

## **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 14 participants (28.57%) that described a negative impact on quality of life, 12 participants (24.49%) that reported some negative impact on quality of life, and 12 participants (24.49%) that described a mix of positive and negative impacts on quality of life. Other participants described no impact on quality of life (n=10, 20.41%), an overall positive impact on quality of life (n=8, 16.33%), and a minimal impact on quality of life (n=8, 16.33%).

The most common themes in relation to a negative impact on quality of life were due to the side effects of treatment or symptoms of conditions that they need to manage (n=18, 36.73%), the mental and emotional impact of their condition (n=16, 32.65%), emotional strain on family or partner/change in relationship dynamics (n=14, 28.57%), intimacy problems (n=11, 22.45%), the need to plan for toilets or to manage stoma (n=10, 20.41%), and reduced capacity for physical activity (n=8, 16.33%).

The most common theme in relation to a positive impact on quality of life was that it brings people together (n=9, 18.37%)

### **Impact on mental health**

In the structured interview, participants were asked if there had been an impact on their mental health. There were 38 participants (77.55%) who gave a description suggesting that overall there was some impact on their mental health and 10 participants (20.41%) 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 way that participants reported managing their mental and emotional health was describing the importance of family and friends (n=19, 38.78%). Other participants described the importance of physical exercise (n=11, 22.45%), mindfulness and/or meditation, consulting a mental health professional (n=9, 18.37%), and maintaining social, lifestyle changes, and hobbies (n=7, 14.29%). There were 11 participants (22.45%) that described no activities to maintain mental health.

### **Regular activities to maintain health**

In the structured interview, participants were asked what were some of the things they needed to do everyday to maintain their health? The most common ways that participants reported managing their health were; being physically active (n=11, 22.45%), keeping busy or keeping a normal routine (n=11, 22.45%), and managing their stoma or incontinence (n=11, 22.45%). Other ways to maintain health were complying with treatment (n=7, 14.29%), socialising with friends and/or family (n=7, 14.29%), maintaining a healthy diet (n=6, 12.24%), and the importance of self care e.g. more rest, support for housework etc. (n=5, 10.20%). There were 7 participants (14.29%) that described no activities to maintain health.

### **Experience of vulnerability**

In the structured interview, participants were asked if there had been times that they felt vulnerable. There were 42 participants (85.71%) who gave a description suggesting that overall they had experiences of feeling vulnerable, and 2 participants (4.08%) 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=25, 51.02%). There 13 participants (26.53%) that described feeling vulnerable when first

diagnosed, first few months after diagnosis, while experiencing side effects from treatment or symptoms from condition (n=10, 20.41%), because of interactions with the medical team (n=8, 16.33%), and 8 participants (16.33%) described feeling vulnerable when having sensitive discussion (diagnosis, treatment decision). Other participants described feeling vulnerable when thinking about disease course/incurable condition (n=5, 10.20%), being vulnerable when they have a loss of independence, e.g in hospital, recovering from surgery (n=5, 10.20%), and when first sent home after being hospitalised without the care/availability healthcare professionals (n=5, 10.20%).

### **Methods to manage vulnerability**

In the structured interview, participants described ways that they managed feelings of vulnerability. Participants described using self help methods such as resilience, acceptance, and staying positive to manage the feeling of vulnerability (n=12, 24.49%), support from family and friends to manage the feeling of vulnerability (n=7, 14.29%), and being supported by nurse or treatment team to manage the feeling of vulnerability (n=6, 12.24%).

### **Impact on relationships**

In the structured interview, participants were asked whether their condition had affected their personal relationships. Overall, there were 17 participants (34.69%) that described that overall, there was a positive impact on relationships. Other participants described a mix of a positive and a negative impact (n=11, 22.45%), a negative impact on relationships (n=9, 18.37%), no impact on relationships (n=8, 16.33%), and an impact on relationships that was neither positive nor negative (n=3, 6.12%)

The most common themes in relation to having a positive impact on relationships were relationships within the family being strengthened (n=22, 44.90%), and people being well-meaning and supportive (n=10, 20.41%). The most common themes in relation to having a positive impact on relationships were relationships suffering, that is people not knowing what to say or do and withdrawing from relationships (n=9, 18.37%), and dynamics of relationships change due to anxiety, exacerbations and/or physical limitations of condition (n=7, 14.29%).

### **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 22 participants (44.90%) that felt there was an additional burden, 20 participants (40.82%) that reported no additional burden, and 6 participants (12.24%) that felt they were not a burden on their family but anticipate this will change in the future.

For people that felt they were not a burden on their family, the most did not give any specific reasons for this (n=14, 28.57%). The main reason that participant described their condition not being a burden in general was that they were very independent and did not need any help (n=8, 16.33%). The most common reasons for feeling that they were a burden on their family was the mental/emotional strain placed on their family (n=12, 24.49%), the extra household duties and responsibilities that their family must take on (n=5, 10.20%), and that the burden was temporary or only during treatment (n=5, 10.20%).

### **Cost considerations**

In the structured interview, participants were asked about any significant costs associated with having their condition. There were 25 participants (51.02%) that described some cost burden and 22 participants (44.90%) 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=12, 24.49%). Other cost burdens were in relation to gap payments (public or private) (n=10, 20.41%), specialist appointments (n=9, 18.37%), and the cost of diagnostic tests and scans (n=8, 16.33%). There were 14 participants (28.57%) that described no cost burden and that nearly everything was paid for through the health system, 12 participants (24.49%) described that there was no cost burden, even if costs exist, and 7 participants (14.29%) that described no cost burden and that nearly everything was paid for through private health insurance.

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

## Impact on quality of life

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Overall, there were 14 participants (28.57%) that described a negative impact on quality of life, 12 participants (24.49%) that reported some negative impact on quality of life, and 12 participants (24.49%) that described a mix of positive and negative impacts on quality of life. Other participants described no impact on quality of life (n=10, 20.41%), an overall positive impact on quality of life (n=8, 16.33%, and a minimal impact on quality of life (n=8, 16.33%).

The most common themes in relation to a negative impact on quality of life were due to the side effects of treatment or symptoms of conditions that they need to manage (n=18, 36.73%), the mental and emotional impact of their condition (n=16, 32.65%), emotional strain on family or partner/change in relationship dynamics (n=14, 28.57%), intimacy problems (n=11, 22.45%), the need to plan for toilets or to manage stoma (n=10, 20.41%), and reduced capacity for physical activity (n=8, 16.33%).

The most common theme in relation to a positive impact on quality of life was that it brings people together (n=9, 18.37%)

### Participant describes an overall negative impact on quality of life

*I've had to go, I've had it on, off sort of girlfriend on off relationship over the years and it definitely stuffed up like not stuffed up the relationship. But I mean we sort of kind of sort of seeing each other again. Oh, yeah. So yeah, the actual thing of having I guess there's been a few issues, some of us, by the psychological of me being I don't want to commit to marriage or something like that if I'm going to die. Yeah, I know that might sound weird or whatever, but I just, you know, it's like, I want to be alive and I don't want to be one of those guys getting married and then dying on the partner or, you know, that kind of thing or having someone have to look after me because I'm really terrible, you know, that kind of stuff. It's been a major psychological hit for me, I guess in that way, relationship wise. And when you're having treatments done of BCG, it's the toxic, cytotoxic, whatever it's called, or some of its toxic effects too. Yeah, you're supposed to take precautions as you I mean, sexual relations. And really it doesn't feel very sexy when you're having urinary tract infections and stuff going on up there and all the rest of it. And so I sort of, um,*

*it's not the most fun feeling to have. And I've had some big operations who have had a catheter in for weeks at a time and stuff like that, um, within the hospital and that sort of thing. And it takes a while for that to sort of feel better.*

*Participant 001\_2022AUBLC*

*Uh, the. I guess the inconvenience of having now is having a urinary diversion. Also being a bit more tired. Yeah. And then, you know, and you've always got in the back of your mind that the cancer will return.*

*Participant 016\_2022AUBLC*

*I think it certainly did affect the quality of life while I was having the BCG. I was paranoid about having a getting a urinary tract infection because I knew, and had heard that if you urinary tract infection when you're on BCG, it can be quite problematic and quite hard to get rid of. And consequently, in all honesty, it did put me off sexual relationships considerably for some time over the BCG, but not, not too severely. But definitely it was in the back of my mind that I don't want to get a urinary tract infection. So that didn't really affect the family. The family are all grown up and doing their own thing now anyway. So and I'm not like looking after children or have any other commitments and I found I could fit it in if like if I had a social occasion to go to, I'd make sure that I had the BCG a day or two beforehand, so I still managed to have a social life. And the other thing that did affect me, apart from the side effects of the relationship, was travel. I tried to organise potentially to go overseas. My husband and I were looking at a trip overseas and I couldn't get health insurance, couldn't get travel insurance. Because they they deemed that because I was having BCG, obviously, for ongoing treatment for cancer. That's the way they saw it. And so they said that they would not cover me for bladder cancer or anything related to that. And my concern was if anything went wrong when I was overseas, that I wouldn't be covered. So we made the decision not to go overseas.*

*Participant 036\_2022AUBLC*

*Because it affected us being diagnosed with it as well. And because it was in the middle of COVID, like right at the start of COVID. When I was first diagnosed then. Every you know. The last two years. It's like shit for everyone. We didn't want to go out anywhere. We didn't want to socialise with our other family members. We were invited to birthday parties. I didn't want to go. I didn't want to mix with anyone because*

*of the fear of catching something and then missing out on an operation or missing out on a check-up and things like that. So yeah, it affected our quality of life.*  
Participant 033\_2022AUBLC

#### **Participant describes some negative impact on quality of life**

*It caused a bit of stress within the family. But again, that was only the first 1 to 2 weeks in terms of my quality of life. No, because I've still got my bladder and it's just inconvenient having to go for surveillance now every 12 months. But that's all. It's just it's a mild inconvenience.*

Participant 020\_2022AUBLC

*It only for the first three months I was a little bit. You know, didn't do too much and was a little bit, not depressed, but a bit concerned. But apart from that, it hasn't affected or hasn't affected my ability to, to play my golf and to go out and enjoy myself. Um, so that really hasn't affected my quality of life at all except for those first three months and March this year, March, February, March issue, when I thought the symptoms had returned, the symptoms show that it the cancer had returned. For those six, eight weeks. It was terrible. I couldn't sleep. Couldn't sleep at all.*

Participant 021\_2022AUBLC

*It obviously does, but obviously does have an impact. It's not disastrous, but it does have an impact. The fact that I mean, I can still do most of the things I used to do, but there's some things that I can't. Family relations. There are some aspects of family relations, of course, that change*

Participant 034\_2022AUBLC

#### **Participant describes an mix of positive and negative impacts on quality of life**

*PARTICIPANT It is it is strengthened my relationship with my wife. Without a doubt, we are far more intimate. We are far more connected. We are far more. Yeah. With my kids, they're young. I've got 10, 12 and 13. Am I going to die tonight? No Okay, good. I'll get back on my device. [Laughs] Yeah, you know, it's that kind of thing. You know, even I was running this morning, I was jogging. Now I, you know, I'm still able to do that with my son. And he goes, gosh, you're not keeping up, Dad. I'm going, no, I'm older than you, and I've got cancer. Then he goes cancer's in your bladder, not your legs. ...*

*INTERVIEWER So you've got a good sense of humour.*

*PARTICIPANT Yeah, that's right. And, and grounding, very supportive family, very supportive friends. So I've lost the train of thought. What was the question? Okay, what was the question?*

*INTERVIEWER No, no, no. That's that's that's exactly right. It was related to that. But also, has it affected your quality of life as well?*

*PARTICIPANT When I had stents in which were partially to do with the bladder cancer resection and partly to do with the kidney stones, I felt like an old man. I couldn't run. I couldn't walk long distances. I hurt when I peed intensely, leading up to it, like getting those out last Thursday I said, I've just gone for a jog this morning for six ks. I feel like a new man. Don't get me wrong. I know I've got cancer. I'm not kidding myself, but it's not holding me back from doing anything like now. Now that those damn foreign objects are out of my bladder, I'm feel, I'm feeling \$1,000,000 physically, but I'm not stupid enough to know that that's not going last right. So.*  
Participant 017\_2022AUBLC

*I think my set, I think my family are I mean, they're all incredibly supportive. I think it did affect them in that period of time. As I said, I had a daughter doing her final year of school, about to face the final exams and her mother's having this major surgery. And we don't know what the outcome is going to be. So there was a lot of stress, a lot of stress that that period of time. Now, five years on, my quality life is great. Most people wouldn't even know I've had this major surgery. I probably go to the toilet more often than a regular person. But, you know, a lot of, you know, 50 year old women go to the toilet a lot anyway. They, you know, I'm, you know, when it when I'm out, I'm cautious of how much liquid I've had just in case. So I suppose that's sort of a bit of a downside. You know, I have to get up in the middle of the night that a lot of people get up in the middle of the night that are my age. So, you know, I just never did before. But, you know, I do now. So I have to say, my quality of life is excellent. I count my lucky stars every day. And I think as a result of this experience, you know, my two girls and myself are just more accepting of things that are happening around us and, you know, and of other people. And, you know, if someone's grumpy towards you, you don't know what's going on in their life. You don't know, you know, because from the outside looking in at me, you would have had no idea that I was facing this. You know, I had this life threatening disease and I was facing these major decisions. So I*

*think we've all come to appreciate each day even more and that the time that we have with each other. So in some respects, I think it's changed everyone's outlook on life and maybe made us even better people.*

*Participant 032\_2022AUBLC*

**Participant describes no impact on quality of life**

*No, it hasn't. I think that, um, you know, it's still pretty close and it's going really well. We've got 14 grandchildren*

*Participant 044\_2022AUBLC*

*No, I don't think so. Our quality of life is still the same.*

*Participant 007\_2022AUBLC*

**Participant describes an overall positive impact on quality of life**

*Yeah, that's right. I suddenly realised that, you know, these things are important and they take, they've taken a different course of interest in, in, you know, my activities and my health and what I'm doing and what tests and then what the outcomes are supposed*

*to be and all that stuff. So it's only improved that way and the way we've been able to talk about things like, you know, wills and all that sort of stuff that you might say, God, they might not be interested in. You know, you put a bit more thought into those things, how you handle your affairs and get your face in check and particularly in another chance, like a terrible thing. But, you know, um, in, in your life, every, everybody has roles and mine to some extent has been technology. And so it's about, it's about, you know, what would happen if I wasn't here? How, how do the bills get paid and all the accounts and things that you have and emails and stuff to have, you know, how would we ever and would someone else, my wife or anybody else and untangle all this new things? But no, I don't think it's been any negative side of it all at all. There's, there's been a generally been a positive sort of a more realistic approach to life. Life doesn't go on forever.*

*Participant 029\_2022AUBLC*

*Quality of life has improved because at the moment it has improved because I'm in remission.*

*Participant 008\_2022AUBLC*

**Table 8.1: Impact on quality of life**

Impact on quality of life	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes an overall negative impact on quality of life	14	28.57	3	15.00	5	50.00	4	28.57	12	27.27	2	40.00	2	11.76	12	37.50
Participant describes some negative impact on quality of life	12	24.49	7	35.00	2	20.00	2	14.29	11	25.00	1	20.00	4	23.53	8	25.00
Participant describes an mix of positive and negative impacts on quality of life	12	24.49	4	20.00	3	30.00	5	35.71	12	27.27	0	0.00	6	35.29	6	18.75
Participant describes no impact on quality of life	10	20.41	5	25.00	2	20.00	1	7.14	8	18.18	2	40.00	3	17.65	7	21.88
Participant describes an overall positive impact on quality of life	9	18.37	6	30.00	1	10.00	1	7.14	8	18.18	1	20.00	4	23.53	5	15.63
Participant describes a minimal impact on quality of life	8	16.33	6	30.00	0	0.00	0	0.00	6	13.64	2	40.00	6	35.29	2	6.25
Other/No response	7	14.29	1	5.00	2	20.00	3	21.43	6	13.64	1	20.00	5	29.41	2	6.25

Impact on quality of life	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes an overall negative impact on quality of life	14	28.57	9	31.03	4	21.05	2	13.33	11	33.33	5	25.00	8	28.57
Participant describes some negative impact on quality of life	12	24.49	8	27.59	4	21.05	4	26.67	8	24.24	4	20.00	8	28.57
Participant describes an mix of positive and negative impacts on quality of life	12	24.49	7	24.14	5	26.32	6	40.00	6	18.18	4	20.00	8	28.57
Participant describes no impact on quality of life	10	20.41	6	20.69	4	21.05	5	33.33	5	15.15	5	25.00	5	17.86
Participant describes an overall positive impact on quality of life	9	18.37	7	24.14	2	10.53	1	6.67	8	24.24	4	20.00	5	17.86
Participant describes a minimal impact on quality of life	8	16.33	6	20.69	2	10.53	3	20.00	5	15.15	5	25.00	3	10.71
Other/No response	7	14.29	2	6.90	5	26.32	1	6.67	6	18.18	0	0.00	7	25.00



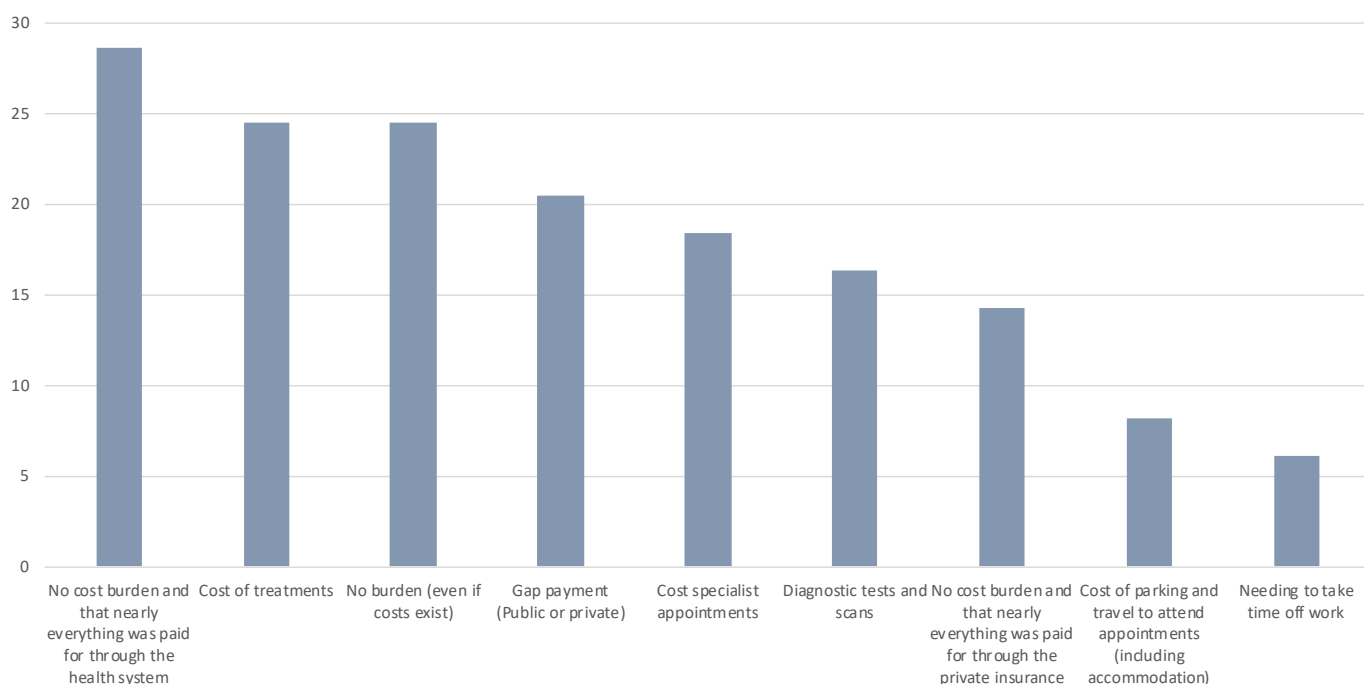


Figure 8.1: Impact on quality of life

Table 8.2: Impact quality of life – subgroup variations

Impact on quality of life	Reported less frequently	Reported more frequently
Participant describes an overall negative impact on quality of life	Invasive (Stage III)	Carer to someone with bladder cancer
Participant describes some negative impact on quality of life	Carer to someone with bladder cancer	University
Participant describes an mix of positive and negative impacts on quality of life	Female	Invasive (Stage III)
Participant describes no impact on quality of life	Invasive (Stage III)	Advanced (Stage IV)
Participant describes an overall positive impact on quality of life	-	Early (Stages 0 and I)
	-	Invasive (Stage III)

Table 8.3: Impact on quality of life (Reasons)

Impact on quality of life (Reasons)	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes negative impact on quality of life due to the side effects of treatment or symptoms of conditions that they need to manage	18	36.73	5	25.00	2	20.00	9	64.29	16	36.36	2	40.00	6	35.29	12	37.50
Participant describes negative impact on quality of life due to the mental and emotional impact of their condition	16	32.65	3	15.00	5	50.00	4	28.57	12	27.27	4	80.00	4	23.53	12	37.50
Participant describes negative impact on quality of life as a result of emotional strain on family or partner/change in relationship dynamics	14	28.57	4	20.00	4	40.00	6	42.86	14	31.82	0	0.00	6	35.29	8	25.00
Participant describes negative impact on quality of life, but that it was only temporary	12	24.49	4	20.00	3	30.00	5	35.71	12	27.27	0	0.00	2	11.76	10	31.25
Participant describes negative impact on quality of life due to intimacy problems	11	22.45	6	30.00	0	0.00	3	21.43	9	20.45	2	40.00	4	23.53	7	21.88
Participant describes negative impact on quality of life due to the need to plan for toilets or to manage stoma	10	20.41	2	10.00	2	20.00	5	35.71	9	20.45	1	20.00	5	29.41	5	15.63
Participant describes negative impact on quality of life as a result of reduced capacity for physical activity	8	16.33	3	15.00	0	0.00	5	35.71	8	18.18	0	0.00	2	11.76	6	18.75
Participant describes negative impact on quality of life as they are unable to travel or need to adapt significantly in order to travel	3	6.12	0	0.00	0	0.00	1	7.14	1	2.27	2	40.00	1	5.88	2	6.25
Participant describes negative impact on quality of life due to reduced social interaction	3	6.12	1	5.00	0	0.00	1	7.14	2	4.55	1	20.00	1	5.88	2	6.25
Participant describes positive impact on quality of life as the diagnosis brings people together	9	18.37	3	15.00	2	20.00	3	21.43	8	18.18	1	20.00	5	29.41	4	12.50
Participant describes positive impact on quality of life as the diagnosis helps you realise what is important (giving perspective)	4	8.16	0	0.00	1	10.00	3	21.43	4	9.09	0	0.00	1	5.88	3	9.38



