on quality of life as a result of fatigue	7	13.46	1	10.00	2	12.50	4	15.38	4	36.36	3	7.32	4	22.22	3	8.82
Participant describes negative impact on quality of life as a result of intimacy problems	5	9.62	1	10.00	0	0.00	4	15.38	1	9.09	4	9.76	1	5.56	4	11.76
Participant describes negative impact on quality of life due to reduced social interaction	5	9.62	1	10.00	3	18.75	1	3.85	1	9.09	4	9.76	4	22.22	1	2.94
Participant describes negative impact on quality of life as a result of side effects of treatment (menopause in particular)	5	9.62	0	0.00	3	18.75	2	7.69	0	0.00	5	12.20	0	0.00	5	14.71

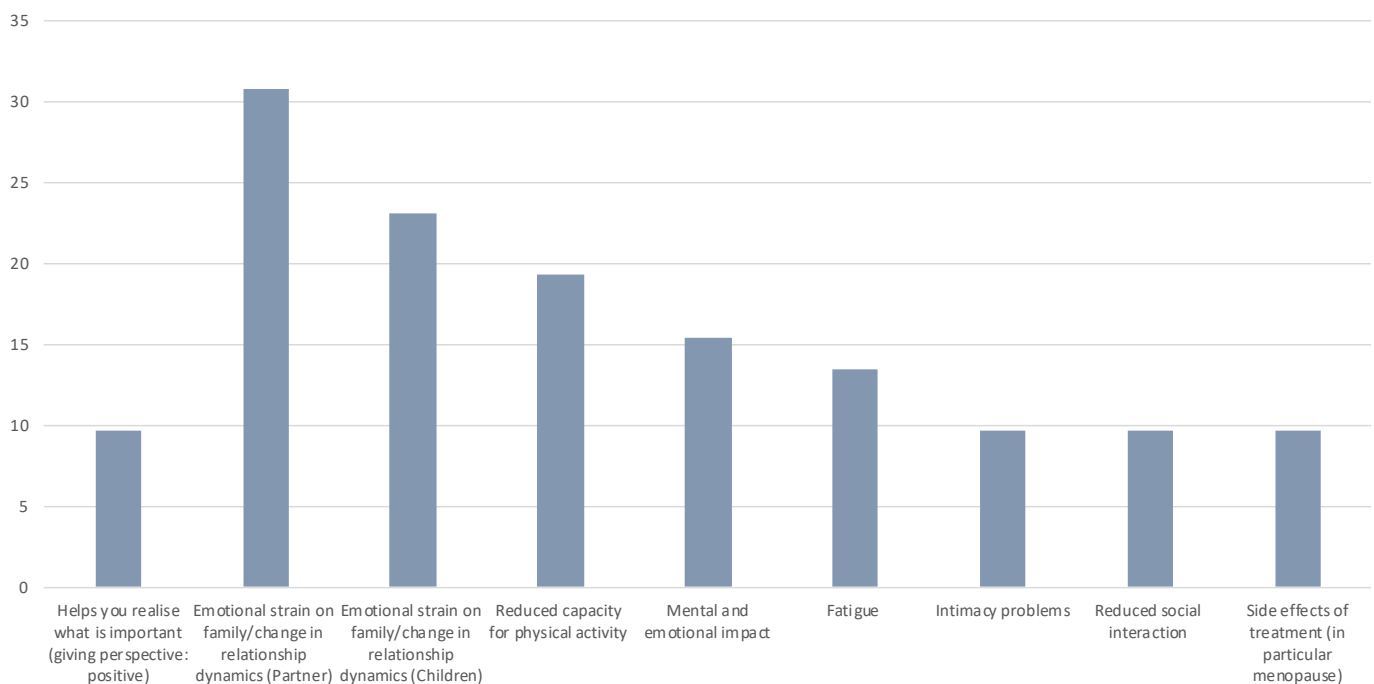


Figure 8.2: Impact on quality of life (Reasons)

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 negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics (Partner)	Aged 25 to 54 Diagnosed in 2016 or before	Aged 55 to 74 Diagnosed in 2017 to 2019
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics (Children)	-	Trade or high school Regional or remote Mid to low status
Participant describes negative impact on quality of life as a result of reduced capacity for physical activity	Stage III and IV Higher status	Diagnosed in 2016 or before Regional or remote Mid to low status
Participant describes negative impact on quality of life as a result of the mental and emotional impact	Stage III and IV	
Participant describes negative impact on quality of life as a result of fatigue	-	Regional or remote
Participant describes negative impact on quality of life as a result of intimacy problems	-	Trade or high school
Participant describes negative impact on quality of life due to reduced social interaction	-	Mid to low status

Impact on mental health

In the structured interview, participants were asked if there had been an impact on their mental health. There were 50 participants (96.12%) who gave a description suggesting that overall there was some impact on their mental health and two participants (3.85%) who gave a description suggesting that overall there was no impact on mental health.

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common ways that participants reported managing their mental and emotional health was using mindfulness or meditation (n=25, 48.08%), physical exercise (n=19, 36.54%), and consulting a mental health professional (n=16, 30.77%). Other ways to maintain mental health were remaining social and enjoying hobbies (n=13, 25.00%), and the importance of family and friends (n=13, 25.00%). There were five participants (9.62%) that described no activities to maintain mental health.

Participant describes using mindfulness and/or meditation

Yeah, but I can do I could could do better. I mentioned that I was into the meditation. And that was really, really helpful. But then I just say with time you do the old life with TV and whatnot. Participant 013_2021AUHRP

Yeah, I like to do craft. Crochet or knit, I find that a bit meditating so I'll do that. I've got a new grandchild expected in January everything everything to celebrate and look forward to. Participant 014_2021AUHRP

I've taken up meditation for mindfulness and I do yoga the best I can at the moment with the wrist problems

and whatnot, but I do what I can to stay flexible and mobile and keep my mind engaged. I've also gone back to reading a lot more. Participant 018_2021AUHRP

Participant describes the importance of physical exercise

Yes, it certainly does affect your mental and emotional health. I think for me a few things, physical activity when I can do it, and I think to a degree that was certainly helpful for me keeping as active as possible, physically. I guess for me the spiritual component. I'm a spiritual person and just using my spiritual-- The word is there. My spirituality has absolutely helped me to be centered and to not be anxious, or to be less anxious is probably a better word, and has given me some more peace and hope. Participant 047_2021AUHRP

Yes. It has impacted it somewhat. I do yoga and that is not just physical, but mentally and emotionally a benefit. The focus on breathing throughout yoga practice makes a big difference to my mental state, and my emotional state is very calm. Anytime that I'm feeling like I'm struggling a bit and need some zen, [chuckles] that's what I rely on yoga for. Participant 044_2021AUHRP

I'm not depressed, it hasn't affected me in that way. I'm not depressed, I'm just not as bright and bubbly as I was, I'm a little bit more serious. [chuckles] What do I do for my mental health? I get out there and do a lot of walking and I meditate. Participant 035_2021AUHRP

Participant describes consulting a mental health professional

I do walk regularly. I do know that helps. There are certain days that are worse than others. I've just started just last week antidepressants, and I've accessed a psychologist again because I had stopped that for seven months, I was doing pretty well. It just comes and goes, and I think with every-- you do get a lot of anxiety when you have a new pain or it's just something new, or when you have a scan coming up. That will be ongoing, speaking with other people, that will be ongoing. Participant 049_2021AUHRP

Yes. I recognized that I needed to see a psychologist. I obviously went and got that all sorted straight away, but it just took months before it could happen. I've got mindfulness journals, I try and do exercise when I can. Sometimes I'm really unmotivated [chuckles]. Participant 048_2021AUHRP

I'm seeing the psychologist. I do what I can. It's just talking, it's talking to my friends. I started a blog. It originally started for me to try and talk my feelings but it actually has ended up being a blog page where I'm now giving people an inside of a journey of cancer, especially with a young woman. That's helped me immensely as well. Participant 008_2021AUHRP

Participant describes using coping strategies such as remaining social, lifestyle changes and hobbies

Little things like that I think everybody that's with anything that trauma that you've been through, I think. Yes, I feel- and coping I like talking, walking, exercising, going to the beach, getting out and about, seeing people, don't isolate yourself. Then some days, if I feel "I just don't want to do much today," and I've learned now that tomorrow when I wake up, I'm going to feel better, and I do. I do. Participant 009_2021AUHRP

I'll try and distract myself and I read a lot and I knit and I sew and all those kinds of things and do the garden and what have you. I'll try to carry on as normal. Participant 012_2021AUHRP

I've had quite a bit of psychological help. I've joined breast cancer groups, The Dragon Boats Australia, to be with other women with the same problem so that you've got somewhere to feel comfortable and your new normal, I think is the best way to put it. You have to find the new normal and you have to build your life around the new normal. Participant 018_2021AUHRP

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

Now that I'm feeling okay, I try to do a walk every day. For most days, go for a walk, have lunch with a friend. I haven't been able to visit family. From this weekend, yes. Participant 015_2021AUHRP

So I try, my outlook for the entire time was just to look for anything positive. I just felt like the minute I focused on the negative that it would start to take over. So I just kept positive about it all. And even now I'm still the same way. And I just found that being able to talk to family and friends about it made a lot easier. I really found just even even if it was only 15 minutes a day that I could manage like going for a walk or doing a bit of exercise that really helped. Participant 020_2021AUHRP

I would try, and I know that going for walk or being physically active actually does really help me. I guess trying to keep emotionally engaged with friends and family, but also recognizing that, for me, timeout is also important. As I said, I'm single, I live by myself, I need time by myself to recharge. Recognizing what my needs have been has been important. Participant 023_2021AUHRP

Participant describes no activities to maintain mental health

Look, initially, yes, it did. With time, I think with the first one, and with time, you feel like just get on with life. Plus, I had young children, so I just got on with it. It did, initially. I think there's always a fear of dying, the fear of re-occurrence. When I had to go and have my annual mammogram or ultrasound, that caused considerable amounts of anxiety. Participant 046_2021AUHRP

Yes, absolutely. As an ongoing thing, every year you go, and you've got to have your scans and the ultrasound, and that causes what we call scanxiety. You've got the anxiety in the lead up through those tests because it brings back all those memories of when you were diagnosed, and then you've got to wait to get the results from those tests and make sure that they haven't found anything additional and you don't have to go through it all again. On an annual basis, it really does, at that point of view, impact your mental health. It does take you a while. Obviously, I don't think you ever get over that anxiety and fear that it's going to come back. From a mental health perspective, you've always got that in the back of your mind, and it was a fear that you never had prior to breast cancer. Participant 037_2021AUHRP

No. Look, initially, I probably could have done with seeing somebody, but no, I'm fine. Participant 022_2021AUHRP

Table 8.5: Impact on mental health

Impact on mental health	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant gives a description suggesting that overall, there was at least some impact on mental health	50	96.15	19	100.00	20	95.24	11	91.67	27	93.10	23	100.00	19	100.00	31	93.94
Participant gives a description suggesting that overall, there was no impact on mental health	2	3.85	0	0.00	1	4.76	1	8.33	2	6.90	0	0.00	0	0.00	2	6.06

Impact on mental health	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant gives a description suggesting that overall, there was at least some impact on mental health	50	96.15	10	100.00	16	100.00	24	92.31	10	90.91	40	97.56	17	94.44	33	97.06
Participant gives a description suggesting that overall, there was no impact on mental health	2	3.85	0	0.00	0	0.00	2	7.69	1	9.09	1	2.44	1	5.56	1	2.94

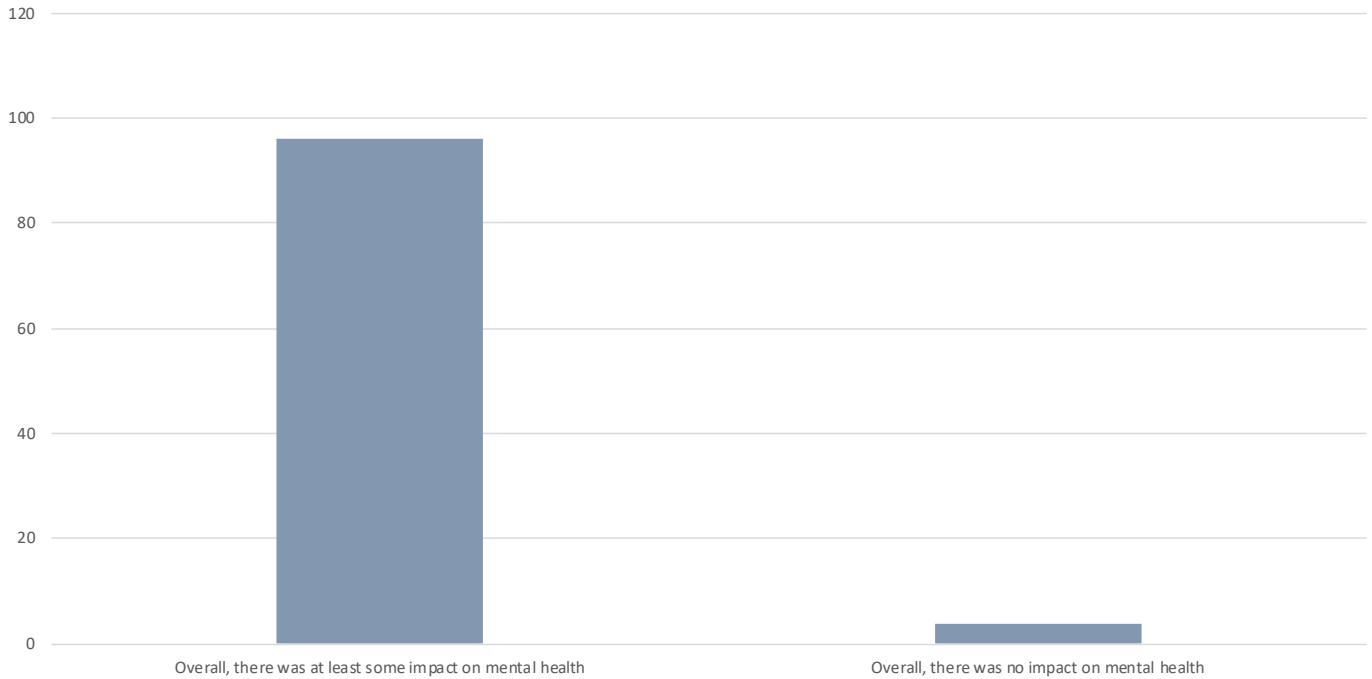


Figure 8.3: Impact on mental health

Table 8.6: Regular activities to maintain mental health

Regular activities to maintain mental health	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes using mindfulness and/or meditation	25	48.08	9	47.37	10	47.62	6	50.00	13	44.83	12	52.17	9	47.37	16	48.48
Participant describes the importance of physical exercise	19	36.54	6	31.58	7	33.33	6	50.00	11	37.93	8	34.78	10	52.63	9	27.27
Participant describes consulting a mental health professional	16	30.77	4	21.05	8	38.10	4	33.33	8	27.59	8	34.78	4	21.05	12	36.36
Participant describes using coping strategies such as remaining social, lifestyle changes and hobbies	13	25.00	6	31.58	5	23.81	2	16.67	7	24.14	6	26.09	6	31.58	7	21.21
Participant describes the importance of family and friends in maintaining their mental health	13	25.00	5	26.32	4	19.05	4	33.33	5	17.24	8	34.78	7	36.84	6	18.18
Participant describes no activities to maintain mental health	5	9.62	3	15.79	2	9.52	0	0.00	3	10.34	2	8.70	3	15.79	2	6.06

