

Section 7

Care and support

Section 7: Experience of care and support

Care coordination

A Care Coordination questionnaire was completed by participants within the online questionnaire. The Care Coordination questionnaire comprises a total score, two scales (communication and navigation), and a single question for each relating to care-coordination and care received. A higher score denotes better care outcome.

The **Care coordination: communication** scale measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. The average score indicates that participants had moderate communication with healthcare professionals.

The **Care coordination: navigation** scale navigation of the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. The average score indicates that participants had good navigation of the healthcare system.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. The average score indicates that participants had moderate communication, navigation and overall experience of care coordination.

The **Care coordination: care coordination global measure** scale measures the participants overall rating of the coordination of their care. The average score indicates that participants scored rated their care coordination as good.

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. The average score indicates that participants rated their quality of care as good.

Experience of care and support

In the structured interview, participants were asked what care and support they had received since their diagnosis. This question aims to investigate what services patients consider to be support and care services. The most common theme was that participant did not receive any support (n=18, 36.73%). This was followed by receiving support through charities (n=15, 30.61%), hospital and clinical setting (including nurse support) (n=14, 28.57%), online, phone or social media peer support (n=12, 24.49%), and face-to-face peer support (n=8, 16.33%). There were 5 participants (10.20%) that described not needing any help or support.

Care coordination

A Care Coordination questionnaire was completed by participants within the online questionnaire. The Care Coordination questionnaire comprises a total score, two scales (communication and navigation), and a single question for each relating to care-coordination and care received. A higher score denotes better care outcome. Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 7.1.

The overall scores for the cohort were in the second highest quintile for **Care coordination: Navigation** (mean=25.43, SD=4.82), **Care coordination: Care coordination global measure** (median=8.00, IQR=3.50), **Care coordination: Quality of care global measure** (median=8.00, IQR=2.50) indicating good communication, good care coordination, and good quality of care

The overall scores for the cohort were in the middle quintile for **Care coordination: Communication** (mean=39.77, SD=9.52), **Care coordination: Total score** (mean=65.19, SD=13.06), indicating moderate communication, and moderate care coordination.

The **Care coordination: communication** scale measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations,

and financial entitlements. The average score indicates that participants had moderate communication with healthcare professionals.

The **Care coordination: navigation** scale navigation of the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. The average score indicates that participants had good navigation of the healthcare system.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. The average score indicates that participants had moderate communication, navigation and overall experience of care coordination.

The **Care coordination: care coordination global measure** scale measures the participants overall rating of the coordination of their care. The average score indicates that participants scored rated their care coordination as good.

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. The average score indicates that participants rated their quality of care as good.

Table 7.1: Care coordination summary statistics

Care coordination scale (n=47)	Mean	SD	Median	IQR	Possible range	Quintile
Communication*	39.77	9.52	40.00	13.50	13 to 65	3
Navigation*	25.43	4.82	25.00	6.50	7 to 35	4
Total score*	65.19	13.06	68.00	16.00	20 to 100	3
Care coordination global measure	7.09	2.08	8.00	3.50	1 to 10	4
Quality of care global measure	7.85	1.92	8.00	2.50	1 to 10	4

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

Care coordination by bladder cancer stage

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

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 7.2). When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used

(Table 7.3). Post hoc pairwise comparisons using Wilcoxon rank sum test was used to identify the source of any differences identified in the Kruskal -Wallis test (Table 7.4).

A one way ANOVA test indicated a statistically significant difference in the Care coordination: Communication scale between groups, $F(2, 39) = 5.18$, $p = 0.0101$. Post hoc comparisons using the Tukey HSD test indicated that the mean score for participants in the early subgroup (mean = 36.22, SD = 7.92) was

significantly lower compared to participants in the invasive subgroup (mean = 23.81, SD = 9.74 p=0.0171).

Post hoc comparisons using the Tukey HSD test indicated that the mean score for participants in the early subgroup (mean = 36.22, SD = 7.92) was significantly lower compared to participants in the advanced subgroup (mean = 43.57, SD = 8.06 p=0.0485).

A one way ANOVA test indicated a statistically significant difference in the Care coordination: Total score scale between groups, $F(2, 39) = 4.84, p = 0.0133$.

