

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 26 participants (52.00%) who described a negative impact on quality of life. There were seven participants (14.00%) who reported a mix of positive and negative impact on quality of life, and six participants (12.00%) who reported an overall positive impact on quality of life, and five participants. There were five participants (10.00%) who described no impact on quality of life, and three participants (6.00%) who described minimal 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 (n=25, 50.00%), the impact of symptoms/side effects (n=15, 30.00%), and the reduced capacity for physical activity (n=8, 16.00%).

Impact on mental health

In the structured interview, participants were asked if there had been an impact on their mental health. There were 45 participants (90.00%) who gave a description suggesting that overall there was some impact on their mental health and three participants (6.00%) who gave a description suggesting that overall there was no impact on mental health.

Regular activities to maintain mental health

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common ways that participants reported managing their mental and emotional health was maintaining social, lifestyle changes, and hobbies (n=18, 36.00%), consulting a mental health professional (n=17, 34.00%), and physical exercise (n=15, 30.00%). There were eight participants (16.00%) who described the importance of accepting their condition and having a positive outlook, and the same number who described the importance of family and friends (n=8, 16.00%). Other ways to maintain mental health included self-care (n=6, 12.00%), and mindfulness or meditation (n=5, 10.00%).

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 way that participants reported managing their health was by being physically active (n=26, 52.00%), followed by the importance of self-care (n=19, 38.00%). There 13 participants (26.00%) who described the importance of understanding their limitations, 12 participants (24.00%) who described maintaining a healthy diet and 11 participants (22.00%) who described the importance of treatment compliance. Other ways of maintaining health included keeping up with daily activities (n=7, 14.00%), and socialising with family and friends (n=5, 10.00%). There were five participants (10.00%) who described no regular activities to maintain their health.

Experience of vulnerability

In the structured interview, participants were asked if there had been times that they felt vulnerable. There were 43 participants (86.00%) who gave a description suggesting that overall they had experiences of feeling vulnerable, and four participants (8.00%) 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 theme was feeling vulnerable during or after treatments (n=20, 40.00%), followed by feeling vulnerable when having negative thoughts (n=15, 30.00%). There were 14 participants (28.00%) who described feeling vulnerable when having sensitive discussions for example at diagnosis and treatment decisions, and nine participants (18.00%) described feeling vulnerable when feeling sick.

Methods to manage vulnerability

In the structured interview, participants described ways that they managed feelings of vulnerability. Participants described support from their medical team to manage the feeling of vulnerability (n=9, 18.00%), and using self-help methods such as resilience, acceptance, and staying positive to manage the feeling of vulnerability (n=7, 14.00%). Other methods included adapting, for example being proactive. Assertive and understanding boundaries (n=6, 12.00%), and getting support from family and friends (n=5, 10.00%).

Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Overall, there were 19 participants (38.00%) who described a mix of positive and negative impacts on relationships. Other participants reported a negative impact on relationships (n=11, 22.00%), no impact on relationships (n=8, 16.00%), and a positive impact on relationships (n=7, 14.00%).

The most common theme in relation to having an impact on relationships was a mixed impact on relationships, some strengthened, others disappeared (n=14, 28.00%). There were eight participants (16.00%) who described relationships suffering, because of people not knowing what to say or do and withdrawing from relationships, and the same number who described no impact on relationships with no specific reason (n=8, 16.00%). Other reasons included relationships with family being strengthened (n=7, 14.00%), and relationships suffering, due to emotional strain (n=6, 12.00%).

Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Overall, there were 19 participants (38.00%) who described a mix of positive and negative impacts on relationships. Other participants reported a negative impact on relationships (n=11, 22.00%), no impact on relationships (n=8, 16.00%), and a positive impact on relationships (n=7, 14.00%).

The most common theme in relation to having an impact on relationships was a mixed impact on relationships, some strengthened, others disappeared (n=14, 28.00%). There were eight participants (16.00%) who described relationships suffering, because of people not knowing what to say or do and withdrawing from relationships, and the same number who described no impact on relationships with no specific reason (n=8, 16.00%). Other reasons included relationships with family being strengthened (n=7, 14.00%), and relationships suffering, due to emotional strain (n=6, 12.00%).

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 30 participants (60.00%) who felt there was an additional burden, and 18 participants (36.00%) who reported no additional burden.

Participants who described that they were no additional burden, mostly did this without giving any examples or explanations (n=13, 26.00%), followed by not being a burden because they manage their condition independently (n=5, 10.00%). For people that felt they were a burden on their family, most commonly did not give any specific reasons for this (n=12, 24.00%). The main reasons for burden on families were the extra household duties and responsibilities that their family must take on (n=10, 20.00%), and the mental/emotional strain placed on their family (n=6, 12.00%).

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. There were 36 participants (72.00%) that described some cost burden and 11 participants (22.00%) who 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=25, 50.00%). Other cost burdens were in relation to diagnostic tests and scans (n=15, 30.00%), taking time off work (n=9, 18.00%), and the cost of private care (n=7, 14.00%). There were six participants (12.00%) who described the cost of specialist appointments, and the same number who described the cost of allied healthcare (n=6, 12.00%), and the cost of parking and travel to attend appointments, including accommodation (n=6, 12.00%). There were six participants (12.00%) that described no cost burden and that nearly everything was paid for through the health system or private coverage.

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. The average score was in the Life was a little distressing range (median = 3.00, IQR = 3.00) (Table 8.29, Figure 8.15).

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 a mean total score of 35.89 (SD = 7.50), which corresponds to moderate levels of anxiety (Table 8.29)

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 26 participants (52.00%) who described a negative impact on quality of life. There were seven participants (14.00%) who reported a mix of positive and negative impact on quality of life, and six participants (12.00%) who reported an overall positive impact on quality of life, and five participants. There were five participants (10.00%) who described no impact on quality of life, and three participants (6.00%) who described minimal 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 (n=25, 50.00%), the impact of symptoms/side effects (n=15, 30.00%), and the reduced capacity for physical activity (n=8, 16.00%).

The most common theme in relation to a positive impact on quality of life was giving perspective on what is important in life (n=5, 18.00%).

Participant describes an overall negative impact on quality of life

Yes, definitely. It's totally different. It's getting better. It's no nowhere near what it was before breast cancer. I've changed my career to a less stressful local-based workplace. I'm not as active as I used to be because every time I get tired. I have to fight just fatigue and then I get a lot of chronic pain. I've had that many surgeries in the last five years. Silly. Every time you have surgery it's like six or eight weeks. Participant_012

Yes. It affected my physical quality of life, because of the symptoms and the significance around just what I've experienced through having done chemo. You're told this in the beginning, but you don't get it until it happens. Yes, so it's one of those things you've got to wait up. Participant_015

Participant describes a mix of positive and negative impact on quality of life

It's affected my quality of life because obviously I only have one breast and I've had side effects, but I think it's strengthened my relationship with my husband most definitely. My kids well, they're teenagers. I've got two older kids that aren't living at home that I get on very well with. My son who's in the car now obviously he likes to keep to himself so it doesn't really say much about whether or not it's affected him at all. My youngest daughter, she was a lot younger when I was diagnosed so I think that she seems to be fine as well. I think that those relationships, like the familial relationships are all fine. My husband's, a different way strengthened our relationship. I don't know why, it just made it better, just stronger. Stronger. Not better, stronger. Participant_022

To me, sort of a yes and a no. I mean, obviously yes, in that it's added a degree of at different times heightened and at other times just low level anxiety to my general life, which I didn't have before my family. I think they did have felt that to some degree, too. So in that respect, if I just find that aspect of quality of life. Yes. But on the other hand, I guess having had this, it's made me, as I probably said earlier, more conscious of how time is precious. And I know it sounds cliché, but it's just what the reality and trying to not, as I say, don't sweat the small stuff. Another cliché, but again, it is true and. So, yes, it has had an impact, but I wouldn't say bad with the negative, there's been some positive swings, swings around, you know, the other way. Participant_023

During treatment, it definitely was difficult because I had the daughter going to the HSC and another daughter first year law school and my son moved from LOCATION to LOCATION. That was a disaster for me personally, but I understood they had to get on with their life. Then, once I started feeling better, we started doing more as an adult family and I think it improved my quality of life. I've gotten a lot fitter, I've lost weight, I make the most of life now. Participant_040

Participant describes an overall positive impact on quality of life

Yes, it has, but I'd have to say it has improved my quality of life, and it's improved everything. I take better care of myself now, I'm way less stressed. I go out of my way to not be a stressed-out person because I believe that that is probably what caused the cancer in the first place. I have a better perspective on everything and now that I've been through that rather than just taking life for granted, I suppose. Participant_005

No, it hasn't. I think the quality and relationship with my family has probably only strengthened as a result of that. I think getting a diagnosis like cancer does impact on those around you, either for the better or worse. With my family, we were very close. Prior to the diagnosis, this only made us a lot closer. Like I said, my family were really supportive as a result of it. I felt very loved and nurtured right the way through treatment and still do. Yes, it has impacted on the quality of my life a little, in regards to the fact, like I say I probably gave up work earlier than what I had originally planned. I probably would have worked a bit longer before I retired, but I was lucky enough to be in a situation where I was able to retire early. Financially, I don't have any issues in that regard. I do have some ongoing health issues and that has impacted a little bit on my day-to-day life. Yes, in that regard, yes. It has impacted although, once again, I look at it like, "Okay, yes, I might have a few long term effects from my chemo, but I'm still here and I'm still able to do most of the things that I want to do." Yes, I'm grateful for that. Participant_013

I think it's probably improved my quality of life and my family life, as in my children. I'm sorry, I didn't have any family support really at the time. I faced that with my husband at the time. Yes, I think now it's just more about living for me and my children. Participant_024

Participant describes no impact on quality of life

Not really. It's just myself and my son. No, but my son's quite-- I don't know whether he's-- I took him with me to get my diagnosis and I said to him in the car before we went in, "What are you going to do if they come back and say I've got cancer and he was like, should be all right." Participant_014

I'm determined that it's not going to affect my quality of life. That's why I went to the physio and stuff like that. At the moment, yes, I'm certainly not as active

as I was, but I have a very loving partner who never made me feel that I was a burden or being sick was a problem so I was very lucky there. I never felt like that. Participant_029

Participant describes an overall minimal impact on quality of life

During treatment, yes, afterwards, no. Participant_009

Not necessarily. I wouldn't say that it's changed me and are now all like live the moment every day. It definitely makes you think about life a bit more, but yes, I don't think it's really changed our quality of life. We're still pretty much doing what we were doing pre-cancer. I have to remind myself most days that, "Hey, you actually had cancer." It's not something that I dwell on. It's not something that I focus on every day. Yes, I don't think it's really drastically changed that quality of life, I suppose. Participant_025

Probably in the beginning. Now we're starting to get on top of things. We have a bit of social life. It's not too bad at the moment. Participant_032

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

Yes, yes. Yes. How much detail do you want to have? Because at the time it was there were all sorts of aspects for my children. There was the stress and the worry for my eldest child, who was sort of taking on more of the caring for my role. And then my younger daughter, she he even now she'll wake up and she'll have a nightmare about losing me. So, yeah, there was that sort of stress and anxiety on my children. There was the pressure on my husband to try and look after all the family and hold on to his job and keep up with that to do work after hours. And the worry, the stress for him about losing me and doing all the appointments, all these random appointments that you couldn't change. And he would just have to try and make it work fit into it. So, yes, at the time, the quality of life, it really affected it. And that's had the ongoing effect. It's just had all these knock on effects with our family life. Participant_001

Yes, it has. My quality of life has decreased for a little bit. I have had to slow down professionally. I was doing really well before my diagnosis and I've had to give up on a lot of things and start again. That's been the hardest for me, starting from dot one in my

profession and having to give up-- I wanted to specialize and I was accepted into it, but I have to turn it all down. Cancer has changed my perspective and I just don't know what's going to happen, so I don't think I'll ever go and specialize again. It's also stopped my husband's progress in a way because we want to be close to our family and medical services. If he ever gets offered promotions or better jobs in some state, we can't just move as freely now as we used to. Participant_016

Yes, it very much has affected my quality of life. I only have my daughter. It hasn't really affected her too much. She's had to help me out a few times, but I would imagine it's stressful for her because her mum has got cancer. I've tried very hard to not let her know everything that's going on. She's had to make meals for me and all that sort of stuff to put in the freezer, "Just come over and keep me company," or whatever, just to try and keep me sane. Like I said, I've tried not to involve her too much. Participant_028

Participant describes negative impact on quality of life as a result of symptoms/side effects

*PARTICIPANT: Mine, yes, but not the family.
INTERVIEWER: How has it affected your quality of life?
PARTICIPANT: That I think when I continue to do things like poorly because I'm in pain and then I get cranky and short with people around me, Participant_006*

Yes, definitely. It's totally different. It's getting better. It's no nowhere near what it was before breast cancer. I've changed my career to a less stressful local-based workplace. I'm not as active as I used to be because every time I get tired. I have to fight just fatigue and then I get a lot of chronic pain. I've had that many surgeries in the last five years. Silly. [crosstalk] Every time you have surgery it's like six or eight weeks. Participant_012

Look, yes, it has, but COVID has a lot to do with that as well. I think if COVID wasn't here and there were no travel restrictions, and there were no restrictions at all, then it would have affected my life a lot more. I haven't really been able to do much because I haven't been well, so you know chemo isn't great. I haven't felt like wanting to do much on weekends and stuff. With COVID here I haven't really been able to travel or go anywhere far anyway. Yes, it has affected my life, but so has COVID. Participant_018

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

Don't really know. I would say probably for a while last year, while I was actually going through treatment things were-- we couldn't live our normal life. I couldn't be out and about and couldn't do things. I was relying a lot more on my son in particular because he lived here, but also my daughter from time to time, to do the things that I couldn't do. Keeping up with housework and cooking and all those sorts of things. Yes. It impacted on them. After surgery, I needed a lot more help, so my daughter moved in for a couple of weeks and things like that. It affected them in that way, but that was during and after the treatment and surgeries and things like that. Now I don't think so. I think now we're pretty much back to-- It's not affecting our quality of life now. Participant_011

Yes, definitely. It's totally different. It's getting better. It's no nowhere near what it was before breast cancer. I've changed my career to a less stressful local-based workplace. I'm not as active as I used to be because every time I get tired. I have to fight just fatigue and then I get a lot of chronic pain. I've had that many surgeries in the last five years. Silly. [crosstalk] Every time you have surgery it's like six or eight weeks. Participant_012

Yes. It affected my physical quality of life, because of the symptoms and the significance around just what I've experienced through having done chemo. You're told this in the beginning, but you don't get it until it happens. Yes, so it's one of those things you've got to wait up. Participant_015

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

Yes, it has, but I'd have to say it has improved my quality of life, and it's improved everything. I take better care of myself now, I'm way less stressed. I go out of my way to not be a stressed-out person because I believe that that is probably what caused the cancer in the first place. I have a better perspective on everything and now that I've been through that rather than just taking life for granted, I suppose. Participant_005

To me, sort of a yes and a no. I mean, obviously yes, in that it's added a degree of at different times heightened and at other times just low level anxiety to my general life, which I didn't have before my family. I think they did have felt that to some degree, too. So in that respect, if I just find that aspect of quality of life. Yes. But on the other hand, I guess having had this, it's made me, as I probably said earlier, more conscious of how time is precious. And I know it sounds cliché, but it's just what the reality and trying to not, as I say, don't sweat the small stuff. Another cliché, but again, it is true and. So, yes, it has had an impact, but I wouldn't say bad with the

negative, there's been some positive swings, swings around, you know, the other way. Participant_023

It's probably changed my point of view on loss in general, in that now I'm like, I've been given a second chance so to speak. Just living your best life and making the most out of every situation. There's people out there that are worse off than me, just because I've had breast cancer, it doesn't make me a sad sack of potatoes for the rest of my life. I've had it, I survived it and I just got to move on now. I'll just continue to be this forward, positive person that I am. Participant_045

Table 8.1: Impact on quality of life

Impact on quality of life	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes an overall negative impact on quality of life	26	52.00	13	56.52	13	48.15	10	52.63	11	44.00	11	42.31	15	62.50	12	50.00	14	53.85
Participant describes a mix of positive and negative impact on quality of life	7	14.00	3	13.04	4	14.81	2	10.53	5	20.00	6	23.08	1	4.17	2	8.33	5	19.23
Participant describes an overall positive impact on quality of life	6	12.00	2	8.70	4	14.81	3	15.79	3	12.00	3	11.54	3	12.50	3	12.50	3	11.54
Participant describes no impact on quality of life	5	10.00	2	8.70	3	11.11	1	5.26	4	16.00	2	7.69	3	12.50	3	12.50	2	7.69
Participant describes an overall minimal impact on quality of life	3	6.00	2	8.70	1	3.70	2	10.53	1	4.00	2	7.69	1	4.17	2	8.33	1	3.85
Other	2	4.00	0	0.00	2	7.41	1	5.26	1	4.00	0	0.00	2	8.33	2	8.33	0	0.00

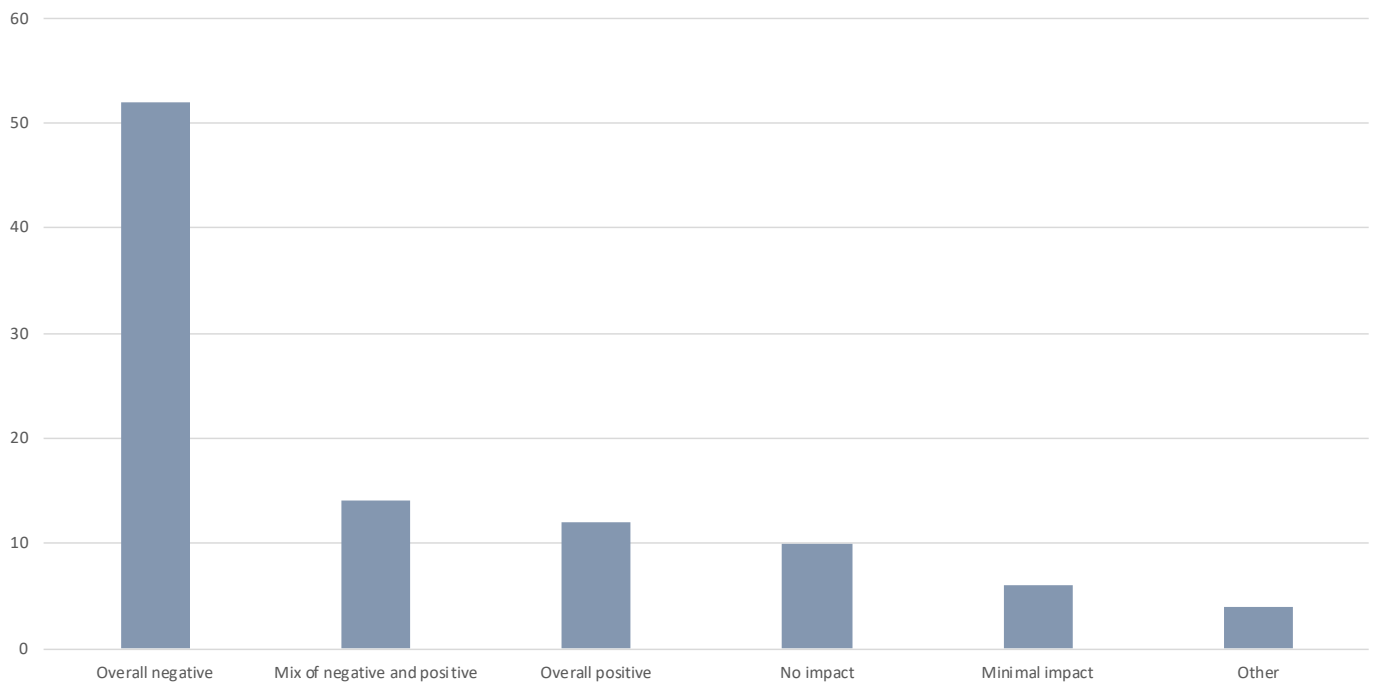


Figure 8.1: Impact on quality of life

Table 8.2: Impact quality of life – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes an overall negative impact on quality of life	Mid to low status Aged 55 to 74	Diagnosed in 2020 or 2021 Higher status Aged 55 to 74
Participant describes no impact on quality of life	-	-

Table 8.3: Impact on quality of life (Reasons)

Impact on quality of life (Reasons)	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics	25	50.00	11	47.83	14	51.85	10	52.63	10	40.00	11	42.31	14	58.33	11	45.83	14	53.85
Participant describes negative impact on quality of life as a result of symptoms/side effects	15	30.00	10	43.48	5	18.52	6	31.58	8	32.00	9	34.62	6	25.00	6	25.00	9	34.62
Participant describes negative impact on quality of life as a result of reduced capacity for physical activity	8	16.00	6	26.09	2	7.41	3	15.79	3	12.00	3	11.54	5	20.83	4	16.67	4	15.38
Participant describes positive impact on quality of life as the diagnosis helps you realise what is important (giving perspective)	5	10.00	3	13.04	2	7.41	1	5.26	4	16.00	4	15.38	1	4.17	1	4.17	4	15.38
Participant describes no impact on quality of life (general comment)	5	10.00	2	8.70	3	11.11	1	5.26	4	16.00	2	7.69	3	12.50	3	12.50	2	7.69