Impact on quality of life (Reasons)	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes negative impact on quality of life due to the side effects of treatment or symptoms of conditions that they need to manage	18	36.73	11	37.93	7	36.84	7	46.67	11	33.33	9	45.00	9	32.14
Participant describes negative impact on quality of life due to the mental and emotional impact of their condition	16	32.65	9	31.03	7	36.84	7	46.67	9	27.27	7	35.00	9	32.14
Participant describes negative impact on quality of life as a result of emotional strain on family or partner/change in relationship dynamics	14	28.57	7	24.14	7	36.84	5	33.33	9	27.27	5	25.00	9	32.14
Participant describes negative impact on quality of life, but that it was only temporary	12	24.49	8	27.59	4	21.05	3	20.00	9	27.27	4	20.00	8	28.57
Participant describes negative impact on quality of life due to intimacy problems	11	22.45	7	24.14	4	21.05	2	13.33	9	27.27	5	25.00	6	21.43
Participant describes negative impact on quality of life due to the need to plan for toilets or to manage stoma	10	20.41	5	17.24	5	26.32	5	33.33	5	15.15	6	30.00	4	14.29
Participant describes negative impact on quality of life as a result of reduced capacity for physical activity	8	16.33	6	20.69	2	10.53	0	0.00	8	24.24	3	15.00	5	17.86
Participant describes negative impact on quality of life as they are unable to travel or need to adapt significantly in order to travel	3	6.12	2	6.90	1	5.26	2	13.33	1	3.03	2	10.00	1	3.57
Participant describes negative impact on quality of life due to reduced social interaction	3	6.12	2	6.90	1	5.26	1	6.67	2	6.06	2	10.00	1	3.57
Participant describes positive impact on quality of life as the diagnosis brings people together	9	18.37	6	20.69	3	15.79	1	6.67	8	24.24	3	15.00	6	21.43
Participant describes positive impact on quality of life as the diagnosis helps you realise what is important (giving perspective)	4	8.16	2	6.90	2	10.53	1	6.67	3	9.09	2	10.00	2	7.14

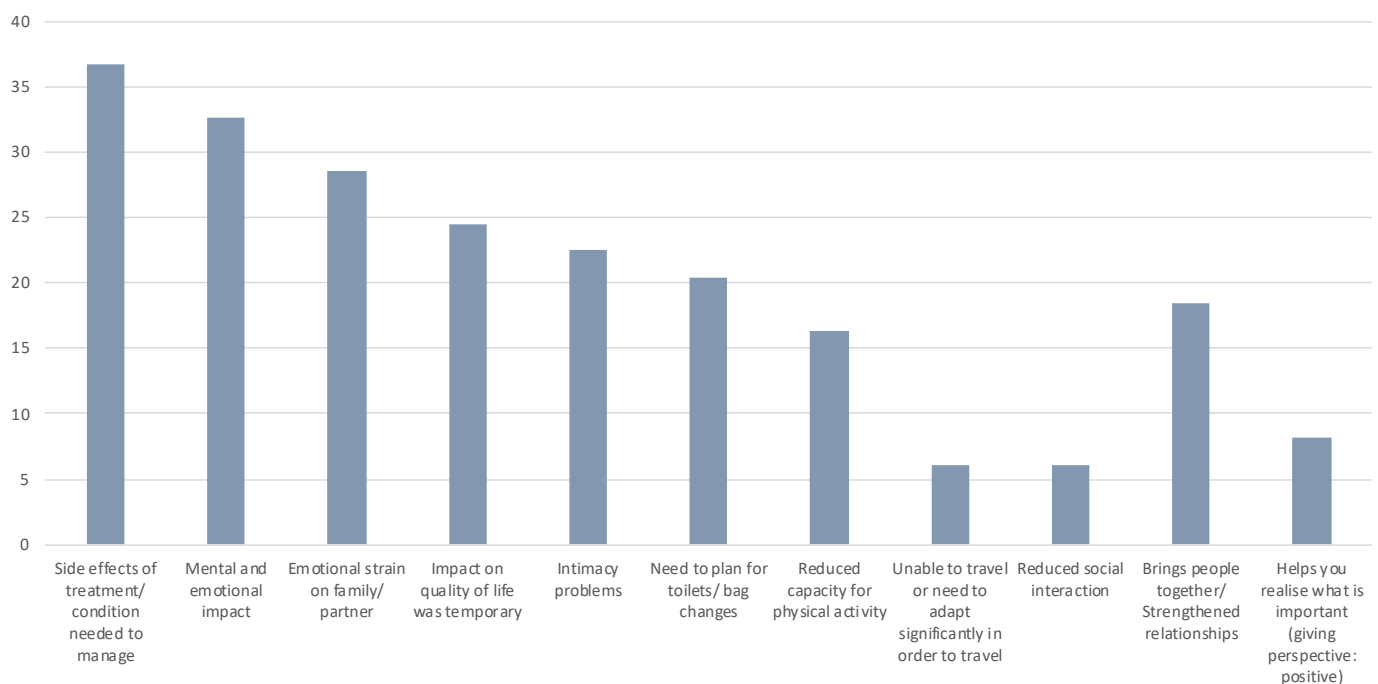


Figure 8.2: Impact on quality of life (Reasons)

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

Impact on quality of life (Reasons)	Reported less frequently	Reported more frequently
Participant describes negative impact on quality of life due to the side effects of treatment or symptoms of conditions that they need to manage	Early (Stages 0 and I) Invasive (Stage III)	Advanced (Stage IV)
Participant describes negative impact on quality of life due to the mental and emotional impact of their condition	Early (Stages 0 and I)	Invasive (Stage III) Carer to someone with bladder cancer Regional or remote
Participant describes negative impact on quality of life as a result of emotional strain on family or partner/change in relationship dynamics	Carer to someone with bladder cancer	Invasive (Stage III) Advanced (Stage IV)
Participant describes negative impact on quality of life, but that it was only temporary	Carer to someone with bladder cancer Female	Advanced (Stage IV)
Participant describes negative impact on quality of life due to intimacy problems	Invasive (Stage III)	Carer to someone with bladder cancer
Participant describes negative impact on quality of life due to the need to plan for toilets or to manage stoma	Early (Stages 0 and I)	Advanced (Stage IV) Regional or remote
Participant describes negative impact on quality of life as a result of reduced capacity for physical activity	Invasive (Stage III) Carer to someone with bladder cancer Regional or remote	Advanced (Stage IV)
Participant describes positive impact on quality of life as the diagnosis brings people together	Regional or remote	Female

## Impact on mental health

In the structured interview, participants were asked if there had been an impact on their mental health. There were 38 participants (77.55%) who gave a description suggesting that overall there was some impact on their mental health and 10 participants (20.41%) who gave a description suggesting that overall there was no impact on mental health.

### Participant describes that there was at least some impact on mental health

*I am on anti-depressants, which I never used to be on prior to going into having bladder cancer. So that's one thing that's come into play. Um. The other thing that that I have now, at long last, I've access to a, um, a psychiatrist psychologist that's been working with me to, uh, I suppose to unpack some of the issues, mentally mental issues that of sort of encountered, encountered since my surgery. Um, so yeah, it definitely has had impacts. Um, and I look, to be honest, I think it will continue to have an impact. So that is the need for me to have access to a mental health professional is probably much more, almost. My need for mental health professional is probably more than what I need an oncologist at the moment. Does that make sense?*

*Participant 035\_2022AUBLC*

*Obviously because you're always sort of worried is it going to be all right? Is the bag going to be all right. And then. Well, you know, it's just a different way to just get on with it and I see patients a lot worse off than me.*

*Participant 018\_2022AUBLC*

*Yes, it certainly has over time. You know, you don't get your bladder removed without a few major issues, but, you know, there's certainly over the years I have I have often chosen to seek some help to work through stuff. So that's something that I do. I do for myself whenever I need it. So I have a few different avenues of that and. And. And that's really helped me.*

*Participant 026\_2022AUBLC*

*Um, you know, everyone has scan anxiety, so before you're about to have a major scan, no matter what,*

*even five years on, everyone has major scan anxiety. You know, I think it's affected me that, you know, whereas before you had a pain in your knee, you would think, oh, you know, I must have done that when I was, you know, doing the latest work out or something. But now you think, oh, that pain wasn't there before. Why have I got that pain? I think it's very conscious of all the niggles in your body, whereas before you weren't. I wasn't that conscious of all the niggles in my body. Scan anxiety is a real thing. Everyone has it. I don't know anyone with any kind of cancer that doesn't feel anxious when they have the scan and then waiting for the results and then actually getting the result that everyone has it. It's, it's very stressful no matter how many years have gone by that you've been cancer free. So, you know, so I obviously never had that before. But you know, you know, you sometimes wake up and you think, oh, gosh, you know, what if, um. But I have to say, I try and just, you know, give my best possible life and continue to try and be healthy and, and keep moving forward.*

*Participant 032\_2022AUBLC*

### Participant describes that there was no impact on mental health

*I don't know. It hasn't affected me. Just carry on*  
*Participant 013\_2022AUBLC*

*Um, not mentally, really, because I was like, I was, but I didn't really. I never thought I was going to die from cancer. Um, again, I feel like I've had cancer for 5 minutes, and then if you know, it's gone. Yeah. Yep. So not mentally dismal.*

*Participant 022\_2022AUBLC*

*I've always been very good with my mental, emotional health. I look after I think I look after it quite well. So I just needed something to focus on. So I focused on because I've been jumping out of aeroplanes for 25 years. And so I just got I guess more deeply into that as a, as a distraction. And yeah, so I didn't know it didn't affect my quality of life at all.*

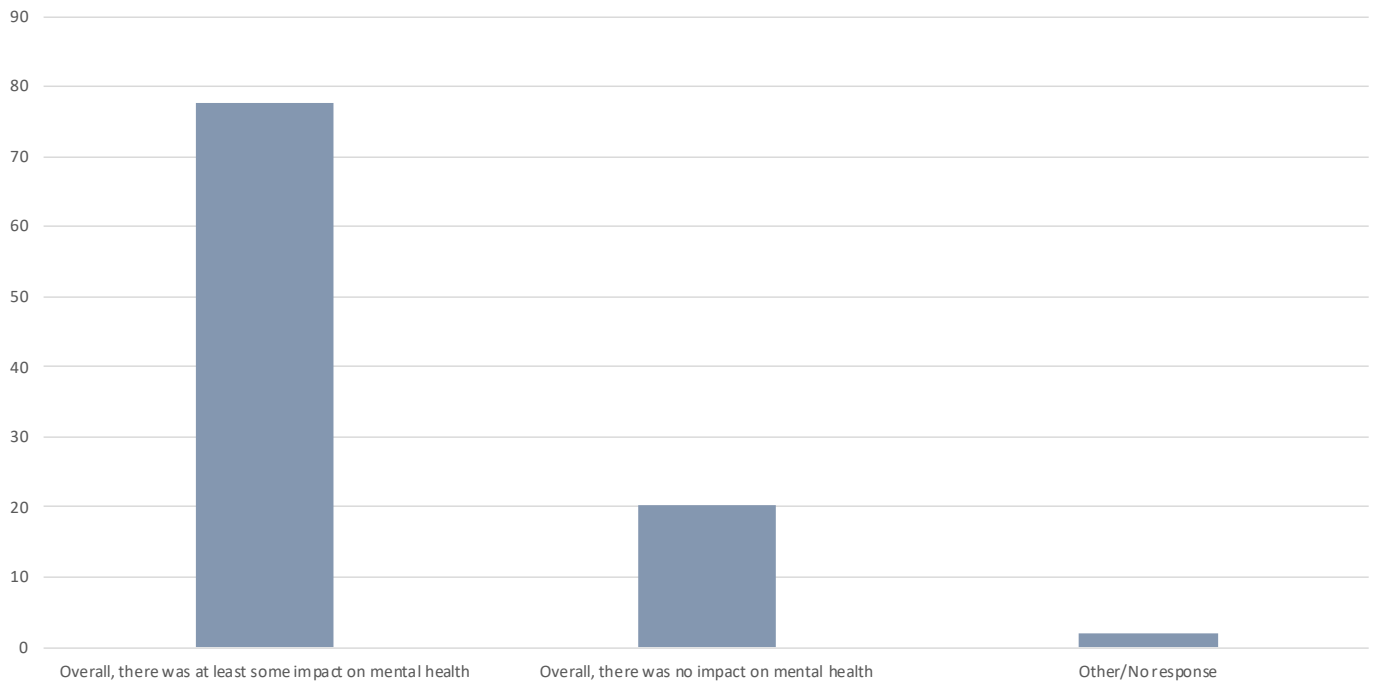
*Participant 020\_2022AUBLC*

**Table 8.5: Impact on mental health**

Impact on mental health	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes that there was at least some impact on mental health	38	77.55	16	80.00	5	50.00	12	85.71	33	75.00	5	100.00	14	82.35	24	75.00
Participant describes that there was no impact on mental health	10	20.41	4	20.00	5	50.00	1	7.14	10	22.73	0	0.00	3	17.65	7	21.88
Other/No response	1	2.04	0	0.00	0	0.00	1	7.14	1	2.27	0	0.00	0	0.00	1	3.13

Impact on mental health	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes that there was at least some impact on mental health	38	77.55	21	72.41	16	84.21	12	80.00	25	75.76	17	85.00	20	71.43
Participant describes that there was no impact on mental health	10	20.41	7	24.14	3	15.79	3	20.00	7	21.21	3	15.00	7	25.00
Other/No response	1	2.04	1	3.45	0	0.00	0	0.00	1	3.03	0	0.00	1	3.57



**Figure 8.3: Impact on mental health**

**Table 8.6: Impact on mental health – subgroup variations**

Impact on mental health	Reported less frequently	Reported more frequently
Participant describes that there was at least some impact on mental health	Invasive (Stage III)	Carer to someone with bladder cancer
Participant describes that there was no impact on mental health	Advanced (Stage IV) Carer to someone with bladder cancer	Invasive (Stage III)

### 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 way that participants reported managing their mental and emotional health was describing the importance of family and friends (n=19, 38.78%). Other participants described the importance of physical exercise (n=11, 22.45%), mindfulness and/or meditation, consulting a mental health professional (n=9, 18.37%), and maintaining social, lifestyle changes, and hobbies (n=7, 14.29%). There were 11 participants (22.45%) that described no activities to maintain mental health.

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

**PARTICIPANT:** You know? Yeah. I mean, I'm pretty, pretty strong and I just know that I'm going to do I've got to get up and I've got to do stuff and actually if anything. I've started to look after my physical and emotional health more than I was

**INTERVIEWER:** Go to yoga. You do your over 60s class.

**PARTICIPANT** Yes that right, I do yoga, I do my over 60s class. We walk, walk, well when we can with all this bloody rain

*INTERVIEWER: Yeah, that's good. That's good for mental health.*

*INTERVIEWER: Yeah. Yeah. So when.*

*PARTICIPANT: I got a really good support network around me.*

*INTERVIEWER: Excellent.*

*PARTICIPANT: And my Friends and my neighbours, they were. Wonderful.  
Participant 004\_2022AUBLC*

*I'm just I think having a couple of close friends that I could talk to about it in my life and helped and I did a bit of exercise, I think helps you just, you know, working full time always distraction are good to, so it just keeps you busy and, you're not, dwelling on on negative things, which is there. But as I think at times, I definitely, and especially early on was very concerned and it would affect me sometimes when I'd think about it well, I'd often think about it, but again, didn't want to talk about it too much.  
024\_2022AUBLC*

*Well, I have. I have an amazing wife and three children. Um, well, he just told me so and, you know, a few close friends. So that was. Being able to be around them and talking to them was good.  
Participant 027\_2022AUBLC*

**Participant describes the importance of physical exercise**

*I try to walk exercise and that's the main thing. Yes, it did affect me very badly two, three years ago. But I mean, as I come closer each procedure that helps me, you know, obviously I get quite anxious about it. I get very anxious when I go, you know, into the procedure at the hospital or whatever it is.  
Participant 008\_2022AUBLC*

*Yes, not really. We do. We make sure that we exercise regularly. So every night we go home, we walk the dog for 20 to 30 minutes. And that's, that's definitely beneficial.  
Participant 010\_2022AUBLC*

*Going for a walk with NAME, I think that helps my mental health that we go walking for probably an hour and a half every morning. That, yeah, that bond I've built with NAME been really good for me. Mental*

*health. And yeah, it's been a really good bond that we've got between ourselves. I'm just really lucky that he lives so close from. Yeah, we can yeah. Walk and we can talk. That's yeah.  
Participant 044\_2022AUBLC*

**Participant describes using mindfulness and/or meditation**

*Um, well, counselling or I actually ended up doing studies, so I ended up studying Mind-Body Medicine and so that was really beneficial for me. And that was, that was to help me deal with, with my health and my life and. So. And then I end up doing a journey practitioner course, which is really beneficial. So all of those things. So it means that I now wouldn't hesitate. If I feel like anything's getting on top of me, then I will deal with it. I'll either go and have a journey session with somebody or a book in some counselling or um.  
Participant 026\_2022AUBLC*

*Look, I did quite a lot of sort of self-hypnosis and listen to support the CDs, you know. Calming ones. And I can't even remember them all now moment, my sister sent me a whole load of, not quite meditation, but that kind of thing. You know, calming stuff. That was what I use more than anything. To try and keep myself calm. And it was looking back and it was quite, you know, at times when you when you. Go to bed, like most of us. The minute you lie down, everything goes round and round in your head. And you're trying to find a place for all and trying to sort of get your head to calm down. Yeah. So that that was difficult.  
Participant 003\_2022AUBLC*

**Participant describes no actions or activities to maintain mental health**

*I don't know. It hasn't affected me. Just carry on  
Participant 013\_2022AUBLC*

*PARTICIPANT: Um, I guess, uh, it might make me a bit more anxious. Um, and. No, no, I don't do anything. As in see anybody about it. No, no. Hmm. Okay.*

*INTERVIEWER: What are some of the things? Yeah. Go on.*

*PARTICIPANT: No, I just. I probably should. Go back to the GP and say, I have been feeling a bit anxious lately. So yeah, but I haven't. I find it hard to get into a GP.  
Participant 025\_2022AUBLC*

**Participant describes consulting a mental health professional**

*Uh, well it does a bit. Well, that has much, and the doctors mainly look after it. I've been to a psychiatrist and a psychologist and, uh, I'm still under them if I need them. At the moment. I'm travelling alright. But I've got some, uh, some, uh, antidepressants to keep me in focus on that.*

*Participant 007\_2022AUBLC*

*I am on anti-depressants, which I never used to be on prior to going into having bladder cancer. So that's one thing that's come into play. Um. The other thing that that I have now, at long last, I've access to a, um, a psychiatrist psychologist that's been working with me to, uh. I suppose to unpack some of the issues, mentally mental issues that of sort of encountered, encountered since my surgery. Um, so yeah, it definitely has had impacts. Um, and I look, to be honest, I think it will continue to have an impact. So that is the need for me to have access to a mental health professional is probably much more, almost. My need for mental health professional is probably more than what I need an oncologist at the moment. Does that make sense?*

*Participant 035\_2022AUBLC*

*PARTICIPANT: And then I had my surgery. And then when I was told that I didn't actually need chemotherapy, I. That's kind of and that was only probably about three months ago. Um, that was kind of when the will sell off. And now I'm suffering depression and anxiety. So yeah, it's taken a big toll. It's just taken about a year to actually come out.*

*INTERVIEWER: Mhm. How are you managing that. Um, those impacts.*

*PARTICIPANT: I'm sorry, I'm seeing counsellors regularly and I'm also, I've been prescribed with a low dose of antidepressants.*

*Participant 009\_2022AUBLC*

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

*Uh, I try a lot of things. Um. Try to go walking. Uh, try to do things I enjoy. Visiting friends, being outdoors. Um. Yeah. That kind of stuff.*

*Participant 005\_2022AUBLC*

*So I like listening to music and then I go to music concerts and stuff like that. It's nice, walking on the beach with the dogs, you know? So yeah, the dogs can really be, so things like that. It's sometimes I go for swimming, but I have to, really it has to be managed quite carefully, it's a pain. But you know, and we've got a place LOCATION, a beach place. So we get down there and it's really nice. Yeah. So do those sort of things.*

*Participant 018\_2022AUBLC*

*Yeah. Yeah, I know. I have this, um, I, I really, really feel it. Um, I did take up some hobbies just before by the cancer. Things are not done ever before, like painting and stuff like that and art and, and spending, spending time with, with friends, I suppose, and, uh, going that extra, extra mile as far as ringing people that, that's also communicating with people with that. That's also part of COVID as well, taking that extra time. Yeah, I don't think it's necessarily about bladder cancer. It does give you something to talk about. Of course, people will have a reason for ringing you as well and then asking how you are, which is um, from that point of view is actually a nice thing that, and you do the same with them. You appreciate your friends that have got, you know, a heart problem or some other problem.*

