

Section 5

Treatment

Section 5: Experience of treatment

Access to healthcare professionals

Participants noted in the online questionnaire the healthcare professionals they had access to for the treatment and management of their condition.

Almost all participants had access to a urologist (n=41, 97.62%), and a general practitioner (GP) (n=40, 95.24%) A total of 26 participants (61.90%) noted that they had access to a nurse for their bladder cancer, there were 14 participants (33.33%) that had a stoma nurse, 17 participants (40.48%) that had a registered nurse, and 7 participants that had a nurse care coordinator (16.67%)

There were 13 participants (30.95%) treated by a physiotherapist, 8 participants (19.05%) treated by a Counsellor or had psychological support, and 5 participants (11.90%) treated by a dietician.

Health care system

In the online questionnaire, participants were asked questions about the healthcare system they used, about private insurance and about whether they were treated as a public or private patient.

The majority of participants had private health insurance (n=27, 64.29%). Throughout their treatment, there were 16 participants (38.10%) that were treated mostly as a private patient, 19 participants (45.24%) were mostly treated as a public patient, and there were 7 participants (16.67%) that were equally treated as a private and public patient.

Throughout their treatment, there were 19 participants (45.24%) that were treated mostly in the private hospital system, 17 participants (40.48%) were mostly treated in the public system, and there were 6 participants (14.29%) that were equally treated in the private and public systems.

Affordability of healthcare

Participants were asked a series of questions about affordability of healthcare in the online questionnaire. The first question was about having to delay or cancel healthcare appointments because they were unable to afford them. Almost all the participants never or rarely had to delay or cancel appointments due to affordability (n = 40, 95.24%).

The next question was about the ability to fill prescriptions. Almost all of the participants never or rarely were unable to fill prescriptions (n=41, 97.62%).

The third question was about the affordability of basic essentials such as food, housing and power. There were 38 participants (90.48%) that never or rarely had trouble paying for essentials, and 2 participants (4.76%) that sometimes found it difficult, and 2 participants (4.76%) often or very often found it difficult to pay for basic essentials.

The final question was about paying for additional carers for themselves or for their family, no participants had paid for additional carers.

Cost of condition

In the online questionnaire, participants estimated the amount they spend per month due to their condition, including doctors' fees, transport, carers, health insurance gaps and complementary therapies. Where the response was given in a dollar amount, it is included below.

The most common amount was \$50 or less (n=9, 21.43%), followed by between \$51 to \$100 (n=7, 16.67%), and \$101 to \$250 (n=5, 11.90%). There were 2 participants (4.76%), that spent \$501 or more a month.

Burden of cost

As a follow up question, for participants that had monthly expenses due to their condition, participants were asked if the amount spent was a burden.

The amount spent was a slightly or not at all significant burden for 36 participants (85.71%), somewhat significant for 4 participants (9.52%), and moderately or extremely significant burden for 2 participants (4.76%).

Changes to employment status

Participants were asked, in the online questionnaire, if they had any changes to their employment status due to their condition. Participants were able to choose multiple changes to employment.

Work status for 7 participants (16.67%) had not changed since diagnosis, and 18 participants (42.86%) were retired or did not have a job. There were 4 participants (9.52%) had to quit their job, 6 participants (14.29%) reduced the number of hours they worked, and 2 participants (4.76%) that accessed their superannuation early. There were 5 participants (11.90%) that took leave from work without pay, and 10 participants (23.81%) that took leave from work with pay.

Changes to carer/partner employment status

Participants were asked, in the online questionnaire, if they had any changes to the employment status of their care or partner due to their condition. Participants were able to choose multiple changes to employment.

Most commonly, participants had partners or carers that did not change their work status due to their condition (n=27, 64.29%). There was a single participant (2.38%) whose partner reduced the number of hours they worked, and 2 partners, (4.76%) that quit their job. No partners participants took leave without pay, and there were 2 partners (4.76%) that took leave with pay.

Reduced income due to condition

Participants noted in the online questionnaire details about and changes to income due to the bladder cancer diagnosis.

Approximately a third of the participants (n=12, 28.57%) indicated in the online questionnaire that they had a reduced family income due to their condition.

Estimated reduction monthly income

As a follow up question, participants were asked if their family or household income had reduced due to their condition. Most commonly, participants monthly income was reduced by more than \$1000 per month (n=5, 11.90%), or reduced by between \$501 to \$1000 per month (n=4, 9.52%).

Summary of treatment

Participants noted in the online questionnaire the different treatments, they had since diagnosis with their condition.

All participants were treated for bladder cancer. There were 40 participants (95.24%) that had surgery, 20 participants (47.62%) that had chemotherapy and 24 participants (57.14%) that had Bacillus Calmetter-Guérin (BCG), 3 participants had radiotherapy (7.14%), and a single participant had immunotherapy (2.38%)

Summary of surgery

In the online questionnaire, participants noted the number of operations (excluding biopsies) that they had for their condition.

There were 40 participants (95.24%) that had surgery for their condition (excluding biopsies). There were 16 participants (38.10%) that had one operation, 9 participants (21.43%) that had two operations, 4 participants (9.52%) that had three operations, and 11 participants (26.19%) that had four or more operations.

Most common types of surgery

Participants completed a series of questions about surgery, including type of surgery, quality of life, and effectiveness of surgery.

There were 40 participants (95.24%) that had surgery for their condition. The most common type of surgery was transurethral resection of bladder tumour (TURBT) (n=30, 71.43%), followed by radical cystectomy (n=19, 45.24%), and urostomy (n= 15, 35.71%).

Quality of life and effectiveness of surgery

Quality of life was rated on a Likert scale from one to seven, where one is “Life was very distressing” and seven is “Life was great”. Effectiveness of treatment was rated on a five-point scale where one is ineffective, and five is very effective. Values are calculated where there was adequate data available (five or more participants).

Median quality of life from surgery ranged from 2.00 to 5.00, in the life was distressing to good range. The median effectiveness of all surgery was between 3.50 to 5.00, in the moderately to very effective range.

On average, quality of life from transurethral resection of bladder tumour (TURBT) was in the 'life was a little distressing' range (median=3.00, IQR = 1.00), and was found to be moderately effective to effective (median=3.50, IQR=2.75).

On average, quality of life from radical cystectomy was in the 'life was distressing' range (median=2.00, IQR=1.00), and was found to be very effective (median=5.00, IQR=0.00).

On average, quality of life from urostomy was in the 'life was good' range (median=5.00, IQR=1.00), and was found to be very effective (median=5.00, IQR=0.00).

Summary of drug treatments

Participants completed a series of questions about drug treatments, including type of treatment, quality of life, and effectiveness of treatment.

There were 20, participants (47.62%) that had chemotherapy. The most common types of chemotherapy were MVAC chemotherapy (methotrexate, vinblastine, doxorubicin/ Adriamycin, and cisplatin), (n=5, 11.90%), and Gemcitabine with cisplatin n=5,11.90%). There were 24 participants (57.14%) that had Bacillus Calmetter-Guérin (BCG).

Median quality of life from drug treatments ranged from 1 to 4, in the life was very distressing to good range. The median effectiveness of all surgery was between 2.5 to 4, in the somewhat effective to effective range.

On average, quality of life from Bacillus Calmetter-Guérin (BCG) was in the 'life was a little distressing to average' range (median=3.50, IQR=2.00), and was found to be somewhat to moderately effective (median=2.50 , IQR=3.25).

On average, quality of life from methotrexate, vinblastine, doxorubicin/Adriamycin, and cisplatin was in the 'life was average' range (median=4.00, IQR=2.00), and was found to be effective (median=4.00, IQR=1.00).

On average, quality of life from gemcitabine with cisplatin was in the 'life was very distressing' range (median=1.00, IQR=2.00), and was found to be effective (median=4.00, IQR=1.00).

Clinical trials discussions

In the online questionnaire, participants were asked if they had discussions with their doctor about clinical trials, and if they did, who initiated the discussion.

There was a total of 10 participants (23.81%) that had discussions about clinical trials, 5 participants (11.90%) had brought up the topic with their doctor, and the doctor of 5 participants (11.90%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n=32, 76.19%).

Clinical trial participation

As a follow up question, participants were asked if they had taken part in a clinical trial, and if they had not taken part if they were interested in taking part.

There were 5 participants (11.90%) that had taken part in a clinical trial, 21 participants (50.00%) that would like to take part in a clinical trial if there was a suitable one, and 16 participants, that have not participated in a clinical trial and do not want to (38.10%).

Description of mild side effects

In the structured interview, participants were asked how they would describe the term 'mild side effects'. The most common description of 'mild side effects' was a specific side effect as an example (n=36, 73.47%). This was followed by describing 'mild side effects' as those that can be self-managed (n=10, 20.41%), those that do not interfere with daily life (n=9, 18.37%), and as those that have a short duration or are reversible (n=7, 14.29%).

Of those who described a specific side effect, the most commonly described side effects were fatigue or lethargy (n=11, 22.45%), mild pain or aches (n=7, 14.29%) and nausea (n=6, 12.24%). Other side effects described by fewer than 5 participants, included hair loss, stoma bag/irritation/leaks, emotion/mental impact, and cystitis/UTIs.

Description of severe side effects

In the structured interview, participants were asked how they would describe the term 'severe side effects'. The most common description of 'severe side effects' was a specific side effect as an example (n=34, 69.39%). Other descriptions of 'severe side effects' included those that impact everyday life/ability to conduct activities of daily living (n=9, 18.37%), and those that are long lasting (n=6, 12.24%). There were 6 participants (12.24%) that were unable to describe severe side effects as they had not experienced them.

Of those who described a specific side effect, the most commonly described side effects were pain (n=18, 36.73%), the emotional or mental impact of the condition, (n=7, 14.29%), and pain when urinating (n=5, 10.20%). Other side effects described by fewer than 5 participants, included fatigue, nausea, fever or infection, and incontinence.

Adherence to treatment

Participants were asked in the structured interview what influences their decision to continue with a treatment regime. The most common themes described were adhering to treatment as per the advice of their specialist/as long as prescribed (n=20, 40.82%), and adhering to treatment as long as treatment is working (n=16, 32.65%). This was followed by adhering to treatment as long as side effects are tolerable (n=12, 24.49%), adhering to treatment for a specific amount of time (n=11, 22.45%), and 7 participants (14.29%) described not giving up on any treatments.

Where participants stated a specific amount of time to adhere to a treatment, the most common amount of time was two to three weeks.

What needs to change to feel like treatment is working

Participants were asked to describe what needs to change to feel like treatment is effective. The most common response from 24 participants (48.89%) was needing to experience evidence of stable disease/no disease progression. There were 14 participants (28.57%) that reported needing to experience a reduction in physical signs/reduced side effects, and 13 participants (26.53%) needed to see specific symptom reduction. The most common specific symptoms were nausea, aches and pains, fatigue and lethargy, and muscle cramping.

What would it mean if treatment worked

Participants were asked what it would mean to them if their treatment worked. The most common response from 16 participants (32.65%) was treatment allowing them to do everyday activities/ return to normal life. There were 12 participants (24.49%) that reported treatment working as having a positive impact on their mental health, 8 participants (16.33%) described treatment leading to a reduction in symptoms/side effects, and 8 participants (16.33%) described treatment allowing them to engage more with social activities and family life. Other participants described that treatment would allow them to keep their bladder (n=6, 12.24%), and allow them to do more exercise (n=6, 12.24%).

Access to healthcare professionals

Participants noted in the online questionnaire the healthcare professionals they had access to for the treatment and management of their condition.

Almost all participants had access to a urologist (n=41, 97.62%), and a general practitioner (GP) (n=40, 95.24%). A total of 26 participants (61.90%) noted that they had access to a nurse for their bladder cancer, there were 14 participants (33.33%) that had a stoma

nurse, 17 participants (40.48%) that had a registered nurse, and 7 participants that had a nurse care coordinator (16.67%).

There were 13 participants (30.95%) treated by a physiotherapist, 8 participants (19.05%) treated by a Counsellor or had psychological support, and 5 participants (11.90%) treated by a dietician (Table 5.1, Figure 5.1).

Table 5.1: Access to healthcare professionals

Healthcare professional	Number (n=42)	Percent
Urologist	41	97.62
Medical Oncologist	16	38.10
Radiation Oncologist	5	11.90
Other specialist	4	9.52
Geneticist	1	2.38
General Practitioner (GP)	40	95.24
Palliative care	1	2.38
Registered Nurse	17	40.48
Stoma nurse	14	33.33
Nurse Care Coordinator	7	16.67
Physiotherapy	13	30.95
Counselling or psychological support	8	19.05
Dietician	5	11.90
Naturopath	1	2.38
Chiropractor	1	2.38

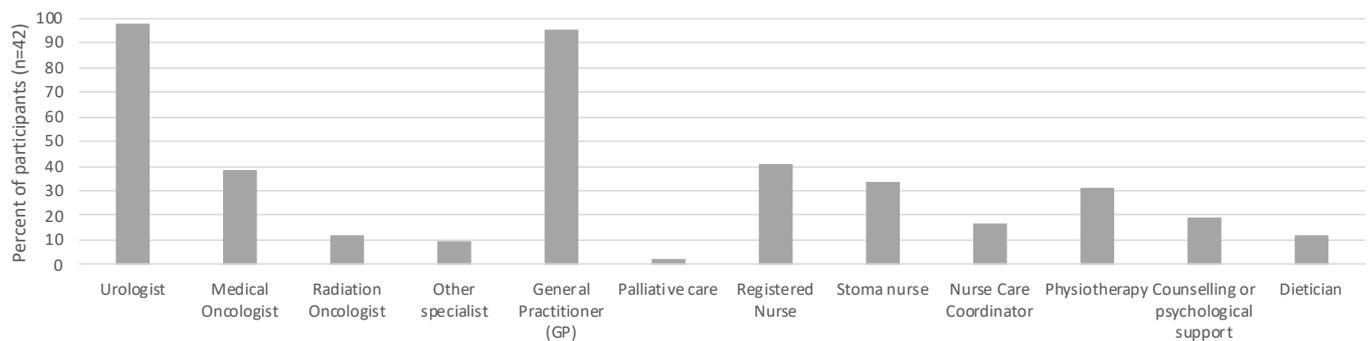


Figure 5.1: Access to healthcare professionals

Health care system

In the online questionnaire, participants were asked questions about the healthcare system they used, about private insurance and about whether they were treated as a public or private patient (Table 5.2, Figures 5.2 and 5.3).

The majority of participants had private health insurance (n=27, 64.29%). Throughout their treatment, there were 16 participants (38.10%) that were treated mostly as a private patient, 19 participants (45.24%) were mostly treated as a public patient, and there were

7 participants (16.67%) that were equally treated as a private and public patient.

Throughout their treatment, there were 19 participants (45.24%) that were treated mostly in the private hospital system, 17 participants (40.48%) were mostly treated in the public system, and there were 6 participants (14.29%) that were equally treated in the private and public systems.

Table 5.2: Health care system

Health care services	Response	Number (n=42)	Percent
Private health insurance	No	15	35.71
	Yes	27	64.29
Throughout your treatment in hospital, have you most been treated as a public or a private patient	Equally as a public and private patient	7	16.67
	Private patient	16	38.10
	Public patient	19	45.24
Which hospital system have you primarily been treated in	Both public and private	6	14.29
	Private	19	45.24
	Public patient	17	40.48



Figure 5.2: Health insurance

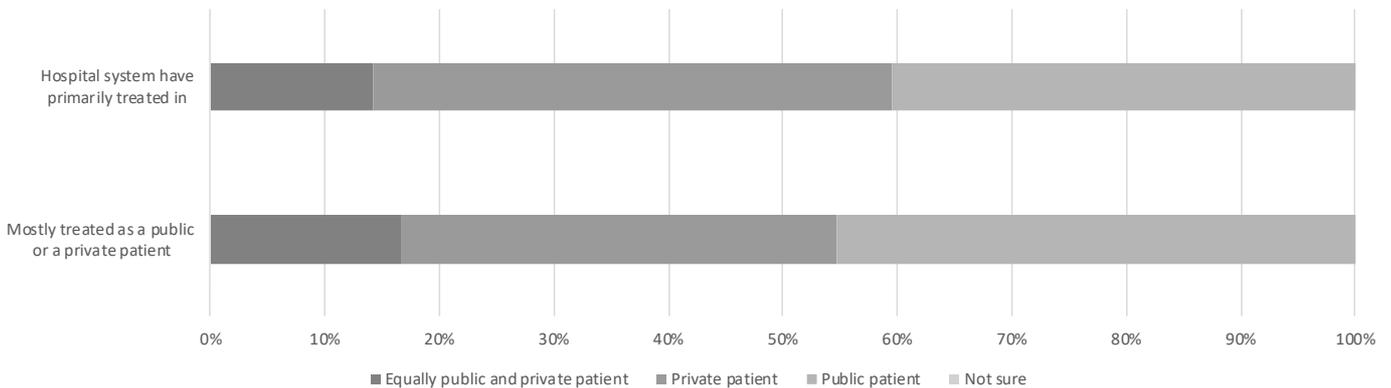


Figure 5.3: Hospital system

Affordability of healthcare

Participants were asked a series of questions about affordability of healthcare in the online questionnaire (Table 5.3, Figure 5.4).

The first question was about having to delay or cancel healthcare appointments because they were unable to afford them. Almost all the participants never or rarely had to delay or cancel appointments due to affordability (n = 40, 95.24%).

The next question was about the ability to fill prescriptions. Almost all of the participants never or rarely were unable to fill prescriptions (n=41, 97.62%).

The third question was about the affordability of basic essentials such as food, housing and power. There were 38 participants (90.48%) that never or rarely had trouble paying for essentials, and 2 participants (4.76%) that sometimes found it difficult, and 2 participants (4.76%) often or very often found it difficult to pay for basic essentials.

The final question was about paying for additional carers for themselves or for their family, no participants had paid for additional carers.