Impact on quality of life (Reasons)	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics	25	50.00	6	37.50	19	55.88	7	35.00	18	60.00	11	57.89	9	40.91	5	55.56
Participant describes negative impact on quality of life as a result of symptoms/side effects	15	30.00	6	37.50	9	26.47	6	30.00	9	30.00	5	26.32	8	36.36	2	22.22
Participant describes negative impact on quality of life as a result of reduced capacity for physical activity	8	16.00	2	12.50	6	17.65	3	15.00	5	16.67	2	10.53	6	27.27	0	0.00
Participant describes positive impact on quality of life as the diagnosis helps you realise what is important (giving perspective)	5	10.00	1	6.25	4	11.76	2	10.00	3	10.00	2	10.53	2	9.09	1	11.11
Participant describes no impact on quality of life (general comment)	5	10.00	1	6.25	4	11.76	2	10.00	3	10.00	1	5.26	2	9.09	2	22.22

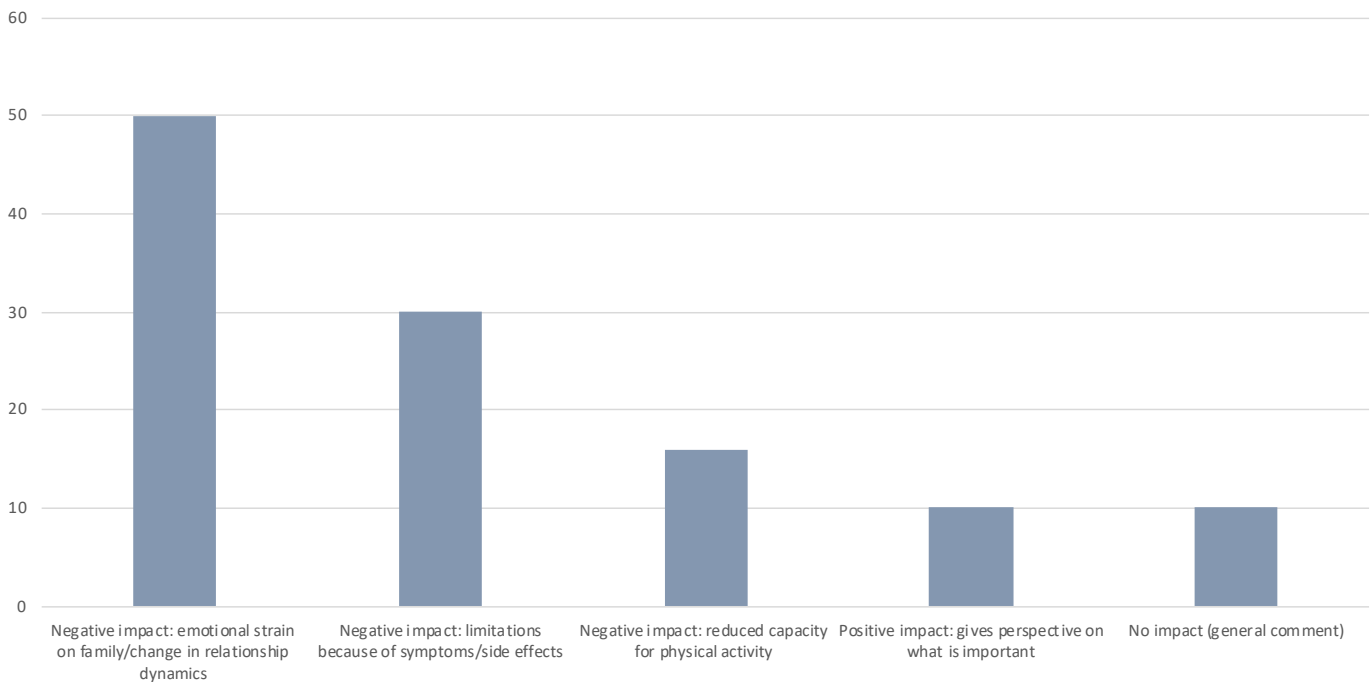


Figure 8.2: Impact on quality of life (Reasons)

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

Theme	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	Regional or remote Mid to low status	-
Participant describes negative impact on quality of life as a result of symptoms/side effects	Advanced breast cancer	Early breast cancer
Participant describes negative impact on quality of life as a result of reduced capacity for physical activity	Aged 55 to 74	Early breast cancer Aged 45 to 54
Participant describes no impact on quality of life (general comment)	-	Aged 55 to 74

Impact on mental health

In the structured interview, participants were asked if there had been an impact on their mental health. There were 45 participants (90.00%) who gave a description suggesting that overall there was some impact on their mental health and three participants (6.00%) who gave a description suggesting that overall there was no impact on mental health.

Participant gives a description suggesting that overall, there was at least some impact on mental health

It does because especially as a female, you lose all your hair and it's debilitating or it was me. Some women say, "Well, I shaved my head before it started falling out myself. Fantastic and I had control." And I conceded off and said I cried the whole time I was sitting my head shaved and couldn't look in a mirror. When I had no hair. How did I look after it? I probably didn't, to be quite honest. I was just at this stage, I was just getting through each day as it came without looking too far ahead because I couldn't cope with it. Participant_027

I think the other day I thought I might actually look up someone to talk to about it, because I didn't really think about it throughout the process because I just wanted to get on with it and keep working so that I could just be focused. Now, you're at the end, it's like, "I actually survived something pretty amazing." It does get a bit overwhelming every now and then. Yes, I get like, "Oh, no." I just start crying like, "Whoa, that was good you know. Well done that you did that." but it might be beneficial for me to go talk to someone about it. That's probably where I'm at right now. Participant_045

Yes, it does affect, obviously. It does affect that side of things. I find I'm a lot more emotional now, just overall. I try to have time out for me all the time, like most days, have a little bit of time to do that. I love walking on the beach or something like that. Being around water helps me. The local cancer support groups, they do pamper days on the coast, so we go to those. They have massage and do different things like that just to treat you, so I try to do them when I can. Participant_046

Table 8.5: Impact on mental health

Impact on mental health	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant gives a description suggesting that overall, there was at least some impact on mental health	45	90.00	22	95.65	23	85.19	17	89.47	22	88.00	24	92.31	21	87.50	20	83.33	25	96.15
Participant gives a description suggesting that overall, there was no impact on mental health	3	6.00	1	4.35	2	7.41	0	0.00	3	12.00	1	3.85	2	8.33	3	12.50	0	0.00
Other	2	4.00	0	0.00	2	7.41	1	5.26	1	4.00	0	0.00	2	8.33	2	8.33	0	0.00

Impact on mental health	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant gives a description suggesting that overall, there was at least some impact on mental health	45	90.00	14	87.50	31	91.18	18	90.00	27	90.00	17	89.47	20	90.91	8	88.89
Participant gives a description suggesting that overall, there was no impact on mental health	3	6.00	2	12.50	1	2.94	1	5.00	2	6.67	1	5.26	1	4.55	1	11.11
Other	2	4.00	0	0.00	2	5.88	2	10.00	0	0.00	2	10.53	0	0.00	0	0.00

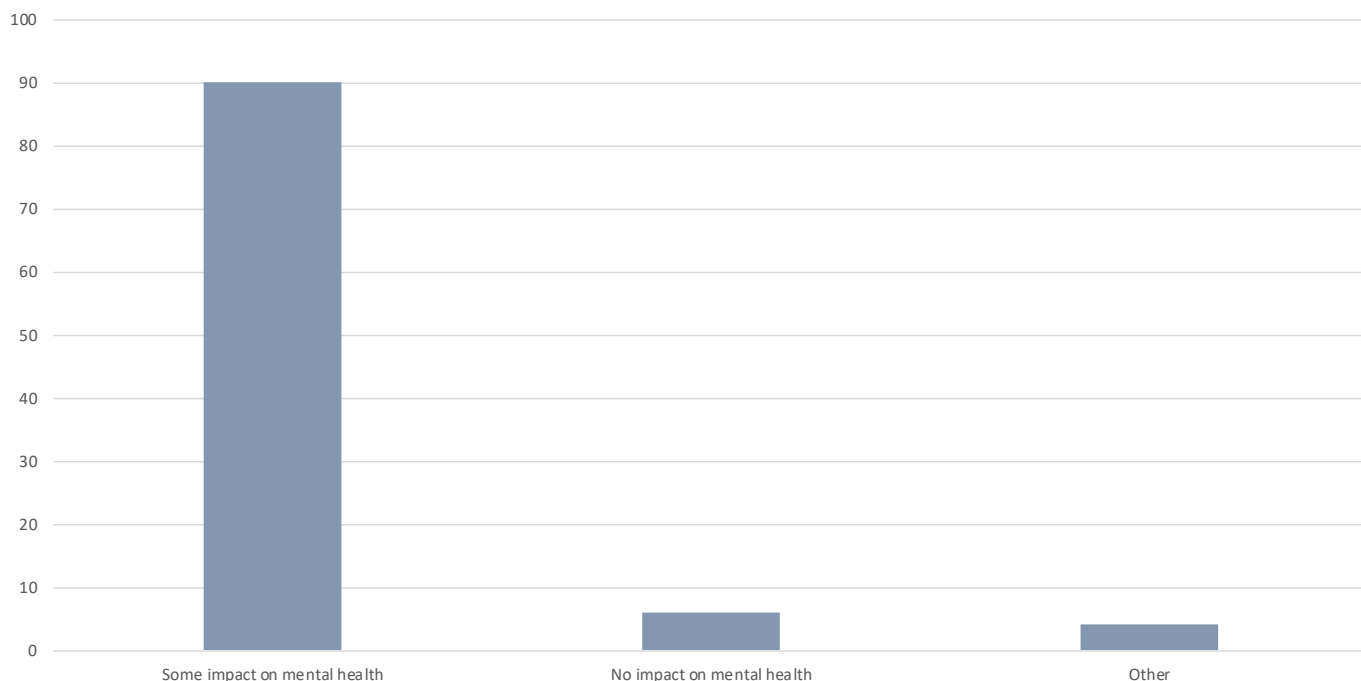


Figure 8.3: Impact on mental health

Regular activities to maintain mental health

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common ways that participants reported managing their mental and emotional health was maintaining social, lifestyle changes, and hobbies (n=18, 36.00%), consulting a mental health professional (n=17, 34.00%), and physical exercise (n=15, 30.00%). There were eight participants (16.00%) who described the importance of accepting their condition and having a positive outlook, and the same number who described the importance of family and friends (n=8, 16.00%). Other ways to maintain mental health included self-care (n=6, 12.00%), and mindfulness or meditation (n=5, 10.00%).

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

It probably does so. And my one go to with gardening. But that's a hard question to answer when you've been in Lockdown's and stuff like that. So because your quality of life is like crappy anyway, because you can't go anywhere and do anything. Gardening has been my so I do that in shorter bursts now than when I used to do it, like I used to be in there all day, but now I only do it like for an hour here and now with it. And we haven't been able to go out with friends that I normally go out with friends and you know, Participant_006

It definitely affects my mental and emotional health. The things that I do, I guess I have those self care strategies. So whether it's having a day in bed or a day of eating chocolate and takeaway food, whether it's booking in with a friend and going out to dinner and cocktails, or whether it's going for a massage or a run or a swim, whether it's just being out in the environment and absorbing some of the sun, whether it's going for a facial, I have access the counsellor who's a friend when need be, sometimes just, I guess, to check in and see how I'm going to talk about some things will come up with some strategies to implement, making sure that I sleep very well and that majority of time I am getting a balanced diet and exercise and looking after myself. I'm better at cancelling things. So whereas once upon a time I would be very much about what anyone in my life needed. Now I'm better about putting myself first and not seeing that is selfish, but just also looking after me. So I guess that's an important strategy, is thinking about what my body needs and giving it in that moment and not feeling guilty about that. Participant_010

Again, 100%. Yes. I'm trying, I'm working on it [crosstalk] doing the exercise. Staying social, I'm trying to stay as social as possible. Participant_019

Participant describes consulting a mental health professional

It does. I think fear of recurrence is way there and it was a big thing for me when suddenly all the treatment stopped and you're just left. Off you go, you're finished now. Even though you know you're going to get checkups every six months or whatever, it's quite hard to cope with. What do I do now? I'm so scared of definitely a recurrence or metastasis. Yes, mental health-wise, I think it had quite a big effect and I did eventually manage to see a psychologist and talk through things and find ways to manage my fears so that they didn't take over my life. Participant_004

Yes, it does. For sure. The things that I've done is seek the support of the psychologist through Breast Cancer WA, and also the breast care nurse calls me about every month and that is very good. They're the main areas of support for my mental health care. Participant_017

Yes, breast cancer has probably, really ruined my mental health, before then I was very happy, easygoing person. Now, I'm constantly worried about the future. Yes, I see a psychologist for that. Participant_018

Seeing a psychologist at the moment. During treatment, no, I didn't. Didn't have the time or that wellness to deal with it at the time. My treatment started so quickly there wasn't time to get in really beforehand, but now I am, yes. Participant_036

Participant describes the importance of physical exercise

Yes, it does affect your emotional and mental health. I work out, I go to the gym. I do personal training once a week. If I don't go to the gym, I walk. I try and do that and it actually helps with my fatigue as well as my mental health. That's a massive change in my life. Done that. I've changed my career. I was working in law now I'm in an office looking after electricians which is super less stressful than where I was. That's what I've done Participant_012

Obviously, yes, as I've mentioned a few times. So I try to keep exercising both for mental and emotional, mental and physical health. I tended to journal, haven't done so as much, but I do occasionally bring myself back there to reflect on where my head is at or

not at all. I try to remember some of the techniques that the counsellors shared with me about managing worry and if I at any time am concerned that I am sliding some way, I'll try to do some things that will help me, whether it's go buy myself a bunch of flowers or listen to some music or take a walk or do I'll do something or go to my favourite movies. I'll do something that will try to soothe a bit if I'm feeling a little bit down or something. Participant_023

Yes, I'm back at work so I have the social aspect. I'm back at my gym three times a week. The physical activity is helping but it's also the social interaction, which helps the mental side because I've got so many friends there who are like, "You're looking so well. You're back at the gym already." and so that kind of thing has really helped me get through it. Participant_027

Participant describes the importance of accepting condition/positive outlook

I'm very aware of that all the emotions of what's going on. I make sure that I deal with them as they come. For me, that means sometimes I'm not happy, I'm sad, and that's okay. I try to focus a lot on why I'm lucky. That's how I deal with it mentally. Participant_007

100%. The stress and the anxiety, I mean, I still get it. I'm trying to be positive and I try to just keep focused on everything's going to be okay, but I mean, you just don't know with triple-negative breast cancer. Unfortunately, it's one of those things where it can go. It could go either way, but I just tried to have a positive spin on it too and not think about that negative side but it still creeps in every day. I'm still trying to push it to the back. I'll have times where I break down because, for me, it's like, "I might not get to see my daughter grow up," I just see things pop into my head frequently and it's all things that I'd have to be talking to my psychologist about. I don't think I would have coped if I didn't have somebody to talk to about. Participant_015

I'm a ridiculously positive person. I've managed to maintain that probably 90% of the time. There are those moments where you do have those awful thoughts that you really don't want to be having. I do allow myself a little more [unintelligible] I think sometimes I'll just allow myself an hour of wallowing and then I step out of it. This is enough because all this

wallowing isn't going to change anything. We really, as a family and as a person, want to focus on the positives and good outcomes. I find that when I let myself slide, that's really difficult. We try as best as possible to drag out of that and then focus on, "Okay this is the hand we're dealt with, what are we going to do about it? Let's be positive. What next?" There's been probably a little change in mood at times, but not desperately. Participant_033

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

I think I touched on the mental side of it where there's always that thought of, "What if it's going to come back?" and, "What are these aches?" I don't think that that's ever going to change. I still like to do the things I used to do before which is like watching telly and all of that kind of stuff. I don't know. I try to be more positive but at times it can be a little bit harder. My husband and I, we have date nights now. We go away camping or caravanning a lot more now than what we used to. I think that we've been trying to see a little bit more and do a little bit more than what we used to do in the past. Participant_022

Absolutely. When I was first diagnosed, it was terrifying. I have a long health history of not being very well with some pretty serious illnesses. In between that period of time from diagnosis to initial diagnosis to having a PET scan, I was terrified about what was my prognosis. Getting your head around having cancer is just an extraordinary thing to try to do. I couldn't even say the word out loud for a couple of weeks. It was so overwhelming, and just that thing where you wake up in the morning for that brief second, you forget what's really going on, and then it just hits you like a ton of bricks. I just be going about my day and it'd be like getting this reality slap every once in a while where it's just I'd go and I would just remember what was going on. It was like my whole body would just flood with this fear. I go for walks every day on the beach, I do a lot of meditation, guided meditations. I've got my psychologist. I do go for walks with friends most days when we're allowed to. I do try to talk to my partner once, if not twice a day. I just make sure that I'm keeping up those human connections, trying to have some enjoyable time, but also practicing well-being techniques that really helped me, and massage really helps a lot, too. Participant_041

Apart from seeing a psychologist and talking to my daughter endlessly, no I don't. I guess I do think it's affected me in some ways. I haven't got the patience I once did. Yes, talking to people helps. Participant_032

Participant describes the importance of self care in maintaining their mental health

Yes, I think it does because I've been diagnosed with PTSD and I've got anxiety. That's why I speak to the psychologists and stuff as well. That's my thing that I'm booking in and going to that all the time. I do a lot of meditation. I'm just giving myself the time to rest, which I probably wouldn't have done ever before. Just really focusing on making sure that I don't have much stress, and that I'm eating well, that I'm exercising, I'm getting massages, all that self-care stuff. Participant_008

It definitely affects my mental and emotional health. The things that I do, I guess I have those self care strategies. So whether it's having a day in bed or a day of eating chocolate and takeaway food, whether it's booking in with a friend and going out to dinner and cocktails, or whether it's going for a massage or a run or a swim, whether it's just being out in the environment and absorbing some of the sun, whether it's going for a facial, I have access the counsellor who's a friend when need be, sometimes just, I guess, to check in and see how I'm going to talk about some things will come up with some strategies to implement, making sure that I sleep very well and that majority of time I am getting a balanced diet and exercise and looking after myself. I'm better at cancelling things. So whereas once upon a time I would be very much about what anyone in my life needed. Now I'm better about putting myself first and not seeing that is selfish, but just also looking after me. So I guess that's an important strategy, is thinking about what my body needs and giving it in that moment and not feeling guilty about that. Participant_010

Obviously, yes, as I've mentioned a few times. So I try to keep exercising both for mental and emotional, mental and physical health. I tended to journal, haven't done so as much, but I do occasionally bring myself back there to reflect on where my head is at or not at all. I try to remember some of the techniques that the counsellors shared with me about managing worry and if I at any time am concerned that I am sliding some way, I'll try to do some things that will

help me, whether it's go buy myself a bunch of flowers or listen to some music or take a walk or do I'll do something or go to my favourite movies. I'll do something that will try to soothe a bit if I'm feeling a little bit down or something. Participant_023

Participant describes using mindfulness and/or meditation

Yes, it has. I think it's quite changed. My personality. I used to be confident and I've become more introverted, more anxious, and I haven't gone back to work because I just get panicky at the thought. It's like I can't deal with stress anymore. I took a long time to get past every morning waking up wondering what's going to happen today, what bad things is going to happen, just that panic and fear every time I'd wake up in the morning. So that's definitely been ongoing. And I think I'm a bit fatalistic as well as to just thinking now I'm probably going to die soon anyway. And just really not I don't I can't picture myself too far ahead in the future, but I do try and meditate and keep myself calm. I try, but I just think I just it's like I've changed my personality. Participant_001

I do personal development courses at different times and just general ones, not specifically related to cancer. I try to spend time doing meditation. I find that helps calm my mind. Participant_037

Absolutely. When I was first diagnosed, it was terrifying. I have a long health history of not being very well with some pretty serious illnesses. In between that period of time from diagnosis to initial diagnosis to having a PET scan, I was terrified about what was my prognosis. Getting your head around having cancer is just an extraordinary thing to try to do. I couldn't even say the word out loud for a couple of weeks. It was so overwhelming, and just that thing where you wake up in the morning for that brief second, you forget what's really going on, and then it just hits you like a ton of bricks. I just be going about my day and it'd be like getting this reality slap every once in a while where it's just I'd go and I would just remember what was going on. It was like my whole body would just flood with this fear. I go for walks every day on the beach, I do a lot of meditation, guided meditations. I've got my psychologist. I do go for walks with friends most days when we're allowed to. I do try to talk to my partner once, if not twice a day. I just make sure that I'm keeping up those human connections, trying to have some enjoyable time, but also practicing well-being techniques that really helped me, and massage really helps a lot, too. Participant_041