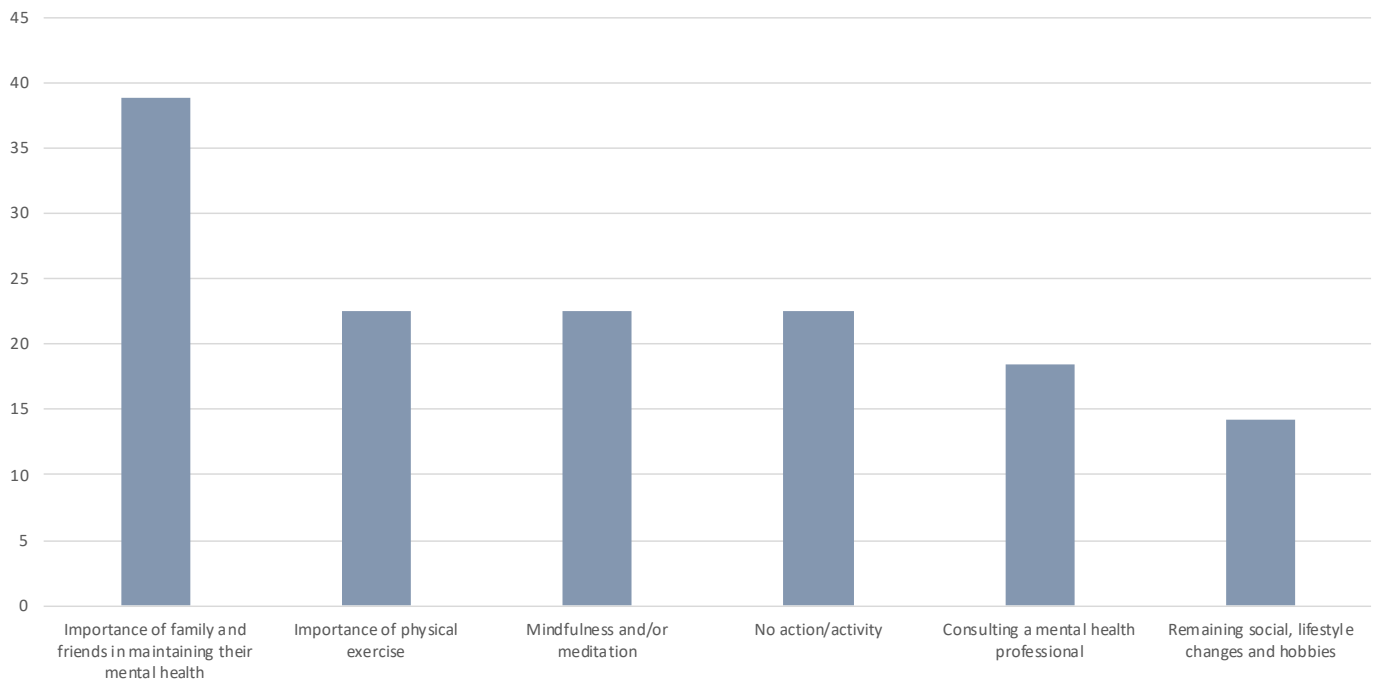
*Participant 029\_2022AUBLC*

**Table 8.7: Regular activities to maintain mental health**

Regular activities to maintain mental health	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes the importance of family and friends in maintaining their mental health	19	38.78	7	35.00	4	40.00	5	35.71	16	36.36	3	60.00	5	29.41	14	43.75
Participant describes the importance of physical exercise	11	22.45	6	30.00	1	10.00	2	14.29	9	20.45	2	40.00	5	29.41	6	18.75
Participant describes using mindfulness and/or meditation	11	22.45	5	25.00	2	20.00	4	28.57	11	25.00	0	0.00	6	35.29	5	15.63
Participant describes no actions or activities to maintain mental health	11	22.45	5	25.00	3	30.00	3	21.43	11	25.00	0	0.00	6	35.29	5	15.63
Participant describes consulting a mental health professional	9	18.37	2	10.00	1	10.00	5	35.71	8	18.18	1	20.00	2	11.76	7	21.88
Participant describes using coping strategies such as remaining social, lifestyle changes and hobbies	7	14.29	3	15.00	3	30.00	0	0.00	6	13.64	1	20.00	2	11.76	5	15.63

Regular activities to maintain mental health	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes the importance of family and friends in maintaining their mental health	19	38.78	12	41.38	6	31.58	4	26.67	14	42.42	7	35.00	11	39.29
Participant describes the importance of physical exercise	11	22.45	5	17.24	5	26.32	3	20.00	7	21.21	3	15.00	7	25.00
Participant describes using mindfulness and/or meditation	11	22.45	7	24.14	4	21.05	4	26.67	7	21.21	6	30.00	5	17.86
Participant describes no actions or activities to maintain mental health	11	22.45	5	17.24	6	31.58	3	20.00	8	24.24	3	15.00	8	28.57
Participant describes consulting a mental health professional	9	18.37	7	24.14	2	10.53	3	20.00	6	18.18	5	25.00	4	14.29
Participant describes using coping strategies such as remaining social, lifestyle changes and hobbies	7	14.29	3	10.34	4	21.05	2	13.33	5	15.15	3	15.00	4	14.29



**Figure 8.4: Regular activities to maintain mental health**

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

Regular activities to maintain mental health	Reported less frequently	Reported more frequently
Participant describes the importance of family and friends in maintaining their mental health	Regional or remote	Carer to someone with bladder cancer
Participant describes the importance of physical exercise	Invasive (Stage III)	Carer to someone with bladder cancer
Participant describes using mindfulness and/or meditation	Carer to someone with bladder cancer	Female
Participant describes no actions or activities to maintain mental health	Carer to someone with bladder cancer	Female
Participant describes consulting a mental health professional	-	Advanced (Stage IV)
Participant describes using coping strategies such as remaining social, lifestyle changes and hobbies	Advanced (Stage IV)	Invasive (Stage III)

**Regular activities to maintain health**

In the structured interview, participants were asked what were some of the things they needed to do everyday to maintain their health? The most common ways that participants reported managing their health were; being physically active (n=11, 22.45%), keeping busy or keeping a normal routine (n=11, 22.45%), and managing their stoma or incontinence (n=11, 22.45%). Other ways to maintain health were complying with treatment (n=7, 14.29%), socialising with friends

and/or family (n=7, 14.29%), maintaining a healthy diet (n=6, 12.24%), and the importance of self care e.g. more rest, support for housework etc. (n=5, 10.20%). There were 7 participants (14.29%) that described no activities to maintain health.



### **Participant describes being physically active**

*PARTICIPANT: And I don't know. The pandemic's also thrown a bit of a spanner in the works about that too somethings that I'd like to do that I haven't done. When we're in lockdown, um, I walk, I suppose. Walking helps me as I walk about 12 Ks a day.*

*INTERVIEWER: It's really good. Yeah. And with your dog early on.*

*PARTICIPANT: The dog. Yeah. Yeah. I've got a dog and I also bought one for my sister as well and. Yeah, yeah. Get that one out as well for the same sort of two or three K for my dog, two, three K separately for hers. They don't walk all together. Participant 001\_2022AUBLC*

*I suppose I just. Yeah. Try and maintain a good level of fitness. And I'd like to say get enough sleep. But, I don't know, because I'm also one that will. Well, especially if I'm going to the toilet, three, four, five, six, even, sometimes seven times a night. It's very hard to get back to sleep afterwards. And sometimes I. Then I'm awake for quite a while. Yeah. So. Yes, definitely. Sleep deprivation is a big part, is what I would say has been the effect of this. Participant 010\_2022AUBLC*

### **Participant describes keeping busy or keeping a normal routine**

*Exercise. Get out. Don't, don't just sit around thinking about things all the time. Yeah, exercise. I'm pretty lucky. I live, like, 5 minutes from the beach, so every day I go for walks on the beach. Just clear the head Participant 033\_2022AUBLC*

*Not at the moment just because the cancer has so far in remission, it's not affecting me at all. I do for my mental well-being. I've been trying to go to the gym once or twice a week. I've been walking, trying to do I can't do 10,000 a day, but I try and do 8000 a day. I'm finding that continuing working is good for my mental well-being. It makes me feel good about myself because I'm useful. And also the money's good. So I find mixing with friends and talking about all the other stuff and having fun really helps me as well. So I sort of try and just have a little those and keep myself in a positive frame as I can. It's all fallen, fallen down a little bit at the moment because of the operation. But up until then I was managing quite well. I thought, you know, remaining reasonably positive and getting on with life.*

### **Participant 036\_2022AUBLC**

*Um, I need to try and just get out of, in front of, you know, get myself, in a predicament that I can't get myself out like. So on a day to day basis, I make an effort of something as simple as getting out of bed, making the bed and getting dressed and going for a walk. And, you know, those kind of things. Like, I just need to try and set a routine for myself in order to tick off the boxes and say that I've done them. Because if I don't, I tend to get into a state that I can't get myself out of, and then I start thinking about everything that's happened. And then I start over thinking, what if the cancer is going to come back? You know, all those kind of questions. So yeah, on a day to day basis, I really have to take control and just move on with life. Participant 009\_2022AUBLC*

### **Participant describes managing their stoma or incontinence**

*I still I still wear a pad as a precaution. Not every time. But, you know, if I'm not feeling well, I certainly wear a pad. You know, so just in case I get the sudden, you know, the urgency. But in general, I mean, as I said, I said in general, I can hold off five or 10 minutes now, which I certainly couldn't do that three years ago, and that would be within 30 seconds. If that. Participant 008\_2022AUBLC*

*Well, I don't have to do too much basically. It's a matter of just making sure everything is kept clean and tidy. You know, I've got to rinse the bag out every morning or change your bag every couple of days, which is, you know, a little bit, you know, just a few wipes and a couple of tissues. You know, it's not really, you know I've got a separate bath mat and just a couple of different little things that, you know, I've just got to be aware of and just go on. You know, you make a few mistakes on the way, a few spillages. Most people I know that have been through it, they have the same issue. Yeah, but apart from that, yeah no dramas Participant 011\_2022AUBLC*

*Oh, just have to change a bag every two days now. Or, if I have this swim, I change it straight away. And so it's just really care the stoma. And I know a patient told me her husband got constant UTIs for the first six months when he was looking after his stoma and I thought, well, I'm probably lucky I'm a HEALTHCARE PROFESSIONAL and I've looked after those before because I'm very careful. So I haven't had any problems with UTIs at all, which has been good. But it*



does change shape sometimes. And it's, you know, a bit ugly, you know, and somebody said to me, Oh, what have you called your stoma? We have to do that. [LAUGHS]. So I said, If I if I could call it anything, it would be, oh, what's her name? Ripley! Because she was in alien, you know, Sigourney Weaver. Oh yeah, she was that Alien. And I said, Oh, she was a really strong woman, but she was dealing with an alien and that's what it looks like. Yeah. So I better be call it that than anything other than a bit of a nuisance for which, I'm fond of it because it saved my life. So you have, you know, true feelings, but it is a bit of a nuisance, too. Yeah.

Participant 018\_2022AUBLC

### Participant describes the importance of complying with treatment

I can do everything I need to do. Okay. So it's just now it's just once every 12 months I have to go through surveillance. Apart from them? No, nothing

Participant 020\_2022AUBLC

Nothing, really. I've just gone on as usual. The only thing I've done is Doctor NAME he said, you should try and do this, what do they call it? Urination rehab or retraining or something, you know, where I drink a lot of water and I got a hold off trying to build up my bladder capacity. So I've just been doing that. I did that for about two months now, have done it, didn't do too much while I had COVID. But so that's the only thing I've done. Try to increase my bladder capacity. So I'm not going to the toilet. During the day I can go 6 hours with out going to the toilet, it is only at night time when I go to sleep. So that's I've done that and that's really helped. Plus the tablet that he and tablet that he gave me, which has helped. So quality of life is at the moment, it's probably as good as I've had since I got diagnosed.

Participant 021\_2022AUBLC

Nothing. It doesn't really does not doesn't really affect my life in any way at the moment, other than needing to make allowances for the three monthly cystoscopy and all the other tests that sit around that I have to plan those. And I have a diary where they're all planned. Um, other than that it has no impact on my life or ability to do the things that we want to do. I mean, travelling and that is sometimes a bit tricky when you've got things happening, but once every three months it's not too bad is the good, good catch in the middle where we can travel and do the things catch up that we need to do. There's a lot of other

things that eat into those into that anyway, that ability.

Participant 029\_2022AUBLC

Yeah, the carer activities, yes. Yeah. Um, and then, like, making sure that I'm there and. After every, you know, sort of BCG or, you know, investigations or surgeries. Yeah. So making sure that I'm there to, like, give him his pain meds and, you know, providing the food. Yeah, whatever, you know, I'm making taking on all the parenting. And so he can rest.

Carer 003\_2022AUBLC

### Participant describes socialising with friends and/or family

**PARTICIPANT:** And so the things I need to do, I need to. I stopped, I'd already stopped drinking to a certain extent. And I completely I stopped drinking, which I think now there's a lesson that I should have learnt about 40 years ago. But anyway, we get there eventually and what else?, just and I continue to do those stretching exercises and I try and exercise regularly. Was that the question I lost it a bit there?

**INTERVIEWER:** What are some of the things that you need to do on a regular basis

**PARTICIPANT:** Exercise, yeah exercise. I'm feeling I'm probably feeling a bit less cheerful this week because, because I haven't been able to go out of the house with COVID and I haven't really been able to exercise. But normally I would be you know, I'd be doing some exercises, keeping myself busy that way. I think I think I'm lucky that, and this was unplanned, but my family all live nearby and my son and daughter and their family. And I've got a sort of a reasonable group of mates, so they're not close friends. I haven't been to most of their houses, but you know, we catch up and we talk and sort of that mateship, stuff I guess.

Participant 006\_2022AUBLC

Um, oh, God, I just get up in the morning and I like to, like, I like to have things. I can't stay home all day. I it would drive me insane. I either have to go for a walk with a friend or go out for coffee or baby, you know, look after my grandkids. Um, yeah. I like to have. I like to be able to do something every day. I don't think I've ever stayed. I mean, I don't like staying home, even if, even if it's only out for a couple of hours, at least you're outside. You're getting fresh air and talking to somebody.

Participant 039\_2022AUBLC

### Participant describes no activities to maintain health

*Oh, nothing really, because I've been it's been off and on, has been there and I've treatment and it has gone away. And so it's sort of come, you know, nothing. Nothing sort of permanent.  
Participant 012\_2022AUBL*

*Not much. Nothing I can remember specifically.  
Participant 019\_2022AUBL*

### Participant describes maintaining a healthy diet

*Yeah, so it definitely that has improved and that's something that's a daily thing. I've just had a bit of a look to see what helps bladder and urinary tract and all that crappy stuff. Um, excuse the pun and you know, there's some particular vitamins that are meant to help and sometimes take those and sometimes don't. But generally getting, you know, organic or locally grown fruit and veg is a better option than the Coles and Woolworths crap. So. Just little things like that that make me I'm sure it's psychosomatic up to a point. A part of it is real as well. But getting healthy as a healthy person.  
Participant 030\_2022AUBL*

*Well, I'm I try and stay fit and healthy. So I walk. I do regular workouts. I eat well. Um. You know, I don't drink a lot. Um, I do still have the odd glass of wine,*

*so. But I don't drink a lot. Um. Um. Um, you know, I try and drink lots of water because that's, that's good for you. Um. That's basically it.  
Participant 032\_2022AUBL*

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

*I'm more aware of. What's going on with my body. I think so. Um. And I'm trying to, you know, take better care.  
Participant 027\_2022AUBL*

*I suppose I just. Yeah. Try and maintain a good level of fitness. And I'd like to say get enough sleep. But, I don't know, because I'm also one that will. Well, especially if I'm going to the toilet, three, four, five, six, even, sometimes seven times a night. It's very hard to get back to sleep afterwards. And sometimes I. Then I'm awake for quite a while. Yeah. So. Yes, definitely. Sleep deprivation is a big part, is what I would say has been the effect of this.  
Participant 010\_2022AUBL*

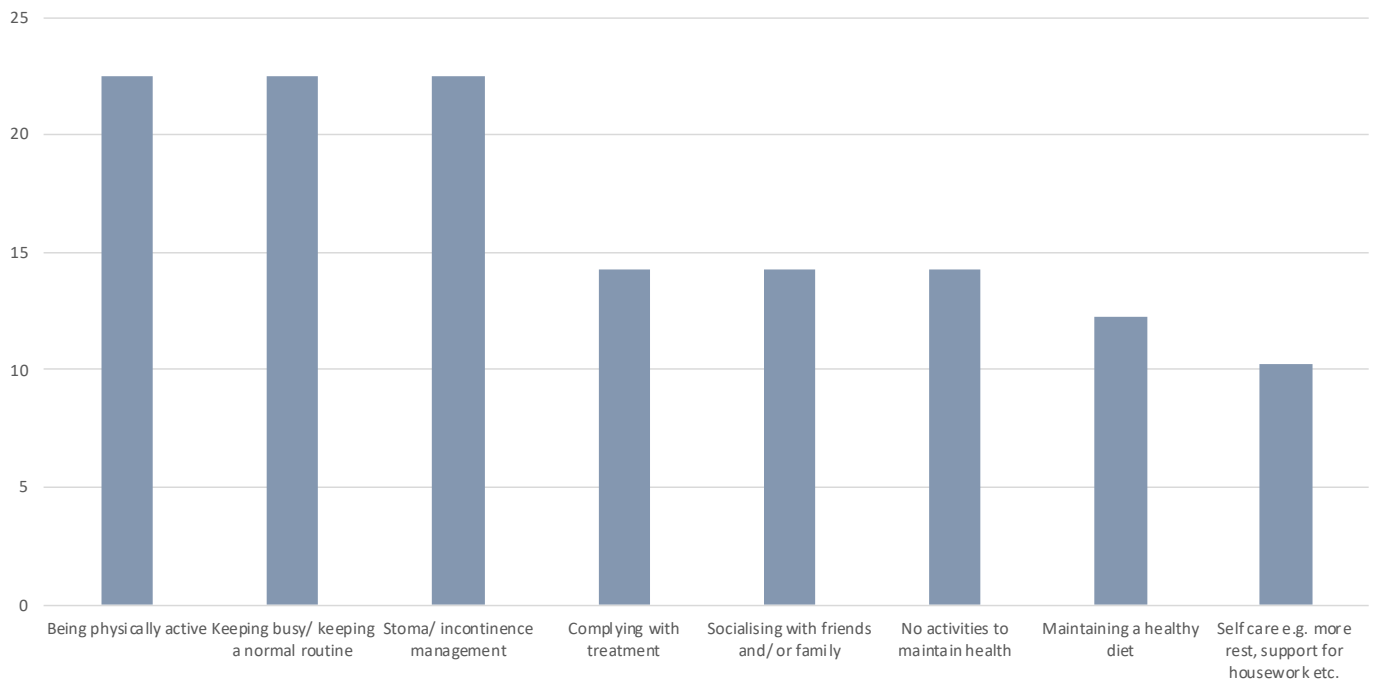
*Get plenty of rest. Drink plenty of water. Reduce the amount of alcohol I drink. Mm. Eat more healthy food. Exercise more.  
Participant 016\_2022AUBL*

**Table 8.9: Regular activities to maintain health**

Regular activities to maintain health	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes being physically active	11	22.45	6	30.00	1	10.00	4	28.57	11	25.00	0	0.00	5	29.41	6	18.75
Participant describes keeping busy or keeping a normal routine	11	22.45	4	20.00	1	10.00	5	35.71	10	22.73	1	20.00	4	23.53	7	21.88
Participant describes managing their stoma or incontinence	11	22.45	4	20.00	2	20.00	5	35.71	11	25.00	0	0.00	3	17.65	8	25.00
Participant describes the importance of complying with treatment	7	14.29	2	10.00	3	30.00	1	7.14	6	13.64	1	20.00	3	17.65	4	12.50
Participant describes socialising with friends and/or family	7	14.29	3	15.00	0	0.00	2	14.29	5	11.36	2	40.00	3	17.65	4	12.50
Participant describes no activities to maintain health	7	14.29	5	25.00	2	20.00	0	0.00	7	15.91	0	0.00	2	11.76	5	15.63
Participant describes maintaining a healthy diet	6	12.24	3	15.00	1	10.00	2	14.29	6	13.64	0	0.00	3	17.65	3	9.38
Participant describes the importance of self care e.g. more rest, support for housework etc.	5	10.20	2	10.00	2	20.00	0	0.00	4	9.09	1	20.00	3	17.65	2	6.25

Regular activities to maintain health	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes being physically active	11	22.45	5	17.24	5	26.32	2	13.33	8	24.24	3	15.00	7	25.00
Participant describes keeping busy or keeping a normal routine	11	22.45	7	24.14	3	15.79	1	6.67	9	27.27	5	25.00	5	17.86
Participant describes managing their stoma or incontinence	11	22.45	9	31.03	2	10.53	2	13.33	9	27.27	7	35.00	4	14.29
Participant describes the importance of complying with treatment	7	14.29	2	6.90	5	26.32	3	20.00	4	12.12	2	10.00	5	17.86
Participant describes socialising with friends and/or family	7	14.29	4	13.79	2	10.53	1	6.67	5	15.15	2	10.00	4	14.29
Participant describes no activities to maintain health	7	14.29	3	10.34	4	21.05	2	13.33	5	15.15	2	10.00	5	17.86
Participant describes maintaining a healthy diet	6	12.24	3	10.34	3	15.79	3	20.00	3	9.09	2	10.00	4	14.29
Participant describes the importance of self care e.g. more rest, support for housework etc.	5	10.20	3	10.34	2	10.53	4	26.67	1	3.03	3	15.00	2	7.14



**Figure 8.5: Regular activities to maintain health**

**Table 8.10: Regular activities to maintain health – subgroup variations**

Regular activities to maintain health	Reported less frequently	Reported more frequently
Participant describes being physically active	Invasive (Stage III) Carer to someone with bladder cancer	-
Participant describes keeping busy or keeping a normal routine	Invasive (Stage III) Regional or remote	Advanced (Stage IV)
Participant describes managing their stoma or incontinence	Carer to someone with bladder cancer University	Advanced (Stage IV) Mid to low status
Participant describes the importance of complying with treatment	-	Invasive (Stage III) University
Participant describes socialising with friends and/or family	Invasive (Stage III)	Carer to someone with bladder cancer
Participant describes no activities to maintain health	Advanced (Stage IV) Carer to someone with bladder cancer	Early (Stages 0 and I)
Participant describes maintaining a healthy diet	Carer to someone with bladder cancer	-
Participant describes the importance of self care e.g. more rest, support for housework etc.	Advanced (Stage IV)	Regional or remote

## Experience of vulnerability

In the structured interview, participants were asked if there had been times that they felt vulnerable. There were 42 participants (85.71%) who gave a description suggesting that overall they had experiences of feeling vulnerable, and 2 participants (4.08%) 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=25, 51.02%). There 13 participants (26.53%) that described feeling vulnerable when first diagnosed, first few months after diagnosis, while experiencing side effects from treatment or symptoms from condition (n=10, 20.41%), because of interactions with the medical team (n=8, 16.33%), and 8 participants (16.33%) described feeling vulnerable when having sensitive discussion (diagnosis, treatment decision). Other participants described feeling vulnerable when thinking about disease

course/incurable condition (n=5, 10.20%), being vulnerable when they have a loss of independence, e.g in hospital, recovering from surgery (n=5, 10.20%), and when first sent home after being hospitalised without the care/availability healthcare professionals (n=5, 10.20%).