Post hoc comparisons using the Tukey HSD test indicated that the mean score for participants in the early subgroup (mean = 60.89, SD = 11.73) was significantly lower compared to participants in the invasive subgroup (mean = 74.30, SD = 12.95 p=0.0150).

The **Care coordination: communication** scale measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. On average, participants in

the invasive subgroup scored higher than participants in the early subgroup. This indicates that healthcare communication was good for participants in the Invasive subgroup, and average for participants in the Early subgroup.

The **Care coordination: communication** scale measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. On average, participants in the advanced subgroup scored higher than participants in the early subgroup. This indicates that healthcare communication was good for participants in the advanced subgroup, and average for participants in the early subgroup.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. On average, participants in the invasive subgroup scored higher than participants in the early subgroup. This indicates that communication, navigation and overall experience of care coordination was good for participants in the invasive subgroup, and average for participants in the early subgroup.

Table 7.2: Care coordination bladder cancer stage summary statistics and one-way ANOVA

Care coordination scale	Group	Number (n=42)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Communication	Early	18	42.86	36.22	7.92	Between groups	733.80	2	366.9	5.176	0.0101*
	Invasive	10	23.81	45.80	9.74	Within groups	2764.10	39	70.9		
	Advanced	14	33.33	43.57	8.06	Total	3497.90	41			
Navigation	Early	18	42.86	24.67	5.28	Between groups	94.50	2	47.24	2.36	0.1080
	Invasive	10	23.81	28.50	3.92	Within groups	780.50	39	20.01		
	Advanced	14	33.33	26.00	3.59	Total	875.00	41			
Total score	Early	18	42.86	60.89	11.73	Between groups	1298.00	2	648.8	4.835	0.0133*
	Invasive	10	23.81	74.30	12.95	Within groups	5233.00	39	134.2		
	Advanced	14	33.33	69.57	10.32	Total	6531.00	41			
Care coordination global measure	Early	18	42.86	6.67	2.28	Between groups	13.79	2	6.895	1.677	0.2000
	Invasive	10	23.81	8.10	1.52	Within groups	160.33	39	4.111		
	Advanced	14	33.33	7.43	1.99	Total	174.12	41			

*Statistically significant at p<0.05

Table 7.3: Care coordination bladder cancer stage summary statistics and Kruskal-Wallis test

Care coordination scale	Group	Difference	Upper	Lower	p adjusted
Communication	Invasive - Early	9.58	1.49	17.67	0.0171*
	Advanced - Early	7.35	0.04	14.66	0.0485*
	Advanced - Invasive	-2.23	-10.72	6.26	0.7994
Total score	Invasive - Early	13.41	2.28	24.54	0.0150*
	Advanced - Early	8.68	-1.37	18.74	0.1022
	Advanced - Invasive	-4.73	-16.41	6.96	0.5900

*Statistically significant at p<0.05

Table 7.4: Care coordination bladder cancer stage one-way post hoc Wilcoxon rank sum test

Care coordination scale	Group	Number (n=42)	Percent	Median	IQR	C ²	dF	p-value
Quality of care global measure	Early	18	42.86	8.00	2.00	3.55	2	0.1695
	Invasive	10	23.81	9.50	1.75			
	Advanced	14	33.33	8.50	2.00			