Table 8.6: Regular activities to maintain mental health

Regular activities to maintain mental health	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes using coping strategies such as remaining social, lifestyle changes and hobbies	18	36.00	10	43.48	8	29.63	3	15.79	11	44.00	10	38.46	8	33.33	6	25.00	12	46.15
Participant describes consulting a mental health professional	17	34.00	9	39.13	8	29.63	8	42.11	9	36.00	9	34.62	8	33.33	6	25.00	11	42.31
Participant describes the importance of physical exercise	15	30.00	10	43.48	5	18.52	5	26.32	6	24.00	10	38.46	5	20.83	5	20.83	10	38.46
Participant describes the importance of accepting condition/positive outlook	8	16.00	6	26.09	2	7.41	4	21.05	4	16.00	4	15.38	4	16.67	1	4.17	7	26.92
Participant describes the importance of family and friends in maintaining their mental health	8	16.00	2	8.70	6	22.22	2	10.53	6	24.00	5	19.23	3	12.50	5	20.83	3	11.54
Participant describes the importance of self care in maintaining their mental health	6	12.00	4	17.39	2	7.41	3	15.79	3	12.00	4	15.38	2	8.33	1	4.17	5	19.23
Participant describes using mindfulness and/or meditation	5	10.00	3	13.04	2	7.41	2	10.53	2	8.00	4	15.38	1	4.17	1	4.17	4	15.38

Regular activities to maintain mental health	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes using coping strategies such as remaining social, lifestyle changes and hobbies	18	36.00	5	31.25	13	38.24	10	50.00	8	26.67	4	21.05	12	54.55	2	22.22
Participant describes consulting a mental health professional	17	34.00	4	25.00	13	38.24	2	10.00	15	50.00	10	52.63	4	18.18	3	33.33
Participant describes the importance of physical exercise	15	30.00	4	25.00	11	32.35	6	30.00	9	30.00	8	42.11	5	22.73	2	22.22
Participant describes the importance of accepting condition/positive outlook	8	16.00	4	25.00	4	11.76	3	15.00	5	16.67	1	5.26	6	27.27	1	11.11
Participant describes the importance of family and friends in maintaining their mental health	8	16.00	2	12.50	6	17.65	3	15.00	5	16.67	2	10.53	4	18.18	2	22.22
Participant describes the importance of self care in maintaining their mental health	6	12.00	1	6.25	5	14.71	2	10.00	4	13.33	3	15.79	3	13.64	0	0.00
Participant describes using mindfulness and/or meditation	5	10.00	0	0.00	5	14.71	0	0.00	5	16.67	2	10.53	3	13.64	0	0.00

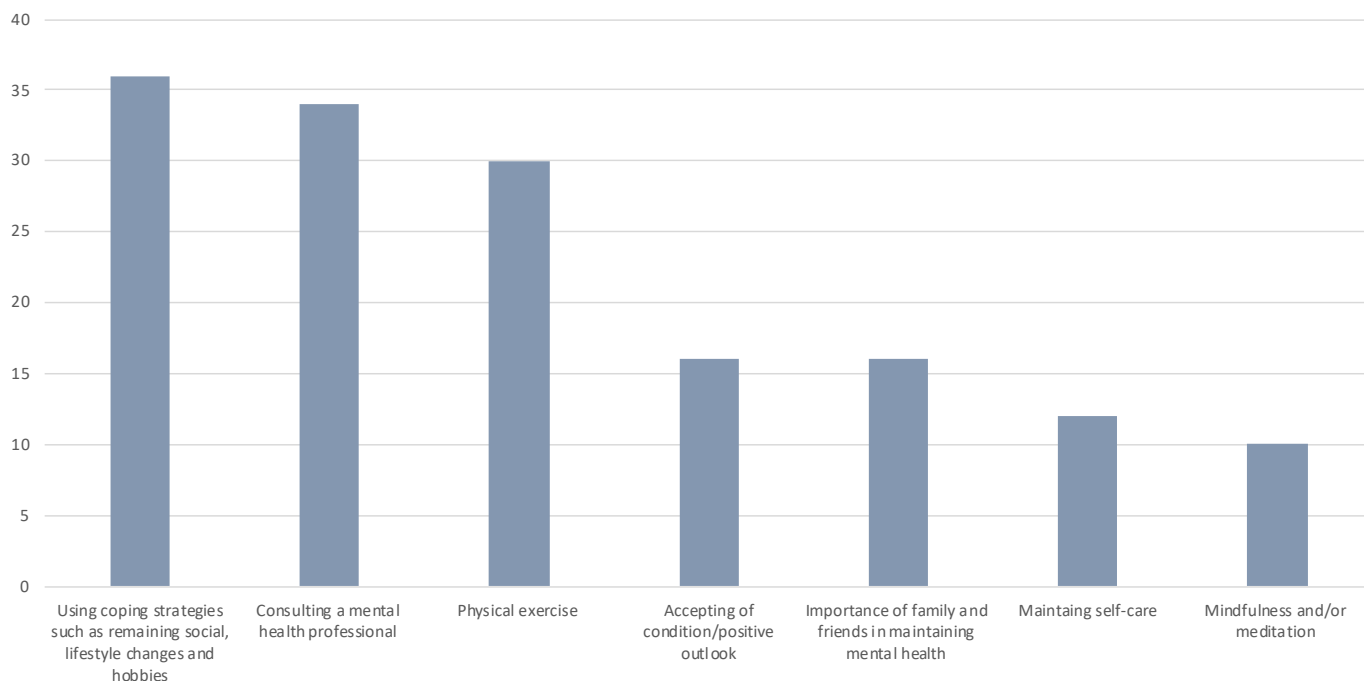


Figure 8.4: Regular activities to maintain mental health

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

Theme	Reported less frequently	Reported more frequently
Participant describes using coping strategies such as remaining social, lifestyle changes and hobbies	Poor physical function Trade or high school Aged 25 to 44 Aged 55 to 74	University Mid to low status Aged 45 to 54
Participant describes consulting a mental health professional	Mid to low status Aged 45 to 54	Higher status Aged 25 to 44
Participant describes the importance of physical exercise	Advanced breast cancer	Early breast cancer Aged 25 to 44
Participant describes the importance of accepting condition/positive outlook	Trade or high school Aged 25 to 44	Early breast cancer University Aged 45 to 54
Participant describes the importance of self care in maintaining their mental health	Aged 55 to 74	-

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 way that participants reported managing their health was by being physically active (n=26, 52.00%), followed by the importance of self-care (n=19, 38.00%). There 13 participants (26.00%) who described the importance of understanding their limitations, 12 participants (24.00%) who described maintaining a healthy diet and 11 participants (22.00%) who described the importance of treatment compliance. Other ways of maintaining health included keeping up with daily activities (n=7, 14.00%), and socialising with family and friends (n=5, 10.00%). There were five participants (10.00%) who described no regular activities to maintain their health.

Participant describes being physically active

Well, I think you have now you have osteoporosis or osteopenia. So I have to do strength training in building. The menopause is expected to be the biggest ongoing thing of my life. And, you know, things like being hot flushes impact because those kind of things are ongoing, things that I manage. Participant_002

Once, again, the exercise that I do, like I say, I exercise daily, so that exercise class, I attend twice a week. In between times, I either walk or run daily. We have a dog, so I take the dog out most days. I either alternate with a walk or run, it just depends on what else I've done that day. As I said, at the moment, I am fairly focused on my diet, because as I said, the chemotherapy has had some residual side effects on my intestine. I'm currently having to monitor my diet. I've found that I have become intolerant to lactose gluten. I'm currently seeing and probably I forgot to

mention this, but I am currently seeing a nutritionist, a guy in LOCATION. I sought him out as a result of my gut issues, just to see whether that may help. I am seeing him and taking some medications, just to see whether that might help. I've had a couple of consults in the last couple of months with him. Participant_013

I just keep active. I need to keep my mind active. I need to keep my body active. I found throughout treatment if I kept my life as normal as possible and try to keep my routine, I got through things better. Even with my radiotherapy, I know people said they had terrible fatigue. I didn't notice that fatigue because I kept my day normal. I did my radiotherapy as the last thing I did during the day, got home, went from my daily walk, made dinner, had dinner, had my rest, and then go to sleep. I found that doing that all throughout treatment helped me because I wasn't being fatigued at the time of the day when I shouldn't be, sort of being fatigued when I should be. Participant_034

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

Sleep is really important, rests, not overbooking myself, only doing things that I want to, not feeling pressured into, overcommit to things, to just being strategic in not doing too much every day, but making sure I do something nice every day yet and counselling if I need to. Participant_010

Yes. I know the last week I've been having a nap for two hours a day during the middle of the day. I'm looking at going back to work shortly. I used to work full time, but I'm going to go back 10 to 15 hours a week to start with, just to try and build up using my brain again and also going back into an office environment. The other thing I've been doing is going to group counseling with other women with breast cancer. That's helped as well, talking to other people. Participant_017

I find I still get fatigued. That has a bit of a bearing in that. I say I either have to exercise or clean on the weekend. I can't do both. I just have to listen to my body. I really pay attention that my feet can feel it coming in. It's not worth. I quit my old job because it was too stressful. I was like that's, I'm not healing me sick again. I'm not going to get sick, and I'm not working [unintelligible] going to be the cause of it. I sort of lucky to pick another job up in between and- well, afterwards. My employer was really, really good through treatments, as well. I can't fault that side of it. It was just my role as such, and it was just an eye-

opener to go, "Well, hang on a minute." I don't need to be doing this and making myself do again. That's part of it. Yes, it's more fatigue these days. Everything else I'm pretty-- Oh, obviously, I've had surgery again, so no heavy lifting and running in that for a little bit longer again. Other than that, I'm pretty stoked in to begin. Participant_021

Participant describes the importance of understanding their limitations

Sleep is really important, rests, not overbooking myself, only doing things that I want to, not feeling pressured into, overcommit to things, to just being strategic in not doing too much every day, but making sure I do something nice every day yet and counselling if I need to. Participant_010

Yes. I know the last week I've been having a nap for two hours a day during the middle of the day. I'm looking at going back to work shortly. I used to work full time, but I'm going to go back 10 to 15 hours a week to start with, just to try and build up using my brain again and also going back into an office environment. The other thing I've been doing is going to group counseling with other women with breast cancer. That's helped as well, talking to other people. Participant_017

Lie down, set a bit more boundaries. Participant_019

I have to minimise my stress. I have to minimise outside stresses and demands on my time if I get overwhelmed. Yeah, it's the state of panic and also just even my energy levels, because they have not returned as much as I've tried, really upping my fitness and diet and everything. I just haven't got the energy. And I felt like I think, you know, all the chemo and all the menopause and everything, everything is just harder. And I just can't do as much as I'd like. I get tired too easily. And my brain, I'm still not as switched on as I was. I forget stuff. Participant_001

Participant describes maintaining a healthy diet

Well, there's nothing that I have to do medical-wise, but I eat a healthy diet, I exercise every day. I walk every day. I do yoga every day. I contact friends regularly. I don't know. That's basically what I do, but no one's ever said, do these things. They just come together. Participant_004

Once a month, I have to do a self-examination to just tick that box and to make sure that I'm not getting a recurrence. I do that. I try to walk maybe four times a week, just to, I guess, keep the lymphatics working. I eat in a certain way so I keep my weight down, but again, just with general health, and not letting weight be a factor for cancer coming back and things like that. How does it not affect me? That's basically it. I take fish oil and-- Yes, pretty much fish oil for inflammation and things like that. Again, I think that inflammation is a factor for stagnation and cancers returning, so those are the things just to keep-- My body has been as best as I can in lieu of doing proper exercise. Participant_005

The most regular thing is healthy eating. That's one thing. I do have to eat, and staying hydrated because I do get headaches more frequently since radiation and things. Staying hydrated, exercising regularly. Those two and healthy eating, exercise, and healthy lifestyle. I think that's the main thing. Participant_016

Participant describes the importance of complying with treatment

Exercise, I have to exercise every day. I have to move. I have to take my medication. Participant_020

Well, I need to I need to wear a lymphedema compression gloves every day. Well, most days to manage some mild lymphedema exercises, to manage the stiffness in my shoulders, which is being chronic now, and try to get strength and mobility back to me. Think again. I just try to building some exercise at least half an hour's some exercise every day. If I can almost stay still working on the sleep. I'm terribly light sleeper. So but I'm trying to keep working on that because I finally learnt how important that is supposed to be. Yeah, I think I think that that's OK. Participant_023

I need to take multiple tablets [chuckles] for dealing with the pain and things like that and other associated issues. I go to a physio and hydrotherapy to try and just get some movement back and things like that, exercises. I see a support group of ladies which just gives me the reassurance of having someone else there to talk to and feed off if you need help or anything like that. Participant_036

Participant describes the importance of keeping up with daily activities

For me to function and to do most of the things I need to do, I need my life to be as close to what it was as possible. That's really important to me. I want to be able to go out and do things, and that's really important. I don't want to cancel things or not be able to do stuff because that affects my ability. I don't want to fall in that pattern of I've got cancer, I'm having chemo, I can't do this, this and this. For me, it's a mental battle, I think, to make sure that I don't allow myself to fall into that pattern of getting out of things or using it to not do things. I find that helpful for me. Obviously, I probably rest more than I did. I didn't use to stop very much. Now I probably do rest more and I allow myself to do that. That's a change, I guess, just going, "Actually, I need a break. I need to just put my feet up for an hour or do something, have a rest." That's different from how I used to be. Where you just power through all day long because that's what the days are for. Really, I don't think there's-- I think I answered your question. Participant_033

I just keep active. I need to keep my mind active. I need to keep my body active. I found throughout treatment if I kept my life as normal as possible and try to keep my routine, I got through things better. Even with my radiotherapy, I know people said they had terrible fatigue. I didn't notice that fatigue because I kept my day normal. I did my radiotherapy as the last thing I did during the day, got home, went from my daily walk, made dinner, had dinner, had my rest, and then go to sleep. I found that doing that all throughout treatment helped me because I wasn't being fatigued at the time of the day when I shouldn't be, sort of being fatigued when I should be. Participant_034

I walk every day. Even during the peak of chemo where I was like out of breath, I still made myself walk. I've got this thing about getting fresh air every single day, but my thing was, is just getting up and getting dressed and having a routine that I have to do it every day. I can't go, "I'm feeling crappy and I'm just going to stay in bed." I pushed myself to not do that because you're not going to achieve anything. I just kept pushing myself every day to get out of bed and get up, get a routine. Dropping my son off was really important to me, at school. Participant_045

Participant describes socialising with friends and/or family

Well, there's nothing that I have to do medical-wise, but I eat a healthy diet, I exercise every day. I walk every day. I do yoga every day. I contact friends regularly. I don't know. That's basically what I do, but no one's ever said, do these things. They just come together. Participant_004

I guess for me right now, what I need to do is just-- Then this is the process I'm trying to get happening at the moment, trying to get back into doing some regular exercise, changing how I eat, getting back into healthier habits. Part of it is also just keeping connections with friends. A lot of it for me at the moment is just getting my body healthy again, just rebuilding my immunity and things like that. Participant_011

I need to take multiple tablets [chuckles] for dealing with the pain and things like that and other associated issues. I go to a physio and hydrotherapy to try and just get some movement back and things like that, exercises. I see a support group of ladies which just gives me the reassurance of having someone else there to talk to and feed off if you need help or anything like that. Participant_036

Participant describes no activities to maintain health

There's nothing that I need to do on a regular basis to control the side effects of my condition. I was fortunate that I didn't have any-- I haven't had any neuropathy for many of the chemos because I did-- I have pus and on my hands and fingers. I have a little bit on two of my toes, but you don't even notice it. I don't think there's anything that I do differently to manage. There's no real side effects that I have. Participant_025

Just not overthink it. Participant_009

Table 8.8: Regular activities to maintain health

Regular activities to maintain health	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes being physically active	26	52.00	12	52.17	14	51.85	9	47.37	13	52.00	12	46.15	14	58.33	12	50.00	14	53.85
Participant describes the importance of self care e.g. more rest, support for housework etc.	19	38.00	11	47.83	8	29.63	9	47.37	9	36.00	11	42.31	8	33.33	5	20.83	14	53.85
Participant describes the importance of understanding their limitations	13	26.00	8	34.78	5	18.52	5	26.32	6	24.00	8	30.77	5	20.83	5	20.83	8	30.77
Participant describes maintaining a healthy diet	12	24.00	6	26.09	6	22.22	2	10.53	9	36.00	6	23.08	6	25.00	5	20.83	7	26.92
Participant describes the importance of complying with treatment	11	22.00	5	21.74	6	22.22	5	26.32	5	20.00	4	15.38	7	29.17	6	25.00	5	19.23
Participant describes the importance of keeping up with daily activities	7	14.00	3	13.04	4	14.81	5	26.32	1	4.00	2	7.69	5	20.83	3	12.50	4	15.38
Participant describes socialising with friends and/or family	5	10.00	2	8.70	3	11.11	2	10.53	3	12.00	1	3.85	4	16.67	3	12.50	2	7.69
Participant describes no activities to maintain health	5	10.00	2	8.70	3	11.11	2	10.53	2	8.00	3	11.54	2	8.33	3	12.50	2	7.69

Regular activities to maintain health	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes being physically active	26	52.00	8	50.00	18	52.94	9	45.00	17	56.67	7	36.84	13	59.09	6	66.67
Participant describes the importance of self care e.g. more rest, support for housework etc.	19	38.00	7	43.75	12	35.29	8	40.00	11	36.67	9	47.37	7	31.82	3	33.33
Participant describes the importance of understanding their limitations	13	26.00	4	25.00	9	26.47	4	20.00	9	30.00	8	42.11	1	4.55	4	44.44
Participant describes maintaining a healthy diet	12	24.00	3	18.75	9	26.47	2	10.00	10	33.33	2	10.53	4	18.18	6	66.67
Participant describes the importance of complying with treatment	11	22.00	2	12.50	9	26.47	3	15.00	8	26.67	2	10.53	6	27.27	3	33.33
Participant describes the importance of keeping up with daily activities	7	14.00	3	18.75	4	11.76	5	25.00	2	6.67	1	5.26	5	22.73	1	11.11
Participant describes socialising with friends and/or family	5	10.00	1	6.25	4	11.76	1	5.00	4	13.33	1	5.26	3	13.64	1	11.11
Participant describes no activities to maintain health	5	10.00	1	6.25	4	11.76	2	10.00	3	10.00	2	10.53	3	13.64	0	0.00

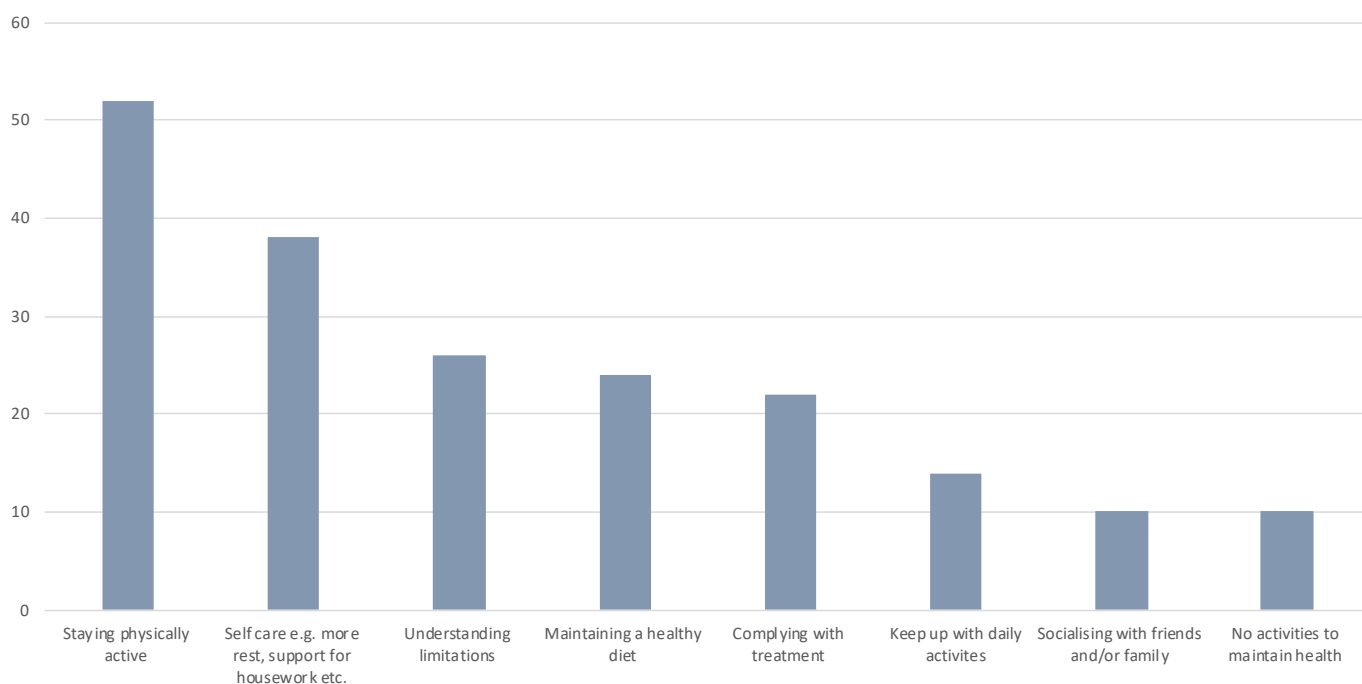


Figure 8.5: Regular activities to maintain health

Table 8.9: Regular activities to maintain health – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes being physically active	Aged 25 to 44	Aged 55 to 74
Participant describes the importance of self care e.g. more rest, support for housework etc.	Trade or high school	University
Participant describes the importance of understanding their limitations	Aged 45 to 54	Aged 25 to 44 Aged 55 to 74
Participant describes maintaining a healthy diet	Poor physical function Mid to low status Aged 25 to 44	Good physical function Aged 55 to 74
Participant describes the importance of complying with treatment	Aged 25 to 44	Aged 55 to 74
Participant describes the importance of keeping up with daily activities	-	Poor physical function Mid to low status

Experience of vulnerability

In the structured interview, participants were asked if there had been times that they felt vulnerable. There were 43 participants (86.00%) who gave a description suggesting that overall they had experiences of feeling vulnerable, and four participants (8.00%) 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 theme was feeling vulnerable during or after treatments (n=20, 40.00%), followed by feeling vulnerable when having negative thoughts (n=15, 30.00%). There were 14 participants (28.00%) who described feeling vulnerable when having sensitive discussions for example at diagnosis and treatment decisions, and nine participants (18.00%) described feeling vulnerable when feeling sick.