### Participant describes being vulnerable during/after treatments

*Vulnerable. I don't know if that's the right word. Only when I was in the hospital to begin. I've never been in hospital. Had had nothing done to me. I couldn't even wipe my own bum after the operation*  
Participant 022\_2022AUBLC

*I would probably most when I first got out of surgery. It was very hard the first week because you never you you, don't think you're going to get out of bed ever again, you know, and especially maybe the first three*

*or four days. And then when you do get out of the hospital, you don't think you're going to be able to drag it out of bed and injure your arse into a shower and then get yourself something to eat. And, you know, it's just it's just a struggle to get everything done.*

*Participant 031\_2022AUBLC*

*Um. Probably the first four days after the surgery, very vulnerable where your being told what you have to do. He didn't want to do any of it. You have to do it because you know it's going to make the next day just a little bit easier. So probably then immediately after the surgery, when I came home and I had a catheter and I had to flush the catheter and manage all on my own. And, um, and. To give myself that clexane through injections, the blood thinning things. You know, you had to administer that yourself straight after the surgery. So, you know, you feel a bit vulnerable then because you think you are doing it right, you know? You know, you've got, you know, stitches and tubes. And so I think that was probably when I felt most vulnerable and then probably when they took out everything and I then had to use the neobladder on my own. I mean, I had support from the hospital, and if I knew if I had a problem, I could have called them. But that was probably, you know, during that period when I personally felt most vulnerable and I suppose, you know, initially after diagnosis as well.*

*Participant 032\_2022AUBLC*

*Every time I was catheterized very vulnerable, I hated it. I hated it with a passion. And one time, they were going to get a man to do it and I was prepared to walk out, a male nurse. I just spat the dummy. I said, I can't do that. I was just that was just my limit of having a male nurse catheterize me for some reason. And it was silly, but it was just me at the time.*

*Participant 036\_2022AUBLC*

**Participant describes being vulnerable when first diagnosed, first few months after diagnosis**

*Yes. Probably the first two weeks when I didn't really know what was going on. I just had this weird cancer. I felt quite vulnerable then. Then I started to gather information and report to people. Then once I, once that was over, the vulnerability went away. I just went back. Let's just deal with it.*

*Participant 020\_2022AUBLC*

*Yeah, yeah, yeah, right. From well, right. From being diagnosed, I thought, well, you know, what the hell? And then I was pretty, um anxious and sensitive, often*

*for weeks after. For even months probably. When you think about it.*

*Participant 027\_2022AUBLC*

*Well, I was pretty vulnerable for about the first six months. ... Really. Really, really, really frightening.*

*Participant 037\_2022AUBLC*

**Participant describes being while experiencing side effects from treatment or symptoms from condition**

*One time in particular, I felt vulnerable was after my surgery I was having I had, that I was running on high temperatures as well that then managed to settle down my temperature using a particular type of drug which I can't remember the name of. But one of the side effects of the drug was it, it stopped me from being able to verbally communicate my thoughts to my thought. Processes were going all over the place. So while it was helping in one respect, I couldn't communicate properly to say, Hey, I think it could be. This particular thing is every time you give me this drug, this is happening to me. I couldn't communicate that. And at that stage, I felt vulnerable. Um, I, I was lucky. My, um, my eldest daughter came to visit me with a partner who is also a doctor. And I was struggling, I, I struggled to, to get my view across to them. I basically had to go so slowly and then NAME who is the doctor understood that it was something about a drug that was not quite right. And he, but he actually spoke to it to the team and said, what? What are you are you giving him? And, and yeah, lo and behold, that stopped. Yeah. And that was good. Yeah. Vulnerability. Yeah. That, that definitely I felt very vulnerable at that point. Um, vulnerability also comes into play once you come home and. You've been so used to having, you know, being looked after in the hospital and now all of a sudden you come back and it's just yourself or yourself and your life coping with the situation that you've got. Yeah. And at that time, I felt vulnerable because I didn't think we knew enough about how to cope with day to day issues. And yeah, so starting the therapy or what happens really if I'm not feeling well, where do I go to?*

*Participant 035\_2022AUBLC*

*Oh, yes, absolutely. Yeah. Yeah. After especially initially when, you know, you don't know much about it. And within, I think two days of my having the first initial tumour removed and I was in hospital and my abdomen just kept blowing up and I'm about 53 kilos. And so I, my abdomen was blowing up with fluidity and to the point where I felt like, I just was commenting to my husband. I look like I'm 34 weeks*

*pregnant. This is ridiculous. What's going on? And then the same time, they'd taken my catheter out and they said, right, you need to void now. And what had happened was my bladder had ruptured. And so fluid as the fluid had leaked out of my bladder and into my peritoneal space to the point where. It was some even starting to be told by my lungs. And I was in a lot of pain that night. And I kept telling the nurses, this is not right. This is not right. I couldn't void, they put the catheter back in. Not much was draining*  
Participant 010\_2022AUBL

*Oh, yeah, work up in recovery room? And I thought, well, that's good, pains under control. And then all of a sudden it hit me like a truck and I had no pain relief whatsoever because they hadn't set PCA up. Yeah, and that was horrible. Anyways, they got the anesthetist and, and gave me something and knocked me out again, which was good, but that was really vivid. So that was pretty horrible. And also because I read my notes when I was in the ward, it's just you shouldn't. But it said something like, oh, pain relief or pain issues or something like that. Change of shift didn't have time to set PCA up or something along those lines. And I just thought, it's really poor. So probably in retrospect, I shouldn't have read my notes, but they were just sitting there. But that really annoyed me because I knew that the anesthetist already knew that it was a very painful operation, and she would have preferred to put a block in. But, you know. So, yeah, the attention to detail was pretty poor for that. So anyway, these things happen.*  
Participant 018\_2022AUBL

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

*When I was first diagnosed and my doctor, my sorry, my specialist told me what my treatment was going to be and what my cancer was. But didn't give me an option. They didn't give me a say in my own treatment. I was very vulnerable in that time because I just had to kind of back down and say, yep, right. I said that, so I do it kind of thing.*  
Participant 009\_2022AUBL

*Especially at the beginning of my when I was first diagnosed. And then when I was first diagnosed and then I was told it was more or less, you know, that I've got low grade. It's not a problem. It's just like, you know, just like getting skin cancers burn off, blah, blah. That went on for about two years. And then the cancer changed. And then I felt, you know, it changed*

*into a different type with a much higher risk. And then I felt vulnerable and then again, at that point.*  
Participant 016\_2022AUBL

*Right from the first time somebody says, sorry to tell you this old son, but you've got this very fatal cancer. That sort of makes you think a bit.*  
Participant 034\_2022AUBL

**Participant describes being vulnerable because of interactions with the medical team**

*At the beginning I felt, well, yes, after the first procedure. And then I was sick at home. And then I got the invoice about two weeks later, which said for the first time I had cancer. I was very vulnerable then, you know. And I rang my GP straight away and said, I haven't been told it's, you know, he put on a brave face and said, oh, well, the surgeon had to send away the specimen to the laboratory, which I understand the process. Yeah, but. But I don't recall. I feel very vulnerable because living by yourself and all that, you know, you're at home, unwell, bleeding all night. Frankly, you know, I didn't know whether to call the hospital or not. Um, now, you know, it passed within about four or five days, that very acute phase. And so very scary. It was very distressing. Yes. And you're isolated and you don't, you know. And the surgeon, as I said, his response when I saw him a month later was, well, I told you, Mr. NAME, I told you this when you came out of surgery, I said, well, I don't remember that I was so sick. Between the anesthetic and the bleeding. I don't remember him saying that at all. Yeah. And I'm not I'm not saying he didn't say it. I'm just saying I didn't hear it.*  
Participant 008\_2022AUBL

*PARTICIPANT: Oh, yes, absolutely. Yeah. Yeah. After especially initially when, you know, you don't know much about it. And within, I think two days of my having the first initial tumour removed and I was in hospital and my abdomen just kept blowing up and I'm about 53 kilos. And so I, my abdomen was blowing up with fluidity and to the point where I felt like, I just was commenting to my husband. I look like I'm 34 weeks pregnant. This is ridiculous. What's going on? And then the same time, they'd taken my catheter out and they said, right, you need to void now. And what had happened was my bladder had ruptured. And so fluid as the fluid had leaked out of my bladder and into my peritoneal space to the point where. It was some even starting to be told by my lungs. And I was in a lot of pain that night. And I kept telling the nurses, this is*



*not right. This is not right. I couldn't void, they put the catheter back in. Not much was draining*

*INTERVIEWER: And then I got to interject, just so I don't miss anything yet, but I just want to focus on what they needed to do. Like what you need to do to address or overcome that vulnerability.*

*PARTICIPANT: Okay, so what I'm what I'm saying it saying then is that well, the nursing staff eventually listened to me and got a doctor and to see me, the doctor, I had to convince there was something wrong. And it was nine, 9:00 at night. She reluctantly sent me for a scan. And of course, the scan showed this had happened. So I felt a bit vindicated. But yeah, just to be listened to, to be examined properly. And I felt that was very, very, very remiss of especially the doctor. And she was to just a at that point she's a resident. She wasn't sure of my specialist and my also should have come in to see me after that, but she didn't. So because of that, I had to have a catheter, go home with a catheter and have it in for two weeks and manage it at home and have scans at my expense to check when it healed. So yeah to be, to b,e felt very vulnerable there in that you pay for you pay the health insurance, you pay for a specialist and then not even looking after you properly and you don't want to have to be your own advocate shouldn't have to be I mean, you might have family members, but in my family, I was the one with the medical knowledge, not my husband, not my sister. And all I could do is sort of say, hey, look, she's not usually a whinger. She's not.*  
*Participant 010\_2022AUBLC*

*Early, only the first two months. I thought, I thought you know, I might be in a lot of trouble. Yeah, especially when I was at one of the doctors before hospital. I asked him when I came out of the anesthetic and they came and saw me when I woke up. So I said how did it go and he said don't no mate. I went ok. He was a young bloke, and I said, Well, what's the consequences? He said. if worst comes to worst, you'll just have to just get another bladder. And he just walked away all the way. That was when I really freaked out.*  
*Participant 021\_2022AUBLC*

**Participant describes being vulnerable when thinking about disease course/incurable condition**

*Ah yeah. A number of times. I can't say, I can't say anything specifically but I think anyone and again I've mentioned some of my mates have had various*

*cancers. I think everyone who goes through actually gets cancer suddenly, you know, like, you know, we all know we're going to die. But yeah, one day, one day. But suddenly they are that you're looking you're looking at a lot closer thinking, oh, okay, this is real. So yeah, I felt vulnerable just in that sort of up and down way that you do when you when you get the diagnosis.*

*Participant 006\_2022AUBLC*

*I think everybody goes through this. Anyone who has. Cancer. It's a bad word. You know, I mean, there's a lot of fear attached with this word. And the truth is, you know, many people don't live through it, you know? I mean, it is. It's called a high, you know, death rate.*

*Participant 028\_2022AUBLC*

*That's a very vulnerable place because you have no idea what's going to happen. I'm looking at my wife and kids going, it's actually easy for me because if I die, I'm dead. But with these guys, they're going to go on without me. So it was me having to lose my wife. It would be absolutely horrendous. So it's actually as hard, if not harder, on the partners or the families as it is to the person that's actually getting cancer, I think.*

*Participant 030\_2022AUBLC*

**Participant describes being vulnerable when they have a loss of independence, e.g in hospital, recovering from surgery**

*Vulnerable. I don't know if that's the right word. Only when I was in the hospital to begin. I've never been in hospital. Had had nothing done to me. I couldn't even wipe my own bum after the operation.*

*Participant 022\_2022AUBLC*

*Oh, Jesus. Definitely after the operation, um, it took me about six months to recover. And I didn't like that feeling of being helpless. Really. I've got stairs here, and I couldn't go up and down the stairs, well I could with help. I've got lovely neighbours who call in on me or whatever. I'm in a block of units sort of thing. My son's working full time, I didn't really want to, you know, sort of trouble him too much. You know, you tend to sort of, again be, I'm Mr Independent so you can do this or not want to help. But having to ask for it is very hard, you know.*

*Participant 023\_2022AUBLC*

*I mean, after when I got home, after being in the hospital for three weeks during the recovery, obviously you can't do too much, you know, in there at home. There were there was certainly a period and probably for about three months that I felt I mean, I live on my own, but I've got family very close by. Um, but because I, I'm a grandmother, so I'm very hands on and I'm usually out and about doing lots of stuff and helping with the kids. I couldn't do any of that. I couldn't go out. I couldn't drive. And I felt really. I felt like a big part of me was missing. Because I just I'm not one for just sort of sitting and even reading. I was finding hard. Some days I felt a bit low. I found it very, very, it was really lovely that a nurse came to see me every second day because again, she was very helpful and comforting, but I certainly felt a big it was as if I'd lost part of myself, like both physically and mentally, because I couldn't do the things that I normally do. I'd lost a certain amount of independence and that was not pleasant, but I knew it was just a short term thing and that it would all come back.*

*Participant 043\_2022AUBLC*

**Participant describes being vulnerable when first sent home after being hospitalised without the care/availability healthcare professionals**

*Um. Probably the first four days after the surgery, very vulnerable where your being told what you have to do. He didn't want to do any of it. You have to do it because you know it's going to make the next day just a little bit easier. So probably then immediately after the surgery, when I came home and I had a catheter and I had to flush the catheter and manage all on my own. And, um, and. To give myself that clexane through injections, the blood thinning things. You know, you had to administer that yourself straight after the surgery. So, you know, you feel a bit vulnerable then because you think you are doing it right, you know? You know, you've got, you know, stitches and tubes. And so I think that was probably when I felt most vulnerable and then probably when they took out everything and I then had to use the neobladder on my own. I mean, I had support from the hospital, and if I knew if I had a problem, I could have called them. But that was probably, you know, during*

*that period when I personally felt most vulnerable and I suppose, you know, initially after diagnosis as well.*

*Participant 032\_2022AUBLC*

*I guess I felt really vulnerable when I was first diagnosed and leading up to the surgery. I guess I, you know, you emotional and everything. Um, and I guess. I don't know. I guess when, when immediately post-op or whatever, when I just felt that I wasn't able to change the appliance and then you'd think, would I ever be able to? But just a few weeks later, when I got more strength, that's when I just made the decision. I had to do it myself. Yeah. So I guess leading up to the surgery and doing chemo was when you were most in after, after surgery and I guess when you came home from hospital the first few weeks was, it was challenging. Until I got, until I got the confidence to look after myself.*

*Participant 039\_2022AUBLC*

**Participant describes being vulnerable waiting for test results/around follow up appointments**

*Like. Yeah. Well, again, this cancer is like every three months. Check-Up and treatment and every like if we do BCG six times every week, you have to take days off and I'm full time worker.*

*Participant 015\_2022AUBLC*

*Yeah, probably a few weeks ago when I was waiting on some test results and some other things and just a few things colliding together. I felt pretty anxious and went and saw my GP, went and rang EAP from work and probably had a anxious time.*

*Participant 017\_2022AUBLC*

*I guess before surgery. Hmm. When you're wondering when, if I'm going to wake up and. And yeah, I think that's really the only time I really thought what was going to happen leading up to the surgery. And even today, I'm coming up to CAT scan. I still have that niggling what happens if it has metastasized. So I'm very vulnerable then. And even just a little bit afterwards when I had sepsis, I felt very vulnerable there as well.*

*Participant 038\_2022AUBLC*

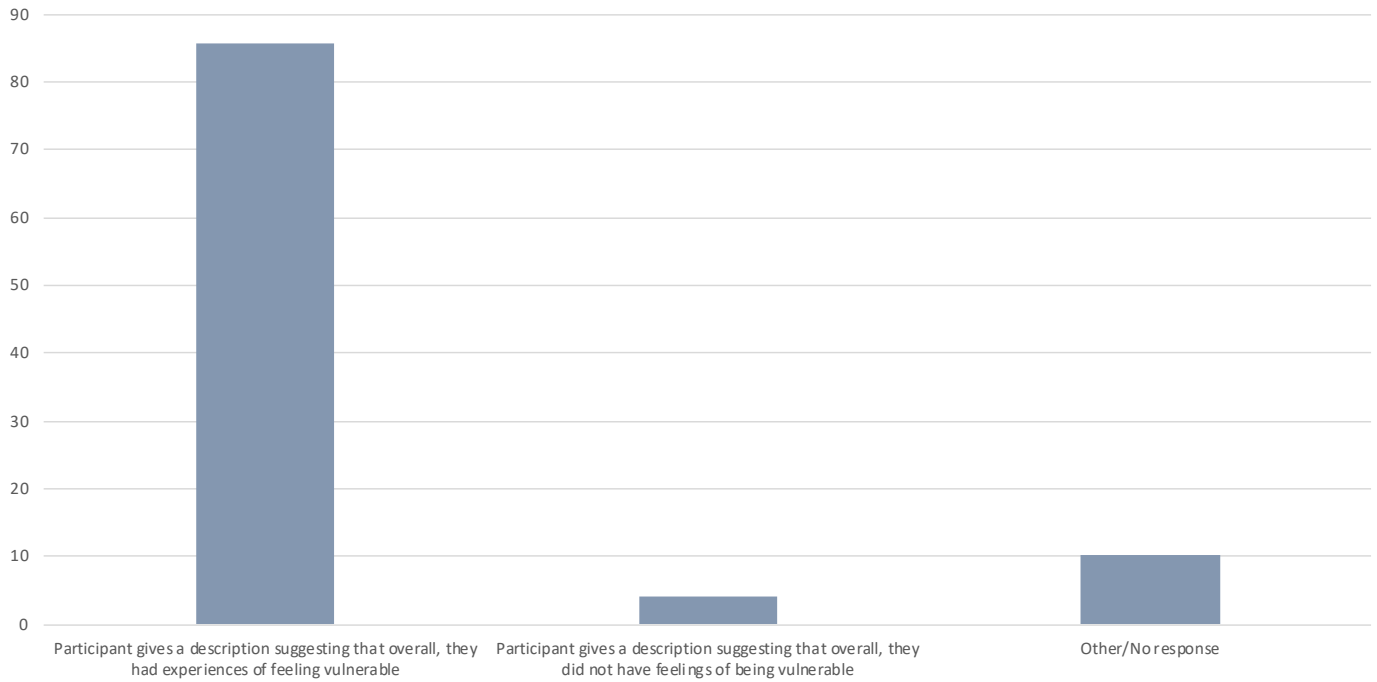


**Table 8.11: Experience of vulnerability**

Experience of vulnerability	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant gives a description suggesting that overall, they had experiences of feeling vulnerable	42	85.71	19	95.00	9	90.00	14	100.00	42	95.45	0	0.00	17	100.00	25	78.13
Participant gives a description suggesting that overall, they did not have feelings of being vulnerable	2	4.08	1	5.00	1	10.00	0	0.00	2	4.55	0	0.00	0	0.00	2	6.25
Other/No response	5	10.20	0	0.00	0	0.00	0	0.00	0	0.00	5	100.00	0	0.00	5	15.63

Experience of vulnerability	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant gives a description suggesting that overall, they had experiences of feeling vulnerable	42	85.71	25	86.21	17	89.47	13	86.67	29	87.88	17	85.00	25	89.29
Participant gives a description suggesting that overall, they did not have feelings of being vulnerable	2	4.08	0	0.00	1	5.26	0	0.00	1	3.03	0	0.00	1	3.57
Other/No response	5	10.20	4	13.79	1	5.26	2	13.33	3	9.09	3	15.00	2	7.14



**Figure 8.6: Experience of vulnerability**

**Table 8.12: Experience of vulnerability (details)**

Experience of vulnerability	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes being vulnerable during/after treatments	25	51.02	11	55.00	4	40.00	10	71.43	25	56.82	0	0.00	12	70.59	13	40.63
Participant describes being vulnerable when first diagnosed, first few months after diagnosis	13	26.53	6	30.00	4	40.00	3	21.43	13	29.55	0	0.00	3	17.65	10	31.25
Participant describes being vulnerable while experiencing side effects from treatment or symptoms from condition	10	20.41	5	25.00	0	0.00	5	35.71	10	22.73	0	0.00	4	23.53	6	18.75
Participant describes being vulnerable when having sensitive discussion (diagnosis, treatment decision)	8	16.33	5	25.00	0	0.00	3	21.43	8	18.18	0	0.00	4	23.53	4	12.50
Participant describes being vulnerable because of interactions with the medical team	8	16.33	4	20.00	2	20.00	2	14.29	8	18.18	0	0.00	4	23.53	4	12.50
Participant describes being vulnerable when thinking about disease course/incurable condition	5	10.20	1	5.00	2	20.00	2	14.29	5	11.36	0	0.00	0	0.00	5	15.63
Participant describes being vulnerable when they have a loss of independence, e.g in hospital, recovering from surgery	5	10.20	2	10.00	2	20.00	1	7.14	5	11.36	0	0.00	4	23.53	1	3.13
Participant describes being vulnerable when first sent home after being hospitalised without the care/availability healthcare professionals	5	10.20	0	0.00	0	0.00	5	35.71	5	11.36	0	0.00	3	17.65	2	6.25
Participant describes being vulnerable waiting for test results/around follow up appointments	4	8.16	3	15.00	0	0.00	1	7.14	4	9.09	0	0.00	1	5.88	3	9.38

Experience of vulnerability	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes being vulnerable during/after treatments	25	51.02	13	44.83	12	63.16	5	33.33	20	60.61	9	45.00	16	57.14
Participant describes being vulnerable when first diagnosed, first few months after diagnosis	13	26.53	8	27.59	5	26.32	5	33.33	8	24.24	5	25.00	8	28.57
Participant describes being while experiencing side effects from treatment or symptoms from condition	10	20.41	7	24.14	3	15.79	2	13.33	8	24.24	5	25.00	5	17.86
Participant describes being vulnerable when having sensitive discussion (diagnosis, treatment decision)	8	16.33	5	17.24	3	15.79	3	20.00	5	15.15	4	20.00	4	14.29
Participant describes being vulnerable because of interactions with the medical team	8	16.33	4	13.79	4	21.05	3	20.00	5	15.15	3	15.00	5	17.86
Participant describes being vulnerable when thinking about disease course/incurable condition	5	10.20	4	13.79	1	5.26	3	20.00	2	6.06	2	10.00	3	10.71
Participant describes being vulnerable when they have a loss of independence, e.g in hospital, recovering form surgery	5	10.20	4	13.79	1	5.26	2	13.33	3	9.09	3	15.00	2	7.14
Participant describes being vulnerable when first sent home after being hospitalised without the care/availability healthcare professionals	5	10.20	2	6.90	3	15.79	1	6.67	4	12.12	1	5.00	4	14.29
Participant describes being vulnerable waiting for test results/around follow up appointments	4	8.16	3	10.34	1	5.26	1	6.67	3	9.09	2	10.00	2	7.14