Table 5.3: Affordability of healthcare

Health services and insurance	Response	Number (n=42)	Percent
Delay or cancel healthcare appointments due to affordability	Never	38	90.48
	Rarely	2	4.76
	Sometimes	1	2.38
	Often	1	2.38
	Very often	0	0.00
Did not fill prescriptions due to cost	Never	40	95.24
	Rarely	1	2.38
	Sometimes	1	2.38
	Often	0	0.00
	Very often	0	0.00
Difficult to pay for basic essentials	Never	31	73.81
	Rarely	7	16.67
	Sometimes	2	4.76
	Often	2	4.76
	Very often	0	0.00
Pay for additional carers for self or family	Yes	0	0.00
	No	42	100.00

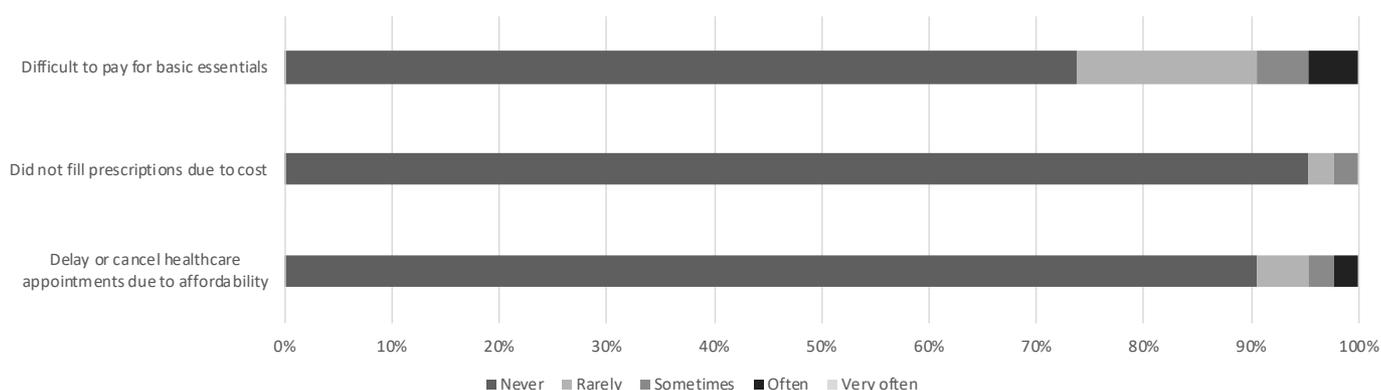


Figure 5.4: Affordability of healthcare

Cost of condition

In the online questionnaire, participants estimated the amount they spend per month due to their condition, including doctors' fees, transport, carers, health insurance gaps and complementary therapies. Where the response was given in a dollar amount, it is included below (Table 5.4, Figure 5.5).

The most common amount was \$50 or less (n=9, 21.43%), followed by between \$51 to \$100 (n=7, 16.67%), and \$101 to \$250 (n=5, 11.90%). There were 2 participants (4.76%), that spent \$501 or more a month.

Burden of cost

As a follow up question, for participants that had monthly expenses due to their condition, participants were asked if the amount spent was a burden (Table 5.5, Figure 5.6).

The amount spent was a slightly or not at all significant burden for 36 participants (85.71%), somewhat significant for 4 participants (9.52%), and moderately or extremely significant burden for 2 participants (4.76%) (Table 5.10, Figure 5.9).

Table 5.4: Estimated monthly out of pocket expenses due to condition

Estimated monthly out of pocket expenses	Number (n=42)	Percent
\$0	7	16.67
\$50 or less	9	21.43
\$51 to \$100	7	16.67
\$101 to \$250	5	11.90
\$251 to \$500	5	11.90
\$501 or more	2	4.76
Not sure	7	16.67

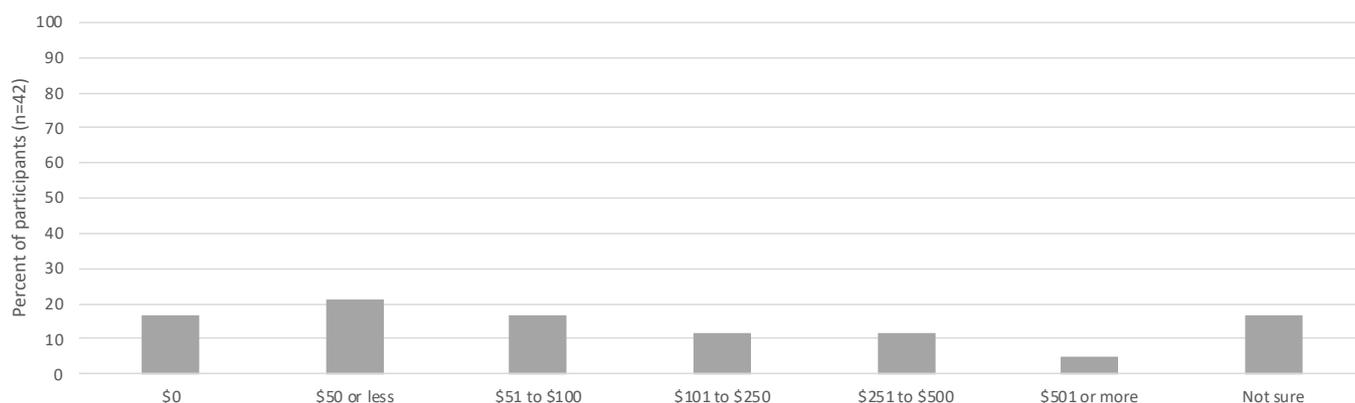


Figure 5.5: Estimated monthly out of pocket expenses due to condition

Table 5.5: Burden of out-of-pocket expenses due to condition

Burden of out of pocket expenses	Number (n=42)	Percent
Extremely significant	1	2.38
Moderately significant	1	2.38
Somewhat significant	4	9.52
Slightly significant	16	38.10
Not at all significant	20	47.62

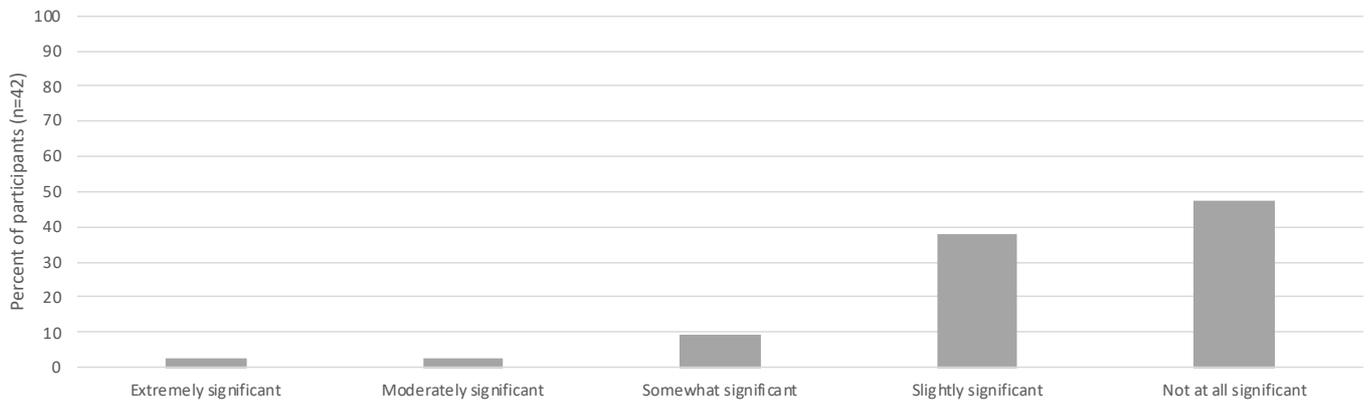


Figure 5.6: Burden of out-of-pocket expenses due to condition

Changes to employment status

Participants were asked, in the online questionnaire, if they had any changes to their employment status due to their condition. Participants were able to choose multiple changes to employment (Table 5.6, Figure 5.7).

Work status for 7 participants (16.67%) had not changed since diagnosis, and 18 participants (42.86%) were retired or did not have a job. There were 4 participants (9.52%) had to quit their job, 6 participants (14.29%) reduced the number of hours they worked, and 2 participants (4.76%) that accessed their superannuation early. There were 5 participants (11.90%) that took leave from work without pay, and 10 participants (23.81%) that took leave from work with pay.

Changes to carer/partner employment status

Participants were asked, in the online questionnaire, if they had any changes to the employment status of their care or partner due to their condition. Participants were able to choose multiple changes to employment. (Table 5.7, Figure 5.8).

Most commonly, participants had partners or carers that did not change their work status due to their condition (n=27, 64.29%). There was a single participant (2.38%) whose partner reduced the number of hours they worked, and 2 partners, (4.76%) that quit their job. No partners participants took leave without pay, and there were 2 partners (4.76%) that took leave with pay.

Table 5.6: Changes to employment status

Changes in work status due to condition	Number (n=42)	Percent
Work status has not changed	7	16.67
Retired or did not have a job	18	42.86
Had to quit job	4	9.52
Reduced number of hours worked	6	14.29
Leave from work without pay	5	11.90
Leave from work with pay	10	23.81
Accessed Superannuation early due to condition	2	4.76

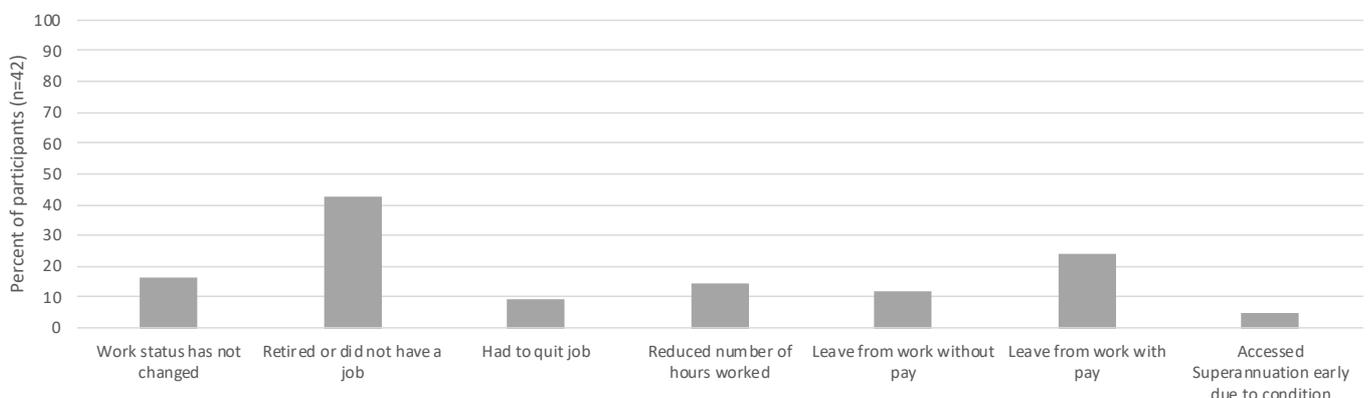


Figure 5.7: Changes to employment status

Table 5.7: Changes to care/partner employment status

Changes to care/partner employment status	Number (n=42)	Percent
Work status has not changed	27	64.29
Retired or did not have a job	10	23.81
Had to quit job	2	4.76
Reduced number of hours worked	1	2.38
Leave from work without pay	0	0.00
Leave from work with pay	2	4.76

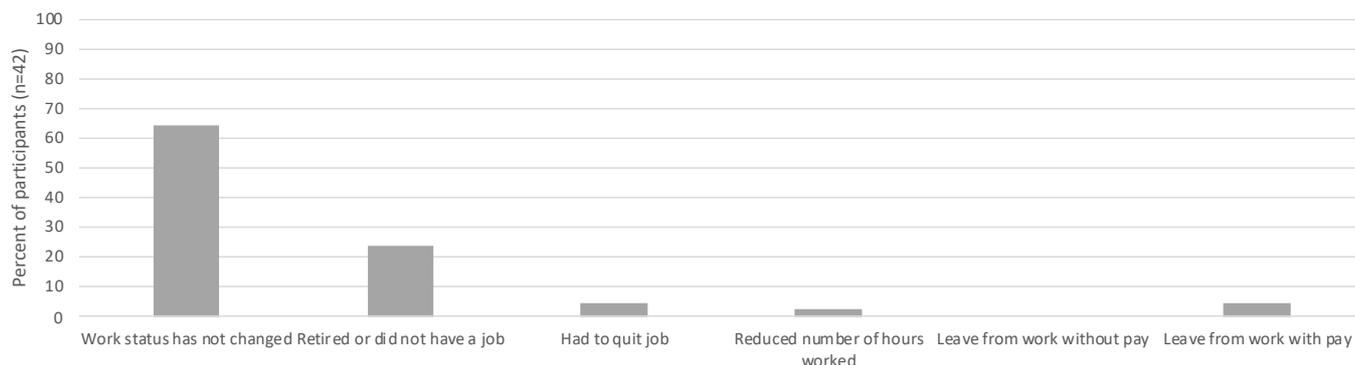


Figure 5.8: Changes to care/partner employment status

Reduced income due to condition

Participants noted in the online questionnaire details about and changes to income due to the bladder cancer diagnosis.

Approximately a third of the participants (n=12, 28.57%) indicated in the online questionnaire that they had a reduced family income due to their condition.

Estimated reduction monthly income

As a follow up question, participants were asked if their family or household income had reduced due to their condition. Where a dollar amount was given, it is included below (Table 5.8, Figure 5.9).

Most commonly, participants monthly income was reduced by more than \$1000 per month (n=5, 11.90%), or reduced by between \$501 to \$1000 per month (n=4, 9.52%).

Table 5.8: Estimated monthly loss of income

Estimated monthly loss of income	Number (n=42)	Percent
\$0	28	66.67
\$500 or less	3	7.14
\$501 to \$1000	4	9.52
\$1001 or more	5	11.90
Not sure	2	4.76

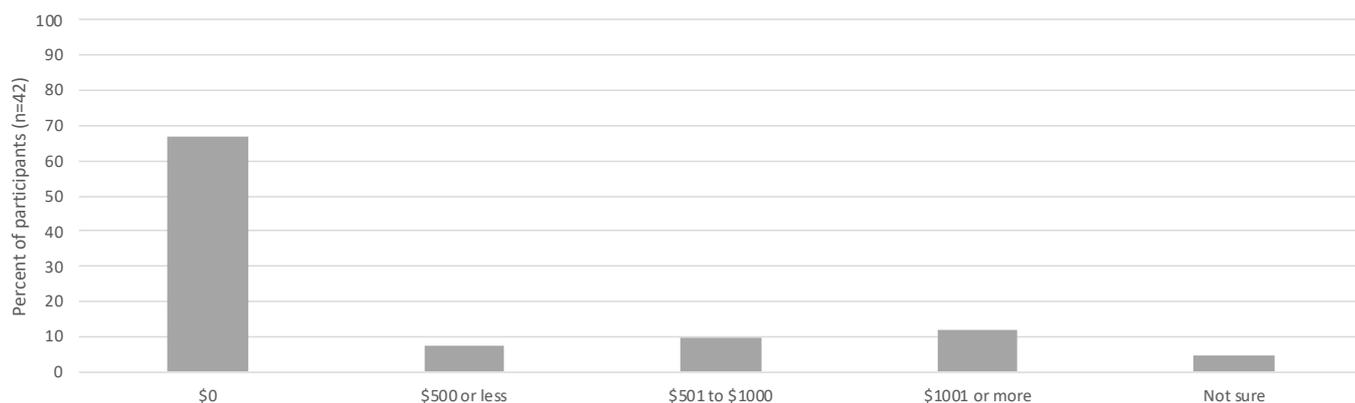


Figure 5.9: Estimated monthly loss of income

Summary of treatment

Participants noted in the online questionnaire the different treatments, they had since diagnosis with their condition (Table 5.9, Figure 5.10).

All participants were treated for bladder cancer. There were 40 participants (95.24%) that had surgery, 20 participants (47.62%) that had chemotherapy and 24 participants (57.14%) that had Bacillus Calmetter-

Guérin (BCG), 3 participants had radiotherapy (7.14%), and a single participant had immunotherapy (2.38%)

Table 5.9: Summary of treatment

Treatments overview	Number (n=42)	Percent
No treatment	0	0.00
Surgery	40	95.24
Transurethral resection of bladder tumour (TURBT)	30	71.43
Radical cystectomy	19	45.24
Urostomy	15	35.71
Bladder reconstruction	4	9.52
Urinary diversion	2	4.76
Surgery for metastases	2	4.76
Partial cystectomy	1	2.38
Fistula repair	1	2.38
nephrostomy stents	1	2.38
Stoma moved	1	2.38
Ureter reattachment	1	2.38
Chemotherapy	20	47.62
MVAC chemotherapy (Methotrexate, vinblastine, doxorubicin/adriamycin, and cisplatin)	5	11.90
Gemcitabine with cisplatin	5	11.90
Mitomycin with fluorouracil (5FU)	3	7.14
CMV chemotherapy (Cisplatin, methotrexate, vinblastine)	2	4.76
Gemcitabine and Docetaxel	2	4.76
Cisplatin	1	2.38
5 FU	1	2.38
Gemcitabine	1	2.38
Gemcitabine and mitomycin	1	2.38
Carboplatin and etoposide	1	2.38
Carboplatin	1	2.38
Gemcitabine with carboplatin	1	2.38
Carboplatin with either paclitaxel or docetaxel	0	0.00
Cisplatin with fluorouracil (5FU)	0	0.00
Immunotherapy	1	2.38
Pembrolizumab	1	2.38
Bacillus Calmetter-Guérin (BCG)	3	7.14
Radiotherapy	3	7.14

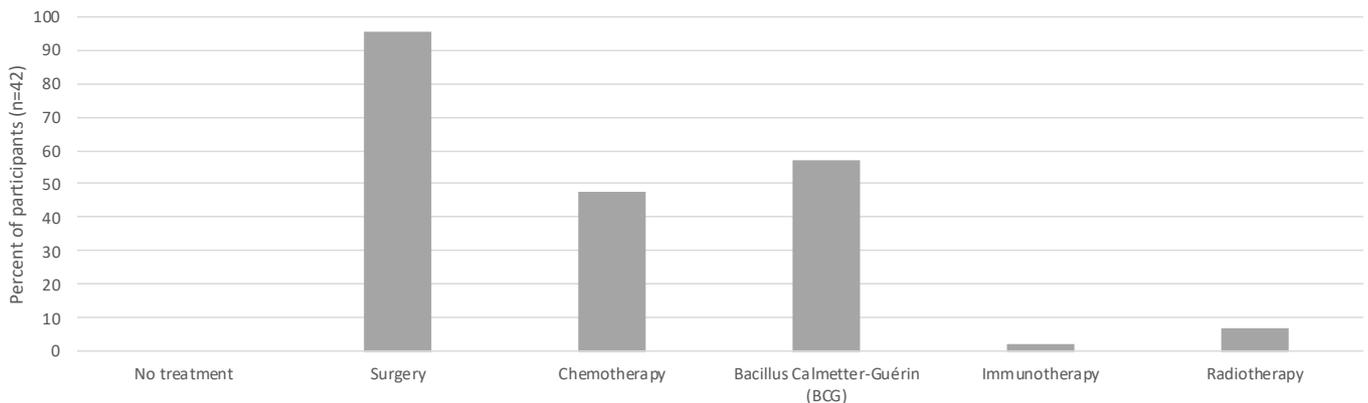


Figure 5.10: Summary of treatment

Summary of surgery

In the online questionnaire, participants noted the number of operations (excluding biopsies) that they had for their condition (Table 5.10, Figure 5.11).