Participant gives a description suggesting that overall, they had experiences of feeling vulnerable

The whole way through. Participant_009

In some ways, having chemo or having cancer during COVID made me feel very vulnerable because obviously, I had no immune system. At the same time, the whole world, everybody around me was more hygiene conscious. Most people were in some kind of working from home. I didn't feel like I was missing out on quite so much because everybody else was also either in lockdown or events were canceled, things weren't happening that would have been. I felt vulnerable in the sense that I live with my son and he was still out in the world working. When there was risks around close to our area, I would get a bit nervous of him coming in bringing anything in. I guess

in some ways, everybody around was more conscious of it and being more careful of it so that helped as well. That's probably the most vulnerable was just not having an immune system and having a pandemic around me. Participant_011

Yes, yes. The main the main times have been when I've been in hospital and I've been on my own after surgery in pain. And some of the some of the things that have happened in hospital have been great. But being put into a shared ward with people having sort of minor operations and then having grandchildren coming to visit. And I'm completely wrecked after having my reconstruction, my hysterectomy and everything and being really unwell and yeah. Trying to say these people are really noisy. Can I have a different room and not having anyone to advocate for me that that was tough and have the attitude to stop sort of joking when they're doing my carpetbag back thing making. So those embarrassing comments made me feel bad. Yeah. Just being just feeling really, really vulnerable in hospital. Participant_001

Participant describes feeling vulnerable during/after treatment

Yeah, I guess really the point of diagnosis, I'm going to say right through treatment, but then again, probably maybe the two in points where around diagnosis and treatment and then into treatment because the triple negative they did or anything to go on it. So it's like, well, the parachute, we don't home, but it's time for you to jump off the cliff. So it's a diagnosis made of training. And in that situation that you've mentioned, where you felt vulnerable. Participant_002

I guess during the AC because I felt so weak and frail. Participant_007

There were a couple of times during of the chemotherapy that I guess I wondered how it was all about you just going to take this one day at a time. But that concept of one day at a time for a really long time on those really bad days, especially when I was coming down off the IV steroids, you just start to wonder if you are able to cope or handle all that there is during after surgery. Some of those those times when you look in the mirror and you've had both your breasts removed and you've got no hair, they were emotionally tough times that were hard to process. Those thoughts of anyone ever want to see me naked again or will find me sexy or love me or those kinds of

things, the emotional moments rather than the physical ones with sometimes really hard the days where I was when I'd finished oral chemo. But still that first month there was a lot of just sleeping in bed. And I just was watching everyone in my life get on with their life and getting married and having kids. And there I was thirty and I'm too tired to get out of bed. So I think they were certainly tough times. Participant_010

Um. I'm just trying to think I mean, obviously, I was scared and nervous at different times going into the big surgery for the first time and never having had surgery like that ever before going under and all of that, probably, probably the most vulnerable I felt so far would have actually been at the beginning of last year, to be honest, when I had to go and get my two year check-up. I actually could very well with the waiting and the uncertainty. And I was seeing a counsellor again at the time try and get through that. I was very anxious and worried. So to be to be honest, to feeling that vulnerable, like feeling like a baby falling apart, that would have been, in my mind, the most out of control. I sort of felt, I think being introspective treatment, it's sort of for me a couple of people who said they feel similarly for me. And I was like, I'm missing, you know, I mean, checking in and then throwing everything at it. We've got a plan. And because my condition. So there's no medication I can take afterwards. And so some people might feel a little bit of the peace of mind that popping a delivery, however often you do that might be the ongoing treatment for me. There's nothing other than my own attempt to try to live a good life and as well a life as I can help in that exercise and whatnot. So I think that's why I really struggled this year, wasn't as bad, had some good techniques. I was taught to manage it. Yes, that probably would have been my most vulnerable I saw. Participant_023

Participant describes feeling vulnerable when having negative thoughts (uncertainty, loneliness, worries)

Yes. Pretty much from the start at times. Probably right at the start when I didn't know what the hell was going on and I was trying to get my head around everything. Probably in the day to stock is middle of the chemo when I was trying everything in one Participant_012

Yes, it would be right at the start, right at the first diagnosis. I was very overwhelmed by everything. Obviously, all the COVID rules and everything in the hospital when I was getting on my test done, just for

an example, I was walking into the hospital and they wouldn't let my husband in with me. I was getting the test done to see if it has advanced anywhere in my body, and I had a bit of a breakdown in the hospital because they are stopping people coming to support people, which is not great. The early diagnosis, you have no idea what's going on, everything is happening. You've got all these appointments. It was a very, very much a crazy time in my life. Participant_018

I suppose a little bit, because you feels like it's all happening to you and you don't really have any control. I suppose there's a bit of vulnerability there and that you'll just need to put your life in the hands of these people who are telling you what to do, but you've only just met them, or guiding you as what to do. There is some vulnerability there. Also with the lack of knowledge and lack of understanding, that makes you quite vulnerable because I didn't have enough information to make decisions. I was floundering about, I guess, just trying to guess at what I should do next. That vulnerability, but I think as soon as I have knowledge and you can make some informed choices and informed decisions, that goes away. I feel in a much better place now to not challenge particularly, but at least to ask questions and to ask questions of my oncologist and the surgeon and say, "Is this the right thing? Do I need to do this? How about that?" and happy to have those conversations. Whereas to start with it felt very much, you just sit there and they tell you what it is that you need to do, and that does make me feel quite vulnerable. Participant_033

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

Yeah, I think after I had the biopsy and I didn't know what it was, I found those days between the Friday and that Tuesday when I got my diagnosis. That was pretty scary. And even after the diagnosis, I think all of that time up until I had the surgery and they removed the tissue and told me that there was no cancer cells. And, you know, I think that you're vulnerable right up until then. It's a very scary time. Yes. Yes. Participant_038

Vulnerable? Yes. It was the same breast surgeon that was telling me that I needed to go off to do it all privately. When I went to get my results from her after the surgery, we went into the room and she looked at my wound, checked it, and-- The tape had come off too early and she was saying, "Oh, they shouldn't

have done that, you shouldn't have--" "That tape needed to stay on there, it needs to be healing, it needed to be safe" The last time she was-- there was no sort of bedside manner happening. She was giving my results, telling me that I'm triple negative, telling me all this sort of stuff, telling me that I'll be having chemo, but barely even sat down behind her desk to be informing me of all this. It was all just rush, rush, rush, rush, "This is what you're doing, this is where you need to go, this is who you need to see." My mum was with me and we both just came away from it going, "Wow, that was really yuk," and didn't really even know what was going on afterward. That was in that same conversation that she was saying, "You can go to the hospital, but you'll be waiting for weeks so you should go and see him privately, blah, blah, blah." I felt very unsettled from that. Participant_005

Yes, it would be right at the start, right at the first diagnosis. I was very overwhelmed by everything. Obviously, all the COVID rules and everything in the hospital when I was getting on my test done, just for an example, I was walking into the hospital and they wouldn't let my husband in with me. I was getting the test done to see if it has advanced anywhere in my body, and I had a bit of a breakdown in the hospital because they are stopping people coming to support people, which is not great. The early diagnosis, you have no idea what's going on, everything is happening. You've got all these appointments. It was a very, very much a crazy time in my life. Participant_018

Constantly. Definitely sitting there, and making decisions, and then being in a hospital room by yourself every week knowing that you've got to go back for more treatment. That whole time-- I men I never was a, "Why me?" Like you really do have to just get on with it, but there are definitely times when you're like, "Oh, I've still got this long to go," or, "What does this week hold," sort of thing. Actually, the worst was probably- obviously, I'm being diagnosed. I actually I was about to come home from hospital after my mastectomy and the geneticists had rung me to say he hadn't had my results yet. I said, "Okay, it was a Friday." I've had a really good day, I'd actually had a hospital pass and went out for lunch and came back in. At literally at five o'clock on the dot, he actually rang again to say, "No, I don't usually do this over the phone, but I thought you'd like to know." I went from these massive high and got told that I was BRCA positive. I look at it now and it means nothing because I've already been diagnosed, but it was such

a good day where I felt good and then it was another result, sort of thing. Participant_021

Participant describes feeling vulnerable when feeling sick/unwell

Yes. When I had the really high fevers and nobody understood what it was, because it's frustrating, even for the doctors. My oncology nurse implied it could be psychological. That was a really frustrating time for me because I was physically unwell. I was having shivers and uncontrolled fevers and I was being told it's all in my head. That time I felt really disappointed and depressed which didn't help me at all. Participant_016

Yes, when I was going through chemo. I was not in a good space because I was so sick. As I said, I had to go

and see the psychologist. Yes, I was in a particularly vulnerable space going through chemo. Participant_029

Yes, I must admit there was one time. It was the last week of radiation or the second last-- I was in the second last week of radiation treatment, and the nurse was really rude to me. It was the first time in the whole process, someone had ever just not been sensitive. She started to tell me off about taking Panadol and not managing my pain appropriately and I don't know this. It was the only time, and I had 10 months of going in and out of hospitals and that sort of stuff, it was this one single time I can say I didn't like it. Yes, this was the only time I can think of. Participant_047

Table 8.10: Experience of vulnerability

Experience of vulnerability	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant gives a description suggesting that overall, they had experiences of feeling vulnerable	43	86.00	20	86.96	23	85.19	15	78.95	23	92.00	21	80.77	22	91.67	19	79.17	24	92.31
Participant gives a description suggesting that overall, they did not have feelings of being vulnerable	4	8.00	2	8.70	2	7.41	3	15.79	1	4.00	2	7.69	2	8.33	2	8.33	2	7.69
Other	2	4.00	0	0.00	2	7.41	1	5.26	1	4.00	0	0.00	2	8.33	2	8.33	0	0.00

Experience of vulnerability	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant gives a description suggesting that overall, they had experiences of feeling vulnerable	43	86.00	12	75.00	31	91.18	14	70.00	29	96.67	15	78.95	19	86.36	9	100.00
Participant gives a description suggesting that overall, they did not have feelings of being vulnerable	4	8.00	3	18.75	1	2.94	3	15.00	1	3.33	2	10.53	2	9.09	0	0.00
Other	2	4.00	0	0.00	2	5.88	2	10.00	0	0.00	2	10.53	0	0.00	0	0.00

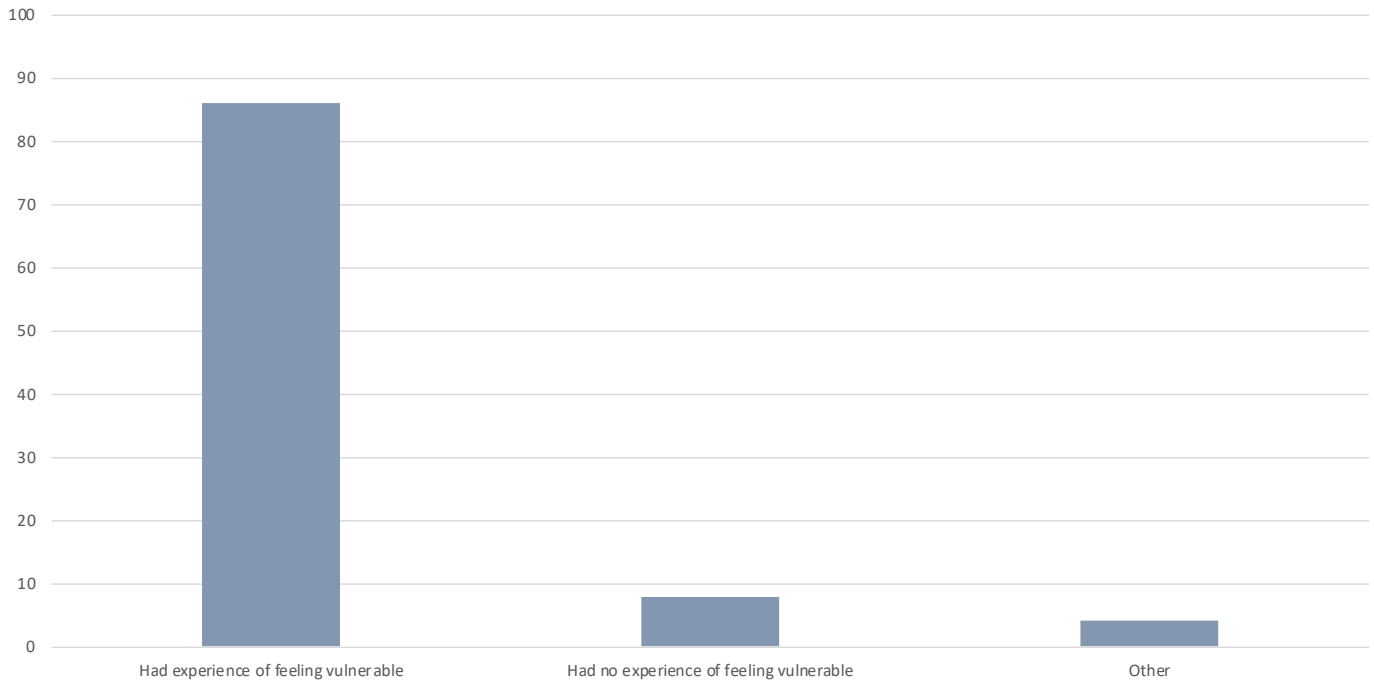


Figure 8.6: Experience of vulnerability

Table 8.11: Experience of vulnerability – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant gives a description suggesting that overall, they had experiences of feeling vulnerable	Regional or remote Mid to low status	Higher status Aged 55 to 74
Participant gives a description suggesting that overall, they did not have feelings of being vulnerable	-	Regional or remote

Table 8.12: Experience of vulnerability (details)

Methods to manage vulnerability	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes feeling vulnerable during/after treatment	20	40.00	7	30.43	13	48.15	3	15.79	14	56.00	11	42.31	9	37.50	8	33.33	12	46.15
Participant describes feeling vulnerable when having negative thoughts (uncertainty, loneliness, worries)	15	30.00	9	39.13	6	22.22	3	15.79	11	44.00	10	38.46	5	20.83	8	33.33	7	26.92
Participant describes feeling vulnerable when having sensitive discussion (treatment, diagnosis)	14	28.00	10	43.48	4	14.81	7	36.84	5	20.00	6	23.08	8	33.33	5	20.83	9	34.62
Participant describes feeling vulnerable when feeling sick/unwell	9	18.00	3	13.04	6	22.22	2	10.53	5	20.00	4	15.38	5	20.83	4	16.67	5	19.23

Methods to manage vulnerability	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes feeling vulnerable during/after treatment	20	40.00	5	31.25	15	44.12	5	25.00	15	50.00	8	42.11	8	36.36	4	44.44
Participant describes feeling vulnerable when having negative thoughts (uncertainty, loneliness, worries)	15	30.00	3	18.75	12	35.29	5	25.00	10	33.33	4	21.05	7	31.82	4	44.44
Participant describes feeling vulnerable when having sensitive discussion (treatment, diagnosis)	14	28.00	5	31.25	9	26.47	6	30.00	8	26.67	6	31.58	6	27.27	2	22.22
Participant describes feeling vulnerable when feeling sick/unwell	9	18.00	1	6.25	8	23.53	1	5.00	8	26.67	2	10.53	5	22.73	2	22.22

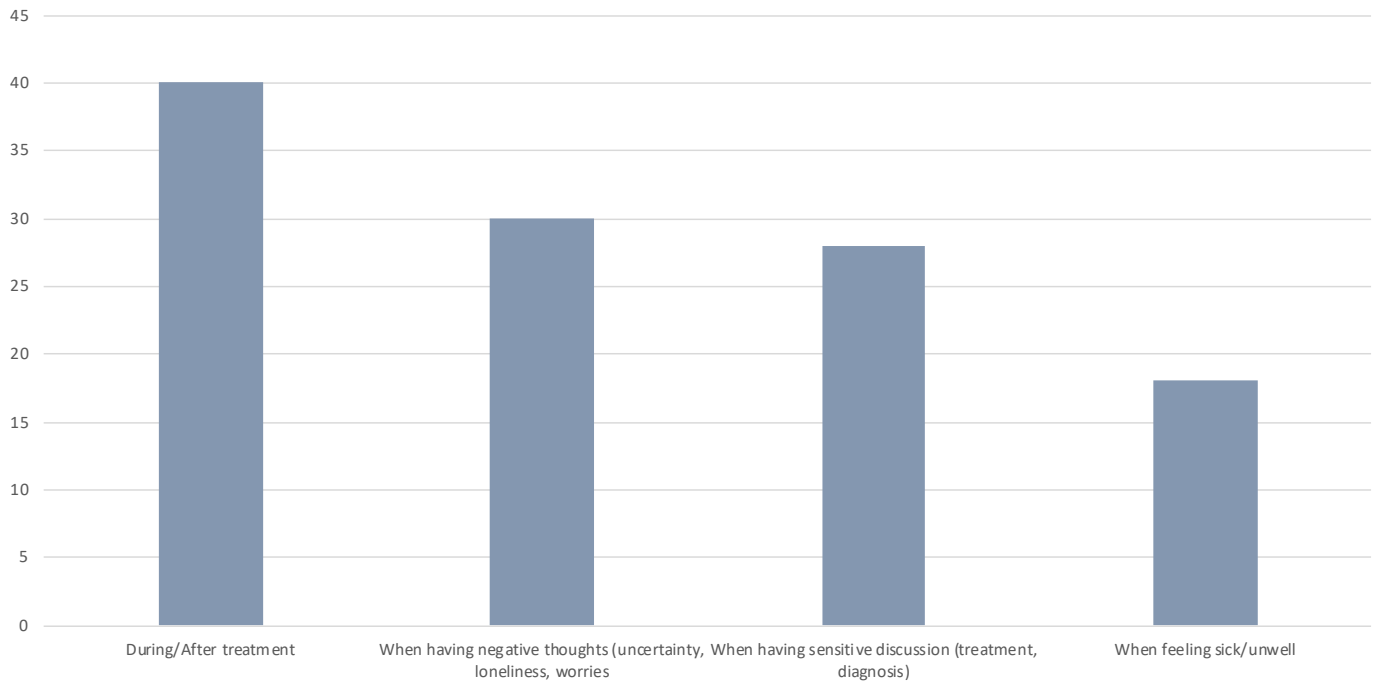


Figure 8.7: Experience of vulnerability (details)

Table 8.13: Experience of vulnerability (details) – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes feeling vulnerable during/after treatments	Stage IV	Stage I
Participant describes feeling vulnerable when having sensitive discussion (diagnosis, treatment decision)	Aged 55 to 74	Aged 25 to 44
Participant describes feeling vulnerable when feeling sick/unwell	Good emotional function Aged 25 to 44	Aged 45 to 54

Methods to manage vulnerability

In the structured interview, participants described ways that they managed feelings of vulnerability. Participants described support from their medical team to manage the feeling of vulnerability (n=9, 18.00%), and using self-help methods such as resilience, acceptance, and staying positive to manage the feeling of vulnerability (n=7, 14.00%). Other methods included adapting, for example being proactive. Assertive and understanding boundaries (n=6, 12.00%), and getting support from family and friends (n=5, 10.00%).