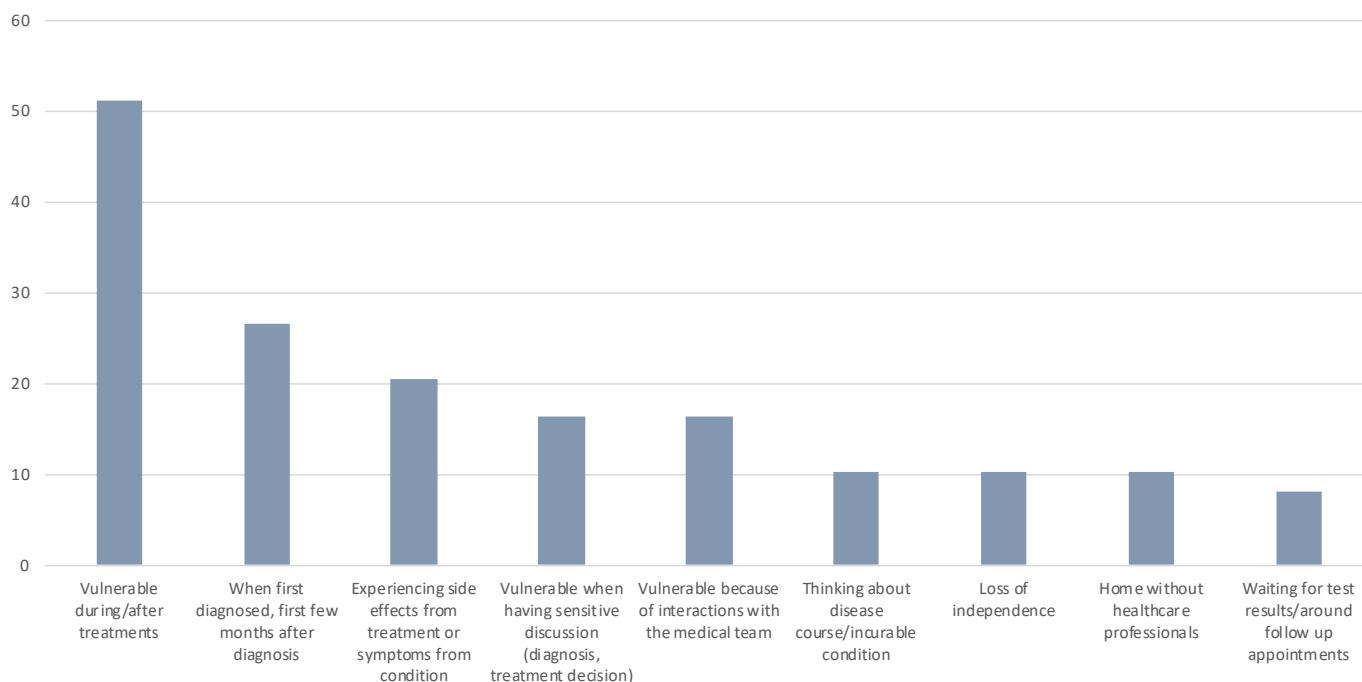


Figure 8.7: Experience of vulnerability (details)

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

Experience of vulnerability	Reported less frequently	Reported more frequently
Participant describes being vulnerable during/after treatments	Invasive (Stage III) Carer to someone with bladder cancer Male Regional or remote	Advanced (Stage IV) Female University
Participant describes being vulnerable when first diagnosed, first few months after diagnosis	Carer to someone with bladder cancer	Invasive (Stage III)
Participant describes being while experiencing side effects from treatment or symptoms from condition	Invasive (Stage III) Carer to someone with bladder cancer	Advanced (Stage IV)
Participant describes being vulnerable when having sensitive discussion (diagnosis, treatment decision)	Invasive (Stage III) Carer to someone with bladder cancer	-
Participant describes being vulnerable because of interactions with the medical team	Carer to someone with bladder cancer	-
Participant describes being vulnerable when thinking about disease course/incurable condition	Carer to someone with bladder cancer Female	-
Participant describes being vulnerable when they have a loss of independence, e.g in hospital, recovering form surgery	Carer to someone with bladder cancer	Female
Participant describes being vulnerable when first sent home after being hospitalised without the care/availability healthcare professionals	Early (Stages 0 and I) Invasive (Stage III) Carer to someone with bladder cancer	Advanced (Stage IV)

## Methods to manage vulnerability

In the structured interview, participants described ways that they managed feelings of vulnerability. Participants described using self help methods such as resilience, acceptance, and staying positive to manage the feeling of vulnerability (n=12, 24.49%), support from family and friends to manage the feeling of vulnerability (n=7, 14.29%), and being supported by nurse or treatment team to manage the feeling of vulnerability (n=6, 12.24%).

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

*Well, so not much. This is a very scary first time round and you don't know what's going on? And you just you just try and stay strong for your family, and you know I've got two kids. And I'm married and I don't think, um, I think is going to go through the motions a little bit and try to just stay strong, maybe it's a male thing, I dunno.*

*Participant 024\_2022AUBLC*

*Well, I did it just by myself, you know. And as I said, I had, you know, a family. I had kids at school. Um, you know, I'd say just basically distract yourself with other things, I mean, that were great, helping me and looking after me. So you just distract yourself and you just want to be better every day because you're needed.*

*Participant 032\_2022AUBLC*

*Oh, I didn't have to do too much. Just, you know, just took comfort in the fact that I'm old enough to live with it and without any regrets. You know, it's just a personal philosophy that helped me get through that bit. Hmm. In other words, I didn't really see it as a complete disaster. I just thought it was one of those things that happens either sooner or later. And I found my one sooner, so, you know, I'm one of the lucky ones.*

*Participant 034\_2022AUBLC*

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

*Okay. I think the best approach I took was I spoke about my fears to everybody. With my family, with my friends. I didn't hold back my feelings. And that helped me to overcome, you know, because, yeah, if you keep it inside, you know, then the worry only grows. And so I tried to talk to everybody, although, I mean, many of*

*my friends, they meant well, but they only made me feel bad because they said, oh, don't worry, don't worry, you'll be fine. You're a strong man. And I think what a silly thing to say. You know, they don't know what I'm going through, you know?*

*Participant 028\_2022AUBLC*

*In that situation, there wasn't anything else I could do in other situations. It's been. When I've been outside of the hospital, because every other time staff has been great in terms of support, in terms of. Vulnerability. Yeah. Talk. Talking. Picking up the phone and talking to a friend or family.*

*Participant 041\_2022AUBLC*

*We talked. Yeah. We talked. My wife and I talked. Yeah. And then put it in to put it in context as we do.*

*Participant 019\_2022AUBLC*

### Participant describes being supported by nurse or treatment team to manage the feeling of vulnerability

*PARTICIPANT: Every time I was catheterised very vulnerable, I hated it. I hated it with a passion. And one time, they were going to get a man to do it and I was prepared to walk out, a male nurse. I just spat the dummy. I said, I can't do that. I was just that was just my limit of having a male nurse catheterise me for some reason. And it was silly, but it was just me at the time.*

*INTERVIEWER: Is there anything that you think could be done to address that vulnerability?*

*PARTICIPANT: I think they were really respectful, but I did notice some were more respectful than others. I ended up having this one nurse who I really found very motherly and respectful, and in the end what they did was they very kindly allowed me to have her every time. And there was another one who was a bit more flippant. She'd get me to expose myself basically for the catheterisation, and then she'd turn around and she'd spend about 5 minutes preparing the solution. And there was only a curtain between me and the outside world. And although they were all very respectful of the curtains drawn, they wouldn't come in. I just didn't feel that I was private and, yet, this one that was quite motherly and nice, she would always get everything all ready until the last possible moment. Then she'd tell me to expose my, and that just felt better because she respected that. I didn't want to be lying like that for too long.*

*Participant 036\_2022AUBLC*

*I mean, after when I got home, after being in the hospital for three weeks during the recovery, obviously you can't do too much, you know, in there at home. There were there was certainly a period and probably for about three months that I felt I mean, I live on my own, but I've got family very close by. Um, but because I, I'm a grandmother, so I'm very hands on and I'm usually out and about doing lots of stuff and helping with the kids. I couldn't do any of that. I couldn't go out. I couldn't drive. And I felt really. I felt like a big part of me was missing. Because I just I'm not one for just sort of sitting and even reading. I was finding hard. Some days I felt a bit low. I found it very, very it was really lovely that a nurse came to see me every second day because again, she was very helpful and comforting, but I certainly felt a big it was as if I'd lost part of myself, like both physically and mentally, because I couldn't do the things that I normally do. I'd lost a certain amount of independence and that was not pleasant, but I knew it was just a short term thing and that it would all come back.*

*Participant 043\_2022AUBLC*

*Actually a nurse in CITY, who does phone consults. They would ring up and ask, how are you going, do I need anything? How I'm going with this. And then when we were, we were told, that in order to try and get rid of the UTIs, to use a catheter every day. She was, she was brilliant. Absolutely brilliant.*

*Participant 040\_2022AUBLC*

**Participant describes that they are unsure how vulnerability can be managed to manage the feeling of vulnerability**

*Uh uh, you can't do much because you know you're there, you can't move, and they have to stick a needle in your back. So the only thing you can do. You're left in your room, on your own. You can start crying. Or then when they said when they gave it another try, and then the radiologist says, Ah, I think you go home without a bag and then you feel it's not working and that they are swearing and yes, they can. The only thing you can do is start crying.*

*Participant 005\_2022AUBLC*

*Ah, well, there's not much. I just have to live with it. There's not much I can.*

*Participant 008\_2022AUBLC*

*In that situation there wasn't anything else I could do.*

*Participant 041\_2022AUBLC*

**Participant describes becoming informed about their condition, available treatment, and statistics to manage the feeling of vulnerability**

*Yeah, that's a good question. I think maybe in the first week it would have been nice if somebody could have sat me down and told me what it is, in essence, giving me lots of information about prognosis and treatment options. Had I had that information in the beginning, I wouldn't probably have felt I was just thinking.*

*Participant 020\_2022AUBLC*

*I don't think I could say I did actively anything. I guess understanding what I was facing to be better informed and to know what the statistics likely were. I was only 49 and even I was 49 when I got diagnosed. And according to the statistics, I was on the very end of that sort of 40 to 49 year old bracket. And the percentage of Australian males that have this or that are diagnosed with bladder cancer in that age group is tiny. And you jump up to the sort of 72, 79 bracket, and that's where everybody sits like there's, hundreds of thousands of people, as opposed to a few of us in the 40 to 49. So straight away, I felt vulnerable because I was out of the ordinary. I wasn't the normal. I didn't fit the normal curve of the demographic. And so you feel vulnerable because you don't understand why there's no. Family history of it. There's no exposure through industrial or some form of employment previously that can sometimes trigger this. So there was no reason why I would have had it or should have had it. And here I was out of the normal. I'm not in demographic for this diagnosis, so I certainly felt vulnerable. With that knowledge and trying to understand why. Not necessarily, why me? But why did it happen? Yeah. Yeah. Which is a bit different. The one that he's like, oh, look, something's going to happen at some point, as it does to everybody. But why? Yeah. I would have thought a whole lot of other things that get be before and bladder cancer, etc.. It sounds like an old man.*

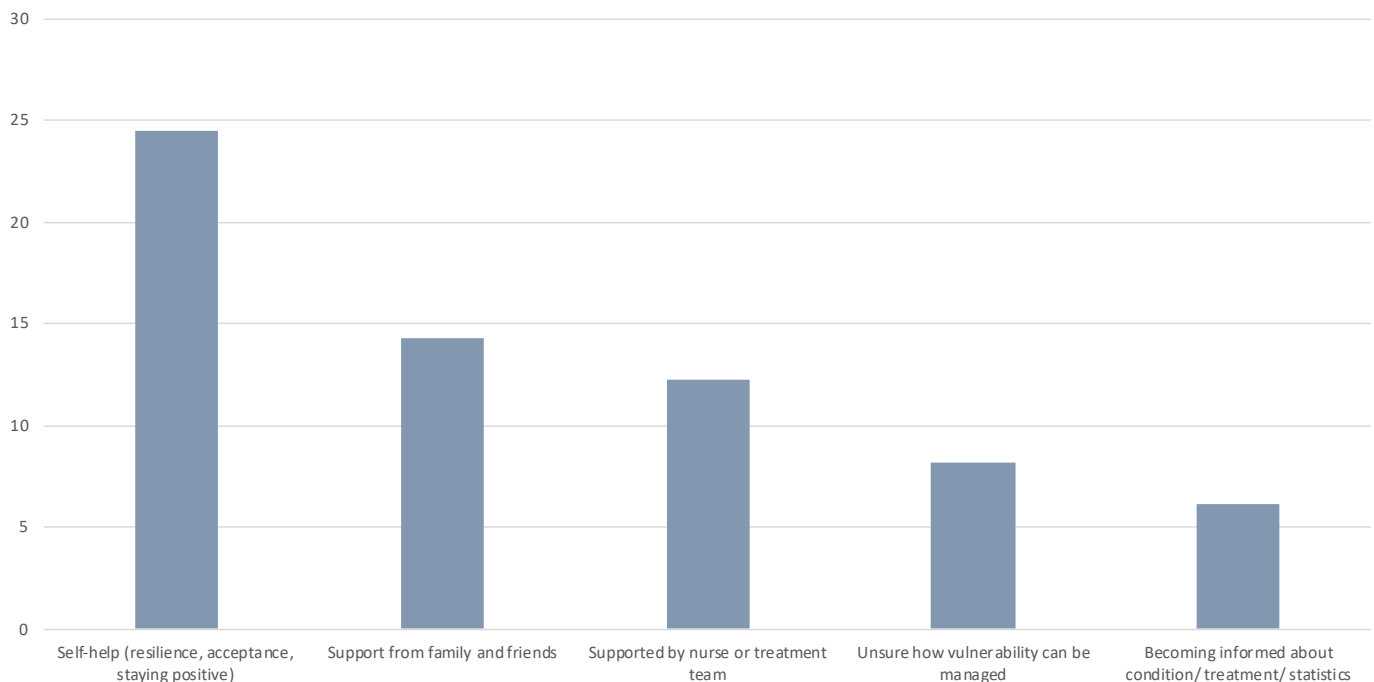
*Participant 030\_2022AUBLC*

**Table 8.14: Methods to manage vulnerability**

Methods to manage vulnerability	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes self-help (resilience, acceptance, staying positive) to manage the feeling of vulnerability	12	24.49	4	20.00	3	30.00	5	35.71	12	27.27	0	0.00	5	29.41	7	21.88
Participant describes support from family and friends to manage the feeling of vulnerability	7	14.29	3	15.00	2	20.00	2	14.29	7	15.91	0	0.00	0	0.00	7	21.88
Participant describes being supported by nurse or treatment team to manage the feeling of vulnerability	6	12.24	0	0.00	1	10.00	5	35.71	6	13.64	0	0.00	3	17.65	3	9.38
Participant describes that they are unsure how vulnerability can be managed to manage the feeling of vulnerability	4	8.16	3	15.00	0	0.00	1	7.14	4	9.09	0	0.00	2	11.76	2	6.25
Participant describes becoming informed about their condition, available treatment, and statistics to manage the feeling of vulnerability	3	6.12	1	5.00	1	10.00	1	7.14	3	6.82	0	0.00	0	0.00	3	9.38

Impact on relationships	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes self-help (resilience, acceptance, staying positive) to manage the feeling of vulnerability	12	24.49	5	17.24	6	31.58	3	20.00	8	24.24	3	15.00	8	28.57
Participant describes support from family and friends to manage the feeling of vulnerability	7	14.29	5	17.24	2	10.53	2	13.33	5	15.15	3	15.00	4	14.29
Participant describes being supported by nurse or treatment team to manage the feeling of vulnerability	6	12.24	4	13.79	2	10.53	1	6.67	5	15.15	2	10.00	4	14.29
Participant describes that they are unsure how vulnerability can be managed to manage the feeling of vulnerability	4	8.16	2	6.90	2	10.53	1	6.67	3	9.09	2	10.00	2	7.14
Participant describes becoming informed about their condition, available treatment, and statistics to manage the feeling of vulnerability	3	6.12	2	6.90	1	5.26	2	13.33	1	3.03	2	10.00	1	3.57



**Figure 8.7: Methods to manage vulnerability**

**Table 8.15: Methods to manage vulnerability– subgroup variations**

Impact on relationships	Reported less frequently	Reported more frequently
Participant describes self-help (resilience, acceptance, staying positive) to manage the feeling of vulnerability	Carer to someone with bladder cancer	Advanced (Stage IV)
Participant describes support from family and friends to manage the feeling of vulnerability	Carer to someone with bladder cancer Female	-
Participant describes being supported by nurse or treatment team to manage the feeling of vulnerability	Early (Stages 0 and I) Carer to someone with bladder cancer	Advanced (Stage IV)

**Impact on relationships**

In the structured interview, participants were asked whether their condition had affected their personal relationships. Overall, there were 17 participants (34.69%) that described that overall, there was a positive impact on relationships. Other participants described a mix of a positive and a negative impact (n=11, 22.45%), a negative impact on relationships (n=9, 18.37%), no impact on relationships (n=8,

16.33%), and an impact on relationships that was neither positive nor negative (n=3, 6.12%)

The most common themes in relation to having a positive impact on relationships were relationships within the family being strengthened (n=22, 44.90%), and people being well-meaning and supportive (n=10, 20.41%). The most common themes in relation to having a positive impact on relationships were

relationships suffering, that is people not knowing what to say or do and withdrawing from relationships (n=9, 18.37%), and dynamics of relationships change due to anxiety, exacerbations and/or physical limitations of condition (n=7, 14.29%).

**Participant described that overall, there was a positive impact on relationships**

*Um, I think it did, but not to me. I think it made some of my family and friends take stock of their situation. I don't think it so much affected their relationship as me. I think after a while they all got used to the idea. I know there was a few of the younger guys that you could you could really see when they you know, I'd be out surfing with them and I'd say, oh yeah, I had bladder cancer. So and it was a genuine shock. And then you'd see them a bit later and you could tell that they really thought, bloody hell, if it can happen to him. So I don't think it affected my relationship too much with most people, I think. I think probably my wife and I became closer, but, you know, normal. As we said recently, normal hostilities have almost resumed [LAUGHS].*

*Participant 006\_2022AUBL*

*No. Probably brought me a bit closer maybe with my sisters. Not that we were distant by any stretch, but yeah, we speak a lot more often now about it. Yeah. So in that regard, you're probably positive. And I've told, I've told the friends that I need to tell them and some of my, my clients that I work for. I've told them because of certain days I can't, you know, or if I can't be there because of the Thursday of my treatment, then, you know, I would give them I would say, look, this is where I'm at. Um. No, I don't think it's changed any. Certainly not professional relationships. And, um, you know, my relationship with my sisters is probably somewhat closer, even though we were quite reasonably close. We're probably better now. Probably more thoughtful for each other.*

*Participant 014\_2022AUBL*

*I have to say, I've been really lucky because while I had a very serious diagnosis and major surgery, I have come out the other side really well. If anything, it's brought my family closer together.*

*Participant 032\_2022AUBL*

**Participant described that overall, there was a mix of a positive and a negative impact**

*Well, friends. Uh, a couple. Yeah. Sometimes you go and talk to friends and they'll look straight at your stomach and you think, Oh, God, what are they looking to see. And my husband never noticed that. He said, oh, I don't think they do. And I said, well, you can, it's subtle. You can notice subtle things, but most of our friends are pretty good, and a couple of them just dropped meals around, even though they weren't meant to with COVID and that was that really nice and helpful and really because I'm just back on track and doing everything I pretty much used to. They don't worry too much. It's just, you know, back normal, but it kind of makes you feel a bit like you're the only one who's got this none of your friends have got it. So you feel a bit of an outsider.*

*Participant 018\_2022AUBL*

*Um. Yeah. Good question. Some people really step up and say all the right things. And some people are absolutely terrified of the C-word and don't know what to say. So they choose not to say anything at all. And to be honest, that's a bit disappointing. But for some people, that might have been exactly the right reaction that they wanted from their friends. But for me, it was people who I let know and I just think. Excuse my language, but, you know, I'd text somebody or call someone, that's really sucks, that's really horrible. I'm really sorry that's happened. Yeah, that's, that's all you're gonna need to hear, because there's nothing anyone can do about it. And it's very cliché, but anybody who said, oh, you're strong, you'll get through it. And so, yeah, I don't know if I will have no I can control some things, but there's a lot I can't control at this. So people who would say, you know, put on a brave face to be strong. Obviously, that doesn't help at all. So it was interesting to see who did step up to check in, see how things were going on a daily or weekly basis. Probably closer to my best mate than ever. So that was good. So it certainly improved some things. And it's a shame that takes the scare did it to make you talking a bit closer to people. Yeah.*

*Participant 030\_2022AUBL*

*Yes, definitely. Yeah. Yeah. Um, we definitely have expectations of how people might support you and react. And some people exceed those and some people, you know, don't like, you know. So you think that your immediate family might be really supportive and sometimes they're just not. So yeah, you just don't know how people are going to be, really. How they going to react and support. So yeah, that's just yeah,*



*I've definitely had some detrimental effects to my immediate family.*

*Carer 003\_2022AUBLC*

**Participant described that overall, there was a negative impact on relationships**

*Yeah. Look, I've noticed some people sort of tend to shy away a bit from you once they hear that you've been diagnosed with terminal cancer. But oh, you know, all in all. I had to give up my job because I became too tired. You know, I couldn't, I sort of get tired and breathless pretty easily. And I was a finance broker before, and I used to. It was stressful job to some extent because, you know, I, I looked after difficult loans like people they've really been to their bank and got knocked back so they come to me as a specialist finance broker and want to keep the houses from being repossessed and all that sort of stuff. So I did. I did a lot of alternative type of loan lending or private lending and all that sort of stuff. Mortgage lending. So say people, their houses, you know, and sometimes I can't help everybody and it can get become stressful a bit, you know. But if I had a bit of a stressful job. So when they told me I was terminal, I thought bugger this, I might as well stop and smell the roses a bit, you know, and. I applied for a disability pension and was granted that. And yes, I was quite thankful for that*  
*Participant 042\_2022AUBLC*