Regular activities to maintain mental health	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes using mindfulness and/or meditation	25	48.08	4	40.00	8	50.00	13	50.00	6	54.55	19	46.34	11	61.11	14	41.18
Participant describes the importance of physical exercise	19	36.54	4	40.00	6	37.50	9	34.62	4	36.36	15	36.59	8	44.44	11	32.35
Participant describes consulting a mental health professional	16	30.77	4	40.00	5	31.25	7	26.92	5	45.45	11	26.83	7	38.89	9	26.47
Participant describes using coping strategies such as remaining social, lifestyle changes and hobbies	13	25.00	1	10.00	6	37.50	6	23.08	3	27.27	10	24.39	2	11.11	11	32.35
Participant describes the importance of family and friends in maintaining their mental health	13	25.00	2	20.00	4	25.00	7	26.92	4	36.36	9	21.95	3	16.67	10	29.41
Participant describes no activities to maintain mental health	5	9.62	2	20.00	1	6.25	2	7.69	1	9.09	4	9.76	3	16.67	2	5.88

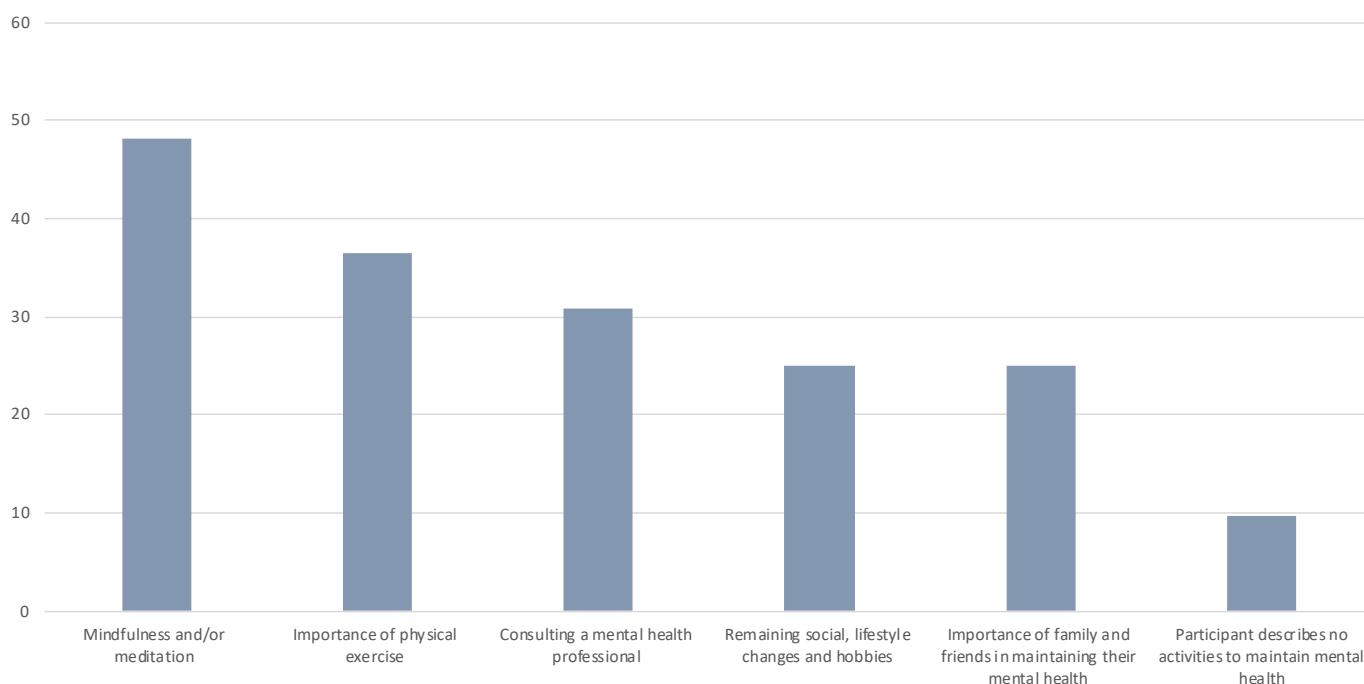


Figure 8.4: Regular activities to maintain mental health

Table 8.7: Regular activities to maintain mental health – subgroup variations

Regular activities to maintain mental health	Reported less frequently	Reported more frequently
Participant describes using mindfulness and/or meditation	-	Mid to low status
Participant describes the importance of physical exercise	-	Stage III and IV Trade or high school Regional or remote
Participant describes consulting a mental health professional	-	Diagnosed in 2017 to 2019
Participant describes using coping strategies such as remaining social, lifestyle changes and hobbies	Diagnosed in 2016 or before Mid to low status	-
Participant describes the importance of family and friends in maintaining their mental health	-	Trade or high school Regional or remote
Participant describes no activities to maintain mental health	-	Diagnosed in 2016 or before

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 ways that participants reported managing their health were by being physically active (n=25, 48.08%), and the importance of self-care (n=24, 46.15%). There were 16 participants (30.77%) that described understanding their limitations, ten participants (19.23%) that described the importance of complying with treatment, and eight participants (15.38%) that described maintaining a healthy diet. There were eight participants (15.38%) that described no activities to maintain health.

Participant describes being physically active

I think it's exercise is the most important thing to me. It's keeping the bloating down. I'm not having a glass of wine in the evening anymore. I have to take magnesium to help me sleep a little bit, but I've

cleaned out. I used to take turmeric for my joint. You can't take that now with tamoxifen. I really spent some time looking at my personal habits. I've never been a big meat eater. I eat a lot of vegetables, but I've really spent time looking at what's in my kitchen cabinet and my diet. Participant 007_2021AUHRP

I think you got to keep as active as you possibly can. Even if that physical activity doesn't help you physically, I think it helps you mentally. You think you're doing something to help you. Participant 010_2021AUHRP

Well, activity is it sounds weird, but for fatigue and aches, actually, you've got to keep moving. Movements, exercise, connecting with others that might understand, and talking, not being afraid to actually just say, "This is good. This is not so good. This is shit. This is happening." It's always there. Participant 043_2021AUHRP

Participant describes the importance of self care e.g. more rest, support for housework etc.

So when I was getting treatment, but mostly I sort of just didn't plan anything for the first week after I lived with my parents for that, that week other than that there wasn't the other two weeks after that I sort of got back to normal life and could go back to living by myself and look after myself and those sorts of things. As the treatments progressed, I did feel it would take me a lot longer to do things than it normally would so, you know, like housework and I'd have to have a bit of a break or something like that. Participant 020_2021AUHRP

Also, taking time to relax. The more I went through treatment and while I was taking the tablets, I couldn't really do much of-- I do cross-stitch like tapestry, and I couldn't do it. I couldn't hold it. I couldn't focus on the pattern, or I just couldn't enjoy it. The last couple of months since I've been off the tablets, I've really, really enjoyed being able to sit down for a few hours at a time and just keep going. It's great. Participant 025_2021AUHRP

I guess sometimes the physical effects, I'm still, "Have I got neuropathy, I can't open jars and stuff?" I used to do a lot for my kids and now it's like, "No, kids, you've got to help out more." Those physical steps. Then there's the mental side of things as well. I'm very much more grateful so I've got a gratitude book. I am much more mindful, mindful practices, being grateful, trusting yourself, and just believing that this is the life that's been chosen for you in some ways. Participant 021_2021AUHRP

Participant describes the importance of understanding their limitations

Really, I've just got to keep up the exercises, and accept the limitations instead of thinking I can get back to where I was. Participant 022_2021AUHRP

I've got to pace myself in terms of if I do overdo it in terms of cleaning and housework and that sort of thing I can flare up my lymphoedema a little bit. I do need to pace myself, but I can do everything that I need to be able to do. It just sometimes takes a few workarounds. I used to spend money on powder-free gloves, so I don't ruin my compression gloves, that sort of thing. I've got to pace myself. Participant 023_2021AUHRP

Yes, okay. I certainly have slowed my day down in terms of I don't live my life at a fast pace. I've made sure that I am-- I have definitely slowed the pace of my days down and I don't rush. I give myself every day plenty of time and I don't push myself to try and accomplish too much in a day. In terms of even mentally planning things, I have to give myself plenty of time to just mentally plan what I'm doing. I try and exercise every day, get some form of physical exercise. My spiritual activity, I pray and meditate every day, first thing in the morning, to help me. Participant 047_2021AUHRP

Participant describes the importance of complying with treatment

Yes. Well, one is, I have the lymphatic drainage once every month or six weeks. If don't have that, I get really, really sore. That's something that I can do. That's an expense too but, yes, that's it. Then the other things are just like using the support staff, using the lubricant, using the cortisone cream for my eyes. All of that daily. Participant 004_2021AUHRP

For the most part, it really hasn't changed much. Life is pretty normal. I have tamoxifen at bedtime. I spoke to the medical oncologist about it because I realized I was getting a lot more cramps and she said it probably is related. I take magnesium now, which has helped with that. I've had restless legs my whole life and it's helped with that too. Participant 011_2021AUHRP

Making sure that you're doing everything possible to reduce the chances of it coming back. You're taking medication, getting your exercise, you're also going to really work on having a positive mindset. When those thoughts come into your mind, you've got to have people that you can talk to and things that you can do that can reduce that stress and reduce that. Just be able to talk through this with people and get that rational response. There's definitely a need to be able to talk to people and do things that are going to reduce that stress. Participant 037_2021AUHRP

Participant describes maintaining a healthy diet

Just eat properly and try and exercise a little bit. I'm just getting back into-- I can walk a bit further in that now, because I'm not feeling like I was. Participant 015_2021AUHRP

Oh, okay. Just got to do my checks and just make sure to look for lumps and things like that and massage my arm for lymphedema, and that's about it. Just eat well and exercise well. Participant 029_2021AUHRP

Okay. Daily walking. I do meditation quite regularly. I try to eat as healthy as possible. Catching up with friends and seeing my mum who is doing really well. She's a bit of an inspiration. Catching up with our children. It's just the daily checking in with the closest friends and family, and walking, meditation is a big thing for me, and doing my lymphedema exercises. There's certain things that I do have to do daily. Participant 049_2021AUHRP

Nothing really like this just my life now. Okay. Yeah. Like, I don't have to have any, like, I'm not having routine follow up anymore. Like, as I was, you know, seeing the oncologist once a year, but then I hit my 10 years, and she was like, No, we're good now. Participant 033_2021AUHRP

I really wasn't affected enough for anything to change. Like I went to work every day. Nothing changed. I'm just very lucky. It was fade to zero. Participant 001_2021AUHRP

Oh, no. No. Not really. No, I don't. Participant 040_2021AUHRP

Participant describes no activities to maintain health

Table 8.8: Regular activities to maintain health

Regular activities to maintain health	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes being physically active	25	48.08	9	47.37	9	42.86	7	58.33	13	44.83	12	52.17	9	47.37	16	48.48
Participant describes the importance of self care e.g. more rest, support for housework etc.	24	46.15	6	31.58	11	52.38	7	58.33	13	44.83	11	47.83	8	42.11	16	48.48
Participant describes the importance of understanding their limitations	16	30.77	7	36.84	7	33.33	2	16.67	7	24.14	9	39.13	8	42.11	8	24.24
Participant describes the importance of complying with treatment	10	19.23	3	15.79	5	23.81	2	16.67	5	17.24	5	21.74	4	21.05	6	18.18
Participant describes maintaining a healthy diet	8	15.38	3	15.79	5	23.81	0	0.00	4	13.79	4	17.39	5	26.32	3	9.09
Participant describes no activities to maintain health	8	15.38	3	15.79	4	19.05	1	8.33	6	20.69	2	8.70	3	15.79	5	15.15

Regular activities to maintain health	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes being physically active	25	48.08	6	60.00	6	37.50	13	50.00	7	63.64	18	43.90	9	50.00	16	47.06
Participant describes the importance of self care e.g. more rest, support for housework etc.	24	46.15	4	40.00	4	25.00	16	61.54	8	72.73	16	39.02	10	55.56	14	41.18
Participant describes the importance of understanding their limitations	16	30.77	3	30.00	3	18.75	10	38.46	6	54.55	10	24.39	10	55.56	6	17.65
Participant describes the importance of complying with treatment	10	19.23	2	20.00	6	37.50	2	7.69	2	18.18	8	19.51	6	33.33	4	11.76
Participant describes maintaining a healthy diet	8	15.38	3	30.00	2	12.50	3	11.54	3	27.27	5	12.20	3	16.67	5	14.71
Participant describes no activities to maintain health	8	15.38	3	30.00	2	12.50	3	11.54	2	18.18	6	14.63	2	11.11	6	17.65

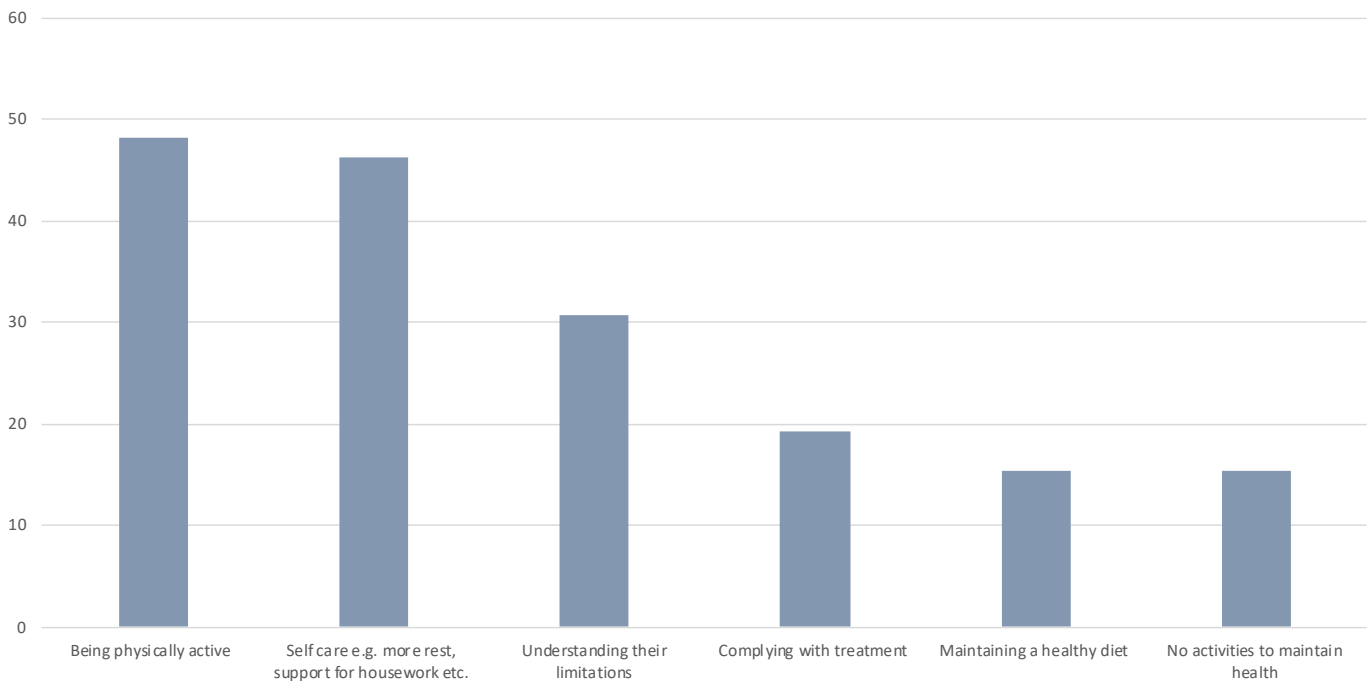


Figure 8.5: Regular activities to maintain health

Table 8.9: Regular activities to maintain health – subgroup variations

Regular activities to maintain health	Reported less frequently	Reported more frequently
Participant describes being physically active	Diagnosed in 2017 to 2019	Stage III and IV Diagnosed in 2016 or before Regional or remote
Participant describes the importance of self care e.g. more rest, support for housework etc.	Stage 0 and I Diagnosed in 2017 to 2019	Stage III and IV Diagnosed in 2020 or 2021 Regional or remote
Participant describes the importance of understanding their limitations	Stage III and IV Diagnosed in 2017 to 2019 Higher status	Trade or high school Regional or remote Mid to low status
Participant describes the importance of complying with treatment	Diagnosed in 2020 or 2021	Diagnosed in 2017 to 2019 Mid to low status
Participant describes maintaining a healthy diet	Stage III and IV	Trade or high school Diagnosed in 2016 or before Regional or remote
Participant describes no activities to maintain health		Diagnosed in 2016 or before

Experience of vulnerability

In the structured interview, participants were asked if there had been times that they felt vulnerable. There were 47 participants (90.38%) who gave a description suggesting that overall they had experiences of feeling vulnerable, and five participants (9.62%) who gave a description suggesting that overall they did not have feelings of being vulnerable.