Participant describes support from medical team to manage the feeling of vulnerability

Oh, yes. A bit of both, really. It did feel totally out of my control. I did seek help via the oncology unit and that's when I got access to all the other information. I got access to information. I got support via the physio. I could understand what was happening a little bit more through the breast care nurse and the oncologist explained to me what was going on. Participant_012

Actually, the health care professionals, I think fix that because they were really amazing, and they also always brought me a warm blanket, which helps. Participant_019

I was because the nurses could see how nervous I was and they did take the time to explain the whole process to me, and then to explain how I might feel the next day and what I could do to alleviate that. The nurses in the day Ward area we're fabulous. Participant_027

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

... looking at that diagnosis information, more information was it makes you feel like you had some control and probably at the end of treatment it was and, you know, logical techniques, I guess, cognitive behavioural sort of strategies to keep things in perspective and face the facts. Participant_002

I think I got maybe more used to them. And when I was in those situations, I just allowed myself the space to feel those feelings because they were valid to try and not get overwhelmed by them, but to acknowledge them and to give my body what they needed. So those days when I was tired, rather than

getting upset about just allowing myself to sleep or ordering takeaway if I couldn't be bothered to cook some days was certainly a lot easier than others. But I think I learnt self care strategies to just give my body what it needed in those moments and also being able to be real with my support network or to people that to my other cancer friends and to be able to talk to them about it and how they would understand, you know, just being able to talk about it helped a lot. Participant_010

I think everything was out of my hands, but I just had to do what I had to do, and keeping a positive attitude as much as I could helped me through it. It was like, okay, this has happened. We're going to deal with it and get on with life. You just had to push it away and do that. Participant_046

Participant describes adapting (e.g, more proactive, assertive, put boundaries) to manage the feeling of vulnerability)

No, I stood there and said, "Well, I'm not going on." I said, "I'm not going in without my husband." What happened was I went got a manager and the manager let him in. They were fine. They were like, "Yes, of course, you can come in," so it was just the person at the door. Now looking back and I think I stand my ground a lot more than what I would have beforehand because I know what they're doing it for but I don't always think it's right. Participant_018

Oh, no, I stood up. I said something. The surgeon who was coming in to put it in, walked in with gloves on, rubber gloves, and I said to him, "Oh, can you change your gloves?" because what have you been doing? It was full COVID situation at that stage as well. Everyone that came into the room came in with no gloves and then put gloves on, but he walked in, opened the door with his hand, and then he was supposed to be cutting open my breasts and putting something in. He's like, "Well, I haven't touched anything." and I said, "I don't know that." I made him change his gloves. That's why I reckon I got such a badly bruised breast because he was very aggressive when he put it in. I did put in a report about him because I wasn't happy. That was the only time. I've had the best, best experiences. I can't fault any practitioner or staff member or receptionist, everyone has been amazing. Participant_045

Aside from trying to schedule the appointments as close as I to each other? There's always a couple of days in between and just, I guess making sure that I tell my family that I'm anxious and I'm stressed and basically leave me alone until I get the results. I don't know. I haven't mentioned, I should have mentioned earlier when you were talking about complimentary things. I've been doing a lot of yoga, and I find that incredibly helpful. At those times when I'm feeling really anxious, the yoga is particularly good. It helps settle, helps me settle, and refocus. Participant_050

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

I think I got maybe more used to them. And when I was in those situations, I just allowed myself the space to feel those feelings because they were valid to try and not get overwhelmed by them, but to acknowledge them and to give my body what they needed. So those days when I was tired, rather than getting upset about just allowing myself to sleep or ordering takeaway if I couldn't be bothered to cook some days was certainly a lot easier than others. But I think I learnt self care strategies to just give my body what it needed in those moments and also being able

to be real with my support network or to people that to my other cancer friends and to be able to talk to them about it and how they would understand, you know, just being able to talk about it helped a lot. Participant_010

I don't know if there is specifically anything that could be done, because I think it's all just a fear of the unknown. I guess the only thing you can do is have a good support system around you. Not just the medical support system, but like family, friends, work colleagues. Having people who can go to appointments with you, or who can make your meal when you don't feel like cooking. I don't think there's anything you can do that really prepares you for it. Participant_020

I did try to address certain things. Basically, with those finances because I didn't work for 18 months, so I was lucky that I could work from home with my job. Obviously, it wasn't every day so you only get paid for the hours that you do. I did have friends and neighbors at the time, not so much family. I really only had my resources that were in my current area, I guess. Participant_024

Table 8.14: Methods to manage vulnerability

Experience of vulnerability (details)	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes support from medical team to manage the feeling of vulnerability	9	18.00	4	17.39	5	18.52	3	15.79	3	12.00	4	15.38	5	20.83	5	20.83	4	15.38
Participant describes self help (resilience, acceptance, staying positive) to manage the feeling of vulnerability	7	14.00	3	13.04	4	14.81	2	10.53	5	20.00	4	15.38	3	12.50	1	4.17	6	23.08
Participant describes adapting (e.g. more proactive, assertive, put boundaries) to manage the feeling of vulnerability	6	12.00	3	13.04	3	11.11	2	10.53	4	16.00	3	11.54	3	12.50	3	12.50	3	11.54
Participant describes support from family and friends to manage the feeling of vulnerability	5	10.00	3	13.04	2	7.41	2	10.53	3	12.00	4	15.38	1	4.17	2	8.33	3	11.54
Experience of vulnerability (details)	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74			
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%		
Participant describes support from medical team to manage the feeling of vulnerability	9	18.00	1	6.25	8	23.53	2	10.00	7	23.33	4	21.05	4	18.18	1	11.11		
Participant describes self help (resilience, acceptance, staying positive) to manage the feeling of vulnerability	7	14.00	3	18.75	4	11.76	2	10.00	5	16.67	4	21.05	2	9.09	1	11.11		
Participant describes adapting (e.g. more proactive, assertive, put boundaries) to manage the feeling of vulnerability	6	12.00	3	18.75	3	8.82	2	10.00	4	13.33	2	10.53	3	13.64	1	11.11		
Participant describes support from family and friends to manage the feeling of vulnerability	5	10.00	3	18.75	2	5.88	3	15.00	2	6.67	2	10.53	2	9.09	1	11.11		

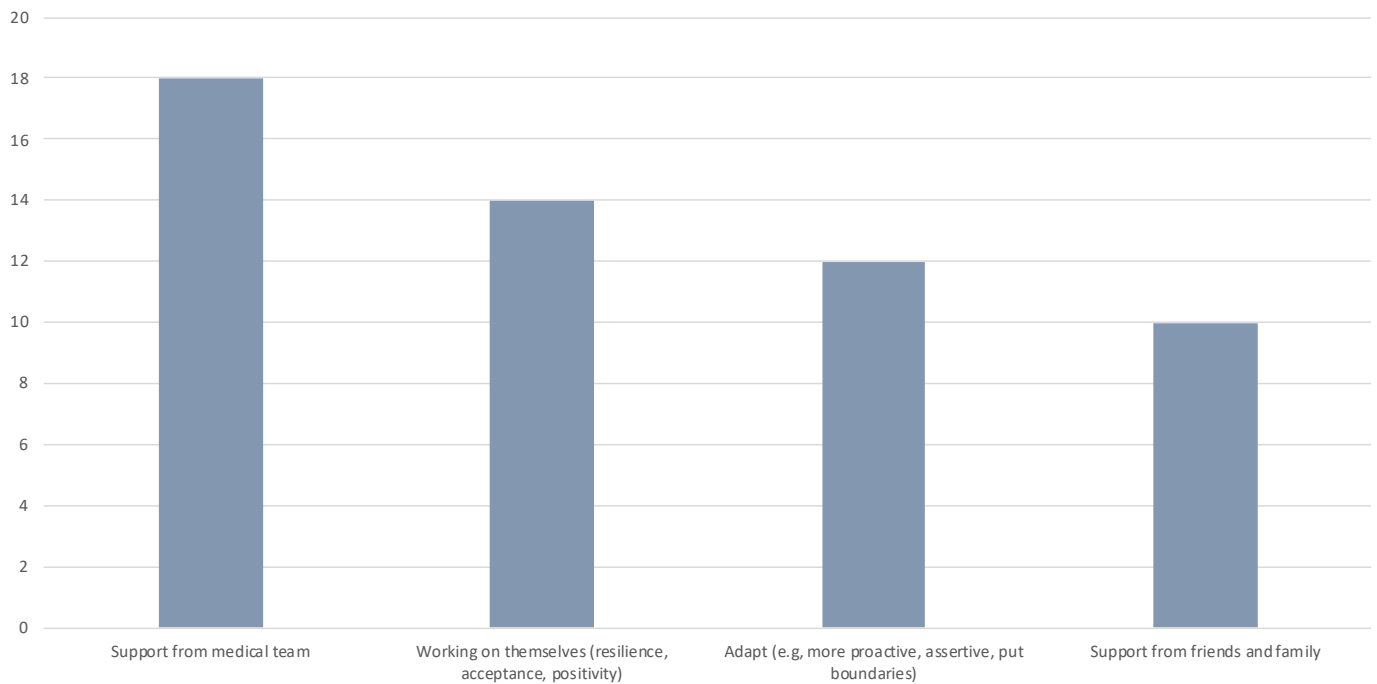


Figure 8.8: Methods to manage vulnerability

Table 8.15: Methods to manage vulnerability– subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes support from medical team to manage the feeling of vulnerability	Regional or remote	-

Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Overall, there were 19 participants (38.00%) who described a mix of positive and negative impacts on relationships. Other participants reported a negative impact on relationships (n=11, 22.00%), no impact on relationships (n=8, 16.00%), and a positive impact on relationships (n=7, 14.00%).

The most common theme in relation to having an impact on relationships was a mixed impact on relationships, some strengthened, others disappeared (n=14, 28.00%). There were eight participants (16.00%) who described relationships suffering, because of people not knowing what to say or do and withdrawing from relationships, and the same number who described no impact on relationships with no specific reason (n=8, 16.00%). Other reasons included relationships with family being strengthened (n=7, 14.00%), and relationships suffering, due to emotional strain (n=6, 12.00%).

Participant gives a description suggesting that overall, there was a mix of positive and negative impact

Some friends yes. We're no longer friends because they decided to make it all about them and share my story on social media, and talk about how it was affecting them. Yes, I've definitely moved on from some friendships, but my family, it's brought us closer. My mum, especially, weirdly, at first she was like, "Oh, you'll be alright; you'll get through this." and I think she realized how serious it was. She's just been really good and doing checks every day, whereas she never used to do any of that. My dad and I both got diagnosed cancer on the same day. Unfortunately, he was at the end of his journey. He passed in March this year. Participant_045

I think it's improved them, if anything, honestly, most of them. Some people just disappeared off the radar a bit, friends and some family actually. Some relationships, have improved, others have just not progressed at all. They're not there anymore. Participant_004

Yes. Nothing's going to be the same because I'm not the same. I actually think, my immediate family, my husband, and my daughter, I think we're closer than ever because we're more grateful for each other. Some friends are a bit-- Everyone's scared of you when you have cancer, and that's all right. I don't really want people in my space with it anyway, so I just want my husband and a handful of very, very close people. I'm a very private person and it's not something I want everyone to know about. Participant_007

Participant gives a description suggesting that overall, there was a negative impact on relationships

Yes, I think it has, some of them dropped off. Some of the friends dropped off. I don't understand. Family, my parents are more like treating me with kid gloves because they're like, "Are you okay? Are you okay? Are you okay?" It's annoying. There's some people they don't fully understand what I'm still going through because they just think if your hair grows back, you're fine again. Participant_008

Well, yeah, it's affected it with my husband for sure, because it's sort of like, you know, intimate stuff, because basically I don't want anyone to touch me anymore. Everyone can just go away. I do not want anyone coming near me because I've had so many people poking and prodding me. I would just back off everyone. So, yeah, I guess that does affect. With my husband, but yeah, even just generally with friends and family, I'm more I keep everyone up on stage. Participant_001

Yes, I guess in the aspect that I'm an adult, but I certainly had to lean on my parents a lot more, so I had to rely on them for that and for my kids. I guess the my friends around me and how they needed to support me, I required them to emotionally and mentally support me more than I normally would outside of cancer treatment. I guess there's that aspect of how much you tell someone like a new partner and being vulnerable with them about what I've been through and my scars. That certainly affects relationships. But also I think the people in my life who just want me to be happy and to move on with my life, I want to say positive, warm and fuzzy things to try and make me feel better. And I think sometimes they can be hurtful without meaning to because they're minimising what I'm going through or just not listening to me when I need them to listen. So I think and it affects the friendships that I have and what I say to who because of it. Participant_010

Participant gives a description suggesting that overall, there no impact on relationships

No, I wouldn't say so. No. Participant_015

No, not at all. Participant_035

Participant gives a description suggesting that overall, there was a positive impact on relationships

No, as I said, I think it's just strengthened the relationships that I have with family and friends. We're probably discussing things more openly and honestly, since having that diagnosis. I don't hold anything back, and I don't think my family does anymore. We've realize, that life is precious, and you just don't know how long you've got, and how well you're going to be. Yes, I think it's just strengthen those relationships. Same with my friends, we're all similar age group. We're, you know, we're getting on in in years. I think, my experience has just made me appreciate those relationships a lot more and vice versa. Participant_013

Yeah, I think I think that it has more. In a positive way, I feel like I've got everyone just surrounded me when I was diagnosed and you like that, I guess I've got stronger relationships with, you know, a few of my friends because of it. Participant_038

Yes. Not in a bad way though. There's people who've turned up and really been there for me that were unexpected. People that I didn't even necessarily know that well who turned up with meals for me every few days. I've got a colleague, for example, who had breast cancer years ago before I met her who has also just really been there for me. I think it's strengthened a few friendships in a lot of ways. Other than my children, the rest of my family don't live in LOCATION, and my mum, my sister are all in WA. I think it was harder on them because they weren't here, and it was in the middle of COVID, and they couldn't get here. Participant_011

Participant described a mixed impact on relationships, some strengthened, others disappeared

It's starting to sound a bit awful but you know who your real friends are, you know who your family members are. The people that weren't there at the time, I think we just don't talk to them anymore. Participant_024

So much, yes. I've become a lot close to my husband, which is great for family. Just emotional support and the physical and beautiful. [unintelligible] that part so much. I have become more close to my mother-in-law as well, because we have to rely on them with the kids. By the same token, some relationships have ceased to exist because some of my girlfriends can't have me being sick because I scare them. Participant_042

Yes. It's actually improved my personal relationship with my husband and my in-laws a lot. I've just grown to respect them a lot and appreciate them. It definitely solidified that. On the same token, with friends, I have identified people who were there for me and those who weren't. I've realized I'm a very emotional person, but it's made me learn to see people for what they are. Overall, it's been good, I would say. It hasn't affected anything negatively. Participant_016

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

Yes, I think it has, some of them dropped off. Some of the friends dropped off. I don't understand. Family, my parents are more like treating me with kid gloves because they're like, "Are you okay? Are you okay? Are you okay?" It's annoying. There's some people they don't fully understand what I'm still going through because they just think if your hair grows back, you're fine again. Participant_008

You find out who your real friends are. I had some friends I didn't hear from the whole entire time and then I had friends that I hadn't seen in years, really set out to try and help me out. It was an interesting experience, you find out who's really going to be there for you in a moment of crisis. Participant_027

With friends certainly, yes. I have lost a lot of friends when I was first diagnosed. Through no fault of my own, I've had people send me emails saying, "We can't handle being around you while you're sick, so you won't be seeing us while you're going through this." Another woman downstairs in our foyer, told me when I lost my hair that it offended her seeing me bald. That I wouldn't be seeing her. I felt like, yes, I have lost a few friends because of it ...

Participant describes no impact on relationships, without specifying reason

Not my parents, actually. Obviously not no one to help, you know. Yeah. It's not like my husband needed someone to come in and look after the kids because I couldn't manage it. It was never anything like that. Participant_003

No, I wouldn't say so. No. Participant_015

Participant describes relationships with family being strengthened

It has affected some friendships but on the whole, I think it has strengthened a lot of my relationships more than anything. Participant_022

Yeah, I think I think that it has more. In a positive way, I feel like I've got everyone just surrounded me when I was diagnosed and you like that, I guess I've got stronger relationships with, you know, a few of my friends because of it. Participant_038

I guess, yes, I've said earlier that it makes you focus on the things that are important. I think focusing on the relationships that are important and looking at whether when you have restrictions to your energy, the things that you do do have to be important and good things. There's no place to deal with toxic sorts of relationships. I had realized that, yes there were a couple that weren't serving me any good in the mix, so they're no longer in the mix. Participant_050

Participant describes relationships suffering, due to emotional strain

Yes, I think it has, some of them dropped off. Some of the friends dropped off. I don't understand. Family, my parents are more like treating me with kid gloves because they're like, "Are you okay? Are you okay? Are you okay?" It's annoying. There's some people they don't fully understand what I'm still going through because they just think if your hair grows back, you're fine again. Participant_008

Yes. What I've noticed is it's always the first thing that they want to talk about. I know that's in a kind and thoughtful way, but sometimes it has affected it because now I feel like I'm just a walking cancer patient. People, that's the first thing they say, "How're you going? How's treatment?" and that's lovely, but really I'd like to just be me. Yes, it's affected it because I'm not me first. It's just you've got no hair, you've got

no eyelashes, you've got no eyebrows. It's quite obvious. That's every time, if I bumped into someone at the supermarket it's "Oh my gosh, how are you? I heard, it's awful." and actually, I'm just me. Yes, it's affected relationships in that way because that's what people see first and you can't move past that. I think they can't move past that. Even family to some extent, you see that too. It's "How are you going? How are you?" Let's just have a laugh and a joke. I don't want to be a patient all the time. Yes, it has been effective. Participant_033

Yes, I guess in the aspect that I'm an adult, but I certainly had to lean on my parents a lot more, so I had to rely on them for that and for my kids. I guess the my friends around me and how they needed to

support me, I required them to emotionally and mentally support me more than I normally would outside of cancer treatment. I guess there's that aspect of how much you tell someone like a new partner and being vulnerable with them about what I've been through and my scars. That certainly affects relationships. But also I think the people in my life who just want me to be happy and to move on with my life, I want to say positive, warm and fuzzy things to try and make me feel better. And I think sometimes they can be hurtful without meaning to because they're minimising what I'm going through or just not listening to me when I need them to listen. So I think and it affects the friendships that I have and what I say to who because of it. Participant_010

Table 8.16: Impact on relationships

Impact on relationships	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant gives a description suggesting that overall, there was a mix of positive and negative impact	19	38.00	9	39.13	10	37.04	7	36.84	9	36.00	7	26.92	12	50.00	11	45.83	8	30.77
Participant gives a description suggesting that overall, there was a negative impact on relationships	11	22.00	4	17.39	7	25.93	5	26.32	6	24.00	7	26.92	4	16.67	3	12.50	8	30.77
Participant gives a description suggesting that overall, there no impact on relationships	8	16.00	4	17.39	4	14.81	3	15.79	4	16.00	6	23.08	2	8.33	6	25.00	2	7.69
Participant gives a description suggesting that overall, there was a positive impact on relationships	7	14.00	4	17.39	3	11.11	2	10.53	4	16.00	4	15.38	3	12.50	2	8.33	5	19.23
Participant gives a description suggesting that overall, there was neither a positive or negative impact on relationships	3	6.00	2	8.70	1	3.70	1	5.26	1	4.00	1	3.85	2	8.33	0	0.00	3	11.54
Other	2	4.00	0	0.00	2	7.41	1	5.26	1	4.00	0	0.00	2	8.33	2	8.33	0	0.00

Impact on relationships	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant gives a description suggesting that overall, there was a mix of positive and negative impact	19	38.00	9	56.25	10	29.41	7	35.00	12	40.00	6	31.58	10	45.45	3	33.33
Participant gives a description suggesting that overall, there was a negative impact on relationships	11	22.00	1	6.25	10	29.41	4	20.00	7	23.33	4	21.05	6	27.27	1	11.11
Participant gives a description suggesting that overall, there no impact on relationships	8	16.00	3	18.75	5	14.71	5	25.00	3	10.00	3	15.79	3	13.64	2	22.22
Participant gives a description suggesting that overall, there was a positive impact on relationships	7	14.00	3	18.75	4	11.76	3	15.00	4	13.33	2	10.53	3	13.64	2	22.22
Participant gives a description suggesting that overall, there was neither a positive or negative impact on relationships	3	6.00	0	0.00	3	8.82	0	0.00	3	10.00	3	15.79	0	0.00	0	0.00
Other	2	4.00	0	0.00	2	5.88	2	10.00	0	0.00	2	10.53	0	0.00	0	0.00

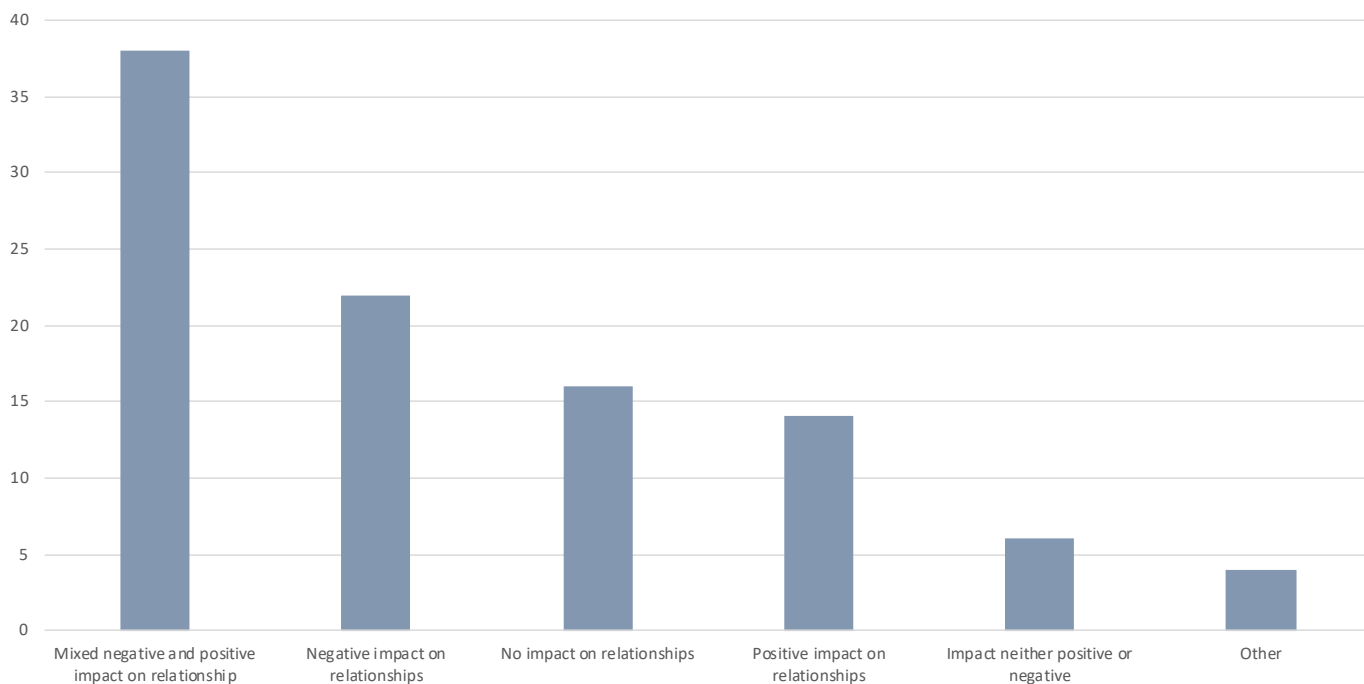


Figure 8.9: Impact on relationships

Table 8.17: Impact on relationships – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes a mixed impact on relationships, some strengthened, others disappeared	Diagnosed before 2020	Diagnosed in 2020 or 2021
Participant describes relationships suffering, that is people not knowing what to say or do and withdrawing from relationships	Early breast cancer Regional or remote	Poor physical function
Participant describes relationships with family being strengthened	-	Aged 55 to 74
Participant describes relationships suffering, due to emotional strain	Trade or high school Aged 55 to 74	University