There were 40 participants (95.24%) that had surgery for their condition (excluding biopsies). There were 16

participants (38.10%) that had one operation, 9 participants (21.43%) that had two operations, 4 participants (9.52%) that had three operations, and 11 participants (26.19%) that had four or more operations.

Table 5.10: Number of surgeries

Number of operations (excluding biopsy)	Number (n=42)	Percent
0	2	4.76
1	16	38.10
2	9	21.43
3	4	9.52
4 or more	11	26.19

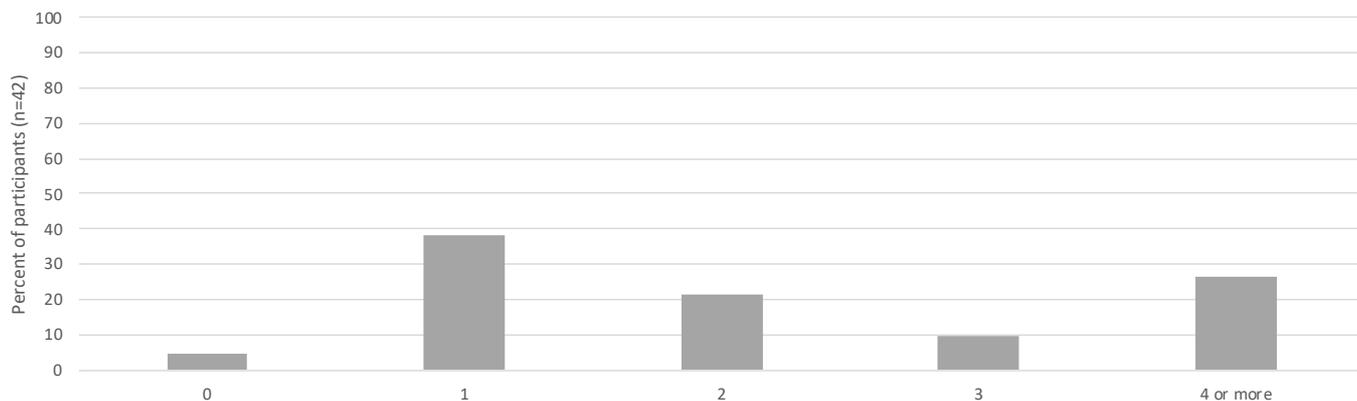


Figure 5.11: Number of surgeries

Surgical treatments

Most common types of surgery

Participants completed a series of questions about surgery, including type of surgery, quality of life, and effectiveness of surgery. A summary of the surgery, quality of life and effectiveness is presented in Table 5.11.

There were 40 participants (95.24%) that had surgery for their condition. The most common type of surgery was transurethral resection of bladder tumour (TURBT) (n=,30, 71.43%), followed by radical cystectomy (n=19, 45.24%), and urostomy (n= 15, 35.71%) (Figure 5.12).

Quality of life and effectiveness

Quality of life was rated on a Likert scale from one to seven, where one is “Life was very distressing” and seven is “Life was great”. Effectiveness of treatment was rated on a five-point scale where one is ineffective, and five is very effective. Values are calculated where there was adequate data available (five or more participants).

Table 5.11: Details of surgeries

Median quality of life from surgery ranged from 2.00 to 5.00, in the life was distressing to good range (Figure 5.13). The median effectiveness of all surgery was between 3.50 to 5.00, in the moderately to very effective range (Figure 5.14).

On average, quality of life from transurethral resection of bladder tumour (TURBT) was in the 'life was a little distressing' range (median=3.00, IQR = 1.00), and was found to be moderately effective to effective (median=3.50, IQR=2.75).

On average, quality of life from radical cystectomy was in the 'life was distressing' range (median=2.00, IQR=1.00), and was found to be very effective (median=5.00, IQR=0.00).

On average, quality of life from urostomy was in the 'life was good' range (median=5.00, IQR=1.00), and was found to be very effective (median=5.00 , IQR=0.00).

Surgery		Transurethral resection of bladder tumour (TURBT)		Radical cystectomy		Urostomy	
		n=30	%	n=19	%	n=15	%
Number (n=42)		30	71.43	19	45.24	15	35.71
Year of surgery	2020-2022	18	64.29	9	50.00	7	50.00
	2018-2019	4	14.29	4	22.22	4	28.57
	2017 or before	6	21.43	5	27.78	3	21.43
Side effects	No complications or side effects	Not collected		Not collected		2	13.33
	Sexual problems					9	60.00
	Urine leakage					7	46.67
	Infections					4	26.67
	Stoma related problems					3	20.00
	Bowel problems					2	13.33
	Extra surgery to fix problems with urostomy					2	13.33
	Hernia					2	13.33
Hospital stay	Kidney stone					1	6.67
	Day surgery	6	20.00	0	0.00	Not collected	
	Overnight	17	56.67	0	0.00		
	2-6 days	6	20.00	2	10.53		
	7-13 days	1	3.33	10	52.63		
	14-20 days	0		3	15.79		
Cost	21 days or more	0		4	21.05		
	\$0	17	56.67	11	57.89	Not collected	
	\$1-\$500	4	13.33	2	10.53		
	\$501-\$1000	4	13.33	1	5.26		
	>\$1000	3	10.00	4	21.05		
Monthly cost	Not sure	2	6.67	1	5.26		
	\$0	Not collected		Not collected		4	26.67
	\$10-\$20					8	53.33
	\$21-\$50					1	6.67
Quality of life	\$51-\$60					2	13.33
		Median	IQR	Median	IQR	Median	IQR
Effectiveness		3.00	1.00	2.00	1.00	5.00	1.00
		3.50	2.75	5.00	0.00	5.00	0.00

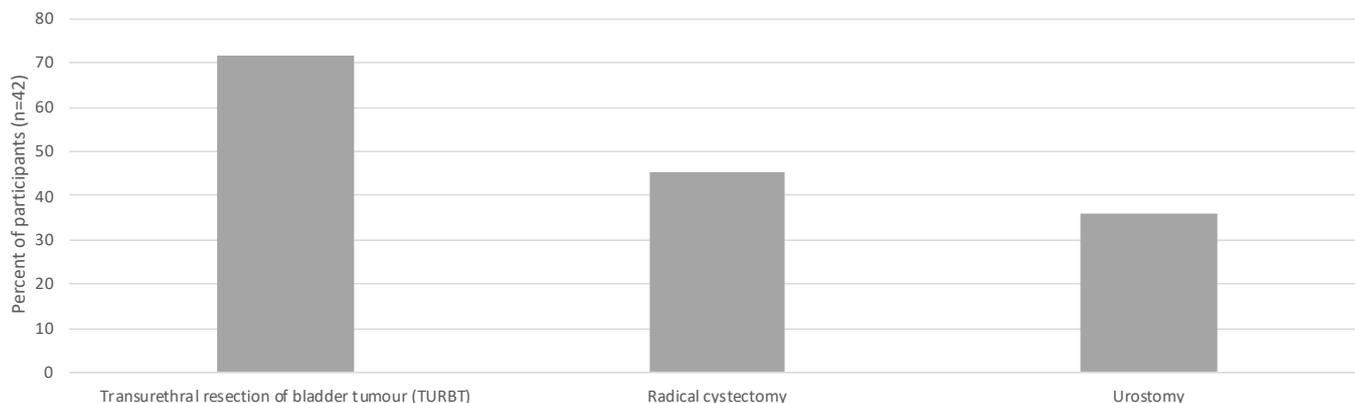


Figure 5.12: Surgery for bladder cancer

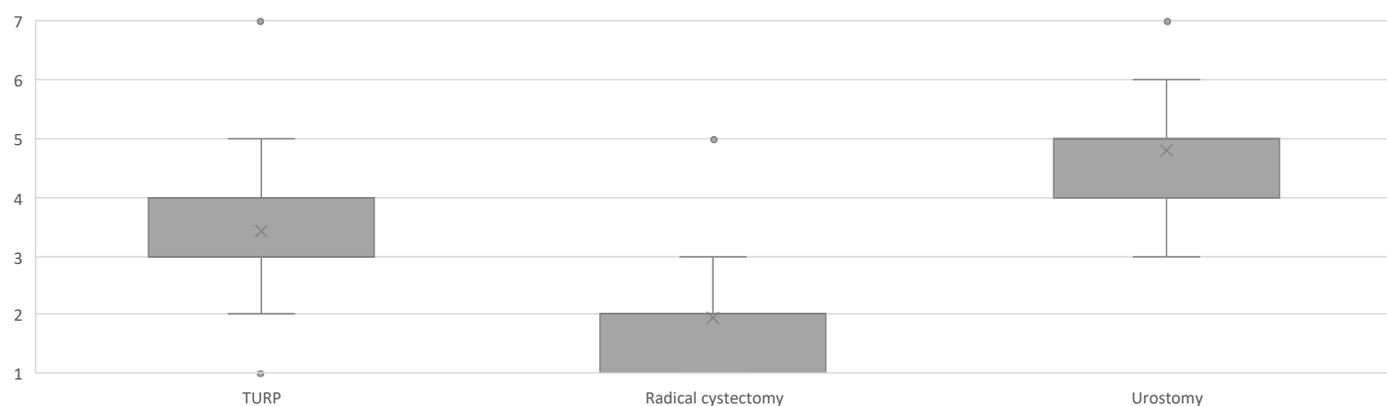


Figure 5.13: Quality of life from surgery

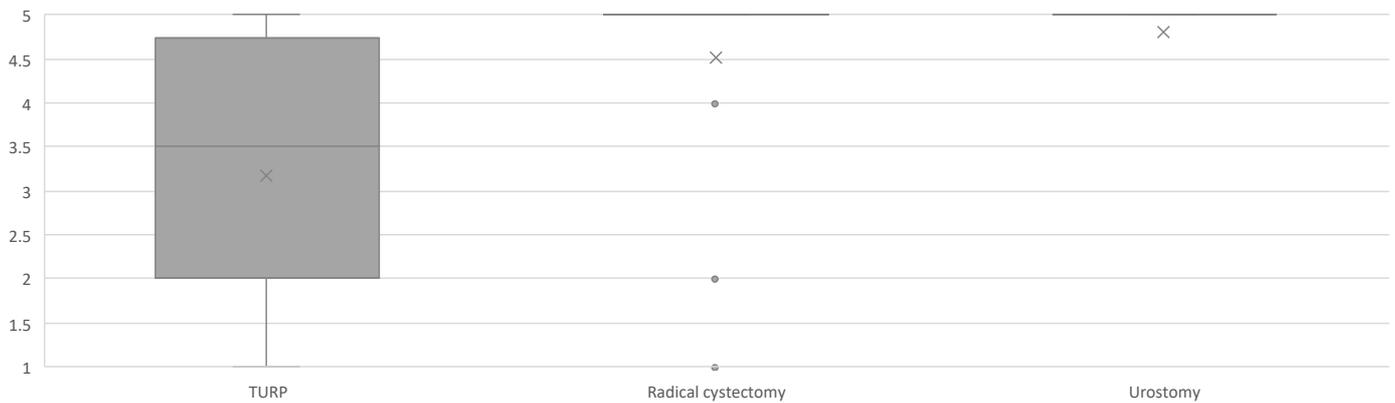


Figure 5.14: Effectiveness of surgery

Summary of drug treatments

Participants completed a series of questions about drug treatments, including type of treatment, quality of life, and effectiveness of treatment.

There were 20 participants (47.62%) that had chemotherapy. The most common types of chemotherapy were MVAC chemotherapy (methotrexate, vinblastine, doxorubicin/Adriamycin, and cisplatin), (n=5, 11.90%), and Gemcitabine with cisplatin n=5, 11.90%). There were 24 participants (57.14%) that had Bacillus Calmetter-Guérin (BCG) (Figure 5.15).

Median quality of life from drug treatments ranged from 1 to 4, in the life was very distressing to good range (Figure 5.16). The median effectiveness of all surgery was between 2.5 to 4, in the somewhat effective to effective range (Figure 5.17).

On average, quality of life from Bacillus Calmetter-Guérin (BCG) was in the 'life was a little distressing to average' range (median=3.50, IQR=2.00), and was found to be somewhat to moderately effective (median=2.50, IQR=3.25).

On average, quality of life from methotrexate, vinblastine, doxorubicin/adriamycin, and cisplatin was in the 'life was average' range (median=4.00, IQR=2.00), and was found to be effective (median=4.00, IQR=1.00).

On average, quality of life from gemcitabine with cisplatin was in the 'life was very distressing' range (median=1.00, IQR=2.00), and was found to be effective (median=4.00, IQR=1.00).

Table 5.12: Detailed summary of drug treatments taken by 5 or more participants (where complete data was available)

Drug treatments (5 or more participants)		Bacillus Calmetter-Guérin (BCG)		Methotrexate, vinblastine, doxorubicin/adriamycin, and cisplatin		Gemcitabine with cisplatin	
		n=24	%	n=5	%	n=5	%
Treatment status	No, it is ongoing	3	12.50	0	0.00	0	0.00
	Yes, I completed BCG as planned	16	66.67	5	100.00	4	80.00
	Yes, I stopped BCG because it wasn't working	3	12.50	0	0.00	0	0.00
	Yes, I stopped BCG early due to side effects	2	8.33	0	0.00	1	20.00
Place treatment given	In-patient at hospital	3	12.50	0	0.00	0	0.00
	Out-patient at hospital or clinic	21	87.50	5	100.00	5	100.00
Time taking treatment	2 months or less	6	25.00	1	20.00	1	20.00
	3-4 months	6	25.00	4	80.00	4	80.00
	1 year	5	20.83	0	0.00	0	0.00
	1.5 -2 years	4	16.67	0	0.00	0	0.00
	3-4 years	3	12.50	0	0.00	0	0.00
	\$0	10	41.67	4	80.00	3	60.00
Monthly expenses	\$1 to \$50	6	25.00	0	0.00	1	20.00
	\$51 to \$100	3	12.50	0	0.00	0	0.00
	\$101 or more	2	8.33	0	0.00	1	20.00
	Not sure	3	12.50	1	20.00	0	0.00
Quality of life	Median	IQR	Median	IQR	Median	IQR	
Effectiveness	3.5	2	4	2	1	2	
	2.5	3.25	4	1	4	1	