In relation to when participants felt most vulnerable, the most common themes were feeling vulnerable during or after treatments (n=19, 36.54%), and feeling vulnerable during the diagnostic procedure (n=19, 36.54%). There were 11 participants (21.15%) that described feeling vulnerable because of interactions with their medical team, and eight participants (15.38%) described feeling vulnerable during the surgical procedure.

Participant describes feeling vulnerable during/after treatment

I think I felt pretty vulnerable that first day at the chemo unit. Just that day. Participant 044_2021AUHRP

Oh, yes. When they were doing the radiation planning stage when you're lying there with your arms above your head and your breasts are exposed and they're taking photographs of your breasts on camera photos, and then the oncologist came in and he drew a circle around the area that was to be radiated, and then the poor girls had to then attach some wire to that. Participant 012_2021AUHRP

Physically vulnerable. I was been on six simulations, That's the most scary part. I'm usually pretty good with needles and they give me those. So it's like that just like that created a lot of anxiety for me. Actually, and I think that for me, was the worst thing from the chemo, I think, cannulated. Mentally, I felt vulnerable because I was just tired. I couldn't do the thing that I

just do and I think I felt bad for my children, but I tried to keep it as normal as possible. Participant 040_2021AUHRP

Participant describes feeling vulnerable during the diagnostic procedure

That i felt vulnerable I didn't, oh, the only time I felt vulnerable with during the biopsy. The biopsy was, you know, you have four people holding you down in that many people in the room and then they clap at the end of it, they think that must be right, whatever they were trying to do that that unnerved me, the clapping. Participant 001_2021AUHRP

Probably from the diagnosis until I went to the specialist because the GP didn't know anything about it, really. He didn't explain it like the specialist did, which was a lot better. Participant 006_2021AUHRP

The worst time was not so much the initial diagnosis. So that was bad enough. It was getting that metastatic diagnosis. So I think waiting is always hard waiting for results. Everyone says that I know, almost once you've got the bad news, even though it's terrible, you kind of your mind goes into planning. Okay, so this is what I need to do. Whereas when you're waiting for the bad news, which might not be bad news, you don't go ahead with that planning, because it may not be needed. So I think that periods between testing and results is really, really difficult. And then for me, it was it was being told that I was going to die in the near future. With with the two sort of most vulnerable periods. Participant 034_2021AUHRP

Participant describes feeling vulnerable because of interactions with their medical team

Yes actually. After I would get a certain type of chemo and nurses would have to come over to my house and

give me an injection. It was pretty in and out but one particular nurse, who I managed to get a couple of times, didn't follow procedure, like hand sanitizing, wearing gloves, or wiping my skin down before. I was really immune-compromised and I just felt like I was someone she had to tick off on her list for the day. That's when I felt very vulnerable there because I felt like I wasn't being heard. Participant 008_2021AUHRP

Yes. With the medical oncologist that I had. She was almost menacing. When I actually suggested that I didn't want to take medication, she went, "I knew it, I should have just given you chemotherapy." I walked out, I burst into tears. I went, "Oh my God, so mean." Then being on the drugs, of course, your hormones are suppressed, you'll gain weight. You don't have a choice. I'm a size 12. I'm not a big, huge girl. She'd make comments and say, "Oh, you're getting fat." I'd be like, "Oh my God, you're so not helpful." Participant 038_2021AUHRP

In LOCATION, yes. I really felt like I wasn't worth the effort. It really was and I think I said quite bluntly, "If you can't be compassionate during this process for someone who's got a disease that they may not make it through, don't be here." But generally speaking, most of the people that you come across, there are a few for who it's just a job. But generally speaking in the cancer side of things, in the oncology side of things, they're pretty empathetic and they are very supportive, which makes the difficult shit storm much easier to deal with. Participant 018_2021AUHRP

Participant describes feeling vulnerable during the surgical procedure

Emotionally you're just a mess after your surgery. The week I got told when I got told I had breast cancer that

was probably the worst time of my life. You're just in denial, you're just "No, it couldn't be no. Oh, no. I must have dreamt it." Participant 010_2021AUHRP

Going to theatre. That sitting in a bed waiting to go to the theatre, just wanting to run and knowing that you can't. Participant 011_2021AUHRP

Probably just after surgery, I was probably feeling the most vulnerable then. That's probably because it was so painful because of the nerve damage. I know not everybody has that. Not everybody has that nerve damage in their arm, a lot of people don't have it at all. I was probably vulnerable for several weeks because the pain was a constant pain, and I don't know that there was anything really that I could have done. Probably just after surgery, I was probably feeling the most vulnerable then. That's probably because it was so painful because of the nerve damage. Participant 017_2021AUHRP

Participant describes not feeling vulnerable

No, I don't think so. Yes, no, I'm going to say no about that one. Participant 005_2021AUHRP

Not really. Again, I'm a pretty healthy person, really seeing the world, we'll leave it at that. I've been able to do all this on my own with just minimal support from friends. I have felt safe and in a good space. I looked for a top hospital here in Sydney. I had a top surgeon who actually teaches at LOCATION University. I always felt I was in very, very good hands and I trusted the medical system. Participant 007_2021AUHRP

No, not really. Participant 015_2021AUHRP

Table 8.10: Experience of vulnerability (details)

Experience of vulnerability (details)	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes feeling vulnerable during/after treatment	19	36.54	6	31.58	10	47.62	3	25.00	12	41.38	7	30.43	6	31.58	13	39.39
Participant describes feeling vulnerable during the diagnostic procedure	19	36.54	6	31.58	7	33.33	6	50.00	10	34.48	9	39.13	9	47.37	10	30.30
Participant describes feeling vulnerable because of interactions with their medical team	11	21.15	4	21.05	5	23.81	2	16.67	6	20.69	5	21.74	4	21.05	7	21.21
Participant describes feeling vulnerable during the surgical procedure	8	15.38	2	10.53	2	9.52	4	33.33	5	17.24	3	13.04	3	15.79	5	15.15
Participant describes not feeling vulnerable	5	9.62	3	15.79	2	9.52	0	0.00	3	10.34	2	8.70	1	5.26	4	12.12

Experience of vulnerability (details)	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes feeling vulnerable during/after treatment	19	36.54	3	30.00	6	37.50	10	38.46	3	27.27	16	39.02	8	44.44	11	32.35
Participant describes feeling vulnerable during the diagnostic procedure	19	36.54	6	60.00	4	25.00	9	34.62	5	45.45	14	34.15	7	38.89	12	35.29
Participant describes feeling vulnerable because of interactions with their medical team	11	21.15	1	10.00	5	31.25	5	19.23	2	18.18	9	21.95	4	22.22	7	20.59
Participant describes feeling vulnerable during the surgical procedure	8	15.38	2	20.00	5	31.25	1	3.85	1	9.09	7	17.07	4	22.22	4	11.76
Participant describes not feeling vulnerable	5	9.62	0	0.00	2	12.50	3	11.54	0	0.00	5	12.20	0	0.00	5	14.71

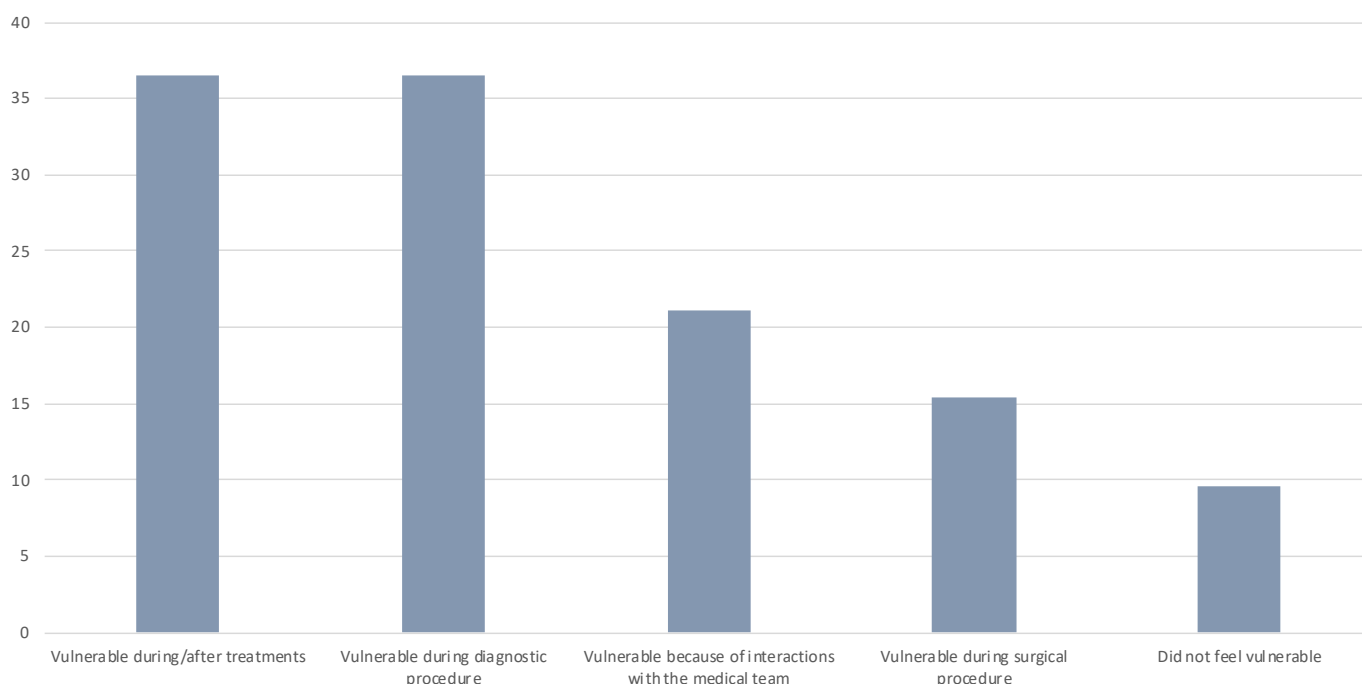


Figure 8.6: Experience of vulnerability

Table 8.11: Experience of vulnerability – subgroup variations

Experience of vulnerability (details)	Reported less frequently	Reported more frequently
Participant describes feeling vulnerable during/after treatment	Stage III and IV	Stage II
Participant describes feeling vulnerable during the diagnostic procedure	Diagnosed in 2017 to 2019	Stage III and IV Trade or high school Diagnosed in 2016 or before
Participant describes feeling vulnerable because of interactions with their medical team	Diagnosed in 2016 or before	Diagnosed in 2017 to 2019
Participant describes feeling vulnerable during the surgical procedure	Diagnosed in 2020 or 2021	Stage III and IV Diagnosed in 2017 to 2019

Methods to manage vulnerability

In the structured interview, participants described ways that they managed feelings of vulnerability. Participants described self-help, such as resilience, acceptance and staying positive to manage the feeling of vulnerability (n=16, 30.77%). Others described support from their nurse or treatment team (n=10, 19.23%), and support from their family and friends (n=8, 15.38%) to manage their vulnerability. There were five participants (9.62%), that were unsure of how to manage their vulnerability.

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

I just had to try and be positive and focus on the positive things in my life. Participant 016_2021AUHRP

I think there's two things. There's the physical aspect, and then there's the mental aspect as well. You can concentrate on the physical and once the treatment has finished, and a lot of people have said that, then

you've really got to figure yourself out mentally, what is it that you've been through. It's funny that at the end, it's virtually, "Well, what do we do now?" It's like, "Well, go and live your life." That is just, "Oh." It may go, "What the heck?" Participant 021_2021AUHRP

Acknowledge it and allow myself to grieve at times. I'm a very, very strong person. I did do amazing. No one even knew. People used to say to me, "Oh my God, you looked radiant. You would never have known you've got breast cancer. We didn't know you were having treatment." To allow myself to be vulnerable and to acknowledge that. It was really important to acknowledge it, but then pick myself up and continue to move forward. Participant 027_2021AUHRP

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

I don't know this was at BreastScreen, New South Wales. I don't know because I'll be honest, everything worked like clockwork, everybody. And I don't think

they could have done it any different. But because mine was only three millimeters to begin with, to try and find it through CT scans and X rays, and then I had to be very still. If they had explained that, to me, like of this is a difficult procedure. This is how you've got to be so still for 20 minutes. If they went on about it, I would have been even more nervous, I think in a way, by not saying anything. much other than we need to do this. It was probably the best thing. And they even had one nurse crouching with her face next to mine. This holding my hands, so I don't think they could have done better. Yeah, just the nature of the fact that it was so small, that it was going to be difficult to pinpoint it and to grab it. Participant 001_2021AUHRP

The oncologist said that to me too, she said, "Don't feel like you-- Other people might think, 'Oh, no, you look fine. You're okay. You look great. You look very healthy and well and all that sort of thing,' but don't underestimate health. Allow yourself, give- be kind to yourself, give yourself time. Don't feel like you have to run them out next week." Participant 009_2021AUHRP

I think speaking regularly, speaking to that breast cancer nurse at HOSPITAL, so she's can be a bit of calm in my storm at times when it gets too bad. Yes, she's been pretty good, she can be a bit of calm, and she's offered me a few suggestions, some of which I've managed to incorporate to into doing stuff. Participant 030_2021AUHRP

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

Yes, I had a partner, so I was very fortunate. My husband's partner. He's an incredible man. But he was he had my back. My daughter had my back. I have a very strong community. So everyone had my back. So I couldn't ask for anything more. If anyone else is just up to me to I had to look forward and not backwards, couldn't change anything. I just have to to fix me. That was my one job. Everyone else was ready to catch me if I failed. You know, I have a couple of moments before I lost it. for all of you because you just kind of it's a bit more disbelief. But why? it was just lucky to do well, and then you start to worry about what else is lurking here. Participant 002_2021AUHRP

Yes. Just be kind to yourself. Don't force. Then my hubby, he'd go, "Darling, you had the surgery three weeks ago, like are you serious? What do you think you should be doing?" You need somebody like that to go, "Hang on, just check what you've been through. Hang on, just rewind a little bit. Three weeks ago you just come out of surgery and now you think you should be able to do this?" Participant 009_2021AUHRP

Well, I think my Savior was one of my best friends from high school. So she, her, she was living with her mom and dad at the time, she was studying at uni, moved back from LOCATION. And so having she was 20 minutes out of town, but just simply having one of my best friends there was really kind of what saved me. Participant 013_2021AUHRP