Table 8.18: Impact on relationships (Reason for impact)

Impact on relationships (Reason for impact)	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes a mixed impact on relationships, some strengthened, others disappeared	14	28.00	8	34.78	6	22.22	6	31.58	6	24.00	4	15.38	10	41.67	9	37.50	5	19.23
Participant describes relationships suffering, that is people not knowing what to say or do and withdrawing from relationships	8	16.00	1	4.35	7	25.93	5	26.32	3	12.00	5	19.23	3	12.50	4	16.67	4	15.38
Participant describes no impact on relationships, without specifying reason	8	16.00	4	17.39	4	14.81	3	15.79	4	16.00	6	23.08	2	8.33	6	25.00	2	7.69
Participant describes relationships with family being strengthened	7	14.00	3	13.04	4	14.81	2	10.53	4	16.00	5	19.23	2	8.33	3	12.50	4	15.38
Participant describes relationships suffering, due to emotional strain	6	12.00	5	21.74	1	3.70	2	10.53	4	16.00	5	19.23	1	4.17	0	0.00	6	23.08

Impact on relationships (Reason for impact)	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant described a mixed impact on relationships, some strengthened, others disappeared	14	28.00	5	31.25	9	26.47	6	30.00	8	26.67	4	21.05	8	36.36	2	22.22
Participant describes relationships suffering, that is people not knowing what to say or do and withdrawing from relationships	8	16.00	0	0.00	8	23.53	2	10.00	6	20.00	3	15.79	3	13.64	2	22.22
Participant describes no impact on relationships, without specifying reason	8	16.00	3	18.75	5	14.71	5	25.00	3	10.00	3	15.79	3	13.64	2	22.22
Participant describes relationships with family being strengthened	7	14.00	2	12.50	5	14.71	3	15.00	4	13.33	1	5.26	3	13.64	3	33.33
Participant describes relationships suffering, due to emotional strain	6	12.00	2	12.50	4	11.76	2	10.00	4	13.33	2	10.53	4	18.18	0	0.00

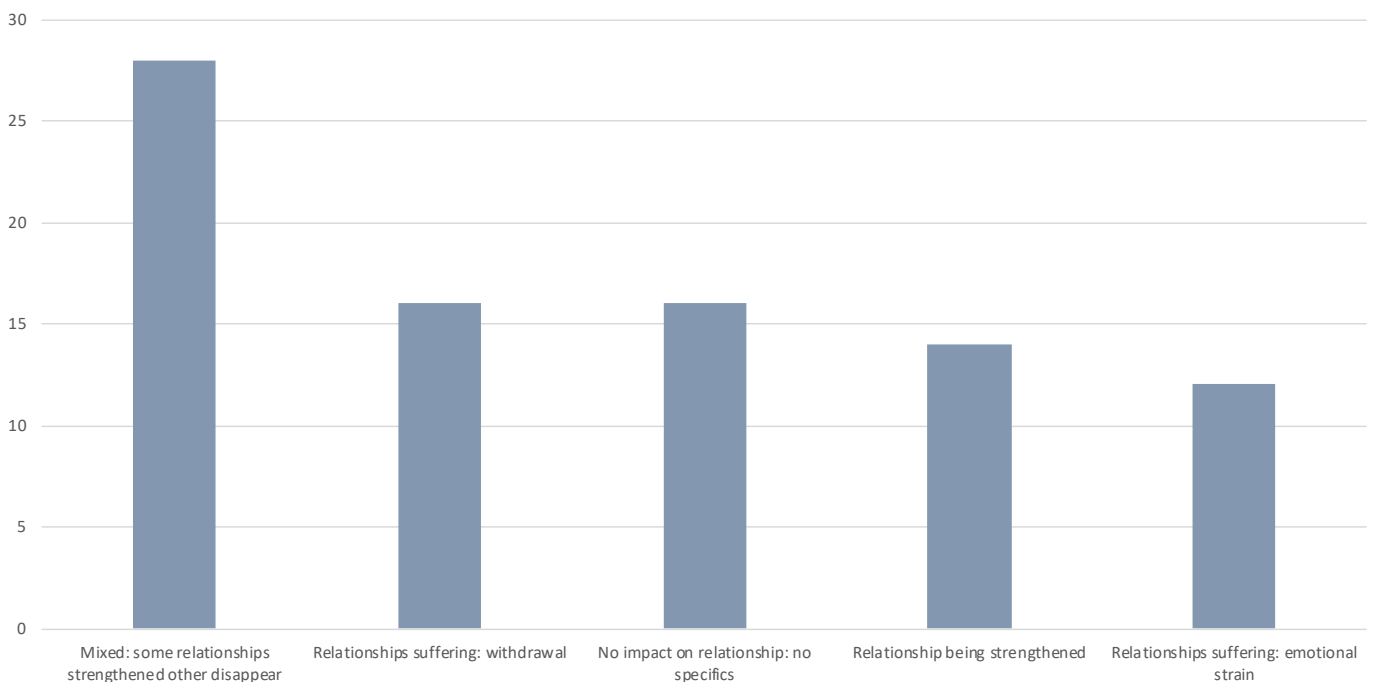


Figure 8.10: Impact on relationships

Table 8.19: Impact on relationships: Reason for impact – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant described a mixed impact on relationships, some strengthened, others disappeared	Diagnosed before 2020	Diagnosed in 2020 or 2021
Participant describes relationships suffering, that is people not knowing what to say or do and withdrawing from relationships	Early breast cancer Regional or remote	Poor physical function
Participant describes relationships with family being strengthened	-	Aged 55 to 74
Participant describes relationships suffering, due to emotional strain	Trade or high school Aged 55 to 74	University

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 30 participants (60.00%) who felt there was an additional burden, and 18 participants (36.00%) who reported no additional burden.

Participants who described that they were no additional burden, mostly did this without giving any examples or explanations (n=13, 26.00%), followed by not being a burden because they manage their condition independently (n=5, 10.00%). For people that felt they were a burden on their family, most commonly did not give any specific reasons for this (n=12, 24.00%). The main reasons for burden on families were the extra household duties and responsibilities that their family must take on (n=10, 20.00%), and the mental/emotional strain placed on their family (n=6, 12.00%).

Participant gives a description suggesting that overall, there was a burden on their family

Well, yeah, yeah. For my husband, yeah. He's had to pick up so much more because I don't have the energy and because for a long time things like just even putting the quilt cover on the bed, putting it, you know, stuff like that was hard and hanging, washing up because I couldn't do the reaching and all the arms stretching and stuff. So he's just more heavy stuff that he's been doing all that. And just because I just get tired or because I'm now more I'm just more anxious. And so definitely it's affected him so much because I'm not I'm not myself. Participant_001

It was during treatment, I don't think it is now. If they've got concerns, I feel reassured that they will discuss them with me. They have in the past, so I don't have any issues that they wouldn't discuss it with me during treatment, yes, I felt like, definitely it did place a burden on them because my girls they participated in a bit of a roster with my husband. They took turns in, you know, taking me to and from LOCATION for my

treatment. That meant they were giving up time from work with it and time from their families, but I was never made to feel like I was a burden. I think that was just in my own mind, I felt that's just an extra workload for them. Participant_013

Yes. I think that-- I don't know. You sort of feel like you're a burden or you get made to feel like you're a burden because there's so many treatments or appointments to get to and whatever else it's like, "Oh, there's your cancer getting in the way again?" It's like, "Yes, well, I didn't ask for it." Participant_034

At the time when I was going through treatment, yes, I felt really guilty about that, but now the only guilt I feel now is that I'm not working so I'm not bringing any income in. Participant_046

Participant gives a description suggesting that overall, there was not a burden on their family

Only because I-- it's difficult to get out. I'm very headstrong to a certain extent. I don't like to put people out. I don't go looking for people to come to chemo with me. Then I have the two treatments that I've had. I've had two friends come with me. They both offer it and then I'm like, "Are you sure you're okay to do this?" They're like, "No, yes, yes. It's fine." Which is good, but then I do feel that I'm a bit of a burden to a certain extent as well. Participant_014

No, I never felt like I was a burden on anybody, and I don't really need any ongoing care at the moment, so definitely, no. Participant_025

No, I don't think it's a burden. I think the burden is that they've got the gene. My mother also has the gene, but she's never had cancer. I have to keep reminding myself of that. Participant_037

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

Yes, absolutely. Participant_009

Oh God, yes. You don't really want to admit this but probably. Participant_012

Yes. I sometimes feel that I'm a burden although I don't try to be, and I do as much as I can. Nobody complained, it's just the way I feel. Participant_032

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

Well, yeah, yeah. For my husband, yeah. He's had to pick up so much more because I don't have the energy and because for a long time things like just even putting the quilt cover on the bed, putting it, you know, stuff like that was hard and hanging, washing up because I couldn't do the reaching and all the arms stretching and stuff. So he's just more heavy stuff that he's been doing all that. And just because I just get tired or because I'm now more I'm just more anxious. And so definitely it's affected him so much because I'm not I'm not myself. Participant_001

Well, the kids have to do a few more extra chores and I figure they probably don't like that but they don't complain, so that's something. Participant_022

Oh, absolutely. My kids are just like-- It's quite funny. Because your kids somehow-- Like my kids at the time, they're 21 and 24 now, two years ago is 19, 22, there had to take on parenting, looking after things and driving me around, and that happened for a while afterwards. Memory-wise, you're not that good so they'd have to correct you, they'd go, "Mum, that's not right. You missed this," or, "we've forgotten that." They'd go, "Mum, mum, you can't do that," it's funny, they're definitely taken on a parent-- when they're older, they should take on a parenting role. I guess, other people in the family that you thought would be closer to help you do things, just didn't do any respite for the kids or for my husband. It's a quite funny thing that you look back on. Participant_047

Participant describes the mental/emotional strain placed on their family

I see it as a burden and they wouldn't. They were obviously extremely happy to just be able to support me in every way possible. But I feel like I was a burden and negatively affected their life. And they obviously

had to look after this 30 year old daughter who. Like most of you, I had moved out of home and was living independently, I was certainly a lot more dependent on them during that year and emotionally and mentally since then. So I feel like that was a burden. Participant_010

That was more early, during active treatment, but yes, I think it is. I think everybody would be less mentally stressed for the next few years to come. Participant_016

It was when I was going through my treatment, I felt like I was a burden. But they seem to think that they would happy. But I didn't want my kids to emotionally deal with them. I'm sick. And all that sort of stuff to me was the bit that the thought of us, which Participant_044

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

I don't think so. Not now, no. Participant_004

No. Especially not now. Participant_021

Participant describes their condition being a burden as they have managed their condition independently

No, because I actually was alone for the whole thing. I was in a city on my own. I just didn't go through it with anyone. Yes, it wasn't. [chuckles] Participant_008

It hasn't been yet. I've been really happy about that because I've managed to maintain all of the things I was doing before, but I was initially really worried about that, that I don't want to be cared for. I don't want people having to do my housework and my cooking and thankfully, that hasn't happened. That was a huge concern. I think it would be again. I don't know how post-surgery, what happens. I assume I may need a little bit more help after that. I don't want that. Yes, I don't want that to burden them. Again, because I just don't want to be a patient. I want to be the matriarch of the family getting on and doing what I do. I don't like that. Participant_033

PARTICIPANT: No, because nobody's had to provide any for me. [chuckles]

INTERVIEWER: Yes, you're living by yourself. You've mentioned.

PARTICIPANT: Yes. Participant_041

Table 8.20: Burden on family

Burden on family	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant gives a description suggesting that overall, there was a burden on their family	30	60.00	14	60.87	16	59.26	10	52.63	15	60.00	14	53.85	16	66.67	11	45.83	19	73.08
Participant gives a description suggesting that overall, there was not a burden on their family	18	36.00	9	39.13	9	33.33	8	42.11	9	36.00	10	38.46	8	33.33	11	45.83	7	26.92
Participant gives a description suggesting that overall, there was not a burden on their family now but they anticipate this will change in the future	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Other	2	4.00	0	0.00	2	7.41	1	5.26	1	4.00	0	0.00	2	8.33	2	8.33	0	0.00

Burden on family	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant gives a description suggesting that overall, there was a burden on their family	30	60.00	11	68.75	19	55.88	10	50.00	20	66.67	13	68.42	11	50.00	6	66.67
Participant gives a description suggesting that overall, there was not a burden on their family	18	36.00	5	31.25	13	38.24	8	40.00	10	33.33	4	21.05	11	50.00	3	33.33
Participant gives a description suggesting that overall, there was not a burden on their family now but they anticipate this will change in the future	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Other	2	4.00	0	0.00	2	5.88	2	10.00	0	0.00	2	10.53	0	0.00	0	0.00

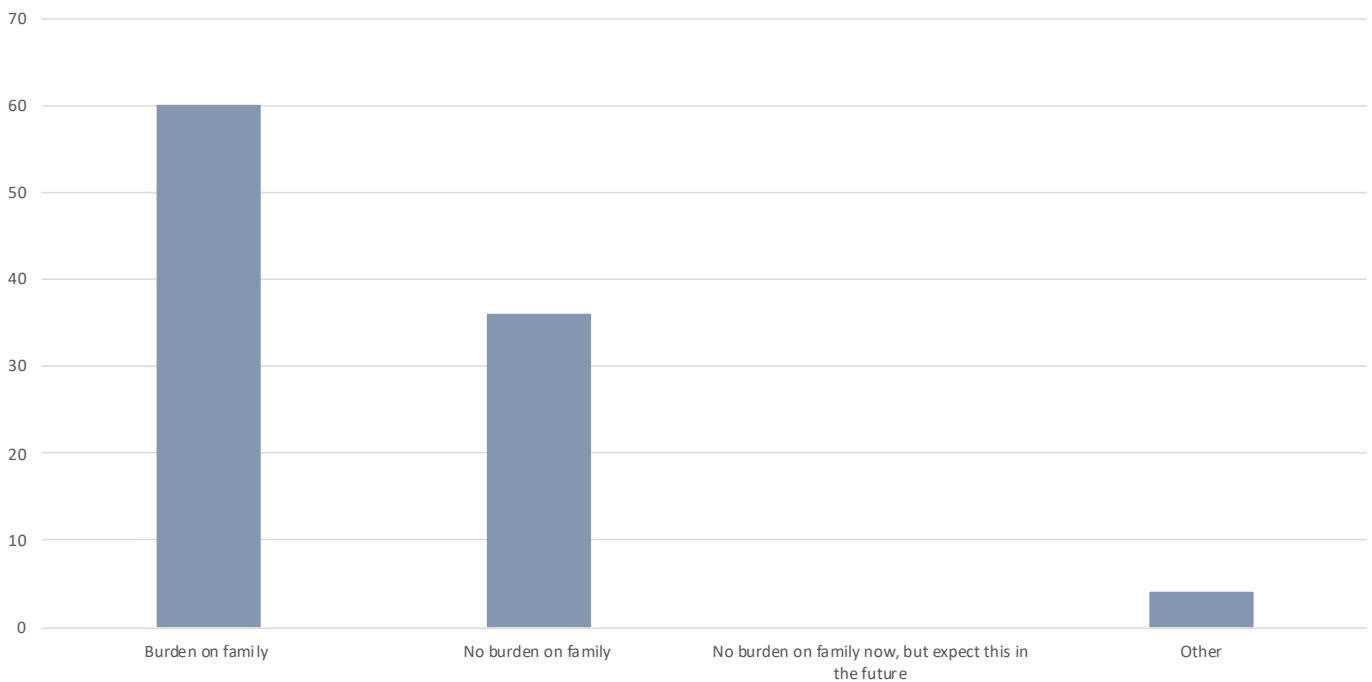


Figure 8.11: Burden on family

Table 8.21: Burden on family – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant gives a description suggesting that overall, there was a burden on their family	Trade or high school	University
Participant gives a description suggesting that overall, there was not a burden on their family	Aged 25 to 44	Aged 45 to 54

Table 8.22: Burden on family (description)

Burden on family (description)	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes their condition being a burden in general (No specific examples)	12	24.00	5	21.74	7	25.93	8	42.11	2	8.00	5	19.23	7	29.17	5	20.83	7	26.92
Participant describes extra household duties and responsibilities that their family must take on	10	20.00	7	30.43	3	11.11	1	5.26	8	32.00	5	19.23	5	20.83	4	16.67	6	23.08
Participant describes the mental/emotional strain placed on their family	6	12.00	3	13.04	3	11.11	0	0.00	5	20.00	4	15.38	2	8.33	2	8.33	4	15.38
Participant describes their condition not being a burden in general (No specific examples)	13	26.00	7	30.43	6	22.22	4	21.05	8	32.00	8	30.77	5	20.83	10	41.67	3	11.54
Participant describes their condition being a burden as they have managed their condition independently	5	10.00	2	8.70	3	11.11	4	21.05	1	4.00	2	7.69	3	12.50	1	4.17	4	15.38

Burden on family (description)	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes their condition being a burden in general (No specific examples)	12	24.00	5	31.25	7	20.59	3	15.00	9	30.00	6	31.58	3	13.64	3	33.33
Participant describes extra household duties and responsibilities that their family must take on	10	20.00	2	12.50	8	23.53	3	15.00	7	23.33	5	26.32	4	18.18	1	11.11
Participant describes the mental/emotional strain placed on their family	6	12.00	1	6.25	5	14.71	2	10.00	4	13.33	2	10.53	3	13.64	1	11.11
Participant describes their condition not being a burden in general (No specific examples)	13	26.00	3	18.75	10	29.41	5	25.00	8	26.67	3	15.79	7	31.82	3	33.33
Participant describes their condition being a burden as they have managed their condition independently	5	10.00	2	12.50	3	8.82	3	15.00	2	6.67	1	5.26	4	18.18	0	0.00

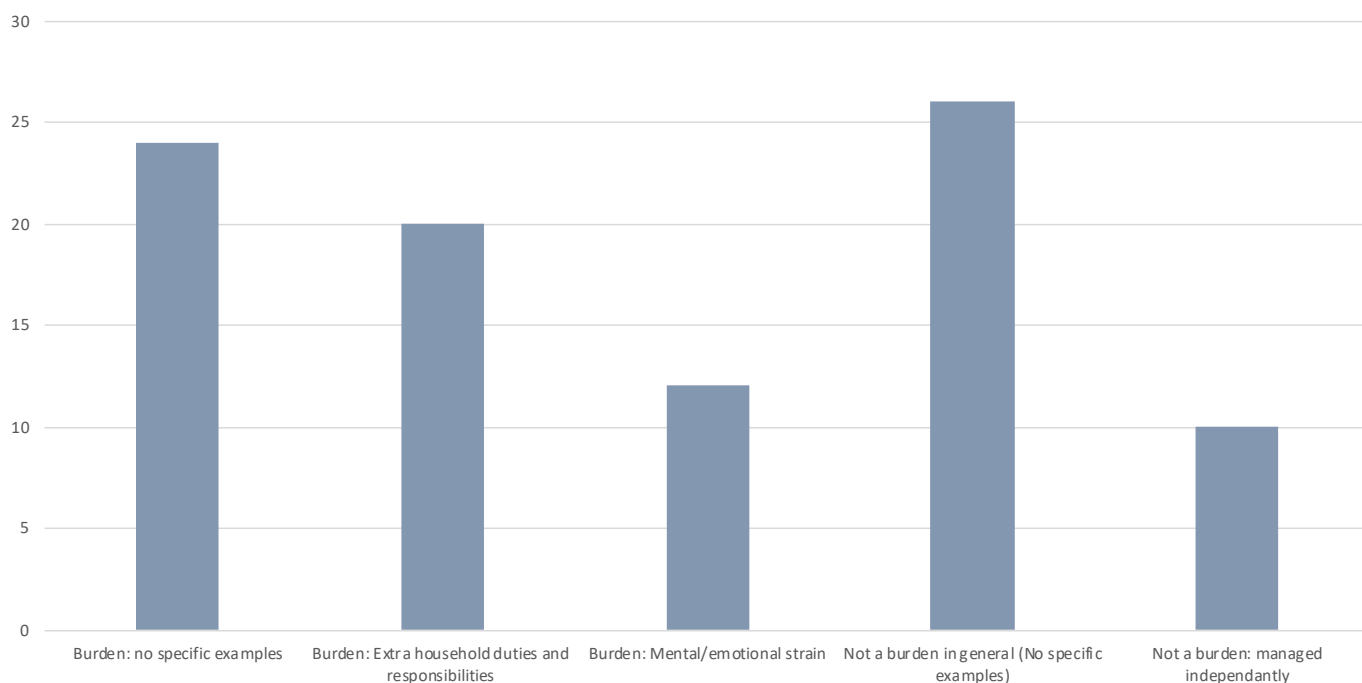


Figure 8.12: Burden on family (description)

Table 8.23: Burden on family (description)– subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes their condition being a burden in general (No specific examples)	Good physical function Aged 45 to 54	Poor physical function
Participant describes extra household duties and responsibilities that their family must take on	Poor physical function	Early breast cancer Good physical function
Participant describes the mental/emotional strain placed on their family	Poor physical function	-
Participant describes their condition not being a burden in general (No specific examples)	University Aged 25 to 44	Trade or high school
Participant describes their condition being a burden as they have managed their condition independently	-	Poor physical function

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. There were 36 participants (72.00%) that described some cost burden and 11 participants (22.00%) who 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=25, 50.00%). Other cost burdens were in relation to diagnostic tests and scans (n=15, 30.00%), taking time off work (n=9, 18.00%), and the cost of private care (n=7, 14.00%). There were six participants (12.00%) who described the cost of specialist appointments, and

the same number who described the cost of allied healthcare (n=6, 12.00%), and the cost of parking and travel to attend appointments, including accommodation (n=6, 12.00%). There were six participants (12.00%) that described no cost burden and that nearly everything was paid for through the health system or private coverage.