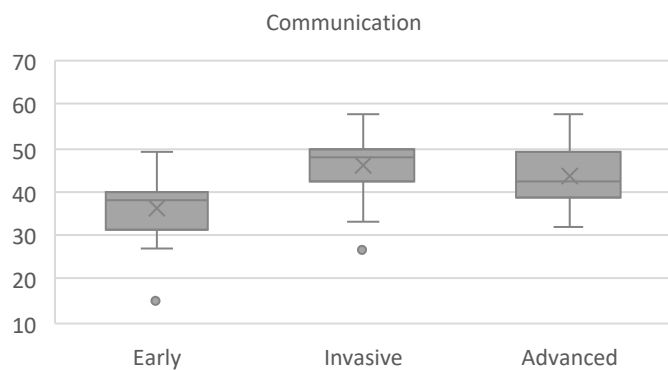


Figure 7.1: Boxplot of Care coordination: Communication bladder cancer stage

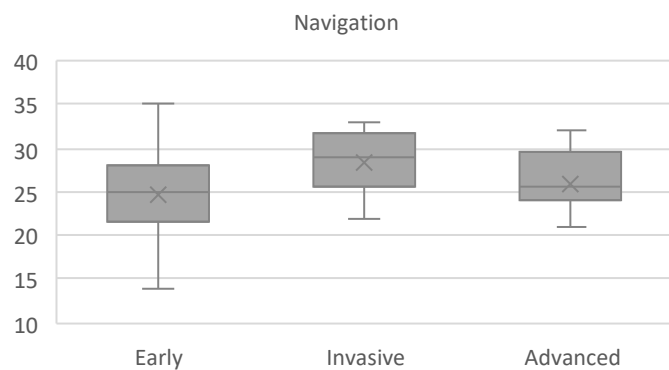


Figure 7.2: Boxplot of Care coordination: Navigation bladder cancer stage

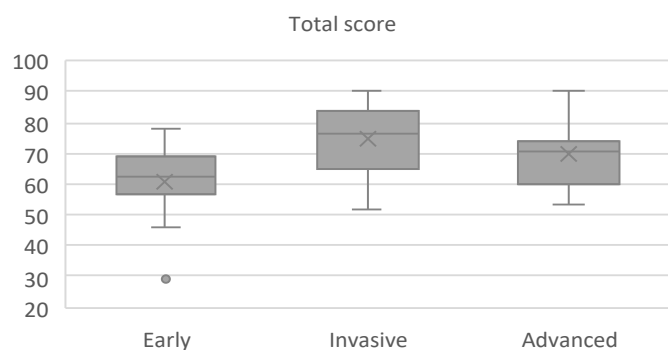


Figure 7.3: Boxplot of Care coordination: Total score bladder cancer stage

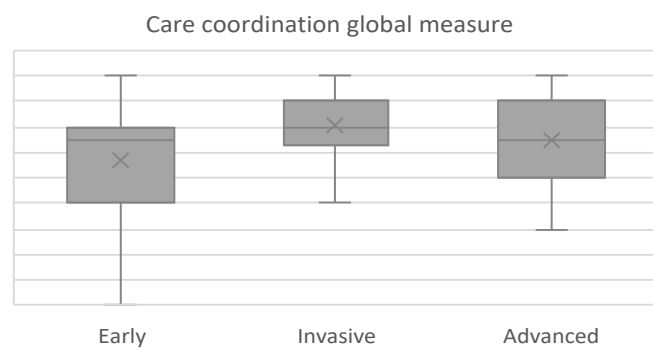


Figure 7.4: Boxplot of Care coordination: Care coordination global measure bladder cancer stage

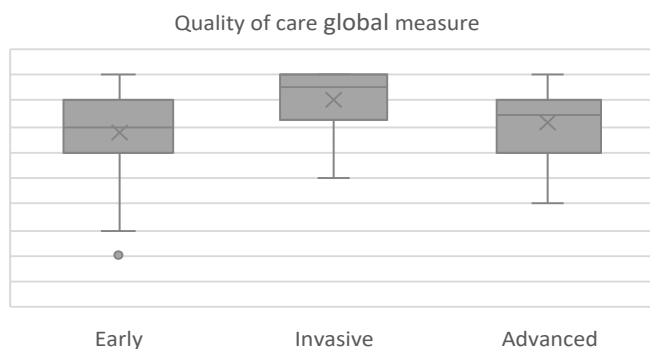


Figure 7.5: Boxplot of Care coordination: Quality of care global measure bladder cancer stage

Care coordination by participant type

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

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.5), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.6).

A two sample t-test indicated that the mean score for the **Care coordination Communication** scale [$t(45) = 2.63$, $p = 0.0116$] was significantly higher for participants in the patient subgroup (Mean = 40.95, SD = 9.24) compared to participants in the carer subgroup (Mean = 29.80, SD = 5.40.)

A two sample t-test indicated that the mean score for the **Care coordination Navigation** scale [$t(45) = 2.62$, $p = 0.0120$] was significantly higher for participants in the patient subgroup (Mean = 26.02, SD = 4.62) compared to participants in the carer subgroup (Mean = 20.40, SD = 3.65.)

A two sample t-test indicated that the mean score for the **Care coordination Total score** scale [$t(45) = 2.93$, $p = 0.0053$] was significantly higher for participants in the patient subgroup (Mean = 66.98, SD = 12.62) compared to participants in the carer subgroup (Mean = 50.20, SD = 3.96.)