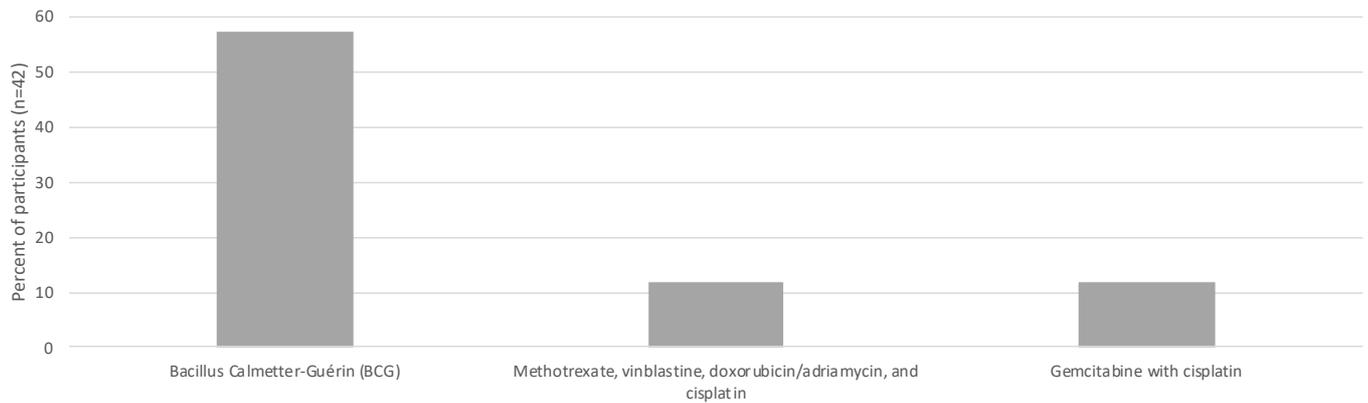


Figure 5.15: Drug treatments

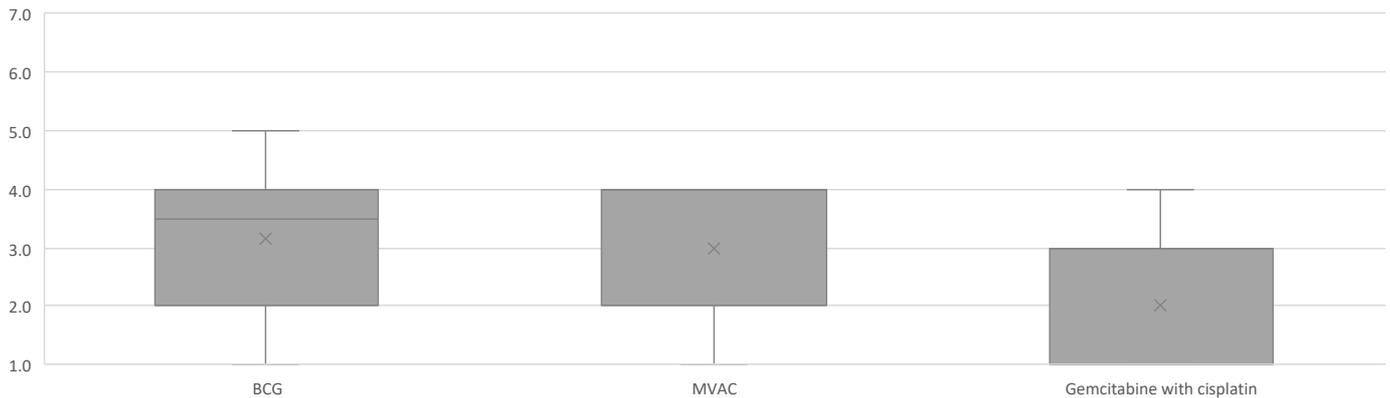


Figure 5.16: Quality of life from drug treatments

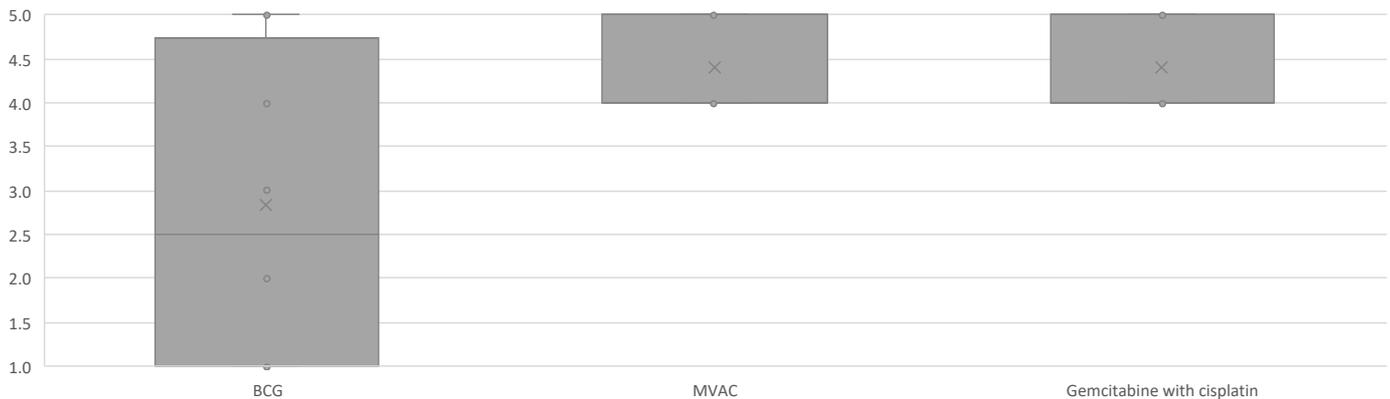


Figure 5.17: Effectiveness of drug treatments

Clinical trials

Clinical trials discussions

In the online questionnaire, participants were asked if they had discussions with their doctor about clinical trials, and if they did, who initiated the discussion (Table 5.13, Figure 5.18).

There was a total of 10 participants (23.81%) that had discussions about clinical trials, 5 participants (11.90%) had brought up the topic with their doctor, and the doctor of 5 participants (11.90%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n=32, 76.19%).

Clinical trial participation

As a follow up question, participants were asked if they had taken part in a clinical trial, and if they had not taken part if they were interested in taking part (Table 5.14, Figure 5.19).

There were 5 participants (11.90%) that had taken part in a clinical trial, 21 participants (50.00%) that would like to take part in a clinical trial if there was a suitable one, and 16 participants, that have not participated in a clinical trial and do not want to (38.10%).

Table 5.13: Clinical trial discussions

Clinical trial discussions	Number (n=42)	Percent
Participant brought up the topic of clinical trials doctor for discussion	5	11.90
Doctor brought up the topic of clinical trials for discussion	5	11.90
Participant has ever spoken to me about clinical trials	32	76.19

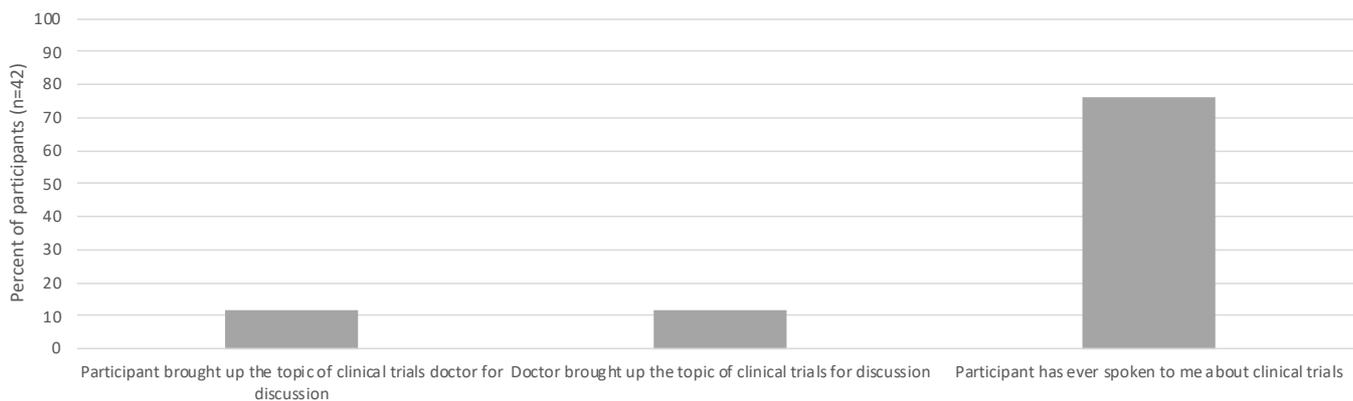


Figure 5.18: Clinical trial discussions

Table 5.14: Clinical trial participation

Clinical trial participation	Number (n=43)	Percent
Has not participated in a clinical trial and does not want to	16	38.10
Has not participated in a clinical trial but would like to if there is one	21	50.00
Has participated in a clinical trial	5	11.90

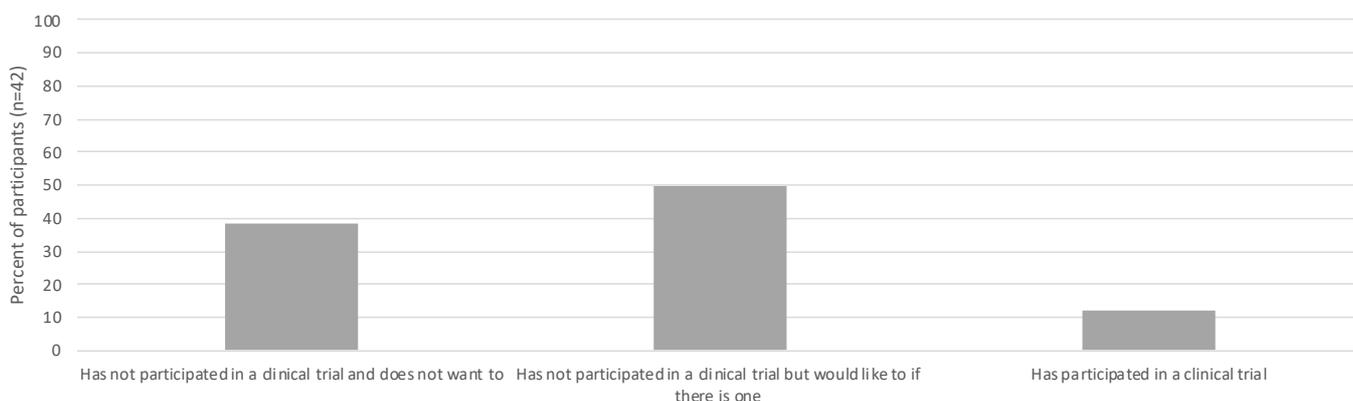


Figure 5.19: Clinical trial participation

Description of mild side effects

In the structured interview, participants were asked how they would describe the term ‘mild side effects’. The most common description of ‘mild side effects’ was a specific side effect as an example (n=36, 73.47%). This was followed by describing ‘mild side effects’ as those that can be self-managed (n=10, 20.41%), those that do not interfere with daily life (n=9, 18.37%), and as those that have a short duration or are reversible (n=7, 14.29%).

Of those who described a specific side effect, the most commonly described side effects were fatigue or lethargy (n=11, 22.45%), mild pain or aches (n=7, 14.29%) and nausea (n=6, 12.24%). Other side effects described by fewer than 5 participants, included hair loss, stoma bag/irritation/leaks, emotion/mental impact, and cystitis/UTIs.

Participant provides a specific side effect as an example: Aches/pain

The blood in the urine didn't hurt. No. I think that I didn't have any soreness. You know, through passing urine or any of that. It was only the, the visible sign of the blood was a bit disconcerting, but didn't hurt. The pain after the cystoscopy, the ones that hurt was quite excruciating. On the first day. Um, just managed with Panadol then and it was very sore. And all the other ones were sore. So the first one wasn't sore. But the other, the other ones were, how many others did I have, I've lost track. In February, that was and July and then October. Those three was more painful. But it was the second one was the most painful. And then the other two after that hurt, but not as extreme. Really, pretty much. I just went to bed and put a hot water bottle on my tummy. And things like that to try

and, I took Panadol. So it was only a few days. After probably two days, I was able to sort of do stuff still a little bit cramped, you know.

Participant 014_2022AUBLC

Maybe just low energy levels sort of thing? You know, I mean, no obvious pain or discomfort or, or if you don't notice it, I think it's mild or if you notice it some times its mild, but if its constantly there then, that's obviously something more severe and more acute.

Participant 024_2022AUBLC

Participant provides a specific side effect as an example: Fatigue/lethargy

And it's something that's uncomfortable but doesn't stop you from doing things. You know, the prime example of that is being, you know, tired having or being a bit lethargic. Mm hmm. The hot sweats, you know? You know, again, uncomfortable. Um, you know, not. Not to. Not too bad. The hair loss. That's, that was a side effect of the chemo. Um, and I would say that, I mean, for me, it was mild because it just was what it was. I couldn't change it. So it wasn't that big of a deal. Didn't stop me going there for anything.

Participant 022_2022AUBLC

Participant provides a specific side effect as an example: Stoma bag/irritation/leaks

Oh, just the irritation of having a bag and, you know, and having a pee in a bag and not use it the normal way. I don't know if any of that sort of is the irritation that comes from the frustration that comes from initially not being as agile. Um, not being able to do the things that you used to do before the operation, but I would say, really, these are my, my effects, my after effects and side effects have been so mild really that I wouldn't even count them as effects. Okay. Just get on with it.

Participant 034_2022AUBLC

Participant describes mild side effects as those that can be self-managed

Probably something probably something manageable. But then when it comes to major, that's something that I can't manage at home.

Participant 033_2022AUBLC

Originally, it was just incontinence, that was the only mild, mild side effects and, you know, it was getting really bad at one stage. Yeah, initially it was pretty mild. You know, it was only a matter of a pad on, if I was going out, if I was in the, the house, I didn't worry

too much, but if I was going out I had to put a pad on, in case of leakages, and wearing dark coloured clothes to instead of light coloured.

Participant 011_2022AUBLC

Oh, well, some just some irritation in the bladder when you go into the toilet. Like a bit like cystitis, I guess. Um, but it's not really bad. I mean, I. I take, um, Panadol or Nurofen sometimes, but, um. That's all. Yeah. So Only enough to just take Panadol, and then it was not too bad at all. So that's what.

Participant 025_2022AUBLC

Participant describes mild side effects as those that do not interfere with daily life

Mild side effects, I would determine. I would say that they are you know, you notice them, but they don't impact your day to day life. They're in a bit of a bit of a nuisance, but they don't stop you from doing anything that you want to do or could do before.

Participant 032_2022AUBLC

Mild I would think of as a potential irritations. Things that don't stop you going about what you ordinarily would. It's a more yeah. More an awareness and possibly a slight caution for, you know, to, not provoke them or not, you know, irritate. No. I would say mild is just something you're aware of, but it doesn't prevent, you know, impacts your day to day behaviour. I would say.

Participant 041_2022AUBLC

Okay. I guess mild side effects are something that didn't affect too much with his day to day existence. And that might be something like the, the loss of his hair. Well, it was a bit depressing. It wasn't the major things. And so that was probably a mild side effect.

Carer 005_2022AUBLC

Participant describes mild side effects as those that have a short duration or are reversible

So mild would be just, I guess, a slight a slight discomfort, maybe a small fever for a day or something like that.

Participant 014_2022AUBLC

Well, the weight loss I suppose because it didn't take long to put it back on again.

Participant 027_2022AUBLC

Mild side effects. Okay. All right. So mild side effect is particularly for chemo. Okay. So I'll cover chemotherapy for the my mild side effects, I would,

quote, qualified as constipation. Okay. It's something that, you know, it's going to happen. But, you know, if you took the right tablet and drank lots of fluids. And yeah, eventually that that and that settled down by itself. The hair loss for me is a mild side effect. Didn't really bother me that I lost, lost hair. Just prior to treatment, I just had a very short haircut anyway, so whatever I lost, I knew was eventually going to come back. Um. What else? I mean, mild for me could be short term, but it could be annoying, but, you know, it's only going to be for a certain period of time. Yeah. Loss of taste, for example. Yeah, like loss of

taste. For me, it was annoying when I was having that because it was, it was more of a mucking around with what I could eat or wanted to eat at the time. But again, I also knew once I got through chemotherapy that it would come back even if that was long term, boy it would be completely different. Yeah, that because they were short term and short term with only the course of chemotherapy that that period of time I can handle that part of it.
Participant 035_2022AUBL

Table 5.15: Description of mild side effects

Description of mild side effects	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 provides a specific side effect as an example	36	73.47	16	80.00	9	90.00	7	50.00	32	72.73	4	80.00	11	64.71	25	78.13
Participant describes mild side effects as those that can be self-managed	10	20.41	6	30.00	1	10.00	3	21.43	10	22.73	0	0.00	5	29.41	5	15.63
Participant describes mild side effects as those that do not interfere with daily life	9	18.37	1	5.00	3	30.00	4	28.57	8	18.18	1	20.00	3	17.65	6	18.75
Participant describes mild side effects as those that have a short duration or are reversible	7	14.29	3	15.00	3	30.00	1	7.14	7	15.91	0	0.00	3	17.65	4	12.50

Description of mild side effects	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 provides a specific side effect as an example	36	73.47	21	72.41	14	73.68	12	80.00	23	69.70	16	80.00	21	75.00
Participant describes mild side effects as those that can be self-managed	10	20.41	5	17.24	5	26.32	2	13.33	8	24.24	6	30.00	5	17.86
Participant describes mild side effects as those that do not interfere with daily life	9	18.37	7	24.14	2	10.53	3	20.00	6	18.18	1	5.00	4	14.29
Participant describes mild side effects as those that have a short duration or are reversible	7	14.29	4	13.79	3	15.79	3	20.00	4	12.12	3	15.00	4	14.29

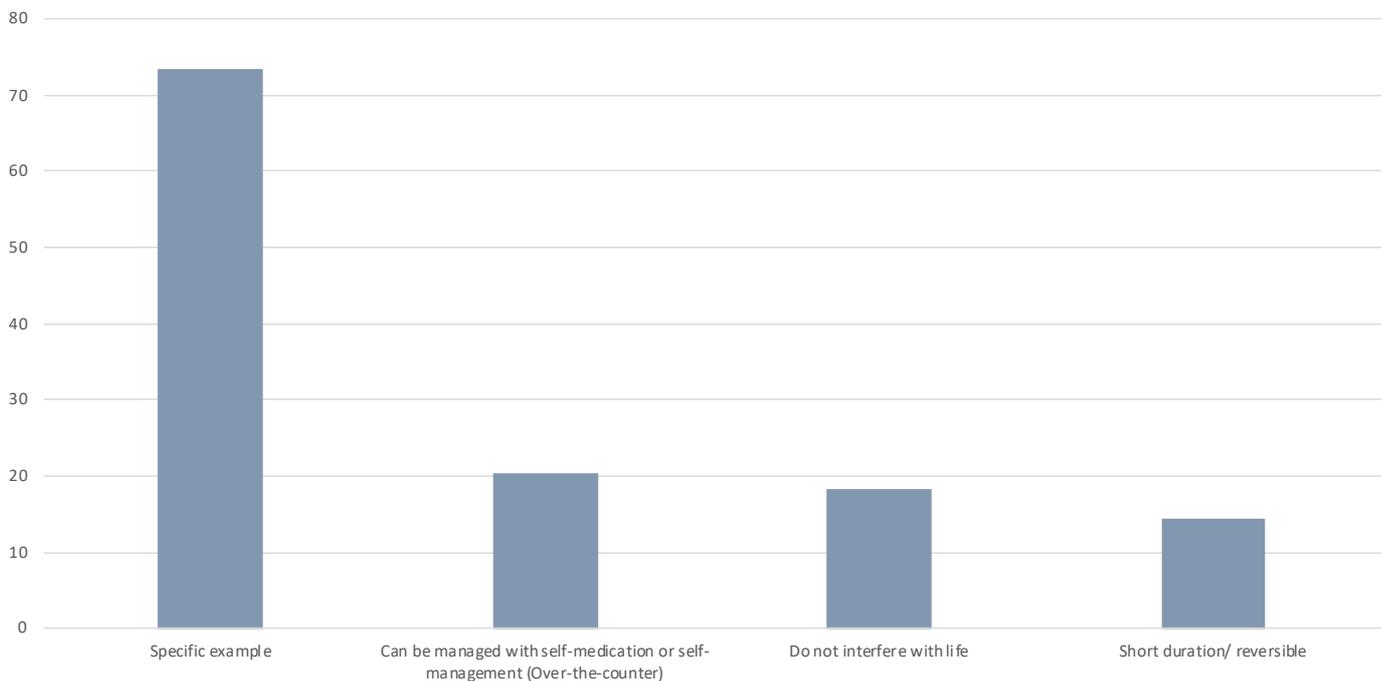


Figure 5.20: Description of mild side effects

Table 5.16: Description of mild side effects – subgroup variations

Description of mild side effects	Reported less frequently		Reported more frequently	
	Advanced (Stage IV)	Invasive (Stage III)	Invasive (Stage III)	Invasive (Stage III)
Participant provides a specific side effect as an example				
Participant describes mild side effects as those that can be self-managed	Carer to someone with bladder cancer			
Participant describes mild side effects as those that do not interfere with daily life	Early (Stages 0 and I)			
Participant describes mild side effects as those that have a short duration or are reversible	Carer to someone with bladder cancer			