*Um. Probably a little bit. Not so much the family, maybe friends because he just doesn't tend to go out very much. In the beginning, he wouldn't go out at all. So I had, you know, we had unfortunately a big argument over it. And I said, well, you get in this car and you get in here now. You know, I was actually dragging him. I said, we're just going to a coffee shop. We have to get out of this house. you have to continue with your life.*

*Carer 001\_2022AUBLC*

*PARTICIPANT Well, I also feel that, which I never felt when I had breast cancer or anything. A lot of people don't contact you when they find out like you don't. And with friends of friends that we've had for years. And I think they found it, I've heard from them.*

*INTERVIEWER Nothing. That's so weird. But that didn't happen with the breast or thyroid cancer.*

*PARTICIPANT Which was bizarre. thyroid cancer was you know, that was but with the breast cancer. No.*

*INTERVIEWER Was like everybody kept on going on. I can support it. Yeah. Yeah. But I have heard that*

*before. It is a strange thing, isn't it? Maybe there are quite a lot of now.*

*PARTICIPANT You know, maybe because it is a bladder or. I don't know. I don't.*

*Participant 004\_2022AUBLC*

**Participant described that overall, there no impact on relationships**

*No, not at all. Not one bit. As a matter of fact half of the people I know don't know about it, oh more than a half. Couple of mates know I've had it. It doesn't ever get brought up. And NAME, my wife, she has been fantastic. Yeah, we just got on as we have the last 30 years. So there's been no dramas there at all.*

*Participant 021\_2022AUBLC*

*No, no, no. Because I've got a, um. A really close bond family. Like a circle and my close friends that have been here for us from day one. Yeah. No, I'd say not. No. When it comes to my children and my wife. No.*

*Participant 033\_2022AUBLC*

*No, I don't think so.*

*Participant 044\_2022AUBLC*

**Participant described that overall, there was an impact on relationships that was neither positive nor negative**

*Yeah. As we discussed before, like with, with my wife, with two daughters, they have also been impacted not not, not badly, but I've also had to be mindful that dad's had bladder cancer. Yeah. Uh, yeah. With friends. Not so much, because I can choose to, to sort of go. And I choose, if somebody wants to know about bladder cancer, I'm. I'm quite comfortable to talk to them about it and, and what what's happened to me and I, I don't try and hide that I have a stoma or anything like that. If somebody has a genuine question, I'm happy to talk and talk about it. Um, but. Yeah. It doesn't stop me from doing those things. I'm still able to go out and meet up with people and talk to other people.*

*Participant 035\_2022AUBLC*

*Uh, not now. I think at the time, it definitely did. Um, but no, I think, I think because of the stage I am at, and that's, I'm sort of, well, three years down the track and trying not to think about any possibility of it re-occurring too much. At the moment I'm in quite a good position, so it's not really affecting my day to day life too much at all.*

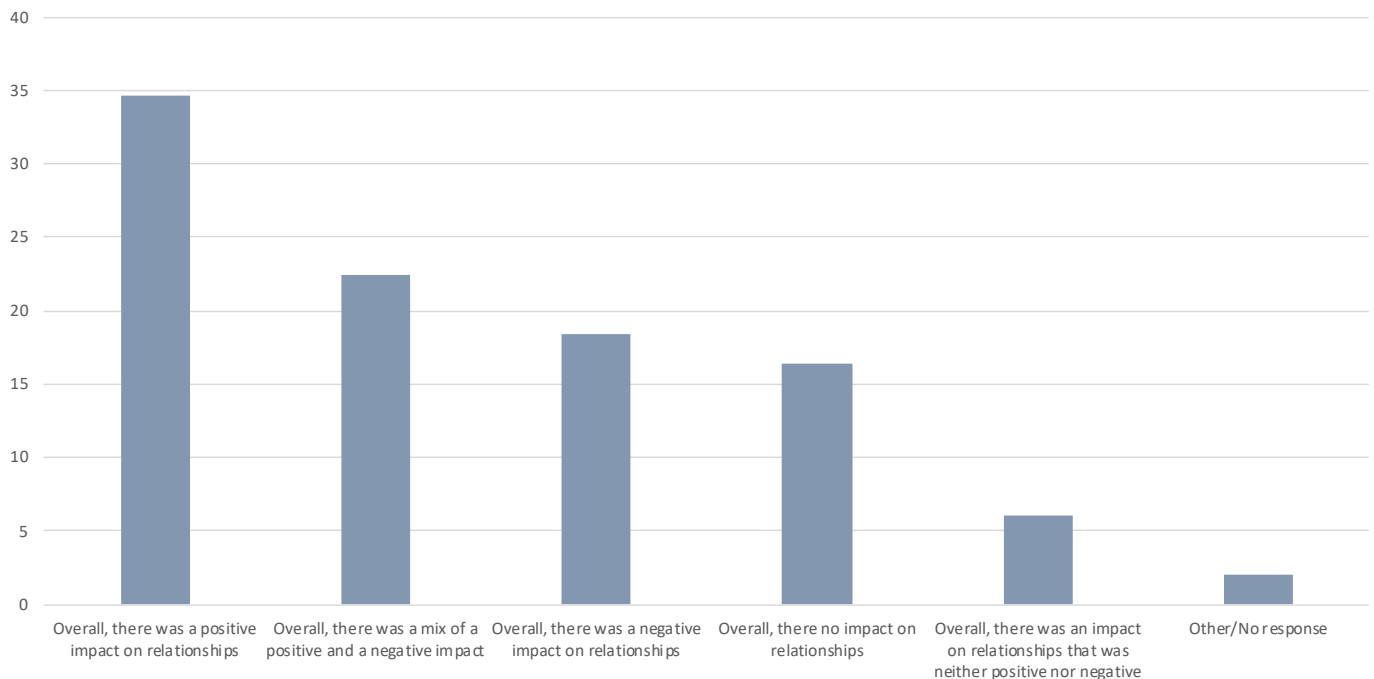
*Participant 036\_2022AUBLC*



**Table 8.16: Impact on relationships**

Impact on relationships	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant described that overall, there was a positive impact on relationships	17	34.69	6	30.00	6	60.00	3	21.43	15	34.09	2	40.00	7	41.18	10	31.25
Participant described that overall, there was a mix of a positive and a negative impact	11	22.45	5	25.00	1	10.00	4	28.57	10	22.73	1	20.00	3	17.65	8	25.00
Participant described that overall, there was a negative impact on relationships	9	18.37	3	15.00	2	20.00	2	14.29	7	15.91	2	40.00	2	11.76	7	21.88
Participant described that overall, there no impact on relationships	8	16.33	5	25.00	1	10.00	2	14.29	8	18.18	0	0.00	3	17.65	5	15.63
Participant described that overall, there was an impact on relationships that was neither positive nor negative	3	6.12	1	5.00	0	0.00	2	14.29	3	6.82	0	0.00	2	11.76	1	3.13
Other/No response	1	2.04	0	0.00	0	0.00	1	7.14	1	2.27	0	0.00	0	0.00	1	3.13

Impact on relationships	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant described that overall, there was a positive impact on relationships	17	34.69	9	31.03	8	42.11	4	26.67	13	39.39	4	20.00	13	46.43
Participant described that overall, there was a mix of a positive and a negative impact	11	22.45	8	27.59	3	15.79	4	26.67	7	21.21	8	40.00	3	10.71
Participant described that overall, there was a negative impact on relationships	9	18.37	6	20.69	3	15.79	5	33.33	4	12.12	4	20.00	5	17.86
Participant described that overall, there no impact on relationships	8	16.33	4	13.79	3	15.79	2	13.33	5	15.15	4	20.00	3	10.71
Participant described that overall, there was an impact on relationships that was neither positive nor negative	3	6.12	1	3.45	2	10.53	0	0.00	3	9.09	0	0.00	3	10.71
Other/No response	1	2.04	1	3.45	0	0.00	0	0.00	1	3.03	0	0.00	1	3.57



**Figure 8.8: Impact on relationships**

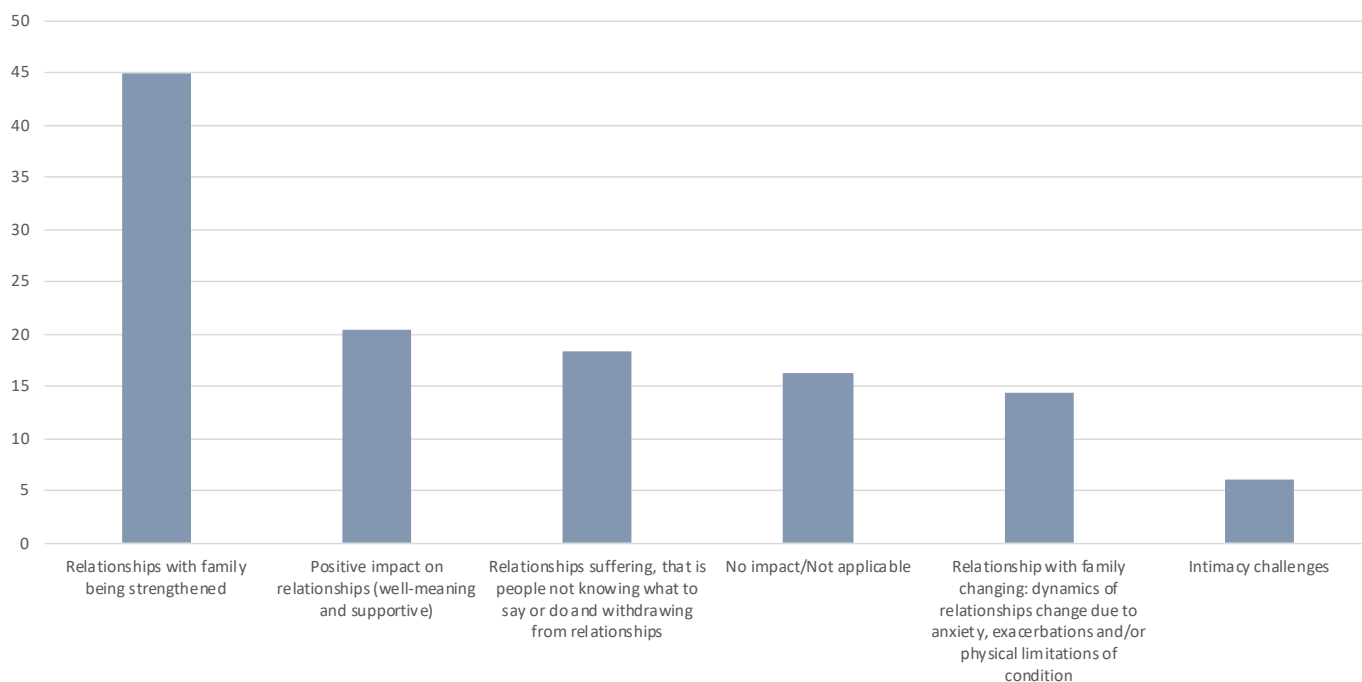
**Table 8.17: Impact on relationships – subgroup variations**

Impact on relationships	Reported less frequently	Reported more frequently
Participant described that overall, there was a positive impact on relationships	Advanced (Stage IV) Mid to low status	Invasive (Stage III) Higher status
Participant described that overall, there was a mix of a positive and a negative impact	Invasive (Stage III) Higher status	Mid to low status
Participant described that overall, there was a negative impact on relationships	-	Carer to someone with bladder cancer Regional or remote
Participant described that overall, there no impact on relationships	Carer to someone with bladder cancer	-

**Table 8.18: Impact on relationships (Reason for impact)**

Impact on relationships (Reason for impact)	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes relationships with family being strengthened	22	44.90	9	45.00	6	60.00	5	35.71	20	45.45	2	40.00	8	47.06	14	43.75
Participant describes a positive impact on relationships, as people are well-meaning and supportive	10	20.41	3	15.00	1	10.00	5	35.71	9	20.45	1	20.00	5	29.41	5	15.63
Participant describes relationships suffering, that is people not knowing what to say or do and withdrawing from relationships	9	18.37	3	15.00	2	20.00	3	21.43	8	18.18	1	20.00	4	23.53	5	15.63
Participant describes that there was no impact on relationships	8	16.33	5	25.00	1	10.00	2	14.29	8	18.18	0	0.00	3	17.65	5	15.63
Participant describes relationship with family changing: dynamics of relationships change due to anxiety, exacerbations and/or physical limitations of condition	7	14.29	5	25.00	0	0.00	1	7.14	6	13.64	1	20.00	2	11.76	5	15.63
Participant describes an negative impact on relationships, due to intimacy challenges	3	6.12	0	0.00	1	10.00	2	14.29	3	6.82	0	0.00	0	0.00	3	9.38

Impact on relationships (Reason for impact)	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes relationships with family being strengthened	22	44.90	15	51.72	7	36.84	7	46.67	15	45.45	10	50.00	12	42.86
Participant describes a positive impact on relationships, as people are well-meaning and supportive	10	20.41	5	17.24	5	26.32	2	13.33	8	24.24	4	20.00	6	21.43
Participant describes relationships suffering, that is people not knowing what to say or do and withdrawing from relationships	9	18.37	6	20.69	3	15.79	4	26.67	5	15.15	4	20.00	5	17.86
Participant describes that there was no impact on relationships	8	16.33	4	13.79	3	15.79	2	13.33	5	15.15	4	20.00	3	10.71
Participant describes relationship with family changing: dynamics of relationships change due to anxiety, exacerbations and/or physical limitations of condition	7	14.29	3	10.34	4	21.05	3	20.00	4	12.12	4	20.00	3	10.71
Participant describes an negative impact on relationships, due to intimacy challenges	3	6.12	3	10.34	0	0.00	2	13.33	1	3.03	3	15.00	0	0.00



**Figure 8.9: Impact on relationships**

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

Impact on relationships (Reason for impact)	Reported less frequently	Reported more frequently
Participant describes relationships with family being strengthened	-	Invasive (Stage III)
Participant describes a positive impact on relationships, as people are well-meaning and supportive	Invasive (Stage III)	Advanced (Stage IV)
Participant describes relationships suffering, that is people not knowing what to say or do and withdrawing from relationships	-	-
Participant describes that there was no impact on relationships	Carer to someone with bladder cancer	-
Participant describes relationship with family changing: dynamics of relationships change due to anxiety, exacerbations and/or physical limitations of condition	Invasive (Stage III)	Early (Stages 0 and I)

## 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 22 participants (44.90%) that felt there was an additional burden, 20 participants (40.82%) that reported no additional burden, and 6 participants (12.24%) that felt they were not a burden on their family but anticipate this will change in the future.

For people that felt they were not a burden on their family, the most did not give any specific reasons for this (n=14, 28.57%). The main reason that participant described their condition not being a burden in general was that they were very independent and did not need

any help (n=8, 16.33%). The most common reasons for feeling that they were a burden on their family was the mental/emotional strain placed on their family (n=12, 24.49%), the extra household duties and responsibilities that their family must take on (n=5, 10.20%), and that the burden was temporary or only during treatment (n=5, 10.20%).

**Participant describes that overall, there was a burden on their family**

*Oh, for sure. As I said before, my husband certainly it's a burden on him because I'm supposed to be helping him with the business. And so therefore he gets so*

*much. He has to work so much more. He'll often bring work home. And then with regard to my children, all live independently and only one in the same city that I live in. But it hasn't really impacted them yet. However, because I'm now booked to have my bladder removed. And it's such major surgery. Both the interstate children are flying up to see me one before and one afterwards. So, I mean, if anything, that's an impact.*

*Participant 010\_2022AUBLC*

*Yeah, definitely. Definitely. You know, my wife has to be strong and I've got two young children and initially, you know. She had to sort of show a brave face, I guess, and. Um. You know, probably really put her in a not on awkward but just in a difficult position because you are facing mortality. I guess that's the first thing you think about is what if I die? Where are we at? So it is a burden. I feel. I felt I was a burden in that regard. I know my wife would say it wasn't, but, I felt that it was. It's because of the uncertainty and the potential. Yeah. Personality of the cancer.*

*Participant 014\_2022AUBLC*

*It has it has been it has been particularly draining on my wife I think. It's not so bad now because it's, I've become a lot more self-sufficient since the recoveries has occurred. But I think that immediate post-op period is a bit of a, a bit of a demanding time for whoever it is that's going to be your carer.*

*Participant 034\_2022AUBLC*

*Oh, I just feel that it was definitely a burden on my husband and I don't know what I would have done without him, to be honest, because he was the one that would come and pick me up after my BCG and he'd have the hot water bottle there and he'd fill it up and then he'd drive me home and be so concerned that he could see how uncomfortable I was. And I just don't know what I would have done without him. I felt quite reliant upon him and he found it very frustrating because he couldn't do anything to help. He wanted to try and take it away from me, but he couldn't. So it was quite stressful for him as well.*

*Participant 036\_2022AUBLC*

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

*No I didn't get any extra care. I've been very independent*

*Participant 002\_2022AUBLC*

*I'm only having like a scan every six months and yeah, life is pretty normal. It's just, um. Yeah, I haven't got any extra, as I said the bag doesn't affect anything I do, everything so know it's no extra care that I have, but I'm staying pretty healthy.*

*Participant 044\_2022AUBLC*

*No. Because I am self sufficient.*

*Participant 037\_2022AUBLC*

**Participant describes that overall, there was not a burden on their family now but they anticipate this will change in the future**

*Not at the moment it's not? No, to be fair, it could be in the future, but no, not at the moment.*

*Participant 008\_2022AUBLC*

*Not at the moment. I do worry down the track. When I was six years difference between NAME and myself, and if anything happens to be, she would have to care for me. So I'll worry about that. But. It's not a problem at the moment because I do all the changes myself and the bags come automatically with me. So yeah, so it's very different.*

*Participant 038\_2022AUBLC*

*Well, luckily not in my case, because I have like as I said, so far, no side effects and no, no bad, you know, outcome. So I am still fit and healthy, so I am not a burden. But if I had the surgery and if I had to have the external stoma, then I would have been some limited in my abilities, you know, and maybe some burden on my family also. But right now, I don't think they have to do anything extra than before.*

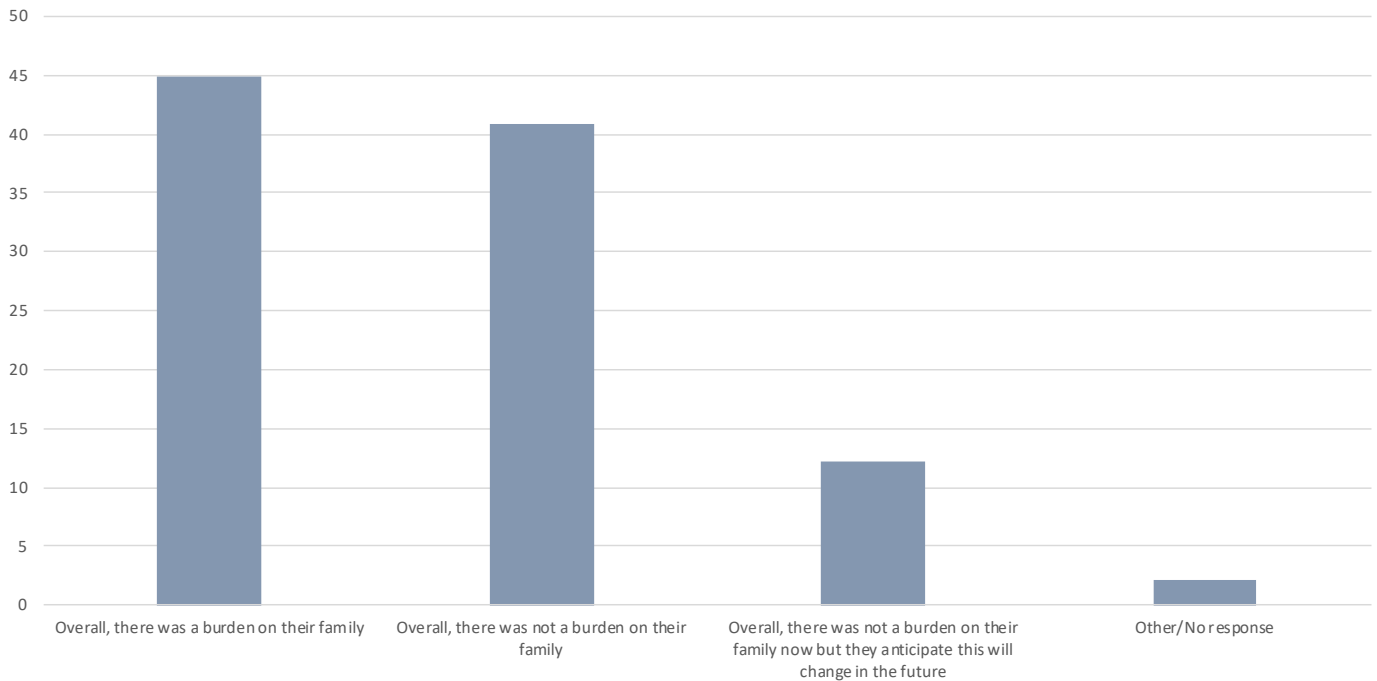
*Participant 028\_2022AUBLC*

**Table 8.20: Burden on family**

Burden on family	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes that overall, there was a burden on their family	22	44.90	7	35.00	3	30.00	9	64.29	19	43.18	3	60.00	6	35.29	16	50.00
Participant describes that overall, there was not a burden on their family	20	40.82	11	55.00	5	50.00	2	14.29	18	40.91	2	40.00	8	47.06	12	37.50
Participant describes that overall, there was not a burden on their family now but they anticipate this will change in the future	6	12.24	2	10.00	2	20.00	2	14.29	6	13.64	0	0.00	2	11.76	4	12.50
Other/No response	1	2.04	0	0.00	0	0.00	1	7.14	1	2.27	0	0.00	1	5.88	0	0.00

Burden on family	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes that overall, there was a burden on their family	22	44.90	17	58.62	5	26.32	9	60.00	13	39.39	11	55.00	11	39.29
Participant describes that overall, there was not a burden on their family	20	40.82	9	31.03	10	52.63	5	33.33	14	42.42	6	30.00	13	46.43
Participant describes that overall, there was not a burden on their family now but they anticipate this will change in the future	6	12.24	3	10.34	3	15.79	1	6.67	5	15.15	3	15.00	3	10.71
Other/No response	1	2.04	0	0.00	1	5.26	0	0.00	1	3.03	0	0.00	1	3.57