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **Care coordination Quality of care global measure scale** [$W = 192.50$, $p = 0.0023$] was significantly higher for participants in the patient subgroup (Median = 9.00, IQR = 2.75) compared to participants in the carer subgroup (Median = 5.00, IQR = 0.00).

The **Care coordination: communication** scale measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. On average, participants in the patient subgroup scored higher than participants in the carer subgroup. This indicates that healthcare communication was average for participants in the patient subgroup, and poor for participants in the carer subgroup.

The **Care coordination: navigation** scale measures the ability of a patient to navigate the healthcare system

including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. On average, participants in the patient subgroup scored higher than participants in the carer subgroup. This indicates that healthcare navigation was good for participants in the patient subgroup, and average for participants in the carer subgroup.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. On average, participants in the patient subgroup scored higher than participants in the carer subgroup. This indicates that communication, navigation and overall experience of care coordination was average for participants in the patient subgroup, and poor for participants in the carer subgroup.

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. On average, participants in the patient subgroup scored higher than participants in the carer subgroup. This indicates that, quality of care was very good for participants in the patient subgroup, and average for participants in the carer subgroup.

Table 7.5: Care coordination by participant type summary statistics and T-test

Care coordination scale	Group	Number (n=47)	Percent	Mean	SD	T	dF	p-value
Communication	Patient	42	89.36	40.95	9.24	2.63	45	0.0116*
	Carer	5	10.64	29.80	5.40			
Navigation	Patient	42	89.36	26.02	4.62	2.62	45	0.0120*
	Carer	5	10.64	20.40	3.65			
Total score	Patient	42	89.36	66.98	12.62	2.93	45	0.0053*
	Carer	5	10.64	50.20	3.96			

*Statistically significant at $p < 0.05$

Table 7.6: Care coordination by participant type summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=47)	Percent	Median	IQR	W	p-value
Care coordination global measure	Patient	42	89.36	8.00	3.00	155.00	0.0836
	Carer	5	10.64	6.00	1.00		
Quality of care global measure	Patient	42	89.36	9.00	2.75	192.50	0.0023*
	Carer	5	10.64	5.00	0.00		

*Statistically significant at $p < 0.05$

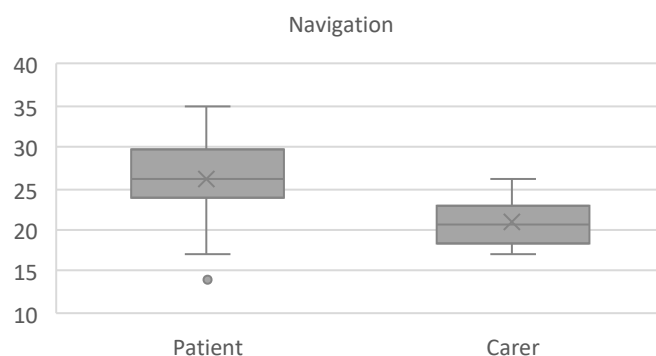
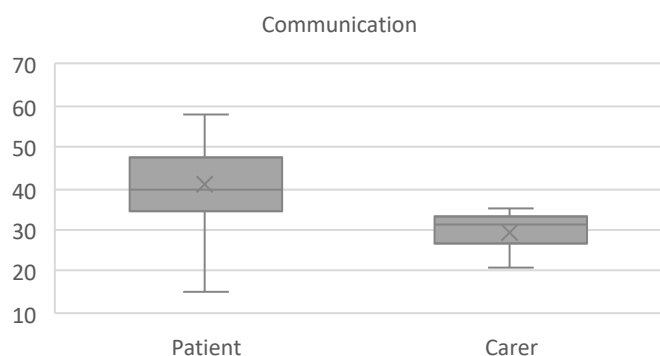