Table 5.17: Description of mild side effects (Specific side effects)

Description of mild side effects (Specific side effects)	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 mild side effects giving the specific example of Fatigue/lethargy	11	22.45	3	15.00	4	40.00	2	14.29	9	20.45	2	40.00	3	17.65	8	25.00
Participant describes mild side effects giving the specific example of Aches/pain (general)	7	14.29	5	25.00	2	20.00	0	0.00	7	15.91	0	0.00	1	5.88	6	18.75
Participant describes mild side effects giving the specific example of nausea	6	12.24	2	10.00	1	10.00	1	7.14	4	9.09	2	40.00	2	11.76	4	12.50
Participant describes mild side effects giving the specific example of Hair loss	4	8.16	0	0.00	2	20.00	1	7.14	3	6.82	1	20.00	1	5.88	3	9.38
Participant describes mild side effects giving the specific example of Stoma bag/irritation/leaks	4	8.16	2	10.00	0	0.00	2	14.29	4	9.09	0	0.00	1	5.88	3	9.38
Participant describes mild side effects giving the specific example of Emotion/mental impact	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 mild side effects giving the specific example of Cystitis/UTIs	3	6.12	2	10.00	1	10.00	0	0.00	3	6.82	0	0.00	2	11.76	1	3.13

Description of mild side effects (Specific side effects)	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 mild side effects giving the specific example of Fatigue/lethargy	6	20.69	4	21.05	3	20.00	7	21.21	3	15.00	5	17.86		
Participant describes mild side effects giving the specific example of Aches/pain (general)	3	10.34	4	21.05	3	20.00	4	12.12	5	25.00	4	14.29		
Participant describes mild side effects giving the specific example of nausea	4	13.79	2	10.53	2	13.33	4	12.12	2	10.00	3	10.71		
Participant describes mild side effects giving the specific example of Hair loss	4	13.79	0	0.00	2	13.33	2	6.06	0	0.00	2	7.14		
Participant describes mild side effects giving the specific example of Stoma bag/irritation/leaks	3	10.34	1	5.26	2	13.33	2	6.06	2	10.00	0	0.00		
Participant describes mild side effects giving the specific example of Emotion/mental impact	2	6.90	1	5.26	2	13.33	1	3.03	1	5.00	1	3.57		
Participant describes mild side effects giving the specific example of Cystitis/UTIs	1	3.45	2	10.53	2	13.33	1	3.03	2	10.00	2	7.14		

Figure 5.36: Description of mild side effects (Specific side effects)

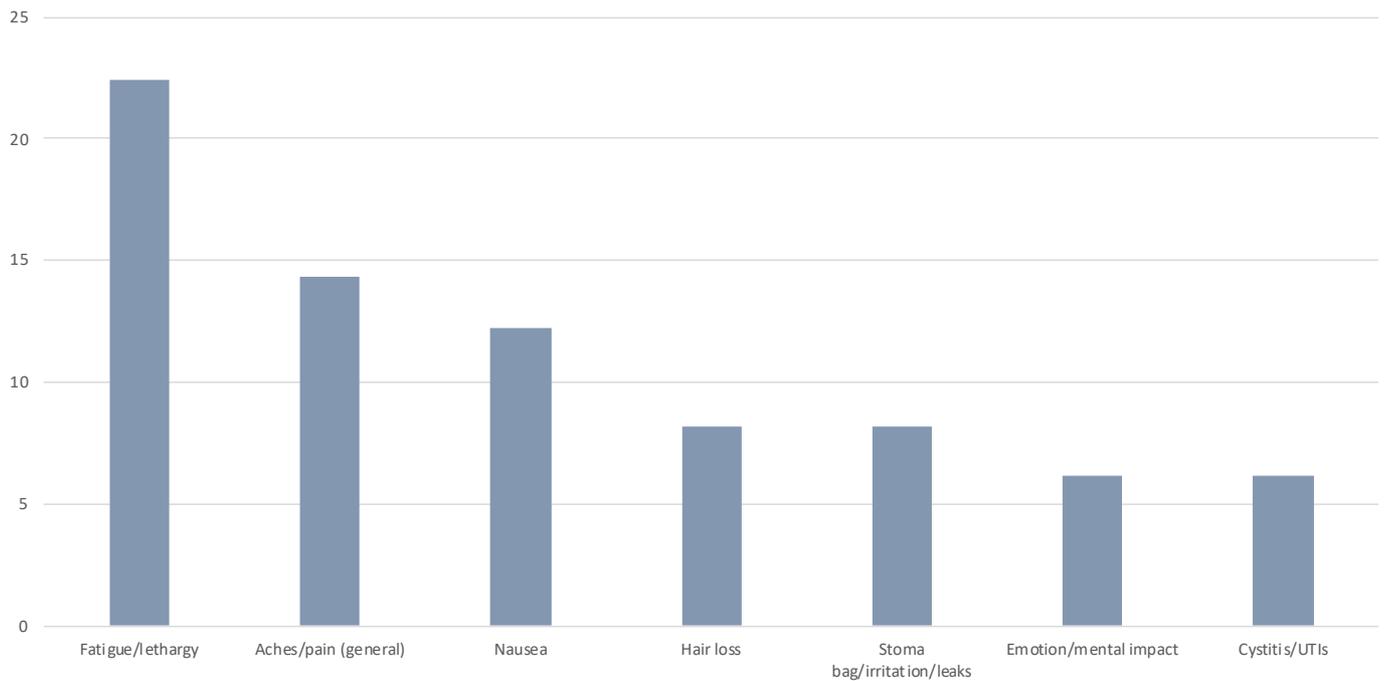


Table 5.21: Description of mild side effects (Specific side effects) – subgroup variations

Description of mild side effects (Specific side effects)	Reported less frequently	Reported more frequently
Participant describes mild side effects giving the specific example of Fatigue/lethargy	-	Invasive (Stage III) Carer to someone with bladder cancer
Participant describes mild side effects giving the specific example of Aches/pain (general)	Advanced (Stage IV) Carer to someone with bladder cancer	Early (Stages 0 and I) Mid to low status
Participant describes mild side effects giving the specific example of nausea	-	Carer to someone with bladder cancer

Description of severe side effects

In the structured interview, participants were asked how they would describe the term 'severe side effects'. The most common description of 'severe side effects' was a specific side effect as an example (n=34, 69.39%). Other descriptions of 'severe side effects' included those that impact everyday life/ability to conduct activities of daily living (n=9, 18.37%), and those that are long lasting (n=6, 12.24%). There were 6 participants (12.24%) that were unable to describe severe side effects as they had not experienced them.

Of those who described a specific side effect, the most commonly described side effects were pain (n=18, 36.73%), the emotional or mental impact of the condition, (n=7, 14.29%), and pain when urinating (n=5, 10.20%). Other side effects described by fewer than 5 participants, included fatigue, nausea, fever or infection, and incontinence.

Participant provides a specific side effect as an example: Aches/pain (general)

It was after the operation. I had a lot of pain. It took about six months to resolve all that. Participant 016_2022AUBLC

Participant provides a specific side effect as an example: Emotion/mental impact

*I got a severe um, mental side effects that were just ongoing, especially at the chemotherapy. Um, but just this the stress and strain that you got mentally during that period of time from diagnosis through to your treatment phases and even ongoing. Yeah. As to how you going to cope with that. So it's the mental stress that the severe side effects
Participant 035_2022AUBLC*

Participant provides a specific side effect as an example: Pain when urinating

*I found it very difficult. I found it difficult to cope with. In the first few days of the after the tumour was removed, I found that very hard you know that it we tend to try and manage the pain and the particularly when I needed to urinate and when I couldn't when you know there's a small amount of urine in the in the bladder would, would cause a lot of pain. And there was no there's no there's no answer to it really. It just got to live through it somehow. Somehow or other.
Participant 029_2022AUBLC*

Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living

And severe side effects means that you're, you know, you're house bound. You can't do or enjoy anything that you want to do you're, you know, basically incapacitated and can't leave the house.

Participant 032_2022AUBLC

And how you would be severe would be not getting out of bed or something like that, I guess. Yeah. And not being able to function. Not being able to go and work.

Participant 014_2022AUBLC

So, yes, the BCG, like I couldn't cope with, because I ended up in my second round of BCG for 6 weeks. I ended up I couldn't work for three days after having the treatment where most people could go back to work the day after. So my body was screaming, stop doing this to me. And I didn't listen to it. So, you know, it ended up the side effects of the BCG were horrific for me. So I mean, the bladder cancer itself, when I had bladder cancer, it wasn't you know, I wasn't really noticing anything much anyway. So, you know, I think. I think it was more. Participant 026_2022AUBLC

Participants reported not experiencing any severe side effects

Well, I didn't have I never had any. I was very lucky. There was nothing. I mean, I guess if, if you were to say severe side effect would be the hair loss. But it wasn't. It was it was just an inconvenience. It wasn't anything really bad. Participant 020_2022AUBLC

*I never really had any, any severe side effects at all now sort of but coming out of hospitals early in the hospital, seven days. And yeah, I sort of just kept walking and I think it was driving. Within four weeks, I went back to driving. Fine. And, and, um, yeah, you know, I just, um, I had a really positive attitude that it was going to be okay and no problem. But yeah, I had a few leaks with me bag, but I just get the hang of it and yeah, these things can happen. And yeah, I went and seen my stoma nurse and we change bags and yeah, I sort of wasn't going to let it get me down but, we can work through this and um, yeah, and it's been great. I haven't any problems at all with my bag and having any issues with it at all.
Participant 044_2022AUBLC*

Participant identifies severe side effects as those that are long lasting

But certainly the severe side effects would be that very high level of pain and continuing pain. And, and also the just the the general discomfort in the bladder area.

Participant 008_2022AUBLC

It was after the operation. I had a lot of pain. It took about six months to resolve all that.

Participant 016_2022AUBLC

Severe ones would be things that impacted and were ongoing, I think be some things you can put up with for a little while, but I guess the severe ones would be the ones, also sort of went on for weeks, but they passed and then the ongoing pain I guess from the surgery is just was something that we didn't know to expect. I think that was that was something that wasn't spelled out to us. Yeah. Ongoing, the pain level would be.

Carer 005_2022AUBLC

Participant describes severe side effects as those that are life threatening or result in hospitalisation

Um. Well, I suppose with severe side effects. When I got the infection that I had to go into hospital for, um. I guess the other one was a few weeks ago when I felt chained to the bathroom for a couple of weeks. I suppose the rest you just deal with because. Otherwise you just deal with it really

Participant 002_2022AUBLC

Hospitalisation. Okay. Yeah. When it gets too severe, I end up in hospital. Because I can't manage that anymore.

Participant 033_2022AUBLC

Severe, I guess, not being able to breathe and having a fever, about 40. That's sort of more severe side of it to me. Um, pain wise. Pain that, um, would almost tempt me to want to take a pain relief pill. Like, I'm talking, like, oh [groans in pain], getting up in, like, that sort of level of pain of, oh [groans in pain again], ten out of ten, you know? Yeah. Like, unbelievable pain. Yeah. Oh. Yeah.

Participant 001_2022AUBLC

Participant identifies severe side effects as requiring medical intervention

Yeah. So it's things where, you know, I would say, certainly some of the aftermath would have gone into severe side effects. And in those situations, it's situations where you'd really like assistance. Situations where you think, I think particularly being alone, I think you'd really like someone else. You know, you need comfort, you need., and possibly medical assistance or medical opinion, at least severe side effects where I would have liked to have gone to air to have things appraised, but I had no manner of getting there. I guess then some. Yeah. Well, I'm not. Well, I'm not well enough to catch a taxi anywhere. Not. Not. Yeah. Not. I don't know. I think I think I hold out too long before trying to get assistance.

Participant 041_2022AUBLC

Also had to have I think they said it was atrial flutter and they gave me something to reverse that which I can't remember them vividly looking and saying is that flutter or fibrillation? I was trying to look at the monitor myself. I couldn't quite see it.

Participant 018_2022AUBLC

Participant identifies severe side effects as impacting their everyday life by being bed ridden

Uh, something that. Yeah, something that basically lays you up. You, you just feel like you can't do anything else because your mind is fully occupied.

Participant 006_2022AUBLC

Severe would be not getting out of bed or something like that, I guess. Yeah. And not being able to function. Not being able to go and work

Participant 014_2022AUBLC

And I probably could cope with it for a day. But I wouldn't want to cope with the ongoing and, you know, I don't know. Just trying to think how I feel about that. Had it gone on for days and days and days, it would have been extremely hard to cope with. You know, you can get laid up for a couple of days, and, you know, you curl up in a ball in bed and try and sort of lie still don't budge or don't move. And. Yeah. So the first that first day, it was very, very painful and I don't think I could have to coped. Well you have to cope, but I think. I might need something a bit stronger if it wasn't going. Yeah. Unless you overcome that.

Participant 003_2022AUBLC

Table 5.19: Description of severe side effects

Description of severe side effects	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 provides a specific side effect as an example	34	69.39	13	65.00	8	80.00	9	64.29	30	68.18	4	80.00	13	76.47	21	65.63
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	9	18.37	4	20.00	2	20.00	3	21.43	9	20.45	0	0.00	5	29.41	4	12.50
Participants reported not experiencing any severe side effects	7	14.29	3	15.00	3	30.00	1	7.14	7	15.91	0	0.00	2	11.76	5	15.63
Participant identifies severe side effects as those that are long lasting	6	12.24	3	15.00	2	20.00	0	0.00	5	11.36	1	20.00	2	11.76	4	12.50
Participant describes severe side effects as those that are life threatening or result in hospitalisation	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 identifies severe side effects as requiring medical intervention	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 identifies severe side effects as impacting their everyday life by being bed ridden	3	6.12	3	15.00	0	0.00	0	0.00	3	6.82	0	0.00	1	5.88	2	6.25

Description of severe side effects	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 provides a specific side effect as an example	34	69.39	20	68.97	14	73.68	11	73.33	23	69.70	13	65.00	20	71.43
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	9	18.37	5	17.24	4	21.05	4	26.67	5	15.15	4	20.00	5	17.86
Participants reported not experiencing any severe side effects	7	14.29	2	6.90	4	21.05	2	13.33	4	12.12	3	15.00	4	14.29
Participant identifies severe side effects as those that are long lasting	6	12.24	2	6.90	4	21.05	4	26.67	2	6.06	3	15.00	3	10.71
Participant describes severe side effects as those that are life threatening or result in hospitalisation	4	8.16	1	3.45	3	15.79	0	0.00	4	12.12	3	15.00	3	10.71
Participant identifies severe side effects as requiring medical intervention	4	8.16	2	6.90	2	10.53	0	0.00	4	12.12	3	15.00	3	10.71
Participant identifies severe side effects as impacting their everyday life by being bed ridden	3	6.12	3	10.34	0	0.00	2	13.33	1	3.03	3	15.00	1	3.57

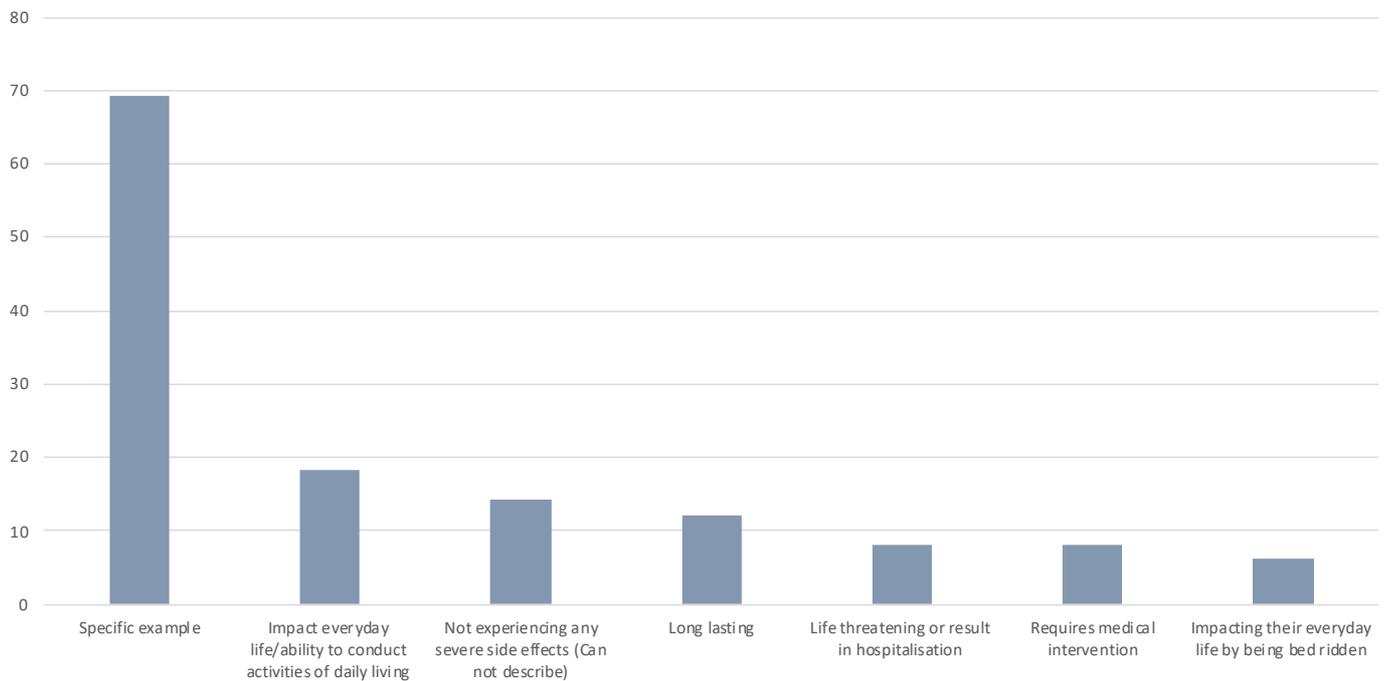


Figure 5.22: Description of severe side effects

Table 5.20: Description of severe side effects – subgroup variations

Description of severe side effects	Reported less frequently	Reported more frequently
Participant provides a specific side effect as an example	-	Invasive (Stage III) Carer to someone with bladder cancer
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	Carer to someone with bladder cancer	Female
Participants reported not experiencing any severe side effects	Carer to someone with bladder cancer	Invasive (Stage III)
Participant identifies severe side effects as those that are long lasting	Advanced (Stage IV)	Regional or remote