Participant describes being unsure of how to manage the feeling of vulnerability

No. Just felt teary for three of four days and overwhelmed and that was it. I never said I think it was just being brave for everyone around, just a bit tired. I don't know, maybe I'm a slow learner, it could take longer for me. Participant 014_2021AUHRP

I don't think I could do anything and I really didn't. I just ended up almost giving up and just going with it. Participant 036_2021AUHRP

I'm not sure there's a lot they can do. You're in so much shock after you get diagnosed that you don't take a lot in, it takes a little while for it to sink in. I think if they were able to give you information on, "Here's some websites you can go to, don't use Dr. Google, here are some documented websites that you can go to-- The questions. Here are some people you can call who might be able to answer the questions that you've got." I think the most vulnerable part is not knowing what's happening until you get your treatment plan. For me, I was lucky that I didn't have to wait a week to get my treatment plan. Other women have to wait up to four or five weeks. Participant 037_2021AUHRP

Table 8.12: Methods to manage vulnerability

Methods to manage vulnerability	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes self help (resilience, acceptance, staying positive) to manage the feeling of vulnerability	16	30.77	3	15.79	6	28.57	7	58.33	6	20.69	10	43.48	7	36.84	9	27.27
Participant describes support from nurse or treatment team to manage the feeling of vulnerability	10	19.23	3	15.79	4	19.05	3	25.00	7	24.14	3	13.04	4	21.05	6	18.18
Participant describes support from family and friends to manage the feeling of vulnerability	8	15.38	2	10.53	5	23.81	1	8.33	3	10.34	5	21.74	4	21.05	4	12.12
Participant describes being unsure of how to manage the feeling of vulnerability	5	9.62	5	26.32	0	0.00	0	0.00	2	6.90	3	13.04	2	10.53	3	9.09

Methods to manage vulnerability	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes self help (resilience, acceptance, staying positive) to manage the feeling of vulnerability	16	30.77	2	20.00	4	25.00	10	38.46	6	54.55	10	24.39	5	27.78	11	32.35
Participant describes support from nurse or treatment team to manage the feeling of vulnerability	10	19.23	2	20.00	4	25.00	4	15.38	0	0.00	10	24.39	3	16.67	7	20.59
Participant describes support from family and friends to manage the feeling of vulnerability	8	15.38	1	10.00	3	18.75	4	15.38	2	18.18	6	14.63	2	11.11	6	17.65
Participant describes being unsure of how to manage the feeling of vulnerability	5	9.62	2	20.00	1	6.25	2	7.69	0	0.00	5	12.20	2	11.11	3	8.82

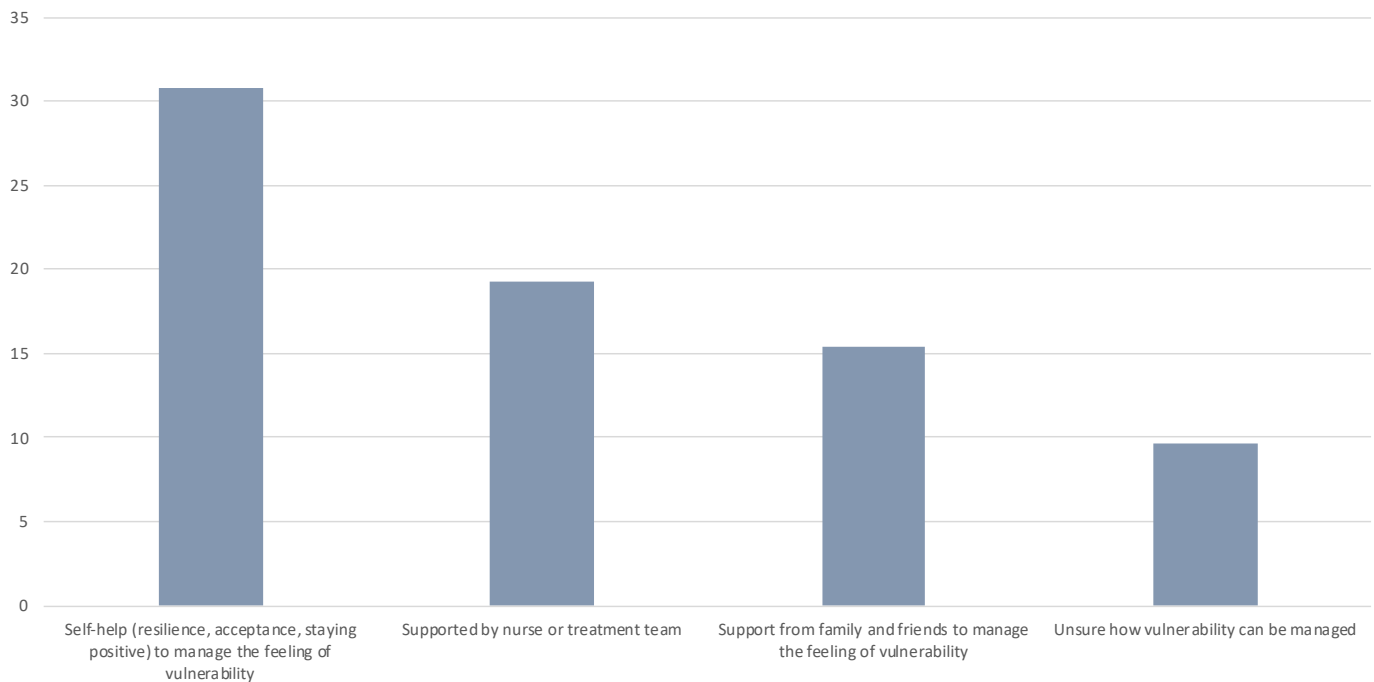


Figure 8.7: Methods to manage vulnerability

Table 8.13: Methods to manage vulnerability– subgroup variations

Methods to manage vulnerability	Reported less frequently	Reported more frequently
Participant describes self help (resilience, acceptance, staying positive) to manage the feeling of vulnerability	Stage 0 and I Aged 25 to 54 Diagnosed in 2016 or before	Stage III and IV Aged 55 to 74 Regional or remote
Participant describes support from nurse or treatment team to manage the feeling of vulnerability	Regional or remote	
Participant describes being unsure of how to manage the feeling of vulnerability		Stage 0 and I Diagnosed in 2016 or before

Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Overall, there were 13 participants (25.00%) that described no impact on relationships, and the same number that described a mix of positive and negative impacts on relationships. Other participants reported a positive impact on relationships (n=12, 23.08%), and a negative impact on relationships (n=9, 17.31%).

The most common themes in relation to having a positive impact on relationships were because of people being well-meaning and supportive (n=11, 21.15%), and from family relationships being strengthened (n=10, 19.23%). The most common theme in relation to having a negative impact on relationships were because of people not knowing what to say or do and withdrawing from relationships (n=16, 30.77%).

Participant describes a positive impact on relationships from people being well-meaning and supportive

I've haven't had those kinds of experiences from close friends or close family so for me, all my friend interactions have been positive only again, meaning well, not not negative, but just did it but you know, but not all bad. Participant 013_2021AUHRP

I don't think that much. A lot of my friends are very supportive and my family too. I don't think it's made a huge difference one way or another, if that makes sense. Participant 036_2021AUHRP

They were quite supportive of it, it's probably like brought us a little bit closer. Most of my friends anyway. I've got really good friends and family network anyway. It probably brought us a little bit closer. Yes, I could see, they really had to rely on my kids and stuff and I was going to chemo from school and stuff like that. They still come around and they're happy to do that. We're very lucky. Participant 040_2021AUHRP

Participant describes relationships with family being strengthened

With friends? Most definitely, with family, no. No, it's actually strengthened the family relationships. More for them towards me rather than the other way. Obviously, I have two children, so they suddenly realised, oh, mummy's not immortal and she's human

and but friends, mention any way, shape or form the word cancer and I would say 99 percent of my friends I haven't heard from since my diagnosis. Participant 003_2021AUHRP

I've lost friends. I have strained relationships with family because of the way they've treated me during treatment, but then it's strengthened my relationship with my husband to like a real depth. I found out who true friends are. Participant 043_2021AUHRP

Yes. Not so much family I think, in a positive way perhaps, we were a relatively close family anyway and it probably brought us a bit closer. I've definitely had an impact on friendships as well in a not-so-great way, my older or as I said, previously best friend I rarely speak to. Another friend who stood up really well during my breast cancer treatment suddenly dropped off the radar about two years after and I've never been able to work out what why. I think just generally. Participant 023_2021AUHRP

Participant describes relationships suffering, that is people not knowing what to say or do and withdrawing from relationships

Yes. I've lost friends. I have people that I thought were my best friends who no longer talk and it's purely and simply because they can't deal. It's not me personally. It's they can't deal with the fear of losing someone so they withdraw. One of my best friends is bipolar and she said to me, "People can see your illness. They can't see mine." Then she stopped talking to me. I can't change that but yes it definitely impacts people. Participant 018_2021AUHRP

One of my close girlfriends. She never came and visited me. Immediately, she lived a few hours away but she was down here a lot seeing her mother. She rang me but she never came and visit with me. Another friend of mine, him and his wife moved away up to LOCATION. I didn't really hear from him. I rang him and I had a cold, I called and I said, "I didn't have a common cold." I said, "I had breast cancer." I said, "You could have picked up the phone." I no longer contact him. We're friends on Facebook but I don't bother with him. I suppose that sort of thing. Participant 027_2021AUHRP

I lost friends. People couldn't really cope with the diagnosis. And I also was probably in such in those friendship groups. Although, you know, those friendships that I lost, I was probably before this all happened. I was the friends that helped them rather than the other way around. And then when I became the friend that needed help people do disappear. You know, you see the true side of which part of your family is supportive and which isn't. Yeah, so just it really opens your eyes to different types of people. But then on the flip side, as well, then I've made friends. Since that, you know, I can't imagine, you know, that.

They're amazing. So you win some you lose some I guess. Participant 033_2021AUHRP

Participant describes a positive impact on relationships (general, no specifics articulated)

Probably for the positive Yes. Yeah. Okay. Participant 020_2021AUHRP

I think I've got really good relationships around me so I think we've been okay. Participant 042_2021AUHRP

Table 8.14: Impact on relationships

Impact on relationships	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant gives a description suggesting that overall, there no impact on relationships	13	25.00	4	21.05	6	28.57	3	25.00	9	31.03	4	17.39	3	15.79	10	30.30
Participant gives a description suggesting that overall, there was a mix of a positive and a negative impact	13	25.00	4	21.05	6	28.57	3	25.00	6	20.69	7	30.43	6	31.58	7	21.21
Participant gives a description suggesting that overall, there was a positive impact on relationships	12	23.08	7	36.84	4	19.05	1	8.33	7	24.14	5	21.74	3	15.79	9	27.27
Participant gives a description suggesting that overall, there was a negative impact on relationships	9	17.31	3	15.79	2	9.52	4	33.33	4	13.79	5	21.74	4	21.05	5	15.15
Participant gives a description suggesting that overall there is an impact on quality of life, but does not describe the impact	3	5.77	1	5.26	2	9.52	0	0.00	1	3.45	2	8.70	3	15.79	0	0.00
Participant gives a description suggesting that overall, there was an impact on relationships that was neither positive nor negative	2	3.85	0	0.00	1	4.76	1	8.33	2	6.90	0	0.00	0	0.00	2	6.06

Impact on relationships	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant gives a description suggesting that overall, there no impact on relationships	13	25.00	1	10.00	6	37.50	6	23.08	2	18.18	11	26.83	4	22.22	9	26.47
Participant gives a description suggesting that overall, there was a mix of a positive and a negative impact	13	25.00	2	20.00	3	18.75	8	30.77	3	27.27	10	24.39	3	16.67	10	29.41
Participant gives a description suggesting that overall, there was a positive impact on relationships	12	23.08	4	40.00	3	18.75	5	19.23	3	27.27	9	21.95	6	33.33	6	17.65
Participant gives a description suggesting that overall, there was a negative impact on relationships	9	17.31	1	10.00	2	12.50	6	23.08	0	0.00	9	21.95	2	11.11	7	20.59
Participant gives a description suggesting that overall there is an impact on quality of life, but does not describe the impact	3	5.77	2	20.00	0	0.00	1	3.85	3	27.27	0	0.00	3	16.67	0	0.00
Participant gives a description suggesting that overall, there was an impact on relationships that was neither positive nor negative	2	3.85	0	0.00	2	12.50	0	0.00	0	0.00	2	4.88	0	0.00	2	5.88

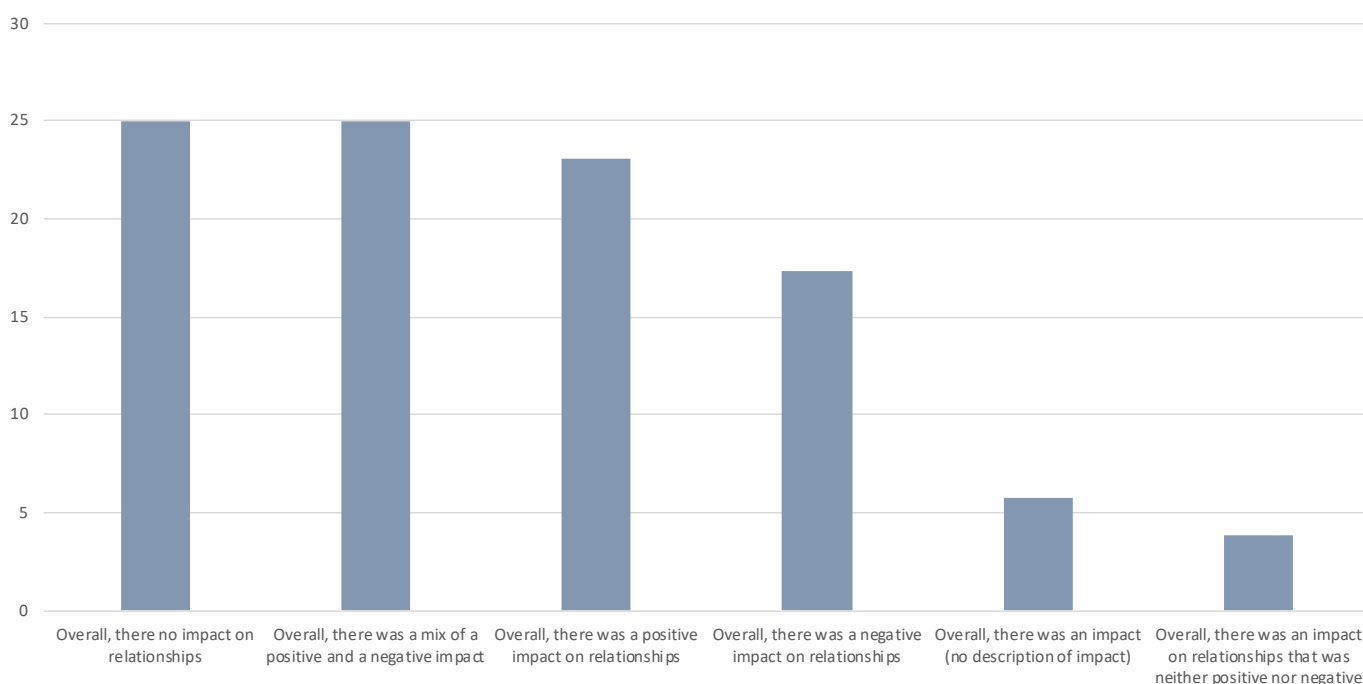


Figure 8.8: Impact on relationships

Table 8.15: Impact on relationships – subgroup variations

Impact on relationships	Reported less frequently	Reported more frequently
Participant gives a description suggesting that overall, there no impact on relationships	Diagnosed in 2016 or before	Diagnosed in 2017 to 2019
Participant gives a description suggesting that overall, there was a positive impact on relationships	Stage III and IV	Stage 0 and I Diagnosed in 2016 or before Mid to low status
Participant gives a description suggesting that overall, there was a negative impact on relationships	Regional or remote	Stage III and IV
Participant gives a description suggesting that overall there is an impact on quality of life, but does not describe the impact	-	Trade or high school Diagnosed in 2016 or before Regional or remote Mid to low status