Participant gives a description suggesting that overall, there was at least some cost burden

It's been extremely expensive. We've reached our Medicare safety net. I don't know how you could have no savings and get cancer. We've ended up having to get someone to come in and help us a few hours a week just with things around the house. Everything just costs a lot of money. It's like all the drugs you have to have. It's very expensive. Participant_007

It's been very expensive because I think the treatment costs me about \$10,000. Then I haven't been working since the last August, but I did get a redundancy payout. It has cost me a lot of money in terms of lost income. It cost me a lot of time because I was trying to get the disability pension and that I'm not disabled enough apparently. That's probably it. I used to keep a running tab of how much money I was spending on the doctors and stuff, but I'm trying to not spend it or think about it now. Participant_008

Oh gosh, I've had heaps of costs. I couldn't work. I had kids at home in daycare, the preschool age. Daycare fees. I did get a bit of help with daycare fees once we filled out the 1,400 forms that we had to fill out. My husband had taken extended time off work and to help. All my lymphatic drainage and massage, I had to pay privately. That's about it, really. When you can't work, you really don't have a lot of money. You have to find out what you can get via the government or through charity support and what's available through on Medicare. Participant_012

Participant gives a description suggesting that overall, there was no cost burden

PARTICIPANT: So it was, I think, the parking and just a couple of weeks off work. But I got covered by so a long service leave so it didn't really affect me greatly. INTERVIEWER: And with any scans or medications, did you have to bear the cost of any of that?

PARTICIPANT: No, all resolved through public hospital Participant_006

No. There's been no issues with costs because it's been minimal. Participant_030

I have been so fortunate. We have been with the same private health insurance for the last seven or eight years, so our level of cover is golden or platinum. Because we've been members for them for so long. Me and my husband are just very lazy people and we forgot to switch the cover [inaudible] so all of my

chemo and radiation and surgery were covered. Participant_042

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

Well, for me, the biggest cost was the surgery. That nearly killed me on its own but other than that, I've really haven't had through the process of the actual treatment, I haven't had any out of profit. The only things that I've paid for would be when I went to see the physio or a massage. Participant_027

It's a huge financial burden. Particularly, we own our own business, so time off work, luckily for me wasn't an issue, but for others, it is. The medical bills aside. Yes. I'd say we probably spent close to \$30,000. My surgery alone was \$20,000, \$21,000. and then ongoing pharmacy deals and medical -the follow-up physio bills and things that. Yes. It's significant. I don't know how you would deal with it if you weren't as financially secure. You'd have to go into the public system I guess. I feel as though being a private patient, I didn't expect there to be so many additional costs. Participant_036

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

I know initially all your scans that you have done out of hospital, when you're not actually in hospital, there is out of pocket expenses that I've had. I do have private health, but there's out of pocket expenses and it can be a few hundred dollars. With my chemo medication, every week when I would go to the pharmacist, I was probably out of pocket about \$60 a week. Not being able to drive so I was out of pocket taxi fares going to hospital to receive my treatments. Then when you get to surgery, I had to make a choice. You've got the choice of going your public and your private. I ended up choosing to go public. It didn't have out of pocket expenses, even though I've had private health cover, because I pay a fortune for private health cover, but I'm just more out of pocket again when it's covered publicly, so I chose to go public. The really significant one for me is, so I've had a double mastectomy. I haven't had a reconstruction yet, because I need to do radiotherapy first. For reconstruction, I'm looking at if I want to do it privately and I want to do it fast. I'm looking at being something like \$30,000 out of pocket. Participant_017

Okay, so the biggest cost for me was the fine needle biopsy, which was just before Christmas, which was like a 500 but I got 400 of that back, obviously, or maybe 150 of it back with Medicare. Then the cost of treatment at the start when I first started chemotherapy, because of all the medication I needed, which was the 8 needle afterwards, which was \$30 a go. Then all the steroids and the anti-nausea, so my medication bill every fortnight was anywhere up to \$100. Participant_018

The costs have been a huge shock. Actually, I had no idea how much cost would be involved in a breast cancer diagnosis. It's been quite an eye-opener. It hasn't affected us too much financially. Luckily we're in a position that we can cope with that. I worry for people who can't, and it also makes me quite angry that we are so massively out of pocket. Things like all the testing, the PET scans, the mammograms, and they want to do them repeatedly, and then another scan and then there's this, and then there's that, and it's costing hundreds of dollars each time with minimal back from Medicare. Those costs are huge. My biggest annoyance with costs, I suppose, was not being asked at the beginning if I wanted to be a public or private patient, that was never mentioned, it was just assumed. Have you got a private health card? Yes, I do. Here you go. That means now that I've had to pay gap fees for the surgeon, and gap fees for the hospital, and additional fees that the person sitting next to me, who's in the public system isn't having to pay and is getting the same treatment. I find that that was a shock. The costs have been huge, obviously, I've given up work now for a short time just while I go through surgery. I don't know, I might work part-time after that. The loss of income has been obviously a challenge, and the costs continue to mount up. Each week there's something else. Participant_033

Yes, diagnosis, that cost us a lot of money. That was a real shock. When I went and had an ultrasound and a biopsy, I was not expecting to be told that it'll be \$500. Me and my husband just about had a heart attack. [chuckles] We've had lots of costs on it. It's cost us money, we've had to travel. My husband had to take time off work. My medication, different medications that I've had to take. I'm trying to think what else, and just different tests. Even doctors, you get rebates back on some of them and some of them you don't. Every time I go see my oncologist, that costs money. Every time I see my surgeon, it costs money. Participant_043

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

It's been very expensive because I think the treatment costs me about \$10,000. Then I haven't been working since the last August, but I did get a redundancy payout. It has cost me a lot of money in terms of lost income. It cost me a lot of time because I was trying to get the disability pension and that I'm not disabled enough apparently. That's probably it. I used to keep a running tab of how much money I was spending on the doctors and stuff, but I'm trying to not spend it or think about it now. Participant_008

Yes, basically, time off work was one. Accessing income support was terrible. Bills, a few, like we've the scans and things that you've still got to go through, so the mammograms and all that you have to pay for afterwards, the ultrasounds. Pretty much all the regular testing. Medication, I didn't have any, so I was lucky there. Paying out for bills and things like that was probably my biggest one. Participant_024

Well, for the surgery, I was very lucky. I spoke to the specialist, and they did it all out-of-pocket on Gov Private Health fund, and there was going to be a large out-of-pocket, but I got that all covered. Scans are very expensive. All your PET scans and all that stuff, that's costly there. Radiation is a ridiculous cost, but I spoke to someone in my cancer support group here and they told me that I should be able to get it all bulk-billed and not have to pay, so I ended up not having to pay. That was going to be something like \$10,000. That was hard. I got that. Well, I'm still on long-term sick leave since surgery, and I haven't felt that I'm ready to go back to work yet. I did try to go back a couple of months ago and I lasted a day and I had to come home and lie down. I couldn't even stand in the shower. I was physically and mentally exhausted. I have been off work for nearly 12 months. I had holidays and long service and everything like that, which took me until February, but I haven't been paid anything since then because I've got some money in the bank put away. I'm not entitled to any Centrelink payments or anything like that. Financially, yes, it's been really tough. There's no form of income. Yes, mentally, it's pretty tough on the family as well as yourself. [crosstalk] It has been [unintelligible] financially and mentally. Participant_046

Participant describes a cost burden in relation to the cost of private care

I had my surgery because I mean, no health funds so I had my surgery privately. That actually, that costs us \$10,000 to trade out. That was literally a credit card job at the time. I got a couple of thousand back between Medicare and my health fund. That sort of helped. Then we had IVF costs in on that, which obviously we had no idea was coming sort of things. That was another 5,000 I think, at the time. I had all this spreadsheet, how much I got back and what day. We did on those two things, which was very out of pocket. Something we never obviously thought was coming. My treatment as such [unintelligible] None of my tests I've had to pay for. It was the surgery and then IVF. Again, I've just paid for surgery again, which I could had publicly but I had the [unintelligible] and it was definitely worth it. I would not change anything about that. The hospital was amazing. Participant_021

While we were out on the farm, we were farming, we got a housekeeper in because we were busy on the farm and I had a child to look after. We paid for a housekeeper, a live-in housekeeper. Then, there was out-of-pocket costs because I went private for surgery and for chemotherapy therapy. Radiotherapy, there was no out-of-pocket because I went public. Then, there was the ongoing costs of the surveillance, like every time I had a mammogram and ultrasound. That was always out-of-pocket. Participant_037

I went privately and say, you know, there was a lot of gaps in everything, particularly the surgery. But yeah, so and I'm still not back at work yet. So that's obviously financially hard on us. And then, you know, it's quite frustrating because when if you go through the public system, you get all the physios, it's for free. And I asked if I could join that group and I said no, because you're a private patient. But just because I pay private health covid doesn't mean I'm rich and I can't afford all the other treatments, you know? So, yeah, that's been a bit frustrating. That's how I do it, because I want to get back to work and I have to get back to work, but I've just got to pay for it. You know that part. I have covered some of that. Participant_038

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

It's been very expensive because I think the treatment costs me about \$10,000. Then I haven't been working since the last August, but I did get a redundancy payout. It has cost me a lot of money in terms of lost income. It cost me a lot of time because I was trying to get the disability pension and that I'm not disabled enough apparently. That's probably it. I used to keep a running tab of how much money I was spending on the doctors and stuff, but I'm trying to not spend it or think about it now. Participant_008

That's probably been one of the very challenging parts as well. My surgery is going to be \$6,000 out of pocket. The specialists, the scans, every biopsy, and I had to go to emergency three times during chemo. One time when I called my oncologist, he was away and the one standing in for him suggested I went to a private hospital. I didn't realize what financial implication that had until the bills came. Even though I have private health insurance, I still had \$800 out of pocket for the pathology tests. It's cost thousands and thousands of thousands out of pocket, and I'm a single mother. I wasn't able to take time off. I've continued working almost full-time through this whole thing, and that's been horrendous. Thank God I'm working from home because a lot of days I work on the sofa, [chuckles] and I was fortunate that I had six weeks of leave that I'd saved up for holidays with my parents in Canada because otherwise, I wouldn't have had enough leave to get me through it. The financial side of it is terrible. Participant_041

Yes, diagnosis, that cost us a lot of money. That was a real shock. When I went and had an ultrasound and a biopsy, I was not expecting to be told that it'll be \$500. Me and my husband just about had a heart attack. [chuckles] We've had lots of costs on it. It's cost us money, we've had to travel. My husband had to take time off work. My medication, different medications that I've had to take. I'm trying to think what else, and just different tests. Even doctors, you get rebates back on some of them and some of them you don't. Every time I go see my oncologist, that costs money. Every time I see my surgeon, it costs money. Participant_043

Participant describes a cost burden in relation to the cost of allied healthcare

Well, for me, the biggest cost was the surgery. That nearly killed me on its own but other than that, I've really haven't had through the process of the actual treatment, I haven't had any out of profit. The only things that I've paid for would be when I went to see the physio or a massage. Participant_027

It's a huge financial burden. Particularly, we own our own business, so time off work, luckily for me wasn't an issue, but for others, it is. The medical bills aside. Yes. I'd say we probably spent close to \$30,000. My surgery alone was \$20,000, \$21,000. and then ongoing pharmacy deals and medical - the follow-up physio bills and things that. Yes. It's significant. I don't know how you would deal with it if you weren't as financially secure. You'd have to go into the public system I guess. I feel as though being a private patient, I didn't expect there to be so many additional costs. Participant_036

I went privately and say, you know, there was a lot of gaps in everything, particularly the surgery. But yeah, so and I'm still not back at work yet. So that's obviously financially hard on us. And then, you know, it's quite frustrating because when if you go through the public system, you get all the physios, it's for free. And I asked if I could join that group and I said no, because you're a private patient. But just because I pay private health covid doesn't mean I'm rich and I can't afford all the other treatments, you know? So, yeah, that's been a bit frustrating. That's how I do it, because I want to get back to work and I have to get back to work, but I've just got to pay for it. You know that part. I have covered some of that. Participant_038

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

Yes, I was off work for six months. The costs, we had initially, where we lived to where my initial treatment was is a fair distance because we used to live that side, and then we moved but I wanted to continue my treatment. The cost of traveling to and from treatment was quite excessive. Then there was parking and tolls, and me being off work didn't help much at all. My husband took up a second job to help us through. I did have some annual leave and sick leave saved up. I had actually quite a lot but it wasn't enough. I was still two months short. My work did help out a little bit after I broke down and they gave me my annual leave in advance, but only a month or the four

weeks, and that was weeded out over two months. so I sort of got half pay and I did a little bit of work from home when I could. Still, obviously, there was a lot of added cost like if I was at the hospital then my husband would get takeout or even cost of parking and coming up to see me. Extra fuel costs. It did all add up obviously COVID hasn't helped that either because my husband lost his job in COVID. We're back on track now but the initial cost of diagnosis it can-- Unless you are financially stable and have some form of insurance, it can get very, very hard especially having to be off of work for so long. Like I say, with my family history I couldn't get any insurance so that was pretty tough. Participant_022

Yes, diagnosis, that cost us a lot of money. That was a real shock. When I went and had an ultrasound and a biopsy, I was not expecting to be told that it'll be \$500. Me and my husband just about had a heart attack. [chuckles] We've had lots of costs on it. It's cost us money, we've had to travel. My husband had to take time off work. My medication, different medications that I've had to take. I'm trying to think what else, and just different tests. Even doctors, you get rebates back on some of them and some of them you don't. Every time I go see my oncologist, that costs money. Every time I see my surgeon, it costs money. Participant_043

I think we could go on forever about this. When I first got diagnosed, I was actually quite shocked at the amount of money outlined for you. You're paying six, seven, eight hundred dollars and only getting two or three back for Medicare. The parking that while you're at the hospital, it could range from five dollars. Twenty five dollars. The pharmacy costs for even just down to having to have Panadol all the time. And, you know, you don't have to have gastro stop antinausea. It was just constant. I just felt like I was out money all the time trying to think of other things. I mean, just petrol for your car to get to appointments, you know, just everything like that. It just it was and it was skyrocketing all the time.. Participant_049

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

PARTICIPANT: So it was, I think, the parking and just a couple of weeks off work. But I got covered by so a long service leave so it didn't really affect me greatly. INTERVIEWER: And with any scans or medications, did you have to bear the cost of any of that PARTICIPANT: No, all resolved through public hospital. Participant_006

I haven't had to pay for anything so far. Participant_014

Table 8.24: Cost considerations

Cost considerations	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant gives a description suggesting that overall, there was at least some cost burden	36	72.00	17	73.91	19	70.37	15	78.95	16	64.00	18	69.23	18	75.00	16	66.67	20	76.92
Participant gives a description suggesting that overall, there was no cost burden	11	22.00	6	26.09	5	18.52	3	15.79	7	28.00	5	19.23	6	25.00	6	25.00	5	19.23
Other	2	4.00	0	0.00	2	7.41	1	5.26	1	4.00	0	0.00	2	8.33	2	8.33	0	0.00

Cost considerations	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant gives a description suggesting that overall, there was at least some cost burden	36	72.00	12	75.00	24	70.59	15	75.00	21	70.00	14	73.68	18	81.82	4	44.44
Participant gives a description suggesting that overall, there was no cost burden	11	22.00	4	25.00	7	20.59	3	15.00	8	26.67	3	15.79	3	13.64	5	55.56
Other	2	4.00	0	0.00	2	5.88	2	10.00	0	0.00	2	10.53	0	0.00	0	0.00

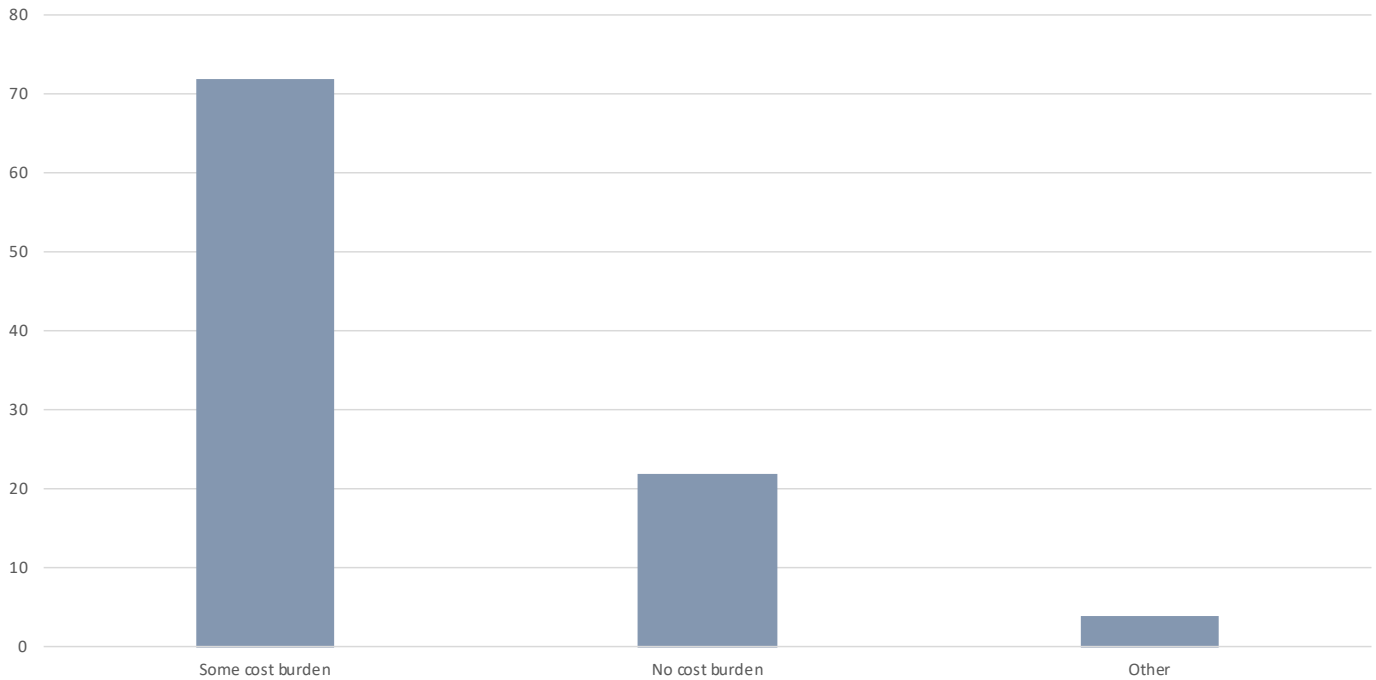


Figure 8.13: Cost considerations

Table 8.25: Cost considerations – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant gives a description suggesting that overall, there was at least some cost burden	Aged 55 to 74	-
Participant gives a description suggesting that overall, there was no cost burden	-	Aged 55 to 74

Table 8.26: Cost considerations (Reasons for cost)