Table 5.21: Description of severe side effects (Specific example)

Description of severe side effects (Specific side effects)	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 severe side effects giving the specific example of Aches/pain (general)	18	36.73	10	50.00	4	40.00	2	14.29	16	36.36	2	40.00	8	47.06	10	31.25
Participant describes severe side effects giving the specific example of Emotion/mental impact	7	14.29	3	15.00	0	0.00	3	21.43	6	13.64	1	20.00	2	11.76	5	15.63
Participant describes severe side effects giving the specific example of Pain when urinating	5	10.20	2	10.00	2	20.00	1	7.14	5	11.36	0	0.00	2	11.76	3	9.38
Participant describes severe side effects giving the specific example of Fatigue/lethargy	4	8.16	2	10.00	0	0.00	0	0.00	2	4.55	2	40.00	2	11.76	2	6.25
Participant describes severe side effects giving the specific example of Nausea or loss of appetite	4	8.16	0	0.00	0	0.00	1	7.14	1	2.27	3	60.00	0	0.00	4	12.50
Participant describes severe side effects giving the specific example of Fever/infection	4	8.16	4	20.00	0	0.00	0	0.00	4	9.09	0	0.00	3	17.65	1	3.13
Participant describes severe side effects giving the specific example of Incontinence that is not manageable	3	6.12	0	0.00	1	10.00	1	7.14	2	4.55	1	20.00	1	5.88	2	6.25

Description of severe side effects (Specific side effects)	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 severe side effects giving the specific example of Aches/pain (general)	18	36.73	9	31.03	9	47.37	6	40.00	12	36.36	10	50.00	10	35.71
Participant describes severe side effects giving the specific example of Emotion/mental impact	7	14.29	6	20.69	1	5.26	2	13.33	5	15.15	3	15.00	2	7.14
Participant describes severe side effects giving the specific example of Pain when urinating	5	10.20	3	10.34	2	10.53	1	6.67	4	12.12	2	10.00	4	14.29
Participant describes severe side effects giving the specific example of Fatigue/lethargy	4	8.16	3	10.34	1	5.26	0	0.00	4	12.12	2	10.00	3	10.71
Participant describes severe side effects giving the specific example of Nausea or loss of appetite	4	8.16	3	10.34	1	5.26	1	6.67	3	9.09	0	0.00	2	7.14
Participant describes severe side effects giving the specific example of Fever/infection	4	8.16	2	6.90	2	10.53	0	0.00	4	12.12	4	20.00	4	14.29
Participant describes severe side effects giving the specific example of Incontinence that is not manageable	3	6.12	2	6.90	1	5.26	2	13.33	1	3.03	0	0.00	2	7.14

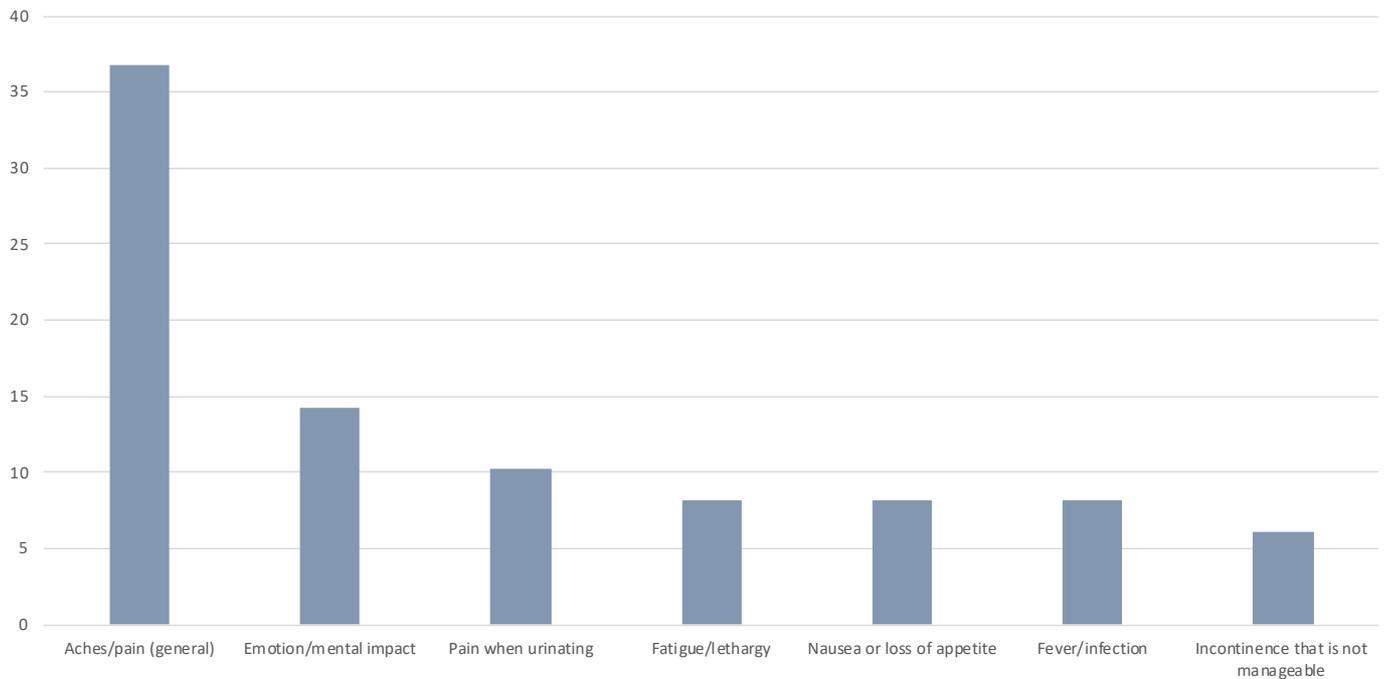


Figure 5.23: Description of severe side effects (Specific example)

Table 5.22: Description of severe side effects (Specific side effects)– subgroup variations

Description of severe side effects (Specific side effects)	Reported less frequently	Reported more frequently
Participant describes severe side effects giving the specific example of Aches/pain (general)	Advanced (Stage IV)	Early (Stages 0 and I) Female University Mid to low status
Participant describes severe side effects giving the specific example of Emotion/mental impact	Invasive (Stage III)	-
Participant describes severe side effects giving the specific example of Pain when urinating	Carer to someone with bladder cancer	-

Adherence to treatment

Participants were asked in the structured interview what influences their decision to continue with a treatment regime. The most common themes described were adhering to treatment as per the advice of their specialist/as long as prescribed (n=20, 40.82%), and adhering to treatment as long as treatment is working (n=16, 32.65%). This was followed by adhering to treatment as long as side effects are tolerable (n=12, 24.49%), adhering to treatment for a specific amount of time (n=11, 22.45%), and 7 participants (14.29%) described not giving up on any treatments.

Where participants stated a specific amount of time to adhere to a treatment, the most common amount of time was two to three weeks.

Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed

And I think I'd, I'd stick with it until I know as long as I was the doctor or specialist was saying it was what was wanting me to do it. I don't think I'd just stop partway.

Participant 025_2022AUBLC

Oh, no, I never do. If the doctor tells me to have something, you know, for a particular time, I just have it. I have issues with it. I will discuss, like with the with the steroid, you know, dexamethasone. They told me to take it so that with the with the on the day of chemotherapy, I was to take four tablets, then two tablets, then one tablet. So like I said, I got too restless and the reduced doses to two and one from 4 to 2. But I discussed with them and I didn't give up.

Participant 028_2022AUBLC

Uh, I am one of those sort of people that if they are told to take a tablet once a day, I take a tablet once a day. So I tend to be very compliant. Like at the at the moment I'm using eyedrops every 2 hours during the day and I'd say that's 80% of the time I'm putting it. And then on the 2 hours if not. Sometimes the other 20% might be an extra half hour here and there, but I do tend to be very compliant.

Participant 036_2022AUBLC

Participant describes adhering to treatment as long as treatment is working

Well. I really didn't have any much too much in the way of medication initially for. There's no medication except for the BCG, and the BCG. Well, it was quite obvious that it was just getting worse and worse.

There's no you know, I could see it, the doctors and nurses could see it just wasn't working. Yeah. Yeah. They the doctors, the one that basically said, you know what? We'll, we'll see about the operation, you know. Which my urologist goes to a board, apparently down at the hospital. They sit down and have a discussion about and figure out who's next in line with who needs the treatments, the most urgently, or who's available for treatment, I suppose they don't do too many at any given time. And with COVID it made it a little bitter harder I think.

Participant 011_2022AUBLC

Yeah. Yeah, I'll say. Well, in my case, really, the only sort of new things that I can try are new types or different makes of the equipment on there have to live with, such as stoma bags and the some of the associated paraphernalia that comes with it. Um. I not really know to ask that, because what I've tried so far is was basically what I came out of the hospital with because it seems to work well. I'm staying with it. I've tried one other. And to and if these things, fail, it is quite messy. So you lose, you lose the sense of security. And so you tend to sort of in a shy away from things that haven't worked for you too well. So you can try things for very long if they don't work. So, you know, maybe once or twice if they don't work, I'll stick with the ones that do, which is common sense. Yeah, there are there are there are improvements that I look for because some of them are not particularly comfortable. And some of the, some of the support systems and the physical support systems belts and things could be improved. But that's a design thing really.

Participant 034_2022AUBLC

Like when I had the bleeding, I as I said before, I took the oregano oil and the flaxseed, though I did that helped me virtually within 24 hours I was much better. I was 90% better within 24 hours. So I think I because I improved so quickly, I, I only use, only took that for about a week or two. Um. So that was pretty straightforward as far as the bladder cancer goes. Well, um, BCG, I think I had about 11. I might have had 11 infusions of that, but it wasn't helping. So that was, that was stopped. And as far as supplements go, I've been taking supplements now for probably, you know, two and a half, three years and. I don't think I've actually. I did have what do you call it? Medical cannabis there for a little while. But once I started the immunotherapy with KEYTRUDA, I stopped taking the medical cannabis because I read somewhere it could

interfere with the immunotherapy. So I didn't want to risk it, so I stopped taking that.

Participant 042_2022AUBLC

Participant describes adhering to treatment as long as side effects are tolerable

Oh, that's a good question. So, well with the BCG. I mean, I guess theoretically I've stuck with it regardless of knowing whether it's working or not, because proof is the long term non-recurrence of the of the thing. So in that in that sense, I stuck with it based on the evidence that it does improve with, with other things. So like I, if I don't think they're working or if I think the side effects are worse than the um, then yeah. What is it? The thing is worse than the treatment. The cure is worse than the treatment. I. I don't stick with it too long. Okay? I have to say I'm a bit, you know, I guess that's not working the CBD. I sort of well because you buy a little tube, it costs three or \$400 and it lasts about a month. So you stick with it because you've paid a lot of money for it.

Participant 006_2022AUBLC

I give it a good go. I can, I can only, I can only point at chemotherapy where I meant to go through four cycles. I did have to stop it at three because I was so ill. I was in hospital, I was around and I said, well, look, it was done in consultation with the oncologist cause I said, what was going to be the benefit of me doing? You know, if I had to do a full cycle, what was the what was the benefit like? A cost benefit for me. So the oncologists were able to come back and say, look, most, most of the benefits that you've had are in the first couple of cycles, cycles 1 to 2 and potentially three. If you do cycle four, you might get an extra 10% top up. Uh, yeah, to be sure, to be sure type of thing. But um. So I made a, made a call on that and said, I don't want to do that because I didn't think I was having any real quality of life myself. By going through that. So, yeah, I would if somebody says me, here's a, here's a treatment that could well help, I would definitely give it, give it a go first.

Participant 035_2022AUBLC

Oh, I would. I would stick with whatever I could. Um, I actually the second load of chemo, after I had my kidney out, I got so sick I could only have three rounds. They had to stop the fourth round. Um, but, and I didn't want to stop, but I knew that the oncologist just said I couldn't take any more. Um, but no, I would. I would try anything and everything.

Participant 039_2022AUBLC

Participant describes adhering to treatment for a specific amount of time

The only thing I've had trouble with is some anti-inflammatories, and I, you know, play with my stomach and, make me sick, so those I stop fairly quickly. If I'm given something that reacts in that way, if it's something that doesn't alleviate whatever it is. I was trying to get rid of I persist with those for a while, you know, at least a couple of weeks.

Participant 022_2022AUBLC

Well, I think you need to stick with it for a while and it depends on what the side effects are. So is it just mild side effects? I'd stick with it till it was proven whether it was working or not working. If it was severe side effects and there was no improvement in the condition, I think I'd be asking questions to the specialist who described it, you know, to, to really get an idea of how long, you know, you need to be on this treatment because it's impacting your quality of life so severely. And it's not working. I'd want to know. So I would be asking questions I didn't know after a few weeks, I think. But they would obviously, I would ask them to set the expectation, you know, we should see some improvement in four weeks, six weeks. So if I got to that point in time and there was still nothing, then I would be asking questions.

Participant 032_2022AUBLC

Honestly, probably less than a month. Okay. But I would obviously consult my doctor first.

Participant 009_2022AUBLC

Well, you'd have to give it time to. To go a new treatment, at least probably three months.

Participant 027_2022AUBLC

Participant describes not giving up on any treatment

I've not given up on any treatments that I've had. I've never given up. And with the BCGs and like, I wanted to continue to BCG and after the week in hospital with the BCG process, it was it was left up to the care of an infectious diseases doctor. Whether or not I'd be able to continue. And he said that because I was I had age in my favour and fitness, that he said that I could continue on with it, that I was strong enough to fight. So I said, you know, do it again. I kept it on.

Participant 001_2022AUBLC

I'm a pretty good fighter. I'll stick with that until. Until the end. For as long or as long as I can. Okay? Yeah, yeah, I don't. I don't quit that easy.

Participant 033_2022AUBLC

I've never really given up on anything. I've just sort of seen it through and eventually sort of spoken to a GP about it. Yeah. I would take a ridiculously long time before I'd give up. On anything. Right. Possibly. I'm not sure if I'm just too, I don't think it's stubborn, I think, I think I just will continue to put up with something.

Participant 041_2022AUBLC

Participant describes not giving up on treatment as they have no other options/will continue despite side effects

Oh, I'd take the advice of my urologist. And it's like I don't know if I would if the urologist said, this is the one thing that's going to 100% improve your chances

of reducing cancer recurring. And yeah, it's got some horrible side effects, but it's going to we just have done that many trials, we've got that much statistical evidence that it improves your chances of low to zero recurrence. I'd do it. I would not do it, like I wouldn't go against my urologist recommendation just because it was a bit sore.

Participant 030_2022AUBLC

Well, I have other, I didn't have a choice. Yeah. That there's, there's not, there's no choice of treatment. It. This is what. And you'll either have it or I don't have it. If I don't have it, then the chances are I'll end up having an cystectomy, which I don't want to have. So I'm really. It's not about giving up on a treatment, there just weren't any options.