Table 8.16: Impact on relationships (Reason for impact)

Reasons for impact on relationships	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes relationships suffering, that is people not knowing what to say or do and withdrawing from relationships	16	30.77	6	31.58	6	28.57	4	33.33	8	27.59	8	34.78	7	36.84	9	27.27
Participant describes relationship with family changing: dynamics of relationships change due to anxiety, exacerbations and/or physical limitations of condition	4	7.69	2	10.53	1	4.76	1	8.33	0	0.00	4	17.39	3	15.79	1	3.03
Participant describes a negative impact on relationships (general, no specifics articulated)	3	5.77	0	0.00	1	4.76	2	16.67	2	6.90	1	4.35	1	5.26	2	6.06
Participant describes a positive impact on relationships from people being well-meaning and supportive	11	21.15	6	31.58	2	9.52	3	25.00	6	20.69	5	21.74	4	21.05	7	21.21
Participant describes relationships with family being strengthened	10	19.23	6	31.58	3	14.29	1	8.33	6	20.69	4	17.39	1	5.26	9	27.27
Participant describes a positive impact on relationships (general, no specifics articulated)	8	15.38	1	5.26	6	28.57	1	8.33	3	10.34	5	21.74	3	15.79	5	15.15

Reasons for impact on relationships	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes relationships suffering, that is people not knowing what to say or do and withdrawing from relationships	16	30.77	3	30.00	3	18.75	10	38.46	3	27.27	13	31.71	3	16.67	13	38.24
Participant describes relationship with family changing: dynamics of relationships change due to anxiety, exacerbations and/or physical limitations of condition	4	7.69	0	0.00	0	0.00	4	15.38	1	9.09	3	7.32	0	0.00	4	11.76
Participant describes a negative impact on relationships (general, no specifics articulated)	3	5.77	0	0.00	2	12.50	1	3.85	0	0.00	3	7.32	2	11.11	1	2.94
Participant describes a positive impact on relationships from people being well-meaning and supportive	11	21.15	2	20.00	3	18.75	6	23.08	3	27.27	8	19.51	6	33.33	5	14.71
Participant describes relationships with family being strengthened	10	19.23	2	20.00	2	12.50	6	23.08	2	18.18	8	19.51	4	22.22	6	17.65
Participant describes a positive impact on relationships (general, no specifics articulated)	8	15.38	2	20.00	3	18.75	3	11.54	3	27.27	5	12.20	3	16.67	5	14.71

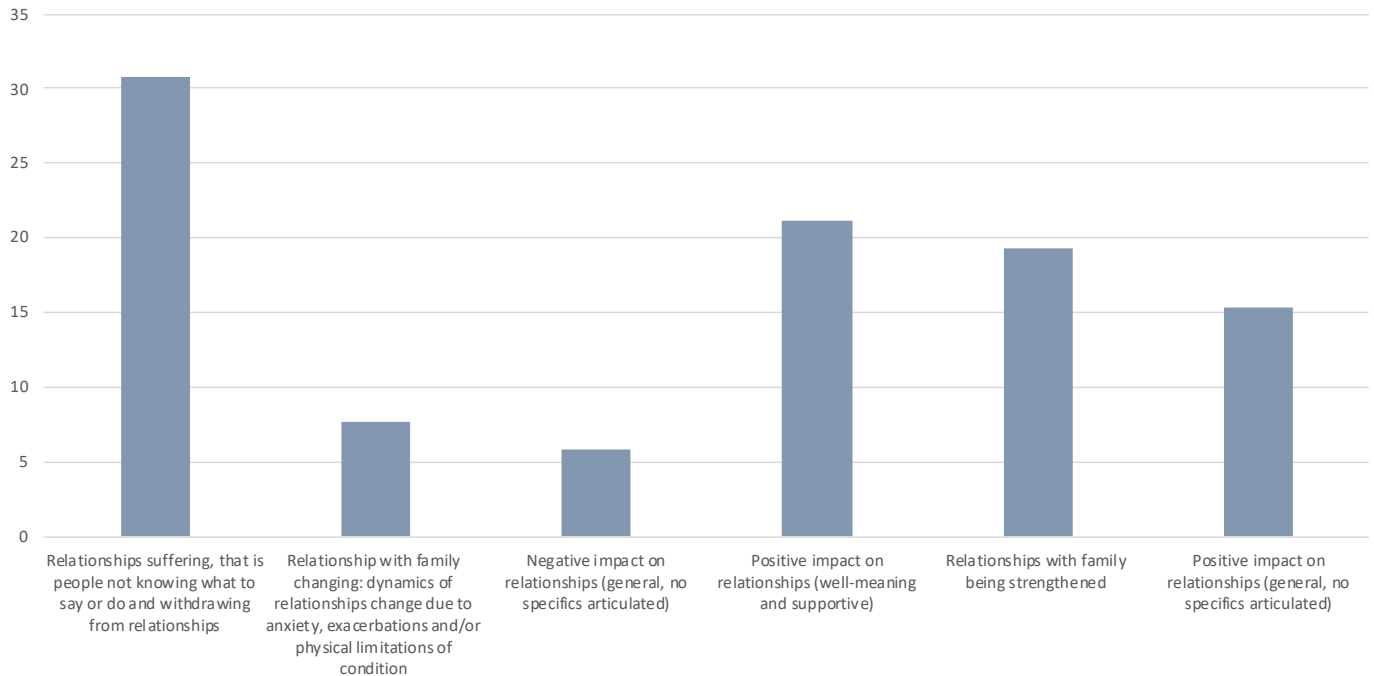


Figure 8.9: Impact on relationships

Table 8.17: Impact on relationships: Reason for impact – subgroup variations

Reasons for impact on relationships	Reported less frequently	Reported more frequently
Participant describes relationships suffering, that is people not knowing what to say or do and withdrawing from relationships	Diagnosed in 2017 to 2019 Mid to low status	-
Participant describes a positive impact on relationships from people being well-meaning and supportive	Stage II	Stage 0 and I Mid to low status
Participant describes relationships with family being strengthened	Stage III and IV Trade or high school	Stage 0 and I
Participant describes a positive impact on relationships (general, no specifics articulated)	Stage 0 and I	Stage II Regional or remote

Burden on family

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Overall, there were 26 participants (50.00%) that felt there was an additional burden, and 26 participants (50.00%) that reported no additional burden.

The main reason that participant described their condition not being a burden in general was that they and remained independent and did not need any help (n=10, 19.23%). For participants that felt they were a burden on their family, the main reason was the extra household duties and responsibilities that their family must take on (n=14, 26.92%). There were six participants (9.62%) that described that the burden on their family was only temporary or during treatment .

Participant describes their condition not being a burden in general (No specific examples)

No, I don't think I do need any extra care or assistance from them. I guess the only thing in terms of a burden is it has implications for my sisters, in terms of they need to do more frequent screening. I don't think that's necessarily overly onerous, though. I guess, in some ways, knowing that there's a risk there might actually be helpful if it gets diagnosed earlier. I think a mammogram every year is probably acceptable. I've done worse for them, I'm sure. Participant 005_2021AUHRP

No, because mine was only stage 1A with a grade 2 lump. I'm back to normal again, for want of a better word, except the pain. Participant 012_2021AUHRP

No. No. I think I've fixed that problem, [chuckles]. Participant 028_2021AUHRP

Participant describes extra household duties and responsibilities that their family must take on

One of my boys is now my-- He takes care of all my financial stuff because my brain is in stupid mode and

I forget basic-- I have a memory-- A short-term memory problem which is shocking. That's not me but it is my new reality. I've severely been impacted cognitively from the chemo so he took over power of attorney pre-chemo and he keeps a check on everything. I run everything by him now because that way I can't make a mistake because some of those mistakes could be costly and I haven't got the money to do that anymore. He takes care of my insurances and registrations. He just tells me, "You need to put this much in the bank every week and I'll take care of them all for you." Because I would forget. I've done so and I'm aware that that's a problem so I have the support but then I feel guilty because he's got to make sure that mom's got her shit together. Participant 018_2021AUHRP

No, I think that I'm probably more likely now to ask my husband to carry the washing out the washing line for a meal or two things. But he's a man that's always wanted to do those things. But in the past, I've always felt able to do them. But no, I was trying to ask him to to give me a hand. Participant 019_2021AUHRP

Participant describes their condition not being a burden in general, as they remained independent or did not need help

No, I didn't have to do anything extra. I've been very independent. Participant 016_2021AUHRP

No, I don't know whether it was because I was stubborn, or whether it's just I was lucky, but I actually didn't need any help from family to be able to maintain my treatment. When I was going through chemo, I could still do my housework. I could still do my cooking, or I could still take the kids to school and stuff like that. Granted that cooking wasn't necessarily a good one when I'd had to have the chemotherapy, that was not fun. Having to cook a bit more then, but other than that, yes, he got off pretty lucky. Participant 025_2021AUHRP

No, because I always told them I was doing so well. I never showed anyone. I didn't want to do that to anyone, so I made sure that I made sure everyone would think that I was doing very well all the time. Participant 029_2021AUHRP

Participant describes their condition being a temporary burden, or a burden during treatment only

Not at this stage. During the time early on when I was having the radiation when I was tired and that sort of thing, they were all quite supportive my immediate family. Participant 010_2021AUHRP

No. Cancer treatment, yes. It was it was a big burden, but not anymore now. Participant 037_2021AUHRP

Not at the moment, no. Certainly during that initial few months of chemo and radiation and the recovery from surgery very much so, but that's all over and done with. Participant 039_2021AUHRP

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

A little bit, but we've also been out of work, we've been able to get through it and we're coming to the end of it now. We've been okay. Participant 042_2021AUHRP

I helped my husband through cancer a few years back. I guess, I know what he's feeling, and I know that I never felt like he was a burden during that time. I guess that sort of helped me in a way. Participant 052_2021AUHRP

Table 8.18: Burden on family

Burden on family	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant gives a description suggesting that overall, there was not a burden on their family	26	50.00	11	57.89	10	47.62	5	41.67	19	65.52	7	30.43	10	52.63	16	48.48
Participant gives a description suggesting that overall, there was a burden on their family	26	50.00	8	42.11	11	52.38	7	58.33	10	34.48	16	69.57	9	47.37	17	51.52

Burden on family	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant gives a description suggesting that overall, there was not a burden on their family	26	50.00	5	50.00	9	56.25	12	46.15	4	36.36	22	53.66	9	50.00	17	50.00
Participant gives a description suggesting that overall, there was a burden on their family	26	50.00	5	50.00	7	43.75	14	53.85	7	63.64	19	46.34	9	50.00	17	50.00

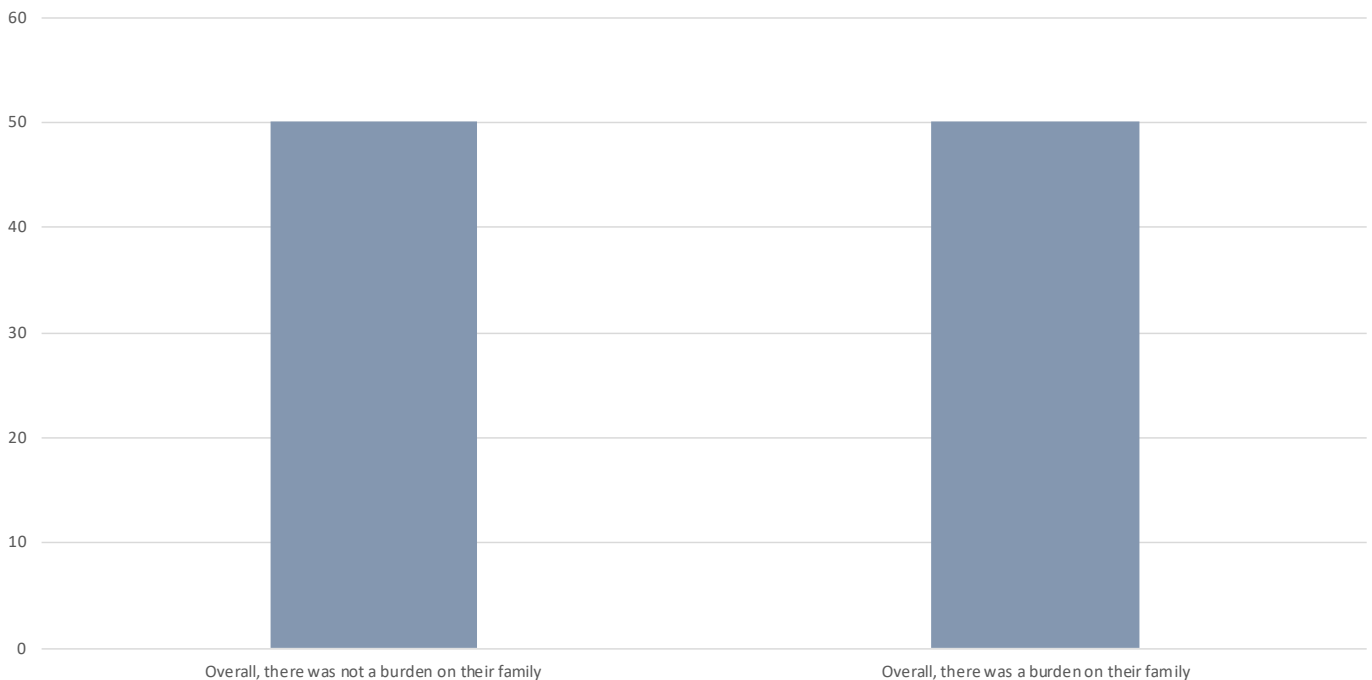


Figure 8.10: Burden on family

Table 8.19: Burden on family – subgroup variations

Burden on family	Reported less frequently	Reported more frequently
Participant gives a description suggesting that overall, there was not a burden on their family	Aged 55 to 74 Regional or remote	Aged 25 to 54
Participant gives a description suggesting that overall, there was a burden on their family	Aged 25 to 54	Aged 55 to 74 Regional or remote

Table 8.20: Burden on family (description)

Burden on family (description)	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes their condition not being a burden in general (No specific examples)	15	28.85	9	47.37	4	19.05	2	16.67	11	37.93	4	17.39	6	31.58	9	27.27
Participant describes extra household duties and responsibilities that their family must take on	14	26.92	5	26.32	6	28.57	3	25.00	5	17.24	9	39.13	7	36.84	7	21.21
Participant describes their condition not being a burden in general, as they remained independent or did not need help	10	19.23	2	10.53	5	23.81	3	25.00	6	20.69	4	17.39	3	15.79	7	21.21
Participant describes their condition being a temporary burden, or a burden during treatment only	6	11.54	2	10.53	1	4.76	3	25.00	2	6.90	4	17.39	3	15.79	3	9.09
Participant describes their condition being a burden in general (No specific examples)	5	9.62	0	0.00	3	14.29	2	16.67	2	6.90	3	13.04	0	0.00	5	15.15