**Figure 8.10: Burden on family**

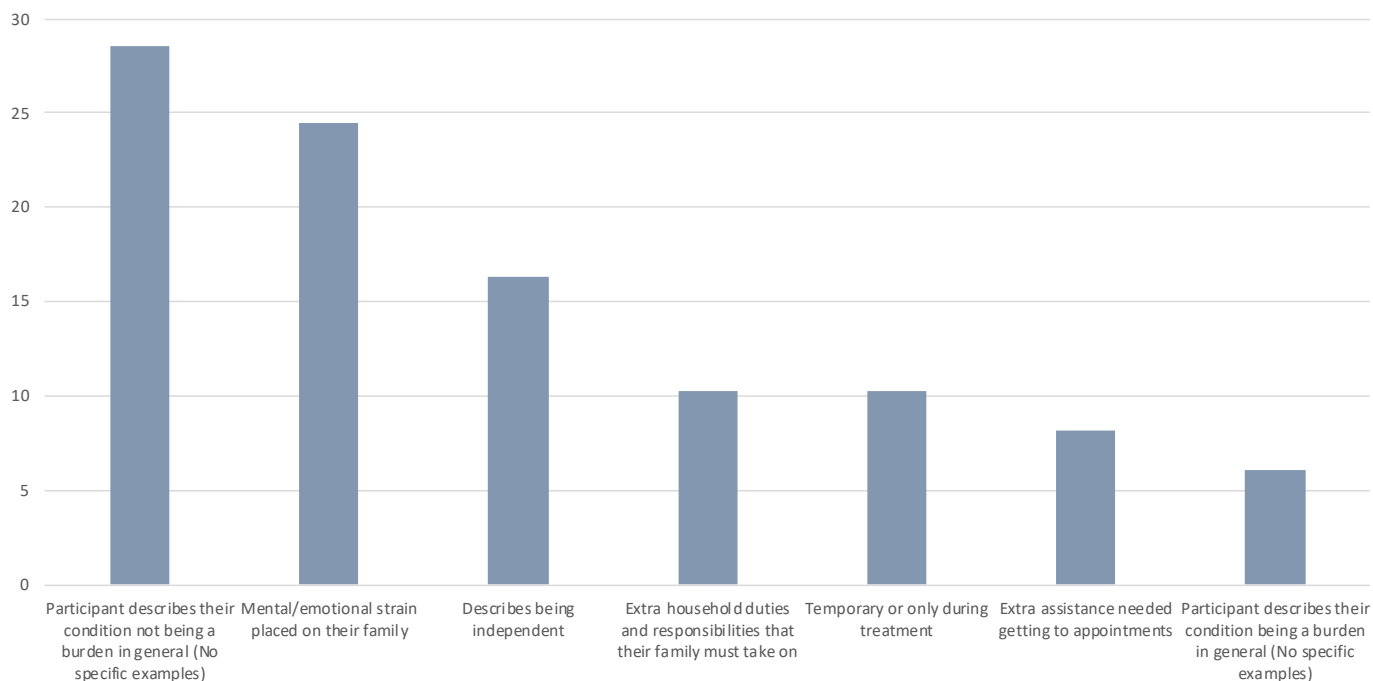
**Table 8.21: Burden on family – subgroup variations**

Burden on family	Reported less frequently		Reported more frequently	
	Invasive (Stage III)	University	Advanced (Stage IV)	Carer to someone with bladder cancer
Participant describes that overall, there was a burden on their family	Advanced (Stage IV)	Mid to low status	Early (Stages 0 and I)	University
Participant describes that overall, there was not a burden on their family	Carer to someone with bladder cancer			
Participant describes that overall, there was not a burden on their family now but they anticipate this will change in the future				

**Table 8.22: Burden on family (description)**

Burden on family (description)	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes their condition not being a burden in general (No specific examples)	14	28.57	7	35.00	4	40.00	2	14.29	13	29.55	1	20.00	6	35.29	8	25.00
Participant describes the mental/emotional strain placed on their family	12	24.49	4	20.00	1	10.00	6	42.86	11	25.00	1	20.00	3	17.65	9	28.13
Participant describes their condition not being a burden, as they are very independent	8	16.33	4	20.00	3	30.00	1	7.14	8	18.18	0	0.00	3	17.65	5	15.63
Participant describes extra household duties and responsibilities that their family must take on	5	10.20	1	5.00	0	0.00	3	21.43	4	9.09	1	20.00	2	11.76	3	9.38
Participant describes their condition being a burden, but that it was temporary or only during treatment	5	10.20	2	10.00	1	10.00	2	14.29	5	11.36	0	0.00	3	17.65	2	6.25
Participant describes extra assistance needed getting to appointments	4	8.16	2	10.00	0	0.00	1	7.14	3	6.82	1	20.00	2	11.76	2	6.25
Participant describes their condition being a burden in general (No specific examples)	3	6.12	0	0.00	1	10.00	1	7.14	2	4.55	1	20.00	0	0.00	3	9.38

Burden on family (description)	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes their condition not being a burden in general (No specific examples)	14	28.57	8	27.59	6	31.58	5	33.33	9	27.27	7	35.00	7	25.00
Participant describes the mental/emotional strain placed on their family	12	24.49	9	31.03	3	15.79	4	26.67	8	24.24	5	25.00	7	25.00
Participant describes their condition not being a burden, as they are very independent	8	16.33	2	6.90	5	26.32	1	6.67	6	18.18	2	10.00	5	17.86
Participant describes extra household duties and responsibilities that their family must take on	5	10.20	4	13.79	1	5.26	1	6.67	4	12.12	1	5.00	4	14.29
Participant describes their condition being a burden, but that it was temporary or only during treatment	5	10.20	2	6.90	3	15.79	1	6.67	4	12.12	3	15.00	2	7.14
Participant describes extra assistance needed getting to appointments	4	8.16	3	10.34	1	5.26	2	13.33	2	6.06	3	15.00	1	3.57
Participant describes their condition being a burden in general (No specific examples)	3	6.12	2	6.90	1	5.26	1	6.67	2	6.06	1	5.00	2	7.14



**Figure 8.11: Burden on family (description)**

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

Burden on family (description)	Reported less frequently	Reported more frequently
Participant describes their condition not being a burden in general (No specific examples)	Advanced (Stage IV)	Invasive (Stage III)
Participant describes the mental/emotional strain placed on their family	Invasive (Stage III)	Advanced (Stage IV)
Participant describes their condition not being a burden, as they are very independent	Carer to someone with bladder cancer	Invasive (Stage III)
Participant describes extra household duties and responsibilities that their family must take on	Invasive (Stage III)	Advanced (Stage IV)
Participant describes their condition being a burden, but that it was temporary or only during treatment	Carer to someone with bladder cancer	-

## Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. There were 25 participants (51.02%) that described some cost burden and 22 participants (44.90%) 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=12, 24.49%). Other cost burdens were in relation to gap payments (public or private) (n=10, 20.41%), specialist appointments (n=9, 18.37%), and the cost of diagnostic tests and scans (n=8, 16.33%). There were 14 participants (28.57%) that described no cost burden and that nearly everything was paid for through the

health system, 12 participants (24.49%) described that there was no cost burden, even if costs exist, and 7 participants (14.29%) that described no cost burden and that nearly everything was paid for through private health insurance.

### Participant describes that there was some cost burden

*I've thought at times. Wow. This is expensive, Like, some of the out-of-pocket expenses. Yeah. Um, and, ah, you. Yeah. I thought, wow, that's really, really expensive. And I've had other people saying to me, they're having cystoscopy, they've gotten out of pocket and, and there's lots of things and, but I've had several operations of like more than seven and a half*

hours. Robotic surgeries and complicated things like that, which I've been I've paid out 5000 out of pocket for anesthesiologist yeah. For one operation and stuff like that for a really high profile anesthesiologist that did an awake intubation on me, you know what sort of stuff. So, um, it's been expensive and I've just thought I could have bought a Harley [Laughs], you know, the cost of these couple of operations. I could have done this or that with the money rather having surgery. Damn.  
Participant 001\_2022AUBLC

**PARTICIPANT** It's mainly the, the testing at the beginning. All the different tests that you have to have. Um, I, the only ongoing fees I have with my urologist is when I see her in the, in her rooms because when I, when she does a cystoscopy now, she doesn't charge me anything. I just, she just charges the, you know, the, the going rate, whatever. You know, the thing with the Medicare rebate, right. But it's the it is the other, you know, like the, you know, the the even the oncologist, you know, it's. Every, every hour, every month or so, there's another slug of another \$160 here. And it, especially when you're on a fixed income, because, as I said, we're both retired now.  
Participant 004\_2022AUBLC

Well, the costs were very high, but, but I had private health insurance that covered some of it. But, you know, I've been saving money up for when I was, when, because you get sicker as you get older. So and I was able to meet the costs, but it wasn't easy.  
Participant 008\_2022AUBLC

I was lucky that my urologist because I'm just having a quick day surgery procedure. They said to me that I wouldn't be out of pocket for. I mean, I've had 23 cystoscopies now and several of them I've had to stay overnight for initially because of complications and apart from that, there's been medications. I have to pay for the BCG, pay for the, which is not exorbitant. That's medication, that medication. Then there's the anti-spasmodics and the scans I had had to have as well although the some scans can be bulk billed like the CT scans checking metastases. So yeah, yeah. That sort of brings me to the present time. So I haven't I mean, I did have one, a, one of the anesthesiologists tried to charge me more than the, my health fund rebate and I queried that and they, he, he waved it on and as my specialist said to me, you know, of course there'll be out of pocket expense when you have a big operation and I can totally understand that. But he was um. Yeah. So it's bad enough that you got cancer, let alone having to pay so much every time since.  
Participant 010\_2022AUBLC

It's been a kerching, kerching, kerching along the whole way. I'm really, really surprised how expensive it's been already. I'm probably, you know, what, am I two months into this? And I'm probably at least 1500 dollars out of pocket already despite having the best medical coverage. The private sector are happy to gouge at all costs. Having said that, I've been challenging on the costs and they've been waving some of their gaps and things like that, which is good. But I've really had to kind of apply quite a bit of pressure to do that. But even my GP, nothing against my GP said he's brilliant. But because I have extended appointments I'm at least \$50 out of pocket, every time I go see my GP and for a while there a couple of appointments a week, you know, for several weeks and you know, every one of those \$50.  
Participant 017\_2022AUBLC

#### **Participant describes that there was no cost burden**

Look, I have I'm retired, so it doesn't affect work. I've got well, we've, we've got a reasonable pension so we can afford I think the BCG was costing me about \$130 every what is it, six months. So you know that I there was no real cost imposition. There was a few times when I'm, I've got I have got private health insurance, too. You know, look, there were costs and but they were not anything to break the bank or even trouble me greatly. So I look, I realise I'm pretty privileged like that. I know some people must really struggle but I, you know it's, it hasn't been a huge burden.  
Participant 006\_2022AUBLC

I'm retired, so I'm 74 years of age. So it's not that that wasn't an issue at the time it wasn't an issue. Uh, problem being in some of them, you know, and then I've got, I have a half hour drive to go to a hospital and you can't get a car park or an hour's drive to go to the same doctor where I can get a car back enough. Yeah, yeah. There's a lot that are at the make, but apart from that. Yeah. No problems at all, realistically.  
Participant 011\_2022AUBLC

**PARTICIPANT:** Nothing. Nothing. I've got really good health insurance and there was barely any out of pocket along the way. It was really good. Yeah.

**INTERVIEWER:** Costs in terms of time of work for you or.

**PARTICIPANT:** It was 12 weeks, but I've got buckets of sick leave, you know, 700 hours or something. So that wasn't a problem at all  
Participant 018\_2022AUBLC

**PARTICIPANT:** So, um. Very lucky, really. Private health insurance. Mhm. Um, it afforded me the robotic surgery over open surgery. And my urologist didn't charge well that urologist that was doing the robotic surgery. He didn't charge me any out of pocket when he could have. The other surgeon did. And, um, it was, you know, because I had the private health insurance, I paid my excess for the year, um, the things that cost me still were the MRI's PET scans. But, but most of the things that was covered. So I'm so lucky in that respect. My GP was bulk billing me all throughout. I happened to speak to a work colleague who had gone through bowel cancer the year before and he got me onto salary continuance. So I got onto that straight away and I had a three month wait period, but that was the three wait month period was basically all of the lead up to the operation. So I was able to get 75% of my wage after my operation.

**INTERVIEWER:** Okay, excellent. I was going to say, what is salary continuance?

**PARTICIPANT:** The continuance, it is an insurance is part of my superannuation. I didn't even, didn't even know I had it.

*Participant 022\_2022AUBLC*

*Well, I don't have any words for the cost. It's I have \$0 costs. I just have to thank my country that they have this wonderful Medicare system that from beginning to end, everything is free*

*Participant 028\_2022AUBLC*

*Well, I've been in the public system. I've never, never provided my credit card to anybody at any stage. So it's been absolutely zero. I've been reimbursed by the trial for any parking at the hospital. In terms of personal life. You know, I obviously spent a lot of hours, um, uh, doing tests and backwards and forwards to the hospital. I haven't, but I haven't regretted that in any, any way. Um, family life that hasn't been impacted. I'm retired, so there's no, there's no impact there.*

*Participant 029\_2022AUBLC*

*Nothing. Hmm. I paid nothing. Hmm. And Department of Veterans Affairs cover for all servicemen. I guess they cover all costs for cancers and mental health issues. So if you've been in the Army, Navy or Airforce. So they will pay for it. So I was covered. I lost no money. I lost nothing. I had retired. Everything was great.*

*Participant 038\_2022AUBLC*

**Table 8.24: Cost considerations**

Cost considerations	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes that there was some cost burden	25	51.02	14	70.00	3	30.00	5	35.71	22	50.00	3	60.00	10	58.82	15	46.88
Participant describes that there was no cost burden	22	44.90	6	30.00	6	60.00	8	57.14	20	45.45	2	40.00	7	41.18	15	46.88
Other/No response	2	4.08	0	0.00	1	10.00	1	7.14	2	4.55	0	0.00	0	0.00	2	6.25

Cost considerations	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes that there was some cost burden	25	51.02	16	55.17	9	47.37	9	60.00	16	48.48	13	65.00	12	42.86
Participant describes that there was no cost burden	22	44.90	11	37.93	10	52.63	4	26.67	17	51.52	5	25.00	16	57.14
Other/No response	2	4.08	2	6.90	0	0.00	2	13.33	0	0.00	2	10.00	0	0.00



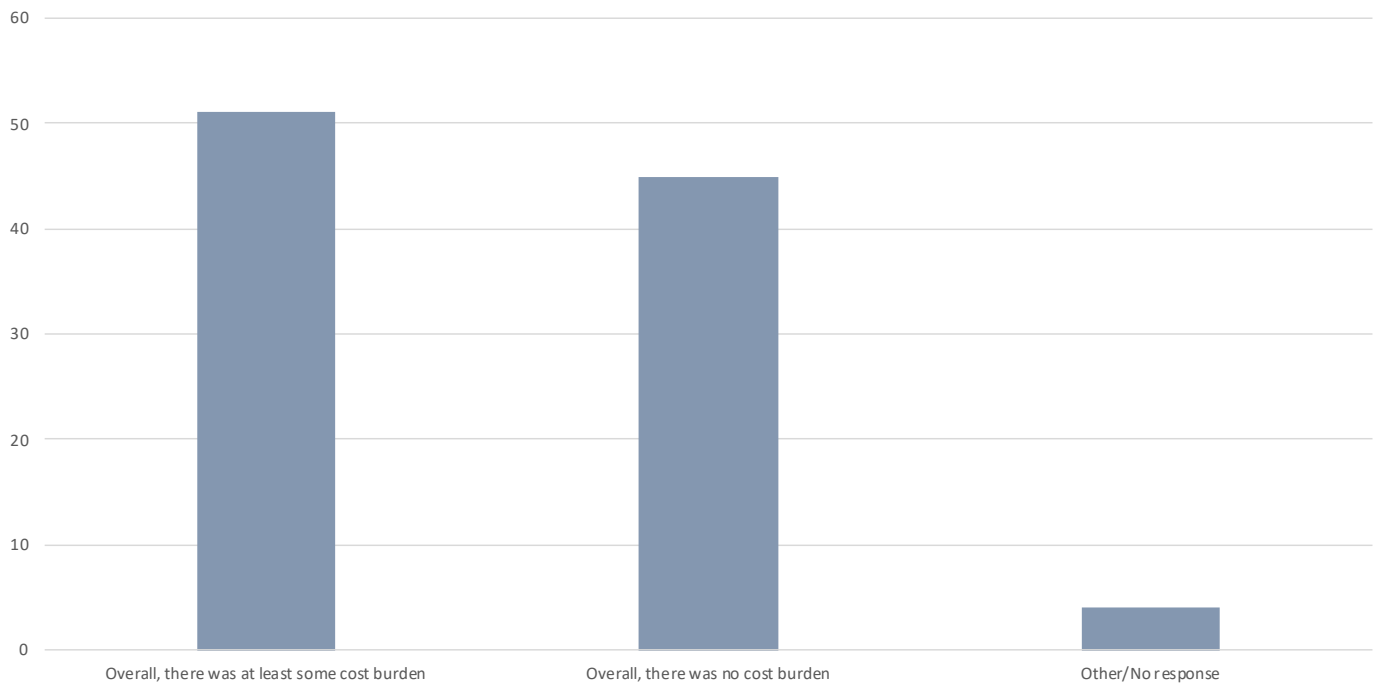


Figure 8.12: Cost considerations

Table 8.25: Cost considerations – subgroup variations

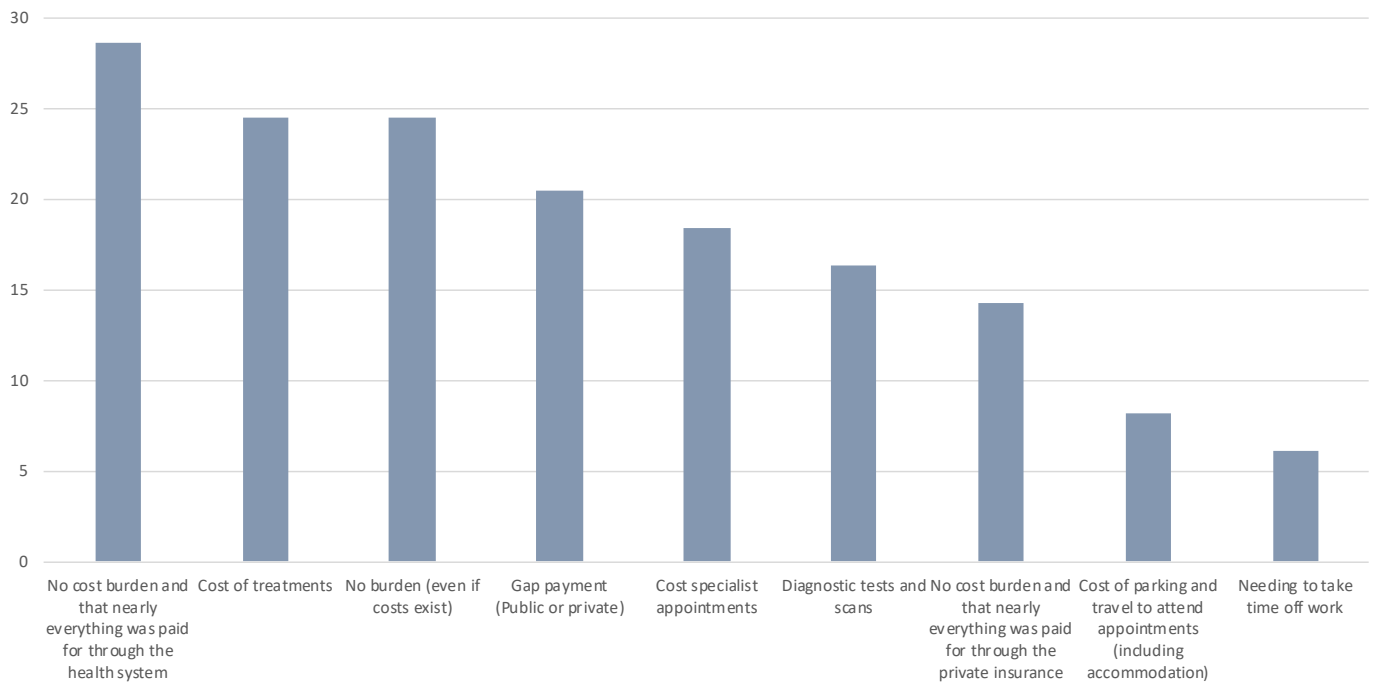
Cost considerations	Reported less frequently	Reported more frequently
Participant describes that there was some cost burden	Invasive (Stage III) Advanced (Stage IV)	Early (Stages 0 and I) Mid to low status
Participant describes that there was no cost burden	Early (Stages 0 and I) Regional or remote Mid to low status	Invasive (Stage III) Advanced (Stage IV) Higher status

Table 8.26: Cost considerations (Reasons for cost)

Cost considerations (Reasons for cost)	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes no cost burden and that nearly everything was paid for through the health system	14	28.57	3	15.00	5	50.00	4	28.57	12	27.27	2	40.00	2	11.76	12	37.50
Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)	12	24.49	7	35.00	2	20.00	2	14.29	11	25.00	1	20.00	4	23.53	8	25.00
Participant describes that there was no cost burden, even if costs exist	12	24.49	4	20.00	3	30.00	5	35.71	12	27.27	0	0.00	6	35.29	6	18.75
Participant describes a cost burden in relation to gap payments (public or private)	10	20.41	5	25.00	2	20.00	1	7.14	8	18.18	2	40.00	3	17.65	7	21.88
Participant describes a cost burden in relation to the cost specialist appointments	9	18.37	6	30.00	1	10.00	1	7.14	8	18.18	1	20.00	4	23.53	5	15.63
Participant describes a cost burden in relation to diagnostic tests and scans	8	16.33	6	30.00	0	0.00	0	0.00	6	13.64	2	40.00	6	35.29	2	6.25
Participant describes that there was no cost burden, as nearly everything was paid for through private insurance	7	14.29	1	5.00	2	20.00	3	21.43	6	13.64	1	20.00	5	29.41	2	6.25
Participant describes a cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	4	8.16	2	10.00	0	0.00	1	7.14	3	6.82	1	20.00	1	5.88	3	9.38
Participant describes a cost burden in relation to needing to take time off work	3	6.12	1	5.00	0	0.00	2	14.29	3	6.82	0	0.00	1	5.88	2	6.25

Cost considerations (Reasons for cost)	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes no cost burden and that nearly everything was paid for through the health system	14	28.57	9	31.03	4	21.05	2	13.33	11	33.33	5	25.00	8	28.57
Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)	12	24.49	8	27.59	4	21.05	4	26.67	8	24.24	4	20.00	8	28.57
Participant describes that there was no cost burden, even if costs exist	12	24.49	7	24.14	5	26.32	6	40.00	6	18.18	4	20.00	8	28.57
Participant describes a cost burden in relation to gap payments (public or private)	10	20.41	6	20.69	4	21.05	5	33.33	5	15.15	5	25.00	5	17.86
Participant describes a cost burden in relation to the cost specialist appointments	9	18.37	7	24.14	2	10.53	1	6.67	8	24.24	4	20.00	5	17.86
Participant describes a cost burden in relation to diagnostic tests and scans	8	16.33	6	20.69	2	10.53	3	20.00	5	15.15	5	25.00	3	10.71
Participant describes that there was no cost burden, as nearly everything was paid for through private insurance	7	14.29	2	6.90	5	26.32	1	6.67	6	18.18	0	0.00	7	25.00
Participant describes a cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	4	8.16	3	10.34	1	5.26	2	13.33	2	6.06	2	10.00	2	7.14
Participant describes a cost burden in relation to needing to take time off work	3	6.12	2	6.90	1	5.26	0	0.00	3	9.09	1	5.00	2	7.14



**Figure 8.13: Cost considerations (Reasons for cost)**

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

Cost considerations (Reasons for cost)	Reported less frequently	Reported more frequently
Participant describes no cost burden and that nearly everything was paid for through the health system	Early (Stages 0 and I) Female Regional or remote	Invasive (Stage III) Carer to someone with bladder cancer
Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)	Advanced (Stage IV)	Early (Stages 0 and I)
Participant describes that there was no cost burden, even if costs exist	Carer to someone with bladder cancer	Advanced (Stage IV) Female Regional or remote
Participant describes a cost burden in relation to gap payments (public or private)	Advanced (Stage IV)	Carer to someone with bladder cancer Regional or remote
Participant describes a cost burden in relation to the cost specialist appointments	Advanced (Stage IV) Regional or remote	Early (Stages 0 and I)
Participant describes a cost burden in relation to diagnostic tests and scans	Invasive (Stage III) Advanced (Stage IV) Male	Early (Stages 0 and I) Carer to someone with bladder cancer Female
Participant describes that there was no cost burden, as nearly everything was paid for through private insurance	Mid to low status	Female University Higher status

## 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. The overall scores for the cohort were in the highest quintile for Fear of progression: Total score

(mean=32.87, SD=8.66), indicating moderate levels of anxiety (Table 8.28).