Cost considerations (Reasons for cost)	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)	25	50.00	13	56.52	12	44.44	12	63.16	10	40.00	12	46.15	13	54.17	12	50.00	13	50.00
Participant describes a cost burden in relation to diagnostic tests and scans	15	30.00	5	21.74	10	37.04	4	21.05	9	36.00	7	26.92	8	33.33	5	20.83	10	38.46
Participant describes a cost burden in relation to needing to take time off work	9	18.00	4	17.39	5	18.52	1	5.26	6	24.00	6	23.08	3	12.50	4	16.67	5	19.23
Participant describes a cost burden in relation to the cost of private care	7	14.00	2	8.70	5	18.52	3	15.79	2	8.00	3	11.54	4	16.67	5	20.83	2	7.69
Participant describes a cost burden in relation to the cost specialist appointments	6	12.00	3	13.04	3	11.11	4	21.05	2	8.00	4	15.38	2	8.33	1	4.17	5	19.23
Participant describes a cost burden in relation to the cost of allied healthcare	6	12.00	2	8.70	4	14.81	2	10.53	2	8.00	3	11.54	3	12.50	4	16.67	2	7.69
Participant describes a cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	6	12.00	4	17.39	2	7.41	3	15.79	3	12.00	5	19.23	1	4.17	3	12.50	3	11.54
Participant describes no cost burden and that nearly everything was paid for through the health system	6	12.00	5	21.74	1	3.70	1	5.26	4	16.00	4	15.38	2	8.33	2	8.33	4	15.38

Cost considerations (Reasons for cost)	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)	25	50.00	7	43.75	18	52.94	9	45.00	16	53.33	11	57.89	11	50.00	3	33.33
Participant describes a cost burden in relation to diagnostic tests and scans	15	30.00	6	37.50	9	26.47	6	30.00	9	30.00	6	31.58	8	36.36	1	11.11
Participant describes a cost burden in relation to needing to take time off work	9	18.00	3	18.75	6	17.65	5	25.00	4	13.33	3	15.79	6	27.27	0	0.00
Participant describes a cost burden in relation to the cost of private care	7	14.00	3	18.75	4	11.76	3	15.00	4	13.33	3	15.79	2	9.09	2	22.22
Participant describes a cost burden in relation to the cost specialist appointments	6	12.00	2	12.50	4	11.76	2	10.00	4	13.33	4	21.05	2	9.09	0	0.00
Participant describes a cost burden in relation to the cost of allied healthcare	6	12.00	1	6.25	5	14.71	4	20.00	2	6.67	4	21.05	2	9.09	0	0.00
Participant describes a cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	6	12.00	3	18.75	3	8.82	3	15.00	3	10.00	1	5.26	3	13.64	2	22.22
Participant describes no cost burden and that nearly everything was paid for through the health system	6	12.00	3	18.75	3	8.82	3	15.00	3	10.00	1	5.26	3	13.64	2	22.22

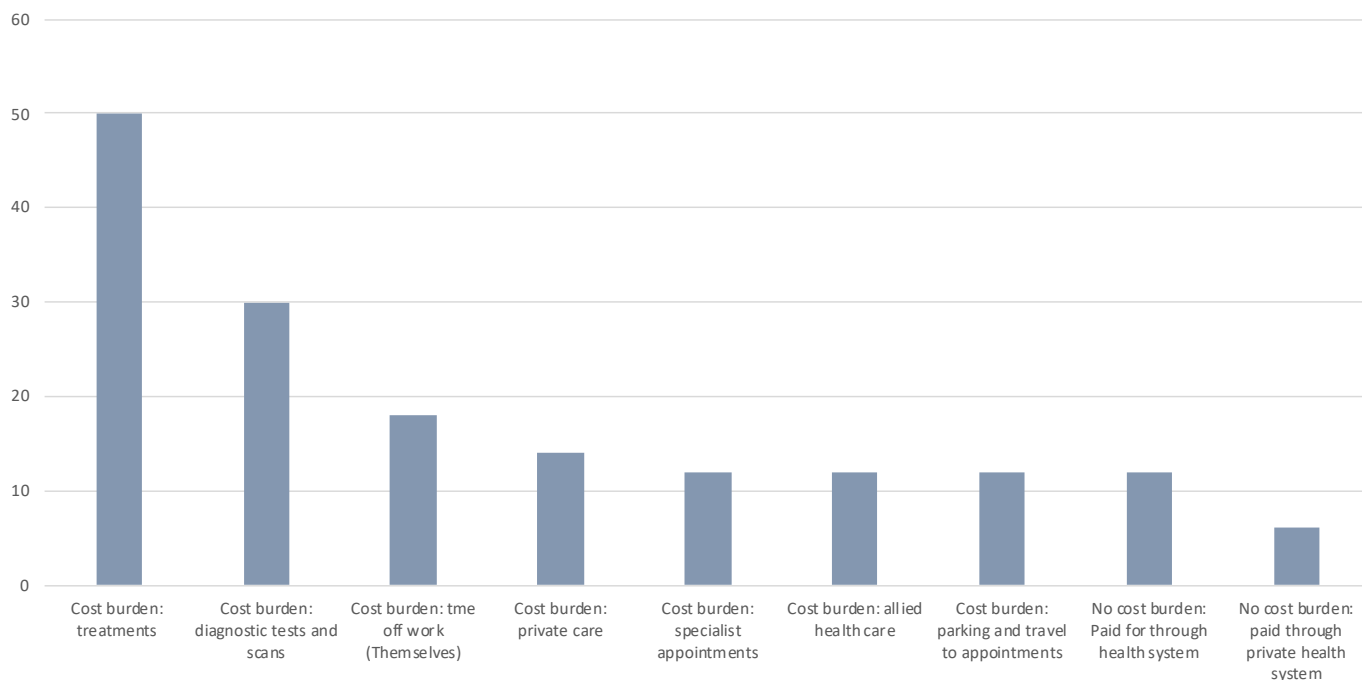


Figure 8.14: Cost considerations (Reasons for cost)

Table 8.27: Cost considerations (Reasons for cost)– subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)	Aged 55 to 74	Poor physical function
Participant describes a cost burden in relation to diagnostic tests and scans	Aged 55 to 74	-
Participant describes a cost burden in relation to needing to take time off work	Poor physical function Aged 55 to 74	-
Participant describes a cost burden in relation to the cost specialist appointments	Aged 55 to 74	-
Participant describes a cost burden in relation to the cost of allied healthcare	Aged 55 to 74	-
Participant describes a cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	-	Aged 55 to 74
Participant describes no cost burden and that nearly everything was paid for through the health system	-	Aged 55 to 74

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.

Table 8.28: Overall impact of condition on quality of life

Impact of condition on quality of life	Number (n=44)	Percent
1 Life is/was very distressing	6	13.64
2 Life is/was distressing	9	20.45
3 Life is/was a little distressing	9	20.45
4 Life is/was average	4	9.09
5 Life is/was good	10	22.73
6 Life is/was very good	5	11.36
7 Life is/was great	1	2.27

The average score was in the Life was a little distressing range (median = 3.00, IQR = 3.00) (Table 8.29, Figure 8.15).

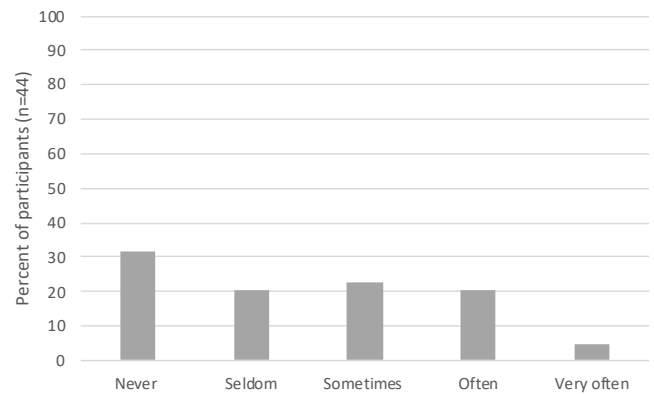


Figure 8.15: Overall impact of condition on quality of life

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 a mean total score of 35.89 (SD = 7.50), which corresponds to moderate levels of anxiety (Table 8.29)

Comparisons of Care co-ordination have been made based on **breast cancer stage** (Table 8.30, Figure 8.16),

physical function (Table 8.31, Figure 8.17), **year of diagnosis** (Table 8.32, Figure 8.18), **education** (Table 8.33, Figure 8.19), **location** (Table 8.34, Figure 8.20), **socioeconomic status** (Table 8.35, Figure 8.21), and **age** (Table 8.36, Figure 8.22).

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 8.29: Fear of progression summary statistics

Fear of progression (n=50)	Mean	SD	Median	IQR	Possible range	Quintile
Total score*	35.89	7.50	36.00	9.25	12 to 60	3

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

Fear of progression by breast cancer stage

Comparisons were made by **breast cancer stage**, there were 23 participants (46.00%) with *Early breast cancer* (Stage I or Stage II) and, 27 participants (54.00%) with *Advanced breast cancer* (Stage III or Stage IV).

Assumptions for normality and variance for a two-sample t-test were not met, a Wilcoxon rank sum test with continuity correction was used (Table 8.30).

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

Table 8.30: Fear of progression total score by breast cancer stage summary statistics and Wilcoxon rank sum tests

Fear of progression	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Total score	Early breast cancer	20	45.45	37.00	12.00	267.50	0.5238
	Advanced breast cancer	24	54.55	36.00	7.25		

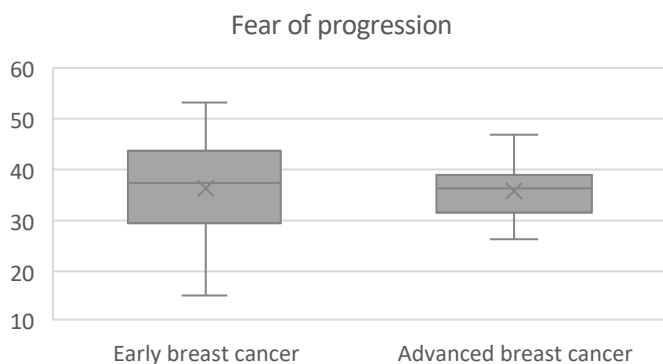


Figure 8.16: Boxplot of Fear of progression total score by breast cancer stage

Fear of progression by physical function

Physical function was evaluated by the SF36 Role functioning/physical, this measures how physical health interferes with work or other activities. Participants that had an SF36 Role functioning/physical score of 40 or less were included in the *Poor physical function* subgroup (n=19, 43.18 %), and participants that scored more than 40 were included in the *Good physical function* subgroup (n=25, 56.82%).

Assumptions for normality and variance for a two-sample t-test were not met, a Wilcoxon rank sum test with continuity correction was used (Table 8.31).

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

Table 8.31: Fear of progression total score by physical function summary statistics and Wilcoxon rank sum tests

Fear of progression	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Total score	Poor physical function	19	43.18	38.00	12.00	294.00	0.1838
	Good physical function	25	56.82	36.00	7.00		

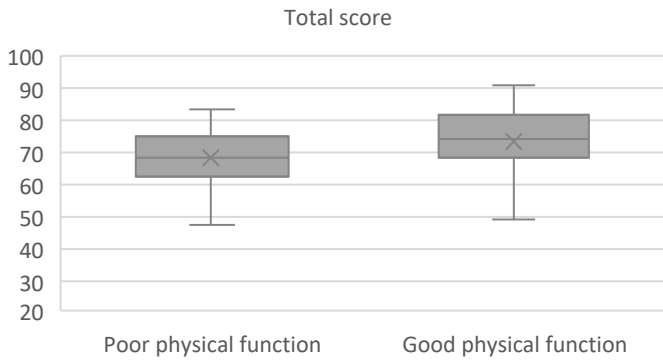


Figure 8.17: Boxplot of Fear of progression total score by physical function

Fear of progression by year of diagnosis

Comparisons were made by the **year of diagnosis**, there were 26 participants that were *Diagnosed before 2020* (52.00%), and 24 participants *Diagnosed in 2020 or 2021* (48.00%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.32).

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

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

Fear of progression	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Total score	Diagnosed before 2020	22	50.00	35.05	8.50	-0.74	42	0.4635
	Diagnosed in 2020 or 2021	22	50.00	36.73	6.43			

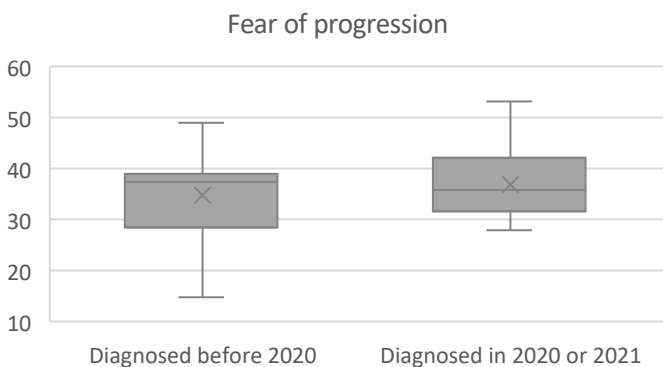


Figure 8.18: Boxplot of Fear of progression total score by year of diagnosis

Fear of progression by education

Comparisons were made by **education** status, between those with *Trade or high school* qualifications, (n = 24, 48.00%), and those with a *University* qualification (n = 26, 52.00%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.33).

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

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

Fear of progression	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Total score	Trade or high school	21	47.73	36.29	8.36	0.33	42	0.7400
	University	23	52.27	35.52	6.79			

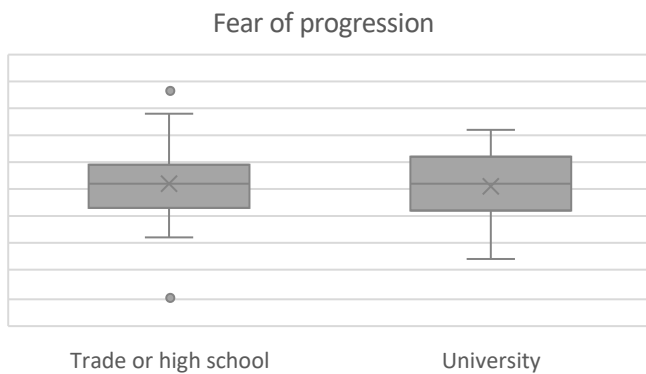


Figure 8.19: Boxplot of Fear of progression total score by education

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 =16, 32.00%) were compared to those living in a major city, *Metropolitan* (n = 34, 68.00%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.34).

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

Table 8.34: Fear of progression total score by location summary statistics and T-test

Fear of progression	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Total score	Regional or remote	14	31.82	35.64	9.01	-0.15	42	0.8851
	Metropolitan	30	68.18	36.00	6.85			

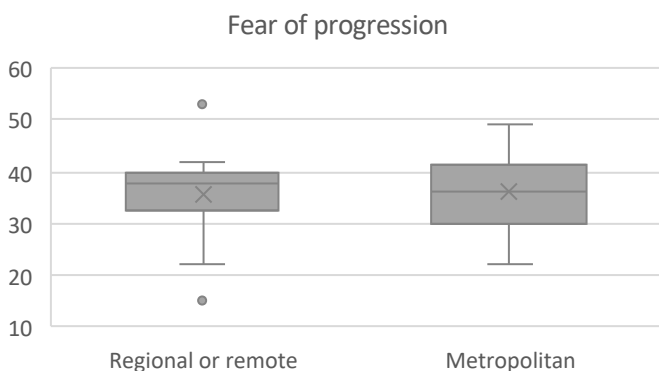


Figure 8.20: Boxplot of Fear of progression total score by location

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 = 20, 40.00%) compared to those with a higher SEIFA score of 7-10, *Higher status* (n = 30, 60.00%).

Assumptions for normality and variance for a two-sample t-test were not met, a Wilcoxon rank sum test with continuity correction was used (Table 8.35).

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

Table 8.35: Fear of progression total score by socioeconomic status summary statistics and Wilcoxon rank sum tests

Fear of progression	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Total score	Mid to low status	17	9.62	37.00	Mid to low status	219.50	0.8186
	Higher status	27	5.98	36.00	Higher status		

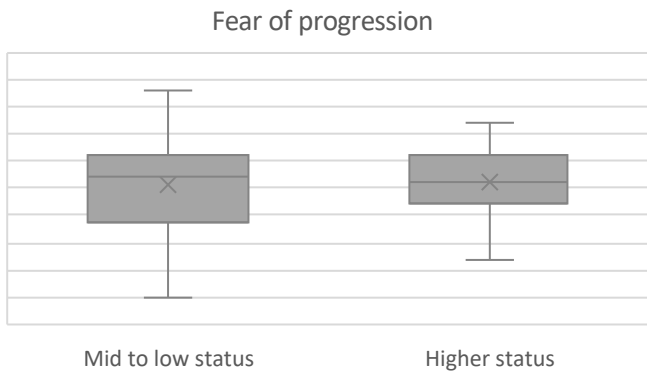


Figure 8.21: Boxplot of Fear of progression total score by socioeconomic status

Fear of progression by age

Participants were grouped according to **age**, with comparisons made between participants *Aged 25 to 44* (n = 19, 38.00%), participants *Aged 45 to 54* (n = 22, 44.00%), and participants *Aged 55 to 74* (n = 9, 18.00%).

A one-way ANOVA test was used when the assumptions for response variable residuals were

normally distributed and variances of populations were equal (Table 8.36).

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

Table 8.36: Fear of progression total score by age summary statistics and one-way ANOVA

Fear of progression	Group	Number (n=44)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Total score	Aged 25 to 44	16	36.36	36.88	6.55	Between groups	24.60	2	12.29	0.21	0.8110
	Aged 45 to 54	19	43.18	35.32	8.51	Within groups	2393.90	41	58.39		
	Aged 55 to 74	9	20.45	35.33	7.47	Total	2418.50	43			

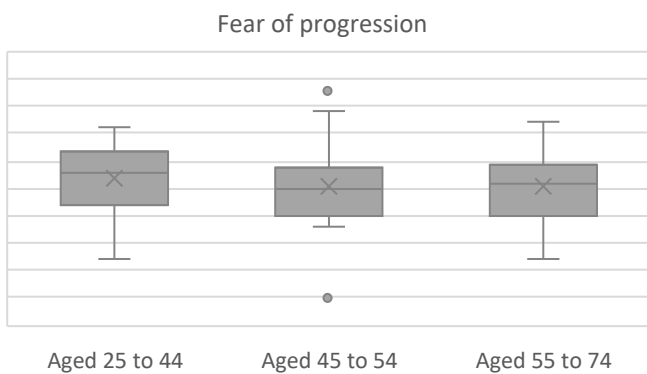


Figure 8.22: Boxplot of Fear of progression total score by age

Anxiety about treatment

Anxiety about treatment with no side effects

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 = 23, 52.27%), there were 10 participants (22.73%) that were sometimes worried about this, and 11 participants (25.00%) were often or very often worried about this (Table 8.37, Figure 8.23).

Table 8.37: Anxiety about treatment with no side effects

If a treatment and it is working well (limited side effects, no progression of disease), worry what will happen if treatment stopped	Number (n=44)	Percent
Never	14	31.82
Seldom	9	20.45
Sometimes	10	22.73
Often	9	20.45
Very often	2	4.55

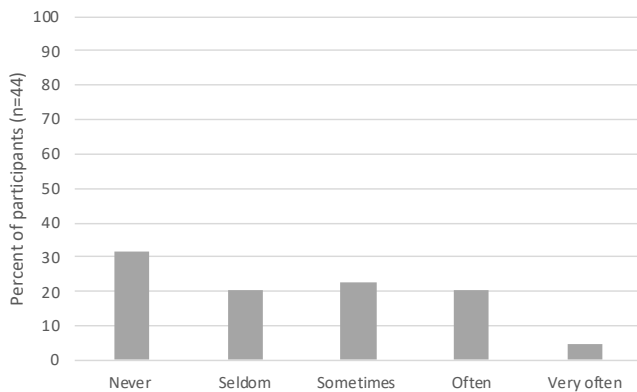


Figure 8.23: Anxiety about treatment with no side effects

Concern about what will happen if successful treatment is stopped

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 = 32, 72.77%), there were 7 participants (15.91%) that were sometimes worried about this, and 5 participants (11.36%) were often or very often worried about this (Table 8.38, Figure 8.24).

Table 8.38: Concern about what will happen if successful treatment is stopped

Anxious if not experiencing any side effects think it doesn't work	Number (n=44)	Percent
Never	21	47.73
Seldom	11	25.00
Sometimes	7	15.91
Often	5	11.36
Very often	0	0.00

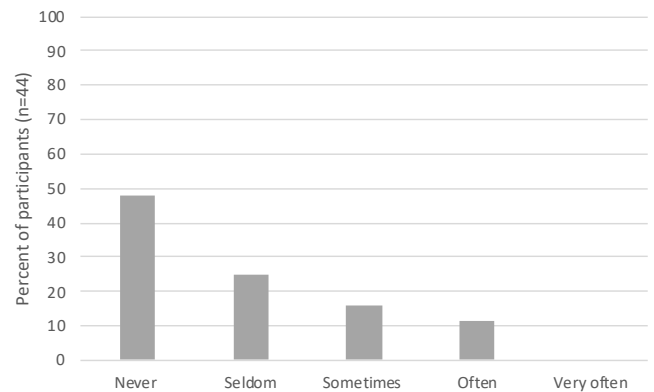


Figure 8.24: Concern about what will happen if successful treatment is stopped