Burden on family (description)	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes their condition not being a burden in general (No specific examples)	15	28.85	3	30.00	6	37.50	6	23.08	2	18.18	13	31.71	3	16.67	12	35.29
Participant describes extra household duties and responsibilities that their family must take on	14	26.92	2	20.00	1	6.25	11	42.31	5	45.45	9	21.95	2	11.11	12	35.29
Participant describes their condition not being a burden in general, as they remained independent or did not need help	10	19.23	2	20.00	2	12.50	6	23.08	2	18.18	8	19.51	5	27.78	5	14.71
Participant describes their condition being a temporary burden, or a burden during treatment only	6	11.54	1	10.00	3	18.75	2	7.69	0	0.00	6	14.63	2	11.11	4	11.76
Participant describes their condition being a burden in general (No specific examples)	5	9.62	0	0.00	3	18.75	2	7.69	1	9.09	4	9.76	3	16.67	2	5.88

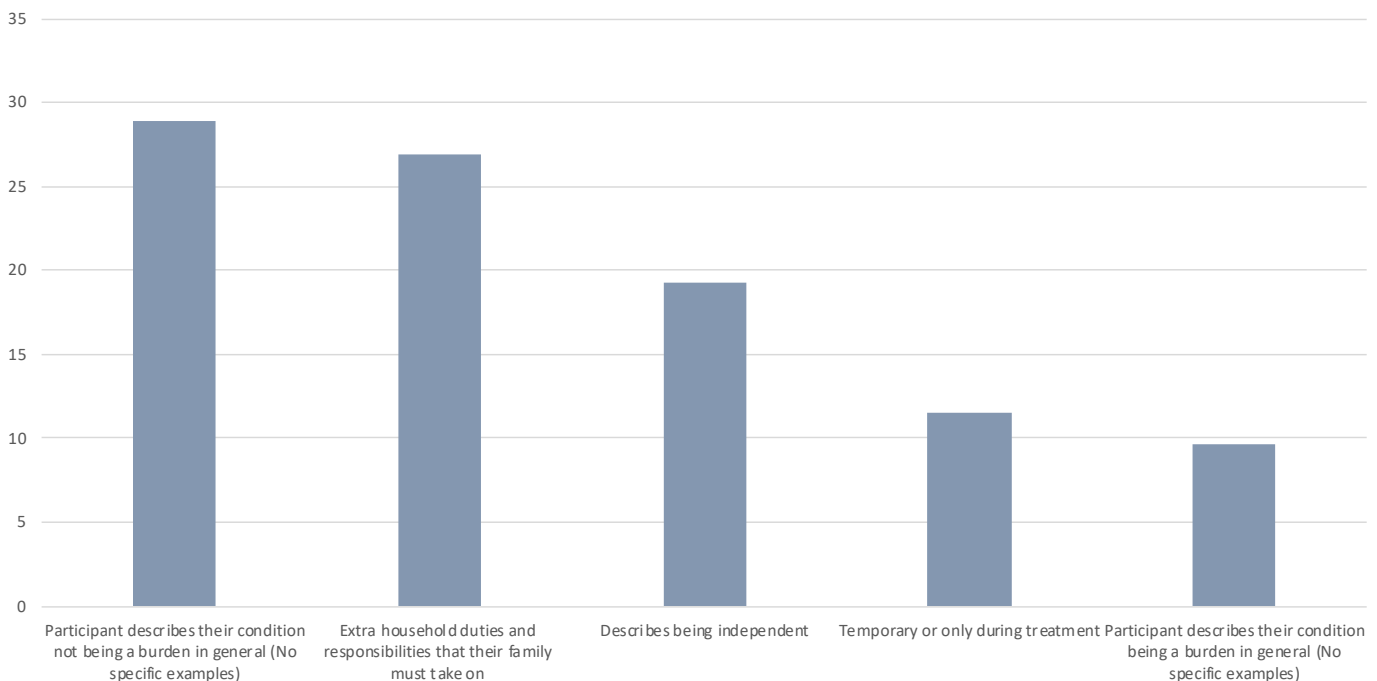


Figure 8.11: Burden on family (description)

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

Burden on family (description)	Reported less frequently	Reported more frequently
Participant describes their condition not being a burden in general (No specific examples)	Stage III and IV Aged 55 to 74 Regional or remote Mid to low status	Stage 0 and I
Participant describes extra household duties and responsibilities that their family must take on	Diagnosed in 2017 to 2019 Mid to low status	Aged 55 to 74 Diagnosed in 2020 or 2021 Regional or remote
Participant describes their condition being a temporary burden, or a burden during treatment only	Regional or remote	Stage III and IV

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. There were 48 participants (92.31%) that described some cost burden and four participants (7.69%) that described no cost burden.

Where participants described a cost burden associated with their condition, it was most commonly in relation to the cost of treatments, including repeat scripts (n=43, 82.69%). Other cost burdens were in relation to taking time off work (n=24, 46.15%), the cost of specialist appointments (n=20, 38.46%), the cost of diagnostic tests and scans (n=20, 38.46%), family members needing to take time off work (n=7, 13.46%), and the cost of parking and travel to attend appointments, including accommodation (n=5, 9.62%). There were seven participants (13.46%) that described no cost burden and that nearly everything was paid for through the health system or private coverage.

Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)

I was at work the day I went for my mammogram and then I couldn't go back because I was having treatment. Then I really couldn't give my work a date when I would go back. As a result of it all, I ended up taking now redundancy. I struggled with that because I absolutely loved my work. I wasn't ready to give up but in hindsight now, I'm over that now. I don't know what you've seen in terms of costs in there. Out of pocket was almost treatment at the time of the radiation. The radiation I think was \$22,000 and I think I got back about \$10 so I was out of pocket \$12,000. What annoyed me and this is just a little bit of a gripe I guess, I've worked all my life. I've paid my Medicare, I've paid private health. Then there's people beside me there who were getting it for free, having exactly the same treatment as me so that was a little bit like-- I know that they probably deserve. Everyone deserves the right to get the treatment but they were there at the private hospital having it for free where I was paying the \$22,000. I've worked hard all my life to get savings to do all that. This isn't nearly true at all but that sum was a little bit, well, I think if it was good enough for them to have it for nothing, it probably was good enough for me to have it for nothing. Participant 004_2021AUHRP

My husband gave up his job to help me through when I wasn't coping. The prosthetics are quite expensive. I know that you get money back, but unfortunately with the Medicare system, you have to find the \$800

first before you get reimbursed, so that system definitely needs to be looked at because a lot of people don't have that kind of disposable income. I paid for physios myself. Complementary treatments aren't covered, so if you want to have anything like [unintelligible] therapy or lymphatic drainage outside of the hospital system, that'll cost you money and it's not cheap. I think in the last five years, I've probably spent close to \$10,000 out of pocket for treatment. Participant 018_2021AUHRP

I think that it's not cheap to get cancer, that's for sure. I was overwhelmed by the information that I had sent to me via the email from my breast surgeon after I saw him. So I received some of the possible figures of how much his fees would be, anaesthetic fees, the hospital, all of those things. And so they came hard and fast. And so I think coping with the unexpected diagnosis, coupled with having all of the cost, I was overwhelmed by it. You know, I was concerned by it. And I mean, I was reassured by my husband, who said, look, you know, we have to do this and don't think about it. But I'm the money manager in the house, so I was concerned. Having said that, I didn't, regardless of how much it was going to cost, I wasn't going to go through the public system because I wouldn't have had any form of control about my choices in the public system. Participant 019_2021AUHRP

Participant describes a cost burden in relation to needing to take time off work

Other than having no money coming in for a year for me. Otherwise, we probably would have-- I did use a charity as well that helped pay bills.

INTERVIEWER: Are you happy to name that charity?

PARTICIPANT: Yes, Be Uplifted Incorporated. They were amazing. They paid bills, this is the local Brisbane one. They support women going through breast cancer and Mummy's Wish, they got me a cleaner for a few months after my surgery, or six weeks or something. There were things like that that were amazing. Participant 024_2021AUHRP

Because of the type of work I do in the hospital, it's demanding, I didn't go back to it. I had time off. It was the first time in my life that I actually went, "Right. You're going to stop and you're going to take care of yourself-

INTERVIEWER: *Excellent.*

PARTICIPANT: *-at any cost." That's exactly what I did. I surrendered to the process. That has left me with a debt. Participant 027_2021AUHRP*

Look, a phenomenal amount, as such. Unfortunately, I did lose my job over my diagnosis. All along though, my employer told me that yes, my job would be there when I returned, but it turned out that no, it wasn't. Unfortunately, in a small community and the stress of it all, it just wasn't worth pursuing that, and good on that lady that has been successful, obviously. That was huge. Probably the other thing is we were able to speak to my oncologist and talk to him about the cost, and he was happy to do a loan scheme, and we just had to pay that off over the years. Then the finding new employment and, of course, not being physically able to stand five days a week, or manage employment five days a week, manage to find employment as such. That was a lot. That was huge. Participant 031_2021AUHRP

Participant describes a cost burden in relation to the cost specialist appointments

Oh, huge impact, yes. Financially I'm out-of-pocket, I would say thousands of dollars out-of-pocket and it's continuing because I've got to, but luckily I'm in a good health fund but I still got to pay the gap, so yes, financially it's taken a toll at work. I can't with my shoulder the way it is and for how tight I am, I've had to reduce my workdays, I work full time but I've used up all my sick leave and I'm taking holidays. I'm using all my annual leave now just to go to work four days a week rather than five but rather than pay, so yes it's impacted my work and impacted me financially. It will continue to impact me financially because you've got to pay the gap every time you see a specialist and you've got to pay \$40 something every month for the medication. Participant 035_2021AUHRP

I've had to pay for the respiratory physician. I've had to pay for scans and X-rays related to the respiratory physician. I guess the other cost in a sense is that I haven't been able to work. My income has been reduced. I'm on income protection. I do have that, but

it has meant that my wage has decreased. Participant 047_2021AUHRP

The costs like the mammogram and the ultrasound, I vaguely remember they were something like \$400 and something, and I think you got \$250 back or something. I had the PET scan which I think might have been bulk billed. My surgeon, he was all bulk billed, so there was no cost there. The medical oncologist, I chose to pay up-front, so I could get it sorted out very quickly. I paid the extra money for him, for private. I can't remember what it was, \$400 and something, and I might have got \$150 back or something, off the top of my head. Biopsy, I think it was out of pocket, maybe \$50 or \$60 with those. Participant 017_2021AUHRP

Participant describes a cost burden in relation to diagnostic tests and scans

I had costs from the original ultrasound scan, from the biopsy, and I had an MRI done. I had costs from that. I have private health insurance, so I had a gap for the first hospital stay. Probably all up, I'm going to guess around \$1,500 to \$2,000. Participant 011_2021AUHRP

The costs like the mammogram and the ultrasound, I vaguely remember they were something like \$400 and something, and I think you got \$250 back or something. I had the PET scan which I think might have been bulk billed. My surgeon, he was all bulk billed, so there was no cost there. The medical oncologist, I chose to pay up-front, so I could get it sorted out very quickly. I paid the extra money for him, for private. I can't remember what it was, \$400 and something, and I might have got \$150 back or something, off the top of my head. Biopsy, I think it was out of pocket, maybe \$50 or \$60 with those. Participant 017_2021AUHRP

I chose to go private with my surgery, so I had to pay for the hospital. I had to pay for the surgeon. I had to pay for the anesthetist. I had to pay for the assistance surgeon. There'd been substantial costs there. Not a lot in terms of medication. When I had to go back and - I had to go back and have more mammograms, ultrasounds and core biopsies. I had to pay for that. I've had to pay for the one physiotherapy, the one that I found the physiotherapist. I've had to pay for her. Participant 047_2021AUHRP

I tell you what, I'm very, very lucky just as a professional. I ended up taking, from the point of diagnosis, I took five days off of work for the surgery and for some time to heal, and luckily I was very supported by my employer, so that was good. From a cost standpoint, my total out-of-pocket including doctor appointments, including the biopsies, et cetera, was about \$8,000. I learned a lot about the healthcare system and that Medicare, they can pay for everything, and that private doesn't pay for everything. Participant 007_2021AUHRP

I'm going to be \$615 out of pocket because that's not the normal follow-through. You should be happy with the mammogram and an ultrasound when lobular breast cancer doesn't always show until it's too late. I've opted to have and pay and I went privately through a private hospital as well. You're continually getting \$100, \$200, \$300 bills. I had to pay for my radiation because well, and it's not even exactly because it's where you went through because my girlfriend went through the same hospital for her radiation and she wasn't charged. I was \$750 out of pocket for that. Which in retrospect isn't a lot of money because it's the total cost of its \$14,000. In retrospect it's not a lot of money but how do they decide who pays and who doesn't. Participant 010_2021AUHRP

Participant describes a cost burden in relation to a family member needing to take time off work

My husband runs his own business. So, you know, any days off, he had to take because he had to take me to treatment or had to be at home for the kids or whatever. We just didn't earn an income because he couldn't work. So yeah. But we also, you know, I was only off work for six months. So we didn't actually qualify for any, you know, external assistance from the government or anything, because I wasn't, you know, in theory that week, you know, what I consider my good week post treatment, I probably could have worked in there. But, you know, no cancer patient wants to work in a hospital when they're undergoing treatment. Yeah, you know what I do? Yeah. So, you know, I was fortunate that I could make that decision. But, and then now with this, the hysterectomy, I'm out of pocket. Probably about \$3,000 for this year. That's just the gap between what the AMA says should be paid and what Medicare actually pays. Participant 033_2021AUHRP

My husband works part-time. We'd just make sure things fitted in that if I needed him, he'd be around. One of my children, the one that lives overseas, a

contract finished, so he came back to Australia while I had chemo and was here. That was very good. He had, I guess, a three-month break from work that he wouldn't have had otherwise. That was a significant cost to him. That's probably it. I wasn't working. I had been made redundant at my request and rather than getting a new job, I just stopped working. Participant 039_2021AUHRP

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

No cost, I'm on a disability pension. Because it is... Well, the first one was cancer related, I did have to wait nearly two years to get the second mastectomy because of the triage system, because they're saying you don't technically have cancer now, but not taking into account the high reoccurrence rate and the high rate of metastases. So, yes, again, it -- that's been very frustrating. Participant 003_2021AUHRP

Well, I had literally just started a new job a week-and-a-half into my diagnosis. I was on probation. That was a loophole for them because they obviously needed to fill the position. I'm currently not working. It's been a very, very costly thing for us as a family. In terms of the treatment itself, I've been very fortunate. I've had that all covered by Medicare, so I'm very, very lucky, but it's been very hard on us. Very, very hard on us to manage without me earning money. Participant 008_2021AUHRP

Luckily, it was all done through the public health system, so I had no costs involved with the operation, no costs involved with radiation. I haven't had any cost. It's all paid. Participant 026_2021AUHRP

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

I'm a bit useless on the subject because my husband tends to fill the load of that. I know that he feels the bills are piling up. There's a lot of expenses, a lot of appointments, a lot of extra things like parking, juggling health insurance, or all that sort of jazz. There's a lot of administrative stuff. It's not just simply the treatment, but all the appointments and the dental appointments and the complementary and, what is it, the Allied stuff, it all adds up. He's actually taken less days at work, but some of that has been part of COVID and having to reduce hours. Because of my ability or health issues, I've obviously had to lessen my hours as well, but he's definitely the breadwinner. I know we're on a good wicket, but I think that does play on his mind. I couldn't tell you the figures because I literally don't know. Participant 051_2021AUHRP

Just the travel back and forwards from LOCATION to LOCATION, the cost of the studio, the cost of food. I wasn't aware of the costs. That was hideous. Participant 031_2021AUHRP