Figure 7.6: Boxplot of Care coordination: Communication participant type

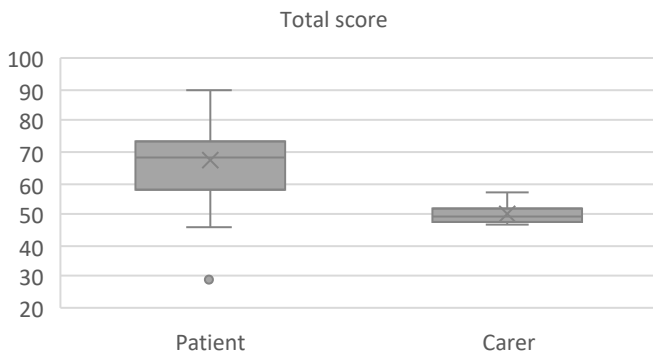


Figure 7.7: Boxplot of Care coordination: Navigation participant type

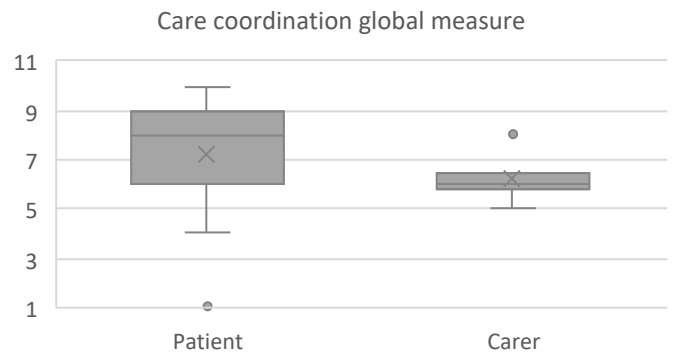


Figure 7.8: Boxplot of Care coordination: Total score participant type

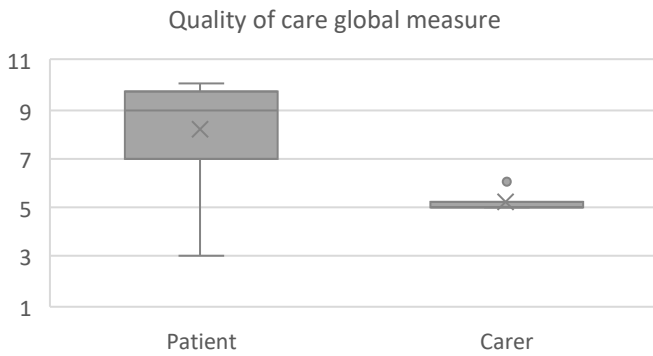


Figure 7.9: Boxplot of Care coordination: Care coordination global measure participant type

Figure 7.10: Boxplot of Care coordination: Quality of care global measure participant type

Care coordination by gender

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

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.7), or when assumptions for normality and variance were not met,

a Wilcoxon rank sum test with continuity correction was used (Table 7.8).

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

Table 7.7: Care coordination by gender summary statistics and T-test

Care coordination scale	Group	Number (n=47)	Percent	Mean	SD	T	dF	p-value
Communication	Female	16	34.04	39.50	9.42	-0.14	45	0.8924
	Male	31	65.96	39.90	9.72			
Navigation	Female	16	34.04	26.31	4.53	0.90	45	0.3707
	Male	31	65.96	24.97	4.98			
Total score	Female	16	34.04	65.81	12.58	0.23	45	0.8178
	Male	31	65.96	64.87	13.50			

Table 7.8: Care coordination by gender summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=47)	Percent	Median	IQR	W	p-value
Care coordination global measure	Female	16	34.04	8.00	3.25	252.00	0.9366
	Male	31	65.96	7.00	3.00		
Quality of care global measure	Female	16	34.04	8.00	2.50	254.50	0.8910
	Male	31	65.96	8.00	2.50		

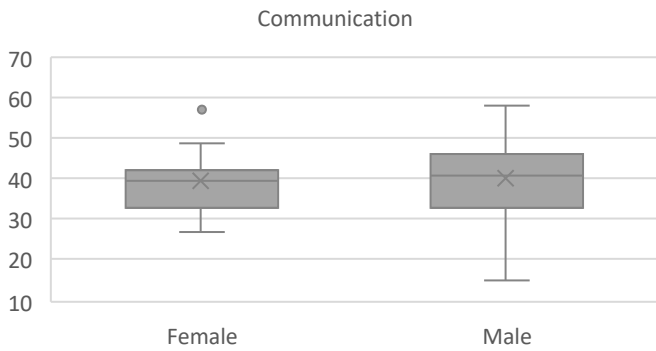


Figure 7.11: Boxplot of Care coordination: Communication gender