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 8.28: Fear of progression summary statistics**

Fear of progression (n=47)	Mean	SD	Median	IQR	Possible range	Quintile
Total score*	32.87	8.66	31.00	11.50	12 to 60	3

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

## Fear of progression by bladder cancer stage

Comparisons were made by Stage. There were 18 participants (42.86%) with early bladder cancer (Stages 0 and I), 10 participants (23.81%) with invasive bladder cancer (Stage III), and 14 participants (33.33%) with advanced bladder cancer (Stage IV).

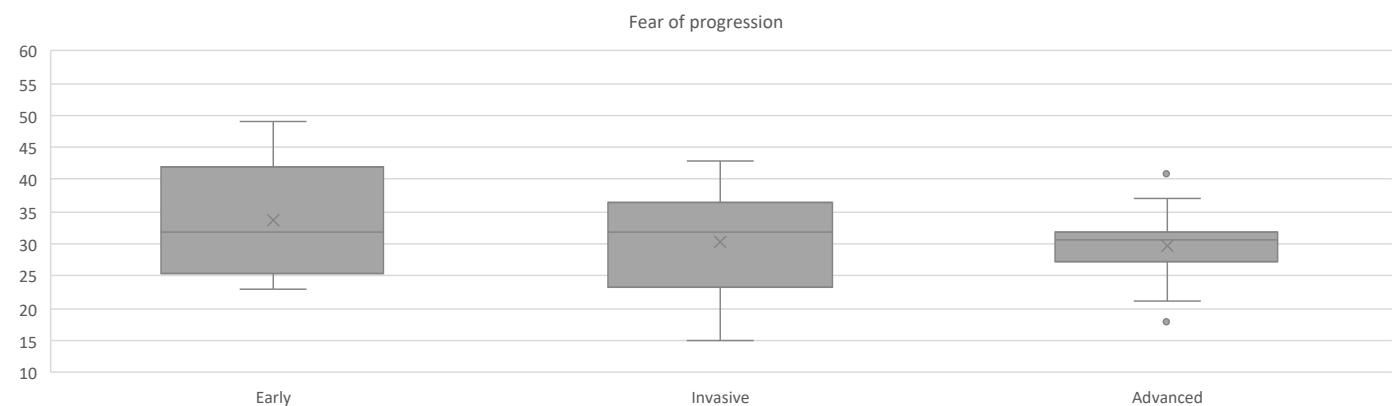
A one-way ANOVA test was used when the assumptions for response variable residuals were

normally distributed and variances of populations were equal (Table 8.29).

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

**Table 8.29: Fear of progression total score by bladder cancer stage summary statistics and one-way ANOVA**

Fear of progression	Group	Number (n=42)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Total score	Early	18	42.86	33.83	8.69	Between groups	164.30	2	82.13	1.30	0.2850
	Invasive	10	23.81	30.30	8.90	Within groups	2472.00	39	63.39		
	Advanced	14	33.33	29.57	6.06	Total	2636.30	41	145.52		



**Figure 8.14: Boxplot of Fear of progression total score by bladder cancer stage**

## Fear of progression by participant type

Comparisons were made by type of participant, there were 42 participants (89.36%) with bladder cancer and, 5 participants (10.64%) that were a carer to someone with bladder cancer.

Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.30).

A two sample t-test indicated that the mean score for the Fear of progression Total score scale [ $t(45) = -3.29$ ,  $p = 0.0020$ ] was significantly lower for participants in the Mid to low status subgroup (Mean = 31.57, SD =

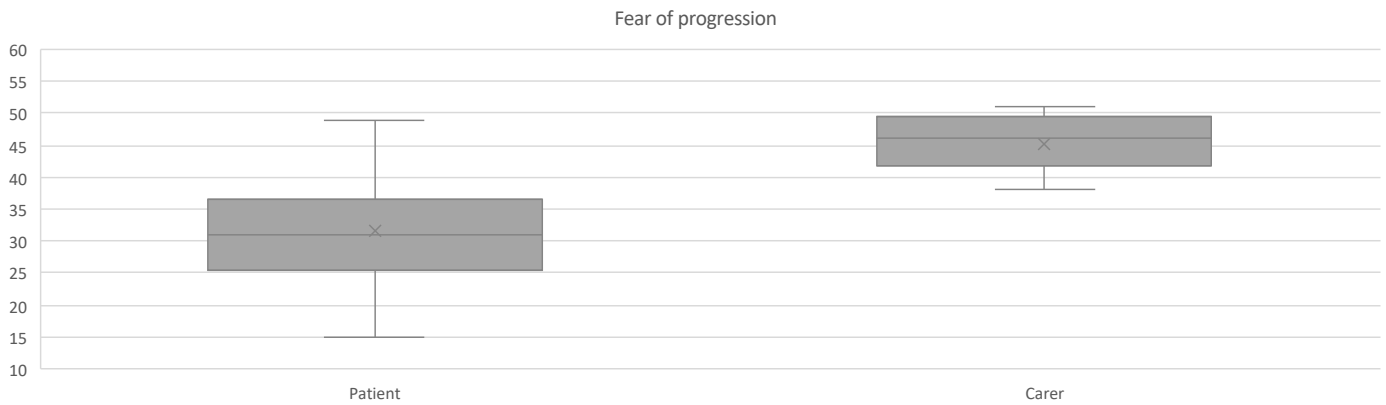
8.02) compared to participants in the Higher status subgroup (Mean = 43.80, SD = 6.06.)

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

**Table 7.30: Fear of progression total score by participant type summary statistics and T-test**

Fear of progression	Group	Number (n=47)	Percent	Mean	SD	T	dF	p-value
Total score	Patient	42	89.36	31.57	8.02	-3.29	45	0.0020*
	Carer	5	10.64	43.80	6.06			

\*Statistically significant at  $p < 0.05$



**Figure 8.15: Boxplot of Fear of progression total score by participant type**

### Fear of progression by gender

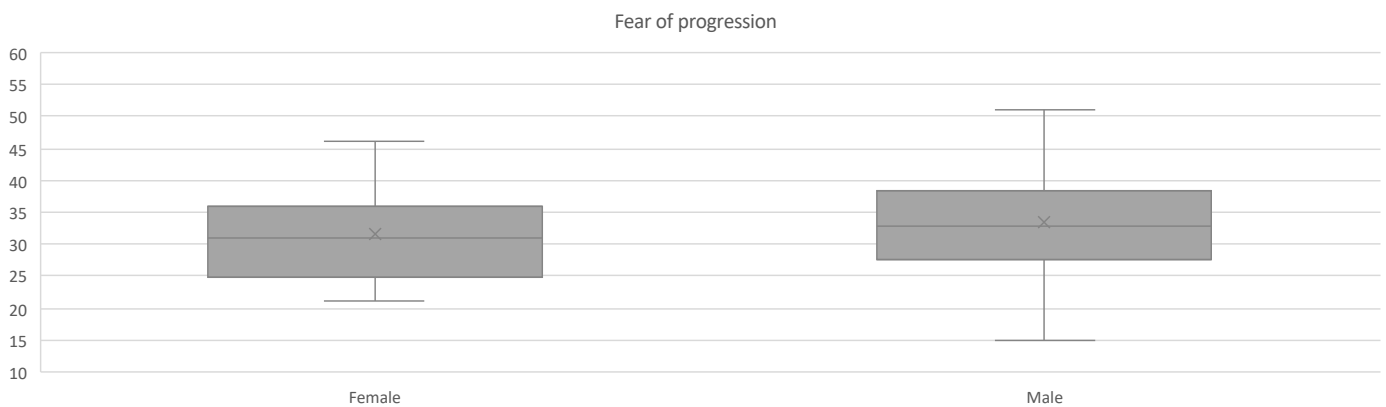
Comparisons were made by gender, there were 16 female participants (34.04%), and 31 male participants (65.96%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.31).

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

**Table 7.31: Fear of progression total score by gender summary statistics and T-test**

Fear of progression	Group	Number (n=47)	Percent	Mean	SD	T	dF	p-value
Total score	Female	16	34.04	31.56	8.33	-0.74	45	0.4625
	Male	31	65.96	33.55	8.89			



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

### Fear of progression by education

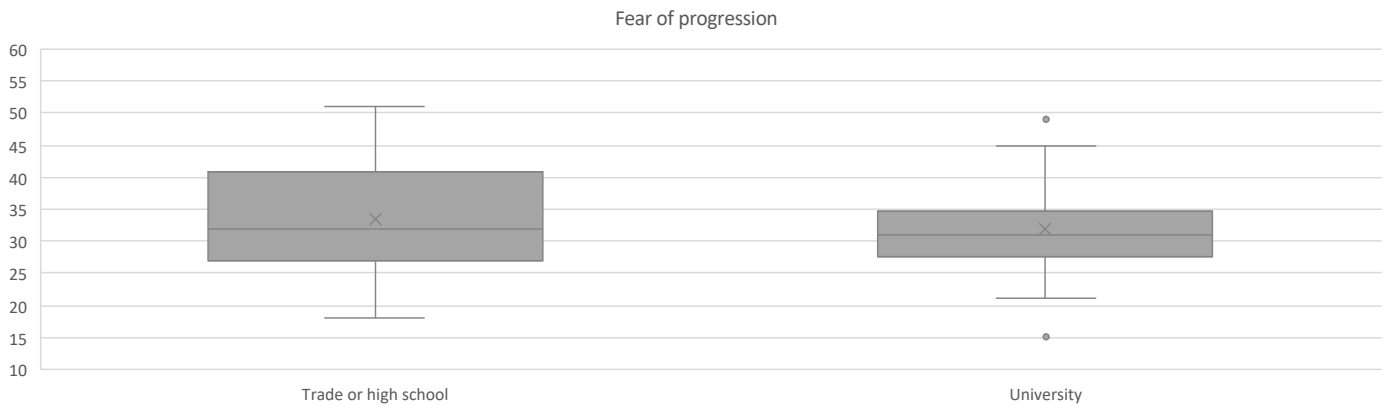
Comparisons were made by education status, between those with trade or high school qualifications (n=29, 61.70%), and those with a university qualification (n=18, 38.30%).

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 **education** for any of the Fear of progression scales.

**Table 7.32: Fear of progression total score by education summary statistics and T-test**

Fear of progression	Group	Number (n=47)	Percent	Mean	SD	T	dF	p-value
Total score	Trade or high school	29	61.70	33.52	8.91	0.64	45	0.5230
	University	18	38.30	31.83	8.39			



**Figure 8.17: 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 or remote area (n=15, 31.91%) were compared to those living in a metropolitan area (n=32, 68.09%).

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 **location** for any of the Fear of progression scales.

**Table 7.33: Fear of progression total score by location summary statistics and T-test**

Fear of progression	Group	Number (n=47)	Percent	Mean	SD	T	dF	p-value
Total score	Regional or remote	15	31.91	35.80	8.74	1.61	45	0.1135
	Metropolitan	32	68.09	31.50	8.41			



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

## Fear of progression by socioeconomic status

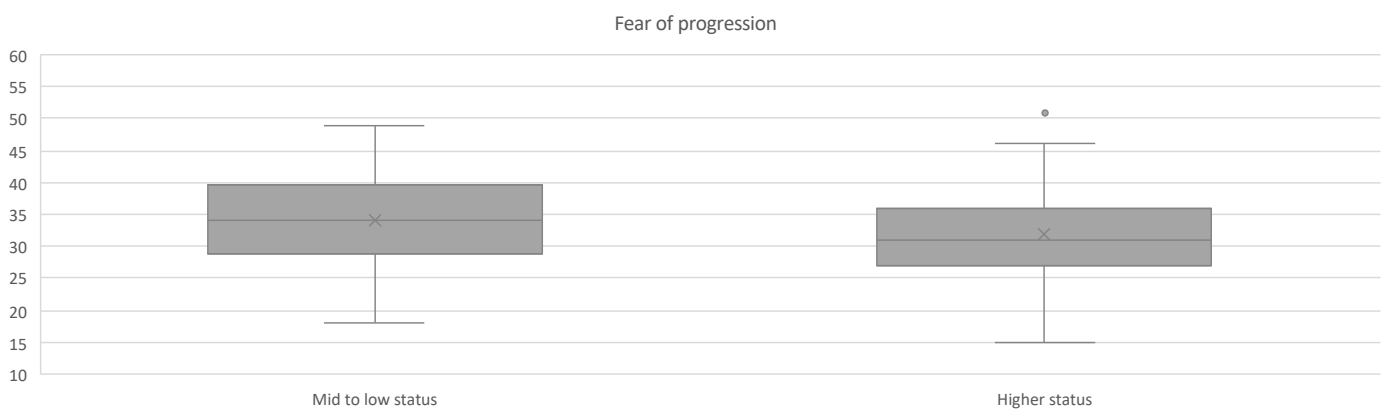
Comparisons were made by socioeconomic status, using the Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a mid to low SEIFA score of 1-6 (n=20, 42.55%) compared to those with a higher SEIFA score of 7-10 (n=27, 57.45%).

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 **socioeconomic status** for any of the Fear of progression scales.

**Table 7.34: Fear of progression total score by socioeconomic status summary statistics and T-test**

Fear of progression	Group	Number (n=47)	Percent	Mean	SD	T	dF	p-value
Total score	Mid to low status	20	42.55	34.05	8.80	0.80	45	0.4285
	Higher status	27	57.45	32.00	8.62			



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

## Anxiety about treatment

An overview of responses to individual fear of progression questions is given in Table 8.35.

### Fear of progression individual questions

On average, participants scored in the “Seldom” range for the following questions: “Has concerns about reaching professional and/or personal goals because of illness:” (median=2.00, IQR=2.00), “When anxious, has physical symptoms such as a rapid heartbeat, stomach ache or agitation” (median=2.00, IQR=1.00), “The possibility of relatives being diagnosed with this disease disturbs participant” (median=2.00, IQR=2.00), “Is disturbed that they may have to rely on strangers for activities of daily living” (median=2.00, IQR=2.00), “The thought that they might not be able to work due to illness disturbs participant” (median=2.00, IQR=2.00).

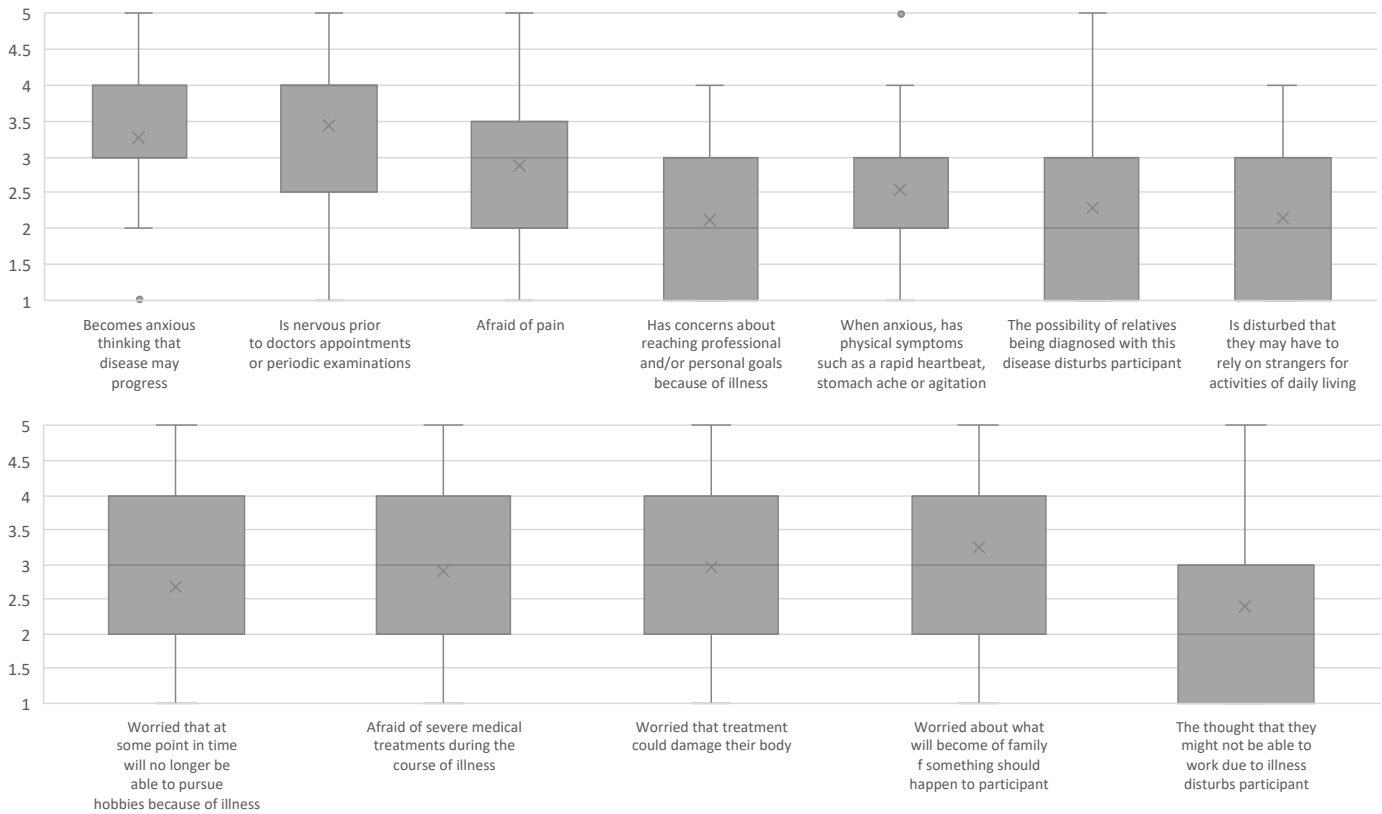
On average, participants scored in the “Sometimes” range for the following questions: “Becomes anxious thinking that disease may progress” (median=3.00, IQR=1.00), “Afraid of pain” (median=3.00, IQR=1.50), “Worried that at some point in time will no longer be able to pursue hobbies because of illness” (median=3.00, IQR=1.50), “Afraid of severe medical treatments during the course of illness” (median=3.00, IQR=1.50), “Worried that treatment could damage their body” (median=3.00, IQR=2.00), “Worried about what will become of family if something should happen to participant” (median=3.00, IQR=2.00).

On average, participants scored in the “Often” range for the following questions: “Is nervous prior to doctors appointments or periodic examinations” (median=4.00, IQR=1.50).



**Table 8.35: Fear of progression individual questions**

Fear of progression (n=47)	Median	IQR	Average response
Becomes anxious thinking that disease may progress	3.00	1.00	Sometimes
Is nervous prior to doctors appointments or periodic examinations	4.00	1.50	Often
Afraid of pain	3.00	1.50	Sometimes
Has concerns about reaching professional and/or personal goals because of illness:	2.00	2.00	Seldom
When anxious, has physical symptoms such as a rapid heartbeat, stomach ache or agitation	2.00	1.00	Seldom
The possibility of relatives being diagnosed with this disease disturbs participant	2.00	2.00	Seldom
Is disturbed that they may have to rely on strangers for activities of daily living	2.00	2.00	Seldom
Worried that at some point in time will no longer be able to pursue hobbies because of illness	3.00	1.50	Sometimes
Afraid of severe medical treatments during the course of illness	3.00	1.50	Sometimes
Worried that treatment could damage their body	3.00	2.00	Sometimes
Worried about what will become of family if something should happen to participant	3.00	2.00	Sometimes
The thought that they might not be able to work due to illness disturbs participant	2.00	2.00	Seldom



**Figure 8.20: Fear of progression individual questions**