There was the parking fees mainly. I've had to buy different bras because I used to wear them with wires. I bought support sleep bras to sleep in at night, and because we're retired, we didn't have to take time off work, so it didn't impede anything like that, but I feel really strongly that Medicaid do not refund anything if you have a core biopsy done in a private place, it's almost \$500. They're always saying, they're advertising about your breast cancer and be alert and all that, and yet the government want to slug nearly \$500 to have that test. I'm sorry, that just needs to be looked at. Participant 012_2021AUHRP

Table 8.22: Cost considerations

Cost considerations	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant gives a description suggesting that overall, there was at least some cost burden	48	92.31	18	94.74	19	90.48	11	91.67	27	93.10	21	91.30	18	94.74	30	90.91
Participant gives a description suggesting that overall, there was no cost burden	4	7.69	1	5.26	2	9.52	1	8.33	2	6.90	2	8.70	1	5.26	3	9.09

Cost considerations	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant gives a description suggesting that overall, there was at least some cost burden	48	92.31	9	90.00	15	93.75	24	92.31	11	100.00	37	90.24	16	88.89	32	94.12
Participant gives a description suggesting that overall, there was no cost burden	4	7.69	1	10.00	1	6.25	2	7.69	0	0.00	4	9.76	2	11.11	2	5.88

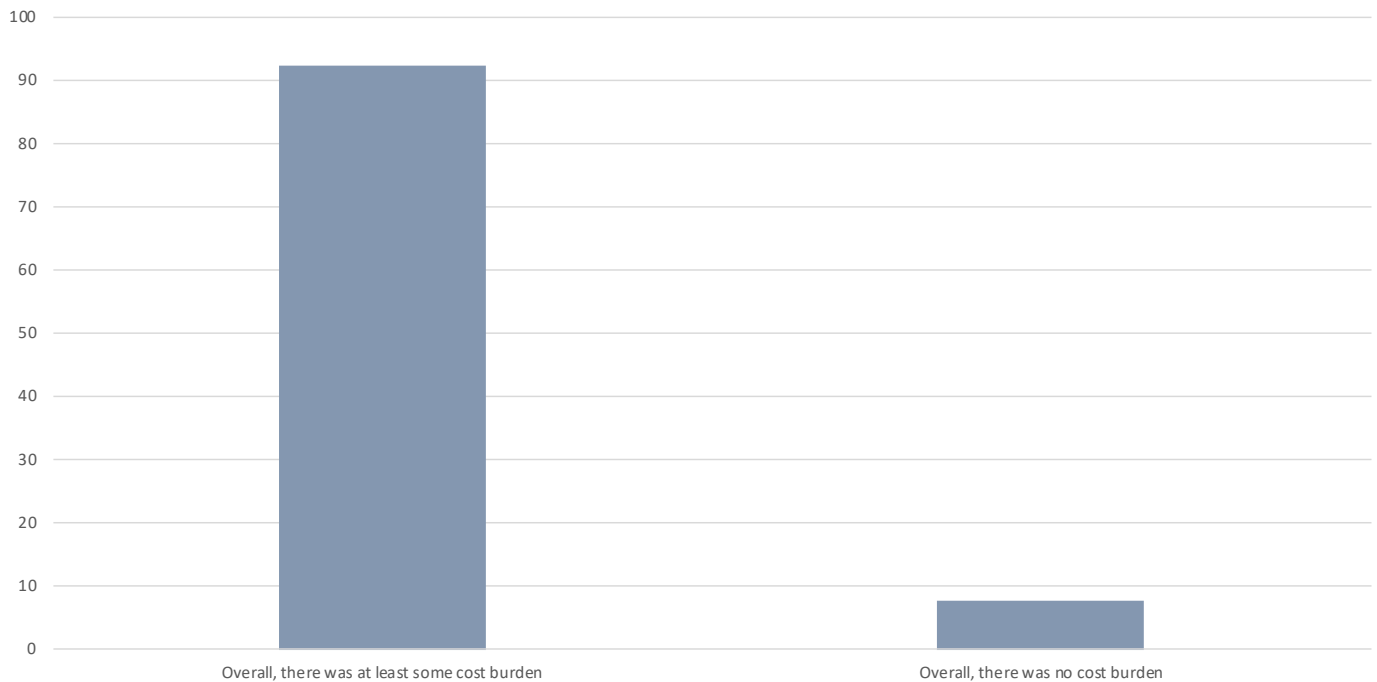


Figure 8.12: Cost considerations

Table 8.23: Cost considerations (Reasons for cost)

Cost considerations (Reasons for cost)	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)	43	82.69	17	89.47	16	76.19	10	83.33	25	86.21	18	78.26	17	89.47	26	78.79
Participant describes a cost burden in relation to needing to take time off work	24	46.15	9	47.37	10	47.62	5	41.67	12	41.38	12	52.17	10	52.63	14	42.42
Participant describes a cost burden in relation to the cost specialist appointments	20	38.46	8	42.11	8	38.10	4	33.33	9	31.03	11	47.83	10	52.63	10	30.30
Participant describes a cost burden in relation to diagnostic tests and scans	20	38.46	10	52.63	5	23.81	5	41.67	9	31.03	11	47.83	6	31.58	14	42.42
Participant describes a cost burden in relation to a family member needing to take time off work	7	13.46	4	21.05	2	9.52	1	8.33	1	3.45	6	26.09	4	21.05	3	9.09
Participant describes no cost burden and that nearly everything was paid for through the health system	7	13.46	1	5.26	4	19.05	2	16.67	4	13.79	3	13.04	1	5.26	6	18.18
Participant describes a cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	5	9.62	2	10.53	3	14.29	0	0.00	1	3.45	4	17.39	2	10.53	3	9.09

Cost considerations (Reasons for cost)	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)	43	82.69	9	90.00	13	81.25	21	80.77	10	90.91	33	80.49	16	88.89	27	79.41
Participant describes a cost burden in relation to needing to take time off work	24	46.15	4	40.00	7	43.75	13	50.00	8	72.73	16	39.02	10	55.56	14	41.18
Participant describes a cost burden in relation to the cost specialist appointments	20	38.46	7	70.00	4	25.00	9	34.62	6	54.55	14	34.15	8	44.44	12	35.29
Participant describes a cost burden in relation to diagnostic tests and scans	20	38.46	3	30.00	8	50.00	9	34.62	5	45.45	15	36.59	9	50.00	11	32.35
Participant describes a cost burden in relation to a family member needing to take time off work	7	13.46	0	0.00	2	12.50	5	19.23	2	18.18	5	12.20	2	11.11	5	14.71
Participant describes no cost burden and that nearly everything was paid for through the health system	7	13.46	1	10.00	2	12.50	4	15.38	0	0.00	7	17.07	1	5.56	6	17.65
Participant describes a cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	5	9.62	1	10.00	2	12.50	2	7.69	2	18.18	3	7.32	1	5.56	4	11.76

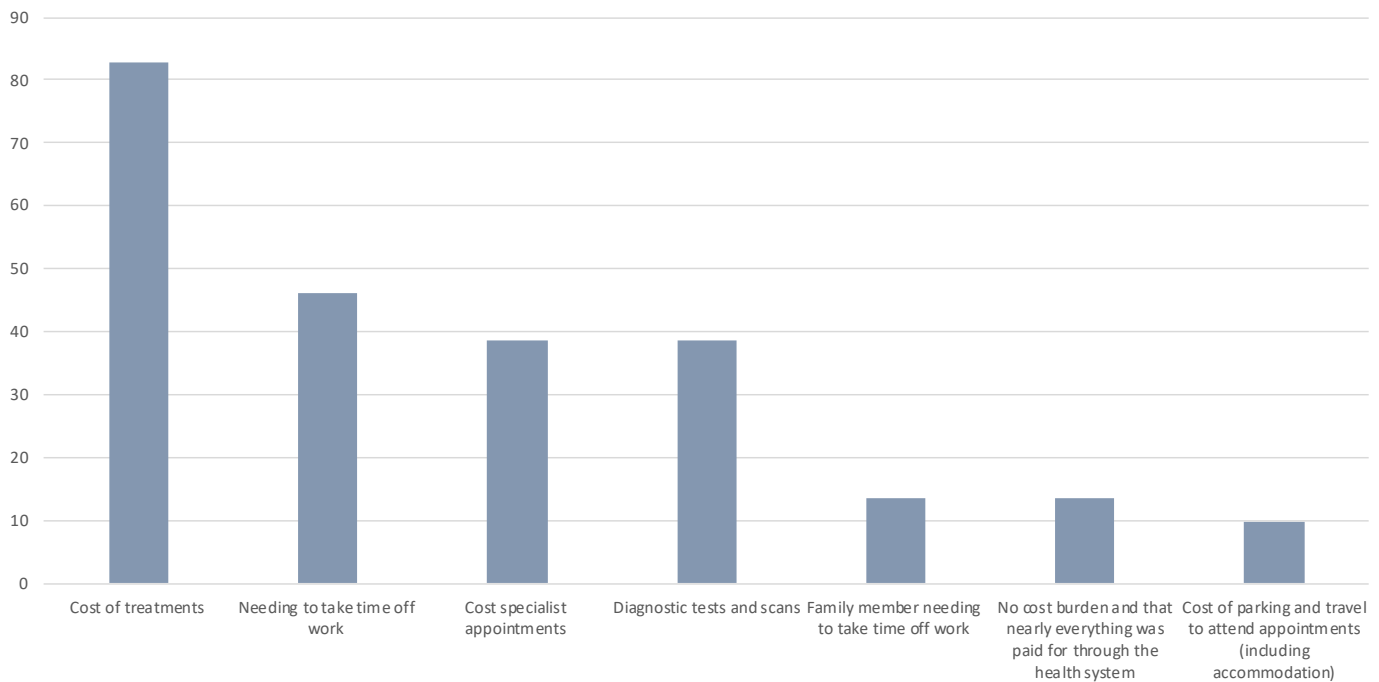


Figure 8.13: Cost considerations (Reasons for cost)

Table 8.24: Cost considerations (Reasons for cost)– subgroup variations

Cost considerations (Reasons for cost)	Reported less frequently	Reported more frequently
Participant describes a cost burden in relation to needing to take time off work	-	Regional or remote
Participant describes a cost burden in relation to the cost specialist appointments	Diagnosed in 2017 to 2019	Trade or high school Diagnosed in 2016 or before Regional or remote
Participant describes a cost burden in relation to diagnostic tests and scans	Stage II	Stage 0 and I Diagnosed in 2017 to 2019 Mid to low status
Participant describes a cost burden in relation to a family member needing to take time off work	Aged 25 to 54 Diagnosed in 2016 or before	Aged 55 to 74
Participant describes no cost burden and that nearly everything was paid for through the health system	Regional or remote	-

Overall impact of condition on quality of life

In the online questionnaire, participants were asked to rate the overall impact their condition on quality of life. Quality of life was rated on a Likert scale from one to seven, where one is Life was very distressing and seven is life was great.

The average score was in the life was average range (median = 4.00, IQR = 2.00) (Table 8.25, Figure 8.14).

Table 8.25: Overall impact of condition on quality of life

Impact of condition on quality of life	Number (n=51)	Percent
1 Life is/was very distressing	3	5.88
2 Life is/was distressing	8	15.69
3 Life is/was a little distressing	13	25.49
4 Life is/was average	10	19.61
5 Life is/was good	12	23.53
6 Life is/was very good	4	7.84
7 Life is/was great	1	1.96

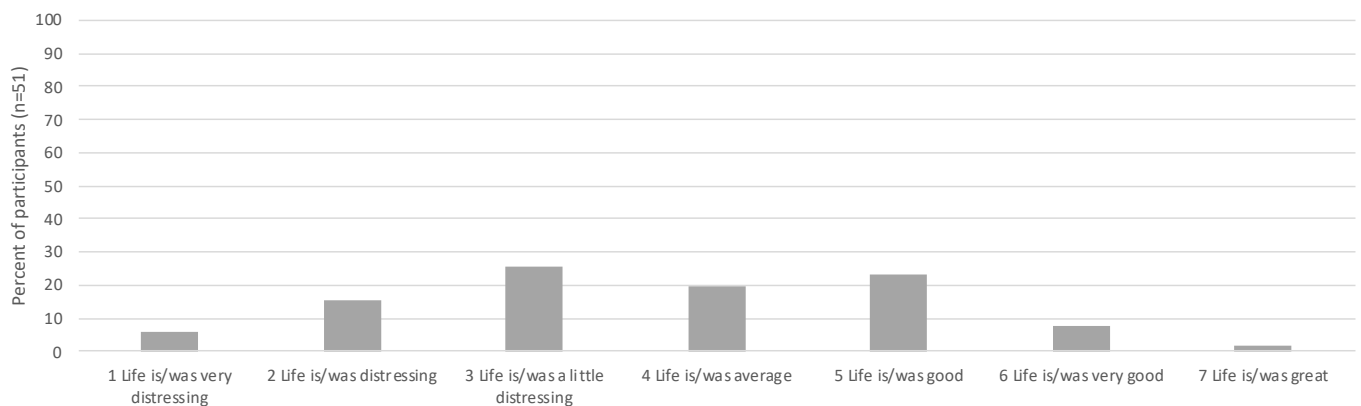


Figure 8.14: Overall impact of condition on quality of life

Experience of anxiety related to disease progression

Fear of progression

The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their conditions. The Fear of Progression questionnaire comprises a total score, between 12 and 60, with a higher score denoting increased anxiety. Summary statistics for the entire cohort are displayed in Table 8.10. Overall the entire cohort had an average score for **Fear of progression: Total score** (mean = 33.86, SD = 8.23) which corresponds to moderate levels of anxiety (Table 8.26).

Comparisons of Care co-ordination have been made based on **stage** (Table 8.27, Figure 8.15), **age** (Table 8.28, Figure 8.16), **education** (Table 8.29, Figure 8.17), **year of diagnosis** (Table 8.30, Figure 8.18), **location** (Table 8.31, Figure 8.19), and **socioeconomic status** (Table 8.32, Figure 8.20).

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

Table 8.26: Fear of progression summary statistics

Fear of progression (n=51)	Mean	SD	Median	IQR	Possible range	Quintile
Total score*	33.86	8.23	34.00	9.50	12 to 60	3

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

Fear of progression by stage

Comparisons were made by breast cancer **stage**, there were 18 participants (35.29%) with *Stage 0 and I* breast cancer, 21 participants (41.18%) with *Stage II*, and 12 participants (23.53%) with *Stage III and IV*.