Participant 002_2022AUBLC

Table 5.23: Adherence to treatment

Adherence to treatment	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 adhering to treatment as per the advice of their specialist/as long as prescribed	20	40.82	6	30.00	4	40.00	7	50.00	17	38.64	3	60.00	6	35.29	14	43.75
Participant describes adhering to treatment as long as treatment is working	16	32.65	7	35.00	3	30.00	4	28.57	14	31.82	2	40.00	6	35.29	10	31.25
Participant describes adhering to treatment as long as side effects are tolerable	12	24.49	2	10.00	3	30.00	3	21.43	8	18.18	4	80.00	4	23.53	8	25.00
Participant describes adhering to treatment for a specific amount of time	11	22.45	5	25.00	3	30.00	2	14.29	10	22.73	1	20.00	6	35.29	5	15.63
Participant describes not giving up on any treatment	7	14.29	2	10.00	2	20.00	2	14.29	6	13.64	1	20.00	1	5.88	6	18.75
Participant describes not giving up on treatment as they have no other options/will continue despite side effects	4	8.16	2	10.00	0	0.00	2	14.29	4	9.09	0	0.00	3	17.65	1	3.13

Adherence to treatment	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 adhering to treatment as per the advice of their specialist/as long as prescribed	20	40.82	11	37.93	9	47.37	6	40.00	14	42.42	6	30.00	12	42.86
Participant describes adhering to treatment as long as treatment is working	16	32.65	10	34.48	5	26.32	2	13.33	13	39.39	7	35.00	10	35.71
Participant describes adhering to treatment as long as side effects are tolerable	12	24.49	8	27.59	4	21.05	5	33.33	7	21.21	2	10.00	8	28.57
Participant describes adhering to treatment for a specific amount of time	11	22.45	5	17.24	5	26.32	5	33.33	5	15.15	5	25.00	5	17.86
Participant describes not giving up on any treatment	7	14.29	5	17.24	2	10.53	1	6.67	6	18.18	2	10.00	4	14.29
Participant describes not giving up on treatment as they have no other options/will continue despite side effects	4	8.16	1	3.45	3	15.79	1	6.67	3	9.09	2	10.00	3	10.71

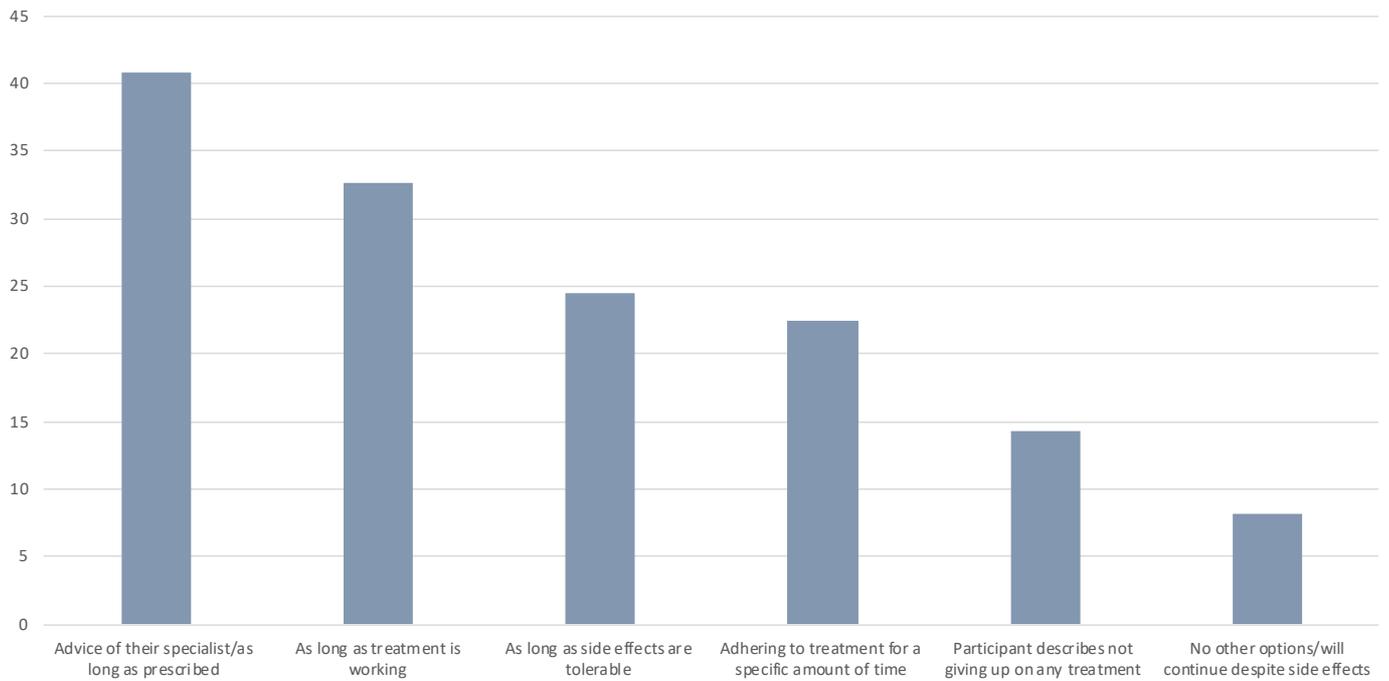


Figure 5.24: Adherence to treatment

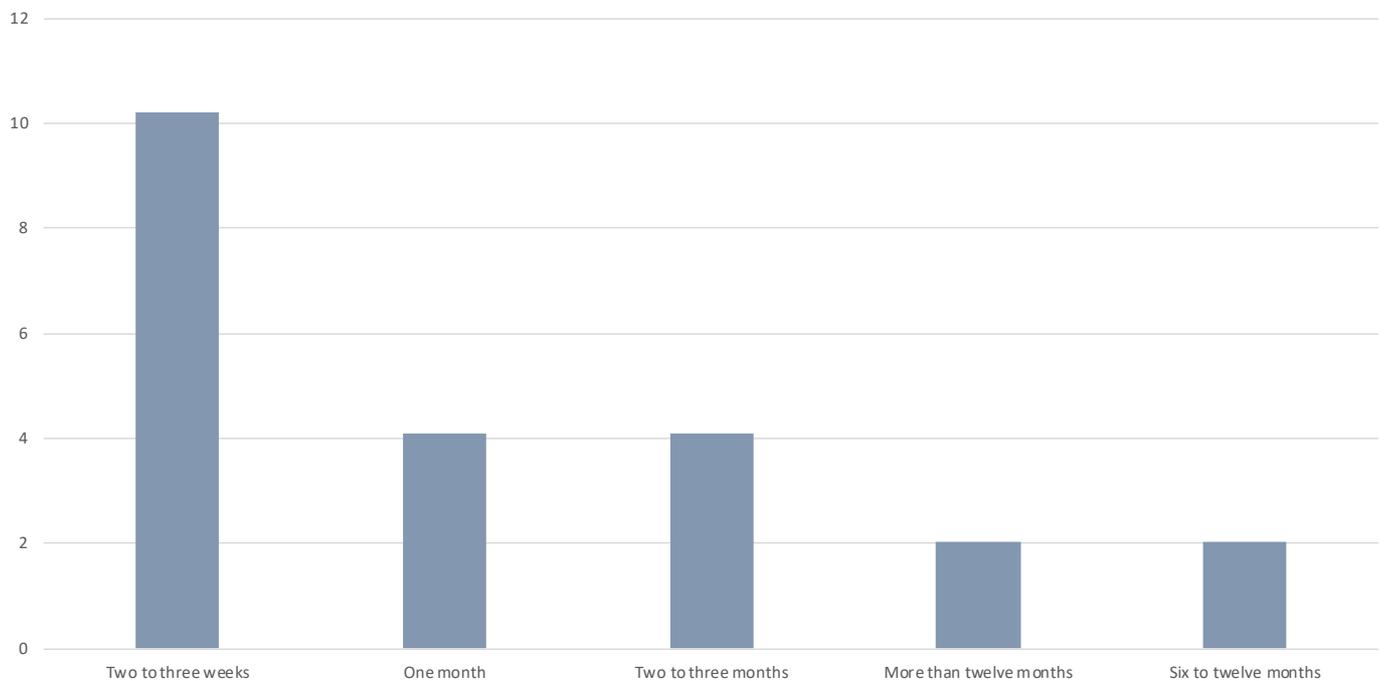


Figure 5.25: Adherence to treatment (Time to adhere to treatment)

Table 5.24: Adherence to treatment – subgroup variations

Adherence to treatment	Reported less frequently	Reported more frequently
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	Early (Stages 0 and I) Mid to low status	Carer to someone with bladder cancer
Participant describes adhering to treatment as long as treatment is working	Regional or remote	-
Participant describes adhering to treatment as long as side effects are tolerable	Early (Stages 0 and I) Mid to low status	Carer to someone with bladder cancer
Participant describes adhering to treatment for a specific amount of time	-	Female Regional or remote

What needs to change to feel like treatment is working

Participants were asked to describe what needs to change to feel like treatment is effective. The most common response from 24 participants (48.89%) was needing to experience evidence of stable disease/no disease progression. There were 14 participants (28.57%) that reported needing to experience a reduction in physical signs/reduced side effects, and 13 participants (26.53%) needed to see specific symptom reduction. The most common specific symptoms were nausea, aches and pains, fatigue and lethargy, and muscle cramping.

Participants reported needing to experience evidence of stable disease/no disease progression

Okay. For me, it's just going. Having a cystoscopy after each round of BCG finished and not having any tumours in there. Having a clear bladder. No progression of the disease from in the last cancer I've had in the bladder has been a high grade non-muscle invasive cancer. So for it to be working, it means that it's either come back without being muscle invasive once again, or it hasn't progressed or I don't have anything. And so far there's been nothing since I've been having BCG. There's been no tumours.

Participant 001_2022AUBLC

I think the delay time between the procedure and saying getting results is the only one because it can be very stressful. You know, between having the procedure, the cystoscopy and then getting the results. Sometimes, you know, it's sort of I know it's hard because you can't get an appointment with the urologist sometimes, but, you know, it's a three or four weeks or something like, you know, sitting around wondering.

Participant 007_2022AUBLC

No, I don't get any of that. If anything, I get increased side effects. I've been told that that doesn't signify whether the treatment's working or not. The only way they know is when they go to check to see if there's any more recurrences.

Participant 002_2022AUBLC

Participants reported needing to experience a reduction in physical signs/reduced side effects

Well. Like I said, what I've got now is working. Put it that way. And then I don't have much issue with any of that. It's just a matter of regularly changing the bag on to every couple of days. Got a couple of minor things. Irritation I suppose from the different tapes

and stuff that I've used at times, I've stop using a couple of different brands because I found that they were give me a bit of skin reaction. I've been pretty consistent what I'm using at the moment, and I've had no problems for about 3 months now, I think, so. Hmm. Yeah. It's only minor irritation now, but it's just because you've got to be, you don't need an infection on your stomach. So you got to keep putting that back on again. So you've got to be careful with them. You know, you don't get any, any major infection, put it that way. Yeah. You get a bit of redness, you're got to sort of treat it straight away.

Participant 011_2022AUBLC

Well, I don't know. That's the thing. I just when I was having the BCG, I didn't know really. I read about it and I was given information in pamphlets and things about what could happen with side effects. But mostly it didn't happen. And I thought at the time, I don't know whether this is working or not because I don't really feel any different.

Participant 025_2022AUBLC

I mean, you know, that maybe you just you, you feel better. You know, you don't you don't have that many side effects.

Participant 044_2022AUBLC

Participants reported needing to see specific symptom reduction

Of course it would have been worrying if I started weeing blood, weeing claret, weeing red wine again sort of thing. So yeah, that would have been a very quick indicator to go to emergency. But yeah, it was probably that was always the main symptom we were looking for all that. Yeah. It was the end result. During the BCG therapy. It. Yeah. You know, no new thingies growing on the wall of the bladder.

Participant 019_2022AUBLC

Yeah. So far. Yeah. So far, the only thing we've tackled as far as side effects is, is the breathing side of it. That's probably been the most debilitating. And I said it was probably a little bit too early into it to work out whether or not we need to change it or, we'll have a chat with the lung specialist in a couple of weeks. Um. I don't think there's a great deal that we can do about anything else.

Participant 040_2022AUBLC

I think typically particularly the treatment I've been having, has been from a pain management

perspective. And so I guess, I guess I've spoken to my GP or a couple of times to, no actually a number of, quite a number of times to the pain management specialist through the cancer centre. Because post surgery I was having a lot of pain that was quite poorly managed and so I had to get, you know, get, get increases in pain, pain relief. And yet I think, a,s as I mentioned before, I think I would have, I would have

*ordinarily just been putting up with this for a lot longer than I should have, except for the encouragement and assistance from a friend to actually join, join me in a telehealth appointment and try, trying to explain to the pain management specialist how much pain I actually really was in and how much it was impacting my life.
Participant 041_2022AUBLC*

Table 5.25: What needs to change to feel like treatment is working

What needs to change to feel like treatment is working	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	%
Participants reported needing to experience evidence of stable disease/no disease progression	24	48.98	12	60.00	3	30.00	6	42.86	21	47.73	3	60.00	12	70.59	12	37.50
Participants reported needing to experience a reduction in physical signs/reduced side effects	14	28.57	5	25.00	6	60.00	3	21.43	14	31.82	0	0.00	5	29.41	9	28.13
Participants reported needing to see specific symptom reduction	13	26.53	3	15.00	2	20.00	5	35.71	10	22.73	3	60.00	2	11.76	11	34.38

What needs to change to feel like treatment is working	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	%
Participants reported needing to experience evidence of stable disease/no disease progression	24	48.98	9	31.03	15	78.95	4	26.67	20	60.61	12	60.00	16	57.14
Participants reported needing to experience a reduction in physical signs/reduced side effects	14	28.57	7	24.14	6	31.58	5	33.33	8	24.24	5	25.00	9	32.14
Participants reported needing to see specific symptom reduction	13	26.53	10	34.48	3	15.79	4	26.67	9	27.27	3	15.00	8	28.57

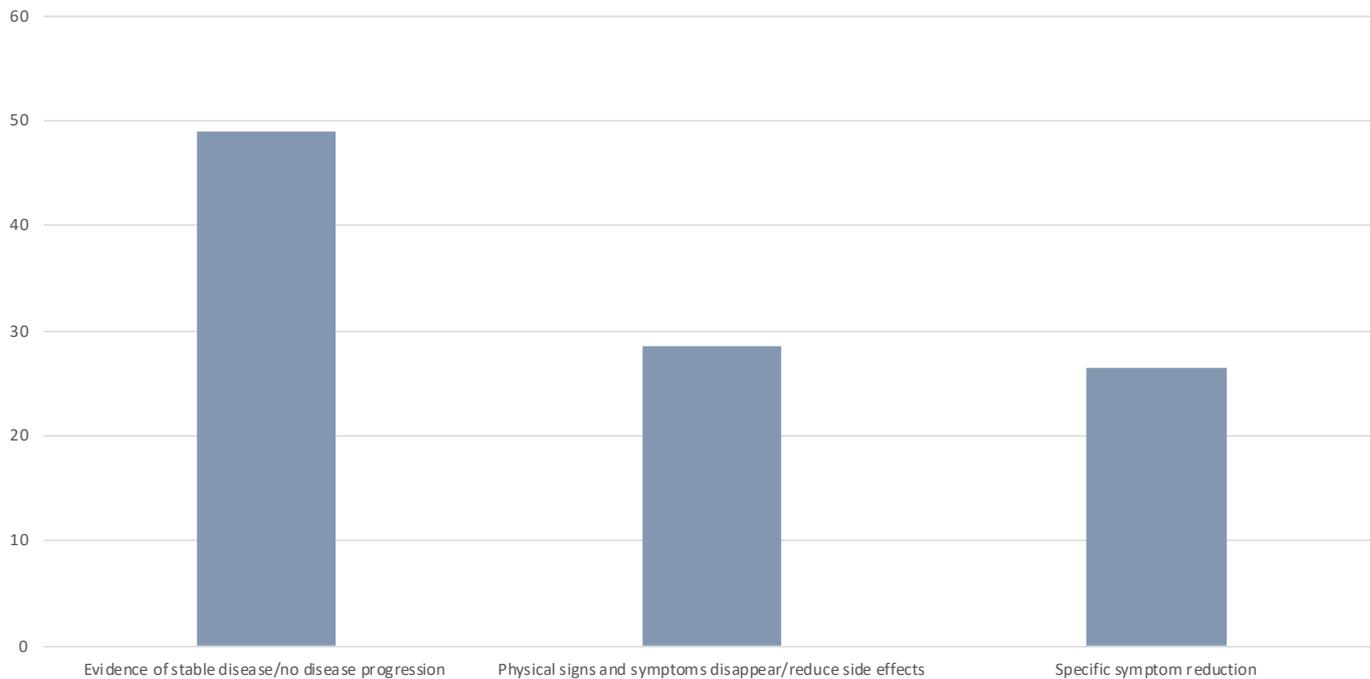


Figure 5.26: What needs to change to feel like treatment is working

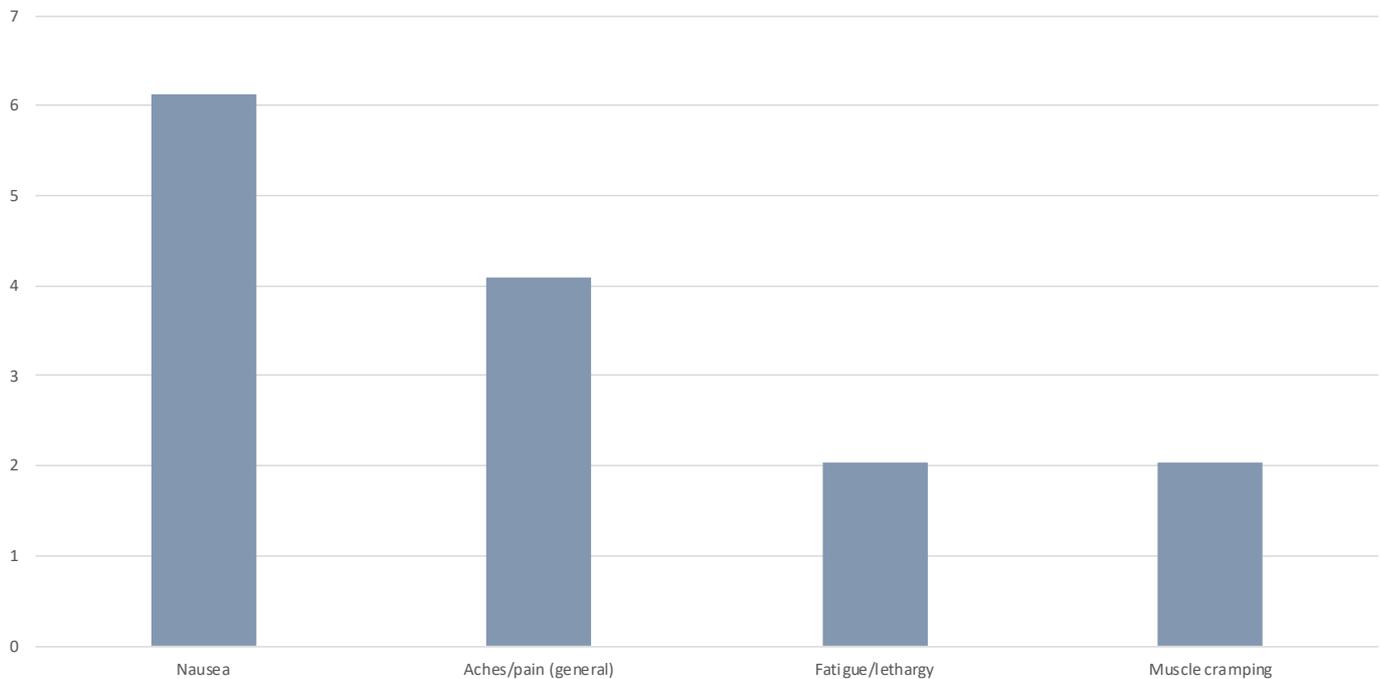


Figure 5.27: What needs to change to feel like treatment is working: specific symptoms

Table 5.26: What needs to change to feel like treatment is working – subgroup variations

What needs to change to feel like treatment is working	Reported less frequently	Reported more frequently
Participants reported needing to experience evidence of stable disease/no disease progression	Invasive (Stage III) Male Trade or high school Regional or remote	Early (Stages 0 and I) Carer to someone with bladder cancer Female University Metropolitan
Participants reported needing to experience a reduction in physical signs/reduced side effects	Carer to someone with bladder cancer	Mid to low status Invasive (Stage III)
Participants reported needing to see specific symptom reduction	Early (Stages 0 and I) Female University Mid to low status	Carer to someone with bladder cancer

What would it mean if treatment worked

Participants were asked what it would mean to them if their treatment worked. The most common response from 16 participants (32.65%) was treatment allowing them to do everyday activities/ return to normal life. There were 12 participants (24.49%) that reported treatment working as having a positive impact on their mental health, 8 participants (16.33%) described treatment leading to a reduction in symptoms/side effects, and 8 participants (16.33%) described treatment allowing them to engage more with social activities and family life. Other participants described that treatment would allow them to keep their bladder (n=6, 12.24%), and allow them to do more exercise (n=6, 12.24%).

Participant describes treatment allowing them to do everyday activities/ return to normal life

So in that case, it would be the anti-spasmodic medication that I was on. Okay. And I can, I can certainly give an example of that because as I said before, when I was just recently before, just in February, and it was suggested that I tried

concurrently two different acting anti-spasmodic and they did work because for the three months previous to that, I felt very my bladder was very irritable. I couldn't go for long without emptying my bladder and to the point where I would have to pre-emptively empty my bladder so I wasn't caught unawares. I would occasionally have a spasm that I could not fight with muscles. And you would have to work hard just to make sure that I was not, and if I did happen to have an accident. So going out, it certainly affected my confidence in going out and whereas since I started the two anti-spasmodic for about, about two weeks. I felt a lot more secure in myself about going out and that I could control my bladder and the spasm wasn't as difficult to kind of combat
Participant 010_2022AUBL

I'm assuming if they'd removed the tumours, I'd be able to carry on with life as I've been doing before I was diagnosed with cancer.
Participant 003_2022AUBL

Um, I guess if I'd. Yeah, look, it was because until I sort of got an idea of what, what was going on and. Yeah. It was one of those things that really restricted what I did, even if not physically, at least mentally. And, you know, not going to do that because it's really going to hurt after. So it mightn't stop me doing, I don't know, working around the house or something like that. But I, I live on the surf coast in STATE and I'm still, still quite still surf quite often and it really. Yeah. Procrastination is part of the surfing thing, but it took me to a new level. I would just get so, I don't know if I could be bothered today

Participant 006_2022AUBLC

Yeah. No, no, that's okay. Like, just the fact that I can function on a day to day basis. Normally, still, like, I've had, I still have a half a bladder It's not huge, but, um, if it didn't work, then I would have a whole lifestyle change. Yeah. So I still live a very normal life.

Participant 009_2022AUBLC

Participant describes treatment working as having a positive impact on their mental health

Yeah, it would be. Yeah. Because one, you would feel that it's working. It would give you hope that, you know, your cancer is either going to go into remission. And, you know, so it would be great because you could do what you wanted. So you know, I think it would be a good thing.

Participant 032_2022AUBLC

Well, it gave me a lot of peace of mind to think that I didn't have to be continually thinking about, you know, this condition I have and whether it was going to get worse or, uh, at some point or just having to go so regularly for checks and into hospital. I just, it's all a bit of a drag, really. Um. So it would just it would be really peace of mind, I think.

Participant 025_2022AUBLC

PARTICIPANT Oh, it would be great if there was some solution to it because, for his quality of life and mental health quality.

INTERVIEWER What would he be? What would he be able to do if he had that solved?

PARTICIPANT Well, you don't have to panic about going away and go away more often and just start enjoying life.

Carer 001_2022AUBLC

Participant describes treatment leading to a reduction in symptoms/side effects

You know, and I guess that's with the medication that I'm on, I take a HRT tablet and that stops of, you know, it holds off the hot flushes. If I forget to take it for a couple of days, I start to feel like ohh. Can I get back on those drugs!

Participant 022_2022AUBLC

Well, I haven't got to that stage yet, but I suppose if, if it did, it was, you know, I mean, I'd hate to have to wear a bag or something like that. Yeah. You know, I'd feel very self-conscious of that or even embarrassed. Um, But, but I'm fortunate. I'm not in that, I'm not in that position at the moment and hopefully I won't be. But, you know, I know that the, the chance of recurrence is 75, 70, 80%. And I've read some of the articles, academic articles on this. So, you know, I'm, you know, I'm, I'm pragmatic that, you know, it may happen. My biggest fear is having to have the BCG treatment again, even, even now I realise it's, it's probably effective. Um, it's, you know, it's most invasive and the problem is you're awake when you have to be awake when they do it. Yeah. Now, if, if I was asleep or knocked out temporarily, I don't think you'd feel the pain. Or you might feel the pain later, but then you wouldn't feel the pain when they're doing it. Yeah. So it's very hard.

Participant 008_2022AUBLC

What? I mean, I'm very tired now, and, you know, I could plan to go and spend time with my kids on the coast or down the coast. But at the moment, I'll even just to go away for a few days ourselves and I go, well, you know, I've got two treatments and all that week.

Participant 004_2022AUBLC

Participant described treatment allowing them to engage more with social activities and family life

I just want to be able to support and help my, my children or my grandchildren. They're my main priority. And every day, I've got nine of them from 10 to 5 months of age. But every day I see, like they all live within 5 minutes of where I live. Five, 10 minutes. The four kids. Um, I just like to spend time with them, my friends, and go on holidays when I want to. Um. Yeah. Like, if I couldn't do that, I'd be. It'd be pretty devastating. I mean, it's just simple things in life. Just simple things.

Participant 039_2022AUBLC

Well, I well, if, if the treatment was working, I guess he would be less depressed about things. He would

feel able to join in family functions better. He'd be able to travel better. Travel is very difficult because of the pain threshold so, and discomfort so you know if, if there was something that could help those things. It would make life a lot easier.

Carer 005_2022AUBLC

So in that case, it would be the anti-spasmodic medication that I was on. Okay. And I can, I can certainly give an example of that because as I said before, when I was just recently before, just in February, and it was suggested that I tried concurrently two different acting anti-spasmodic and they did work because for the three months previous to that, I felt very my bladder was very irritable. I couldn't go for long without emptying my bladder and to the point where I would have to pre-emptively empty my bladder so I wasn't caught unawares. I would occasionally have a spasm that I could not fight with muscles. And you would have to work hard just to make sure that I was not, and if I did happen to have an accident. So going out, it certainly affected my confidence in going out and whereas since I started the two anti-spasmodic for about, about two weeks. I felt a lot more secure in myself about going out and that I could control my bladder and the spasm wasn't as difficult to kind of combat

Participant 010_2022AUBLC

Participant described treatment allowing them to keep their bladder

Well, what is the next step going to be like? Uh, you know, you have to have a surgery. You would not have to remove my bladder. It's going to be different for my life, I think.

Participant 015_2022AUBLC

Okay. If the BCG had worked and I hadn't got bladder cancer again, then I wouldn't have had to have my bladder removed, which has changed everything for me. So, you know, obviously that would have been better, but it's not the case. So then, you know, I'm not dead, so that's good.

Participant 026_2022AUBLC

Well, I haven't got to that stage yet, but I suppose if, if it did, it was, you know, I mean, I'd hate to have to wear a bag or something like that. Yeah. You know, I'd feel very self-conscious of that or even embarrassed. Um, But, but I'm fortunate. I'm not in that, I'm not in that position at the moment and hopefully I won't be. But, you know, I know that the, the chance of recurrence is 75, 70, 80%. And I've read some of the articles, academic articles on this. So, you

know, I'm, you know, I'm, I'm pragmatic that, you know, it may happen. My biggest fear is having to have the BCG treatment again, even, even now I realise it's, it's probably effective. Um, it's, you know, it's most invasive and the problem is you're awake when you have to be awake when they do it. Yeah. Now, if, if I was asleep or knocked out temporarily, I don't think you'd feel the pain. Or you might feel the pain later, but then you wouldn't feel the pain when they're doing it. Yeah. So it's very hard.

Participant 008_2022AUBLC

Participant describes treatment allowing them to do more exercise

Yeah, yeah, definitely. Um, if I didn't have those side effects, um, I, I found myself far less active than what I should have been. I mean, if I can. If I could have found something that would have allowed me to get out into the fresh air more and to be able to do very limited walks, um, you know, some type of physical activity to help my body as well. That, that would have definitely been a big plus.

Participant 035_2022AUBLC

I wouldn't be able to do what I'm doing now. I wouldn't have to go out. I wouldn't be able to see the grandkids as much or I wouldn't be able to enjoy life as much as what I am. That's okay. I still want to feel not alone now that I'm 74 years of age and I'm still very cautious about it. And that's because the treatments actually bugged my dosage getting my vaccinations and all that done on that too. You know, it sort of put me behind the 8 ball with some of it. So that's about the main things it's, it's affected, you know, but I've been out a few weekends out in the kayak before the weather got a bit cooler. I'm looking forward to next spring and next spring and summer actually getting out in the kayak a bit more often. But I'm walking regularly, which I'm struggling to do prior, because I'd have to go somewhere where I can stop and have a squirt, maybe four or 500 metres, you know, very, very awkward. Then I was walking around my backyard, you know, and I've got a big back yard, but not that big. But at least I can go for walk down the street now and you know, whatever.

Participant 011_2022AUBLC

Participant describes treatment allowing them to be cancer free/cured/ live longer

Look forward to being around for quite a bit longer. Um. Yeah. If my life just get back to normal, get on, you know, enjoy life, enjoy life. And, um. Yeah. Work, work, family. All of that sort of thing.
Participant 016_2022AUBL

PARTICIPANT *If it wasn't doing this job, I wouldn't be here.*

INTERVIEWER *Yeah. Right.*

PARTICIPANT *There, There would be fear, there would be frustration. And in my case, there wouldn't be any life. Absolutely not.*
Participant 038_2022AUBL

Participant describes that they would keep trying new treatments, if their treatment did not work.

If it wasn't working. Let's try it, or maybe try something else, which I've done, or just change my diet. Probably not that I drink much, but I'll probably give up alcohol and just try to lead a more and more healthy lifestyle, more exercise. I find the best thing

for me, for anything I've had in the past, is when I want to do my walking. I walk from my place around the SPORTGROUND, which I live next to and. It's better. Okay. I feel much, much better when I do that.
Participant 021_2022AUBL

When you look at alternative treatments, really, I mean, it's. But it's changing diet or another type of chemotherapy or having to actually get the, you know, your bladder removed and having a new bladder put in or a stoma. I mean, you just have to look at everything. Just ultimately you want to live. So that's the cancer, not going away just to try what the other options are. And there are others, you know, from what I'm aware of now, that seems to do as it progresses or if it gets worse. But. Yeah. So we just have go through the process.
Participant 024_2022AUBL

In my words. Yeah, probably wouldn't be here. I probably wouldn't be here because the cancer would just keep spreading. So if we don't go through it and it doesn't work well, you go to the next, next option and you go the next option. But soon enough you are going to run out of options.
Participant 033_2022AUBL

Table 5.27: What would it mean if treatment worked

What would it mean if treatment worked	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 treatment allowing them to do everyday activities/return to normal life	16	32.65	8	40.00	3	30.00	3	21.43	14	31.82	2	40.00	6	35.29	10	31.25
Participant describes treatment working as having a positive impact on their mental health	12	24.49	3	15.00	3	30.00	3	21.43	9	20.45	3	60.00	5	29.41	7	21.88
Participant describes treatment leading to a reduction in symptoms/side effects	8	16.33	4	20.00	2	20.00	2	14.29	8	18.18	0	0.00	5	29.41	3	9.38
Participant described treatment allowing them to engage more with social activities and family life	8	16.33	5	25.00	0	0.00	1	7.14	6	13.64	2	40.00	4	23.53	4	12.50
Participant described treatment allowing them to keep their bladder	6	12.24	4	20.00	2	20.00	0	0.00	6	13.64	0	0.00	3	17.65	3	9.38
Participant describes treatment allowing them to do more exercise	6	12.24	3	15.00	0	0.00	3	21.43	6	13.64	0	0.00	0	0.00	6	18.75
Participant describes treatment allowing them to be cancer free/cured/ live longer	3	6.12	1	5.00	0	0.00	2	14.29	3	6.82	0	0.00	1	5.88	2	6.25
Participant describes that they would keep trying new treatments, if their treatment did not work.	3	6.12	0	0.00	2	20.00	1	7.14	3	6.82	0	0.00	0	0.00	3	9.38

What would it mean if treatment worked	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 treatment allowing them to do everyday activities/return to normal life	16	32.65	11	37.93	4	21.05	7	46.67	8	24.24	8	40.00	8	28.57
Participant describes treatment working as having a positive impact on their mental health	12	24.49	7	24.14	5	26.32	6	40.00	6	18.18	3	15.00	7	25.00
Participant describes treatment leading to a reduction in symptoms/side effects	8	16.33	6	20.69	2	10.53	2	13.33	6	18.18	4	20.00	5	17.86
Participant described treatment allowing them to engage more with social activities and family life	8	16.33	5	17.24	3	15.79	3	20.00	5	15.15	5	25.00	4	14.29
Participant described treatment allowing them to keep their bladder	6	12.24	2	6.90	4	21.05	4	26.67	2	6.06	4	20.00	2	7.14
Participant describes treatment allowing them to do more exercise	6	12.24	5	17.24	1	5.26	1	6.67	5	15.15	3	15.00	4	14.29
Participant describes treatment allowing them to be cancer free/cured/ live longer	3	6.12	2	6.90	1	5.26	1	6.67	2	6.06	1	5.00	1	3.57
Participant describes that they would keep trying new treatments, if their treatment did not work.	3	6.12	2	6.90	1	5.26	0	0.00	3	9.09	0	0.00	2	7.14

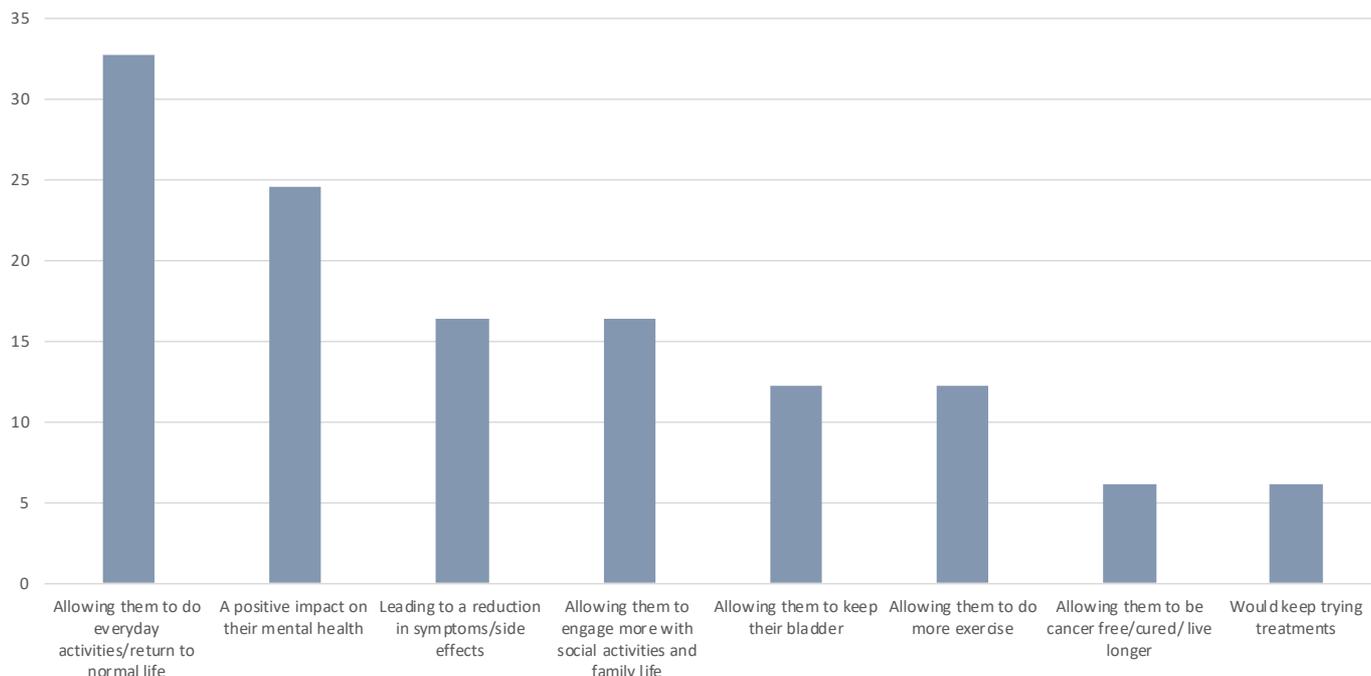


Figure 5.28: What would it mean if treatment worked

Table 5.28: What would it mean if treatment worked – subgroup variations

What would it mean if treatment worked	Reported less frequently	Reported more frequently
Participant describes treatment allowing them to do everyday activities/ return to normal life	Advanced (Stage IV) University	Regional or remote
Participant describes treatment working as having a positive impact on their mental health	-	Carer to someone with bladder cancer Regional or remote
Participant describes treatment leading to a reduction in symptoms/side effects	Carer to someone with bladder cancer	Female
Participant described treatment allowing them to engage more with social activities and family life	Invasive (Stage III)	Carer to someone with bladder cancer
Participant described treatment allowing them to keep their bladder	Advanced (Stage IV) Carer to someone with bladder cancer	Regional or remote
Participant describes treatment allowing them to do more exercise	Invasive (Stage III) Carer to someone with bladder cancer Female	-