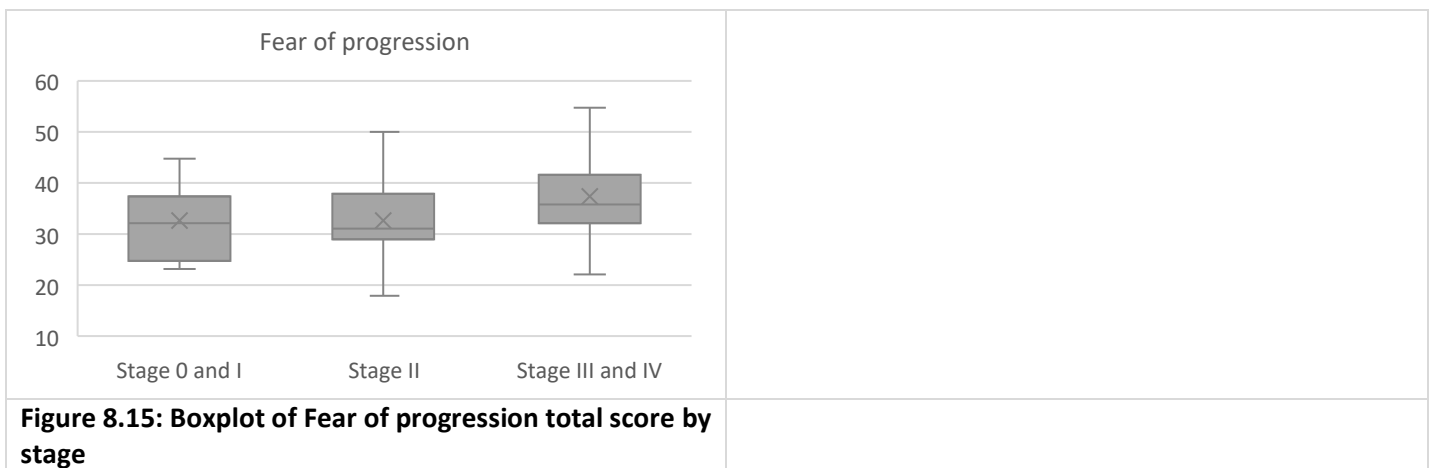
The assumptions for response variable residuals were normally distributed and variances of populations were

equal, a one-way ANOVA test was used. No significant differences between groups was observed (Table 6.27).

No significant differences were observed between participants by **stage** for the Fear of progression total score.

Table 8.27: Fear of progression total score by stage summary statistics and one-way ANOVA

Fear of progression	Group	Number (n=51)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Total score	Stage 0 and I	18	35.29	32.44	7.37	Between groups	229.10	2	114.56	1.743	0.1860
	Stage II	21	41.18	32.90	8.01	Within groups	3154.90	48	65.73		
	Stage III and IV	12	23.53	37.67	9.29	Total	3384.00	50			



Fear of progression by age

Participants were grouped according to **age**, with comparisons made between participants *Aged 25 to 54* (n=29, 56.86%) and participants *Aged 55 to 74* (n=22, 43.14%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 6.28).

No significant differences were observed between participants by **age** for the Fear of progression total score.

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

Fear of progression	Group	Number (n=51)	Percent	Mean	SD	T	dF	p-value
Total score	Aged 25 to 54	29	56.86	34.31	8.67	0.44	49	0.6601
	Aged 55 to 74	22	43.14	33.27	7.76			

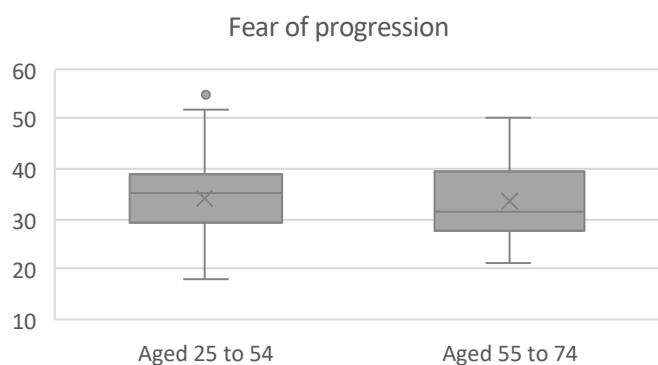


Figure 8.16: Boxplot of Fear of progression total score by age

Fear of progression by education

Comparisons were made by **education** status, between those with trade or high school qualifications, *Trade or high school* (n=19, 37.25%), and those with a university qualification, *University* (n= 32, 62.75%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 6.29).

No significant differences were observed between participants by **education** for the Fear of progression total score.

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

Fear of progression	Group	Number (n=51)	Percent	Mean	SD	T	dF	p-value
Total score	Trade or high school	19	37.25	33.21	8.65	-0.43	49	0.6671
	University	32	62.75	34.25	8.08			

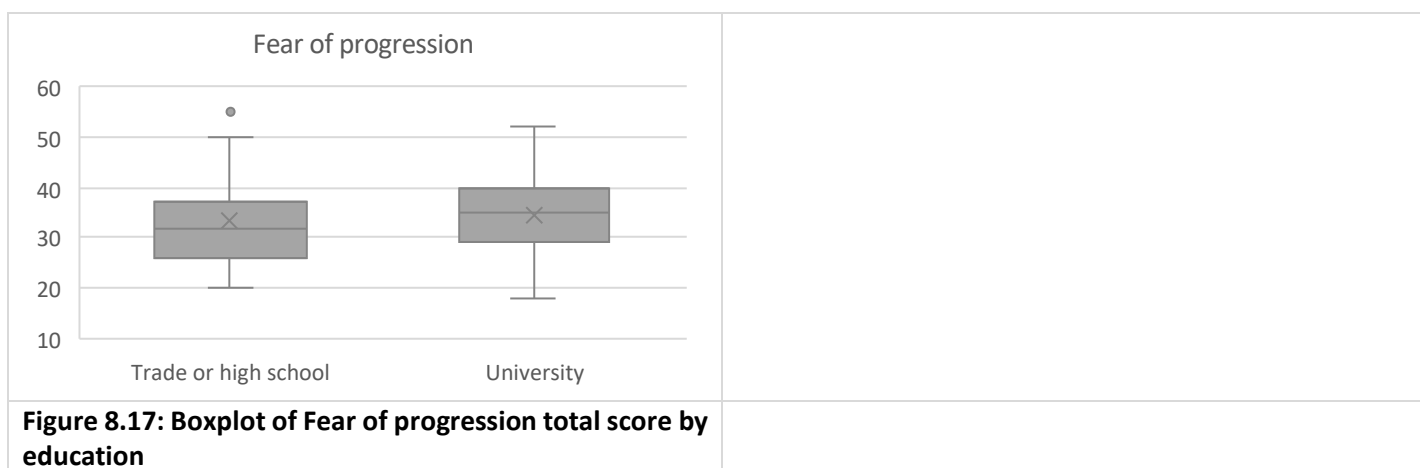


Figure 8.17: Boxplot of Fear of progression total score by education

Fear of progression by year of breast cancer diagnosis

Participants were grouped according to the **year of breast cancer diagnosis**, with 9 participants (17.65%) *Diagnosed in 2016 or before*, 16 participants (31.37%) *Diagnosed in 2017 to 2019*, and 26 participants (50.98%) *Diagnosed in 2020 or 2021*.

The assumptions for response variable residuals were normally distributed and variances of populations were

equal, a one-way ANOVA test was used. No significant differences between groups was observed (Table 6.30).

No significant differences were observed between participants by **year of breast cancer diagnosis** for the Fear of progression total score.

Table 8.30: Fear of progression total score by year of breast cancer diagnosis summary statistics and one-way ANOVA

Fear of progression	Group	Number (n=51)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Total score	Diagnosed in 2016 or before	9	17.65	32.22	6.24	Between groups	31.00	2	15.35	0.22	0.8040
	Diagnosed in 2017 to 2019	16	31.37	34.44	10.61	Within groups	3353.00	48	69.86		
	Diagnosed in 2020 or 2021	26	50.98	34.08	7.36	Total	3384.00	50			

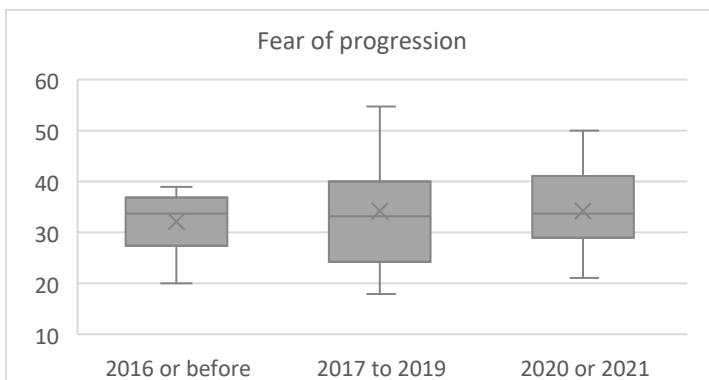


Figure 8.18: Boxplot of Fear of progression total score by year of breast cancer diagnosis

Fear of progression by location

The **location** of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. Those living in regional/rural areas, *Regional or remote* (n=10, 19.61%) were compared to those living in a major city, *Metropolitan* (n=41, 80.39%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 6.31).

No significant differences were observed between participants by **location** for the Fear of progression total score.

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

Fear of progression	Group	Number (n=51)	Percent	Mean	SD	T	dF	p-value
Total score	Regional or remote	10	19.61	33.09	7.67	-0.35	49	0.7291
	Metropolitan	41	80.39	34.08	8.45			

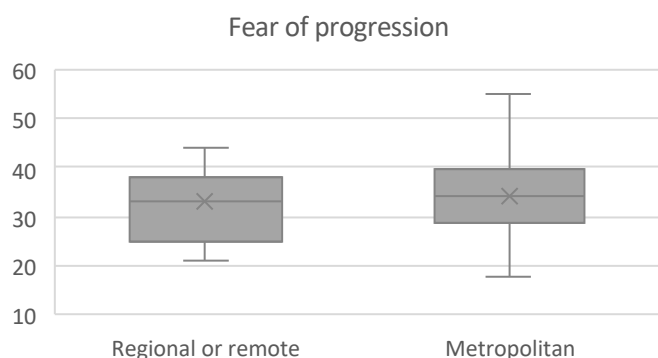


Figure 8.19: Boxplot of Fear of progression total score by location

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, *Mid to low status* (n=17, 33.33%) compared to those with a higher SEIFA score of 7-10, *Higher status* (n=34, 66.67%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 6.32).

No significant differences were observed between participants by **socioeconomic status**, for the Fear of progression total score.

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

Fear of progression	Group	Number (n=51)	Percent	Mean	SD	T	dF	p-value
Total score	Mid to low status	17	33.33	31.06	8.35	-1.76	49	0.0852
	Higher status	34	66.67	35.26	7.92			

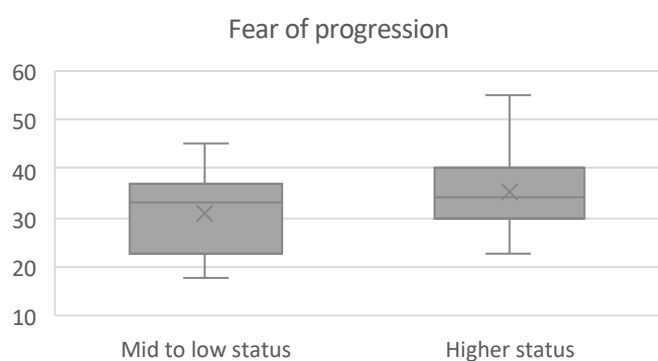


Figure 8.20: Boxplot of Fear of progression total score by socioeconomic status

Anxiety about treatment

Anxiety about treatment with no side effects

Participants were asked if a treatment is working well (limited side effects, no progression of disease), did they worry about what will happen if treatment is stopped.

The majority of participants were never or seldom worried about this (n = 42, 82.35%), there were 6 participants (11.76%) that were sometimes worried about this, and 3 participants (5.88%) were often or very often worried about this (Table 8.33, Figure 8.21).

Table 8.33: Anxiety about treatment with no side effects

Anxious if not experiencing any side effects think it doesn't work	Number (n=51)	Percent
Never	28	54.90
Seldom	14	27.45
Sometimes	6	11.76
Often	3	5.88
Very often	0	0.00

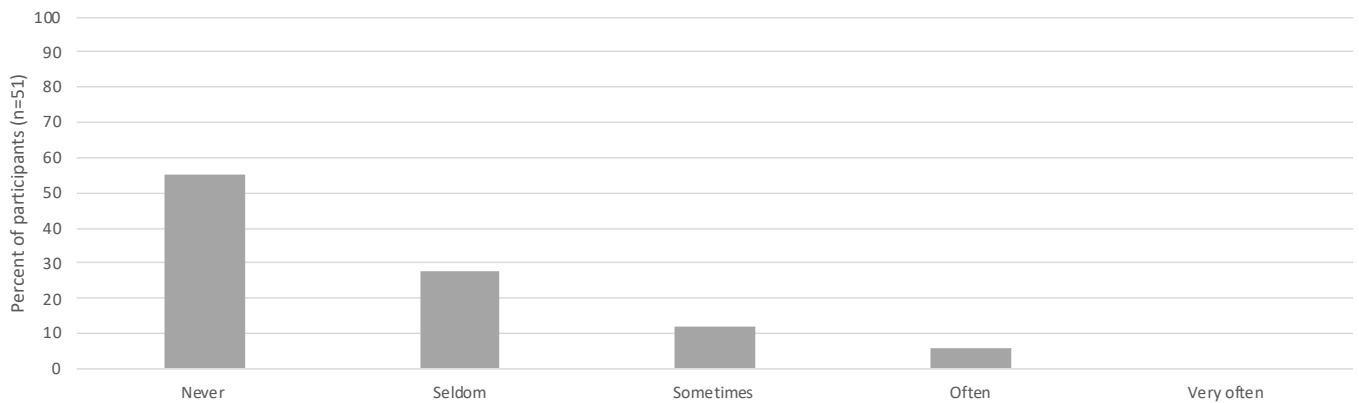


Figure 8.21: Anxiety about treatment with no side effects

Concern about what will happen if successful treatment is stopped

Participants reported how concerned they were about treatments working if they did not experience any side effects.

The majority of participants were never or seldom worried about this (n = 27, 52.94%), there were 15 participants (29.41%) that were sometimes worried about this, and 9 participants (17.65%) were often or very often worried about this (Table 8.34, Figure 8.22).

Table 8.34: Concern about what will happen if successful treatment is stopped

If a treatment and it is working well (limited side effects, no progression of disease), worry what will happen if treatment stopped	Number (n=51)	Percent
Never	10	19.61
Seldom	17	33.33
Sometimes	15	29.41
Often	2	3.92
Very often	7	13.73

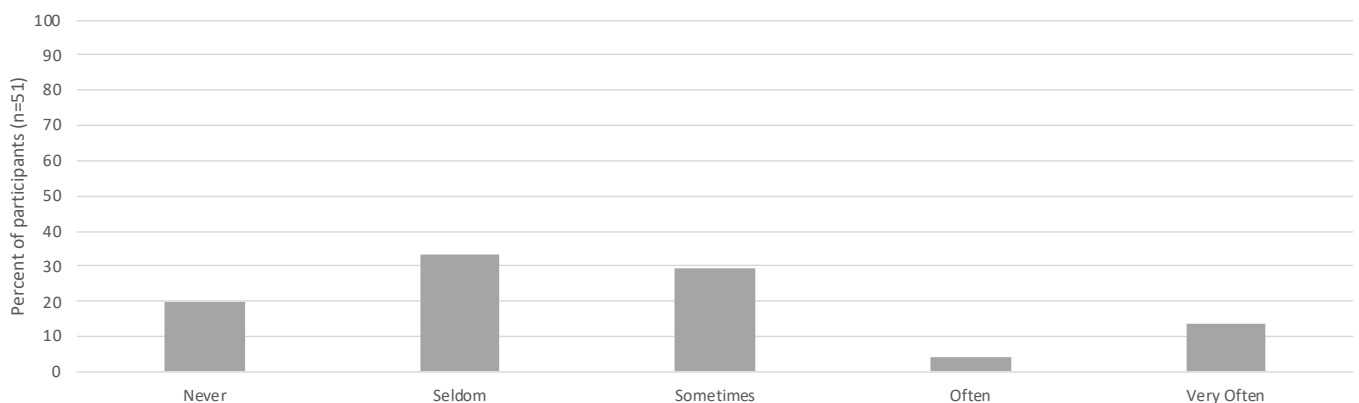


Figure 8.22: Concern about what will happen if successful treatment is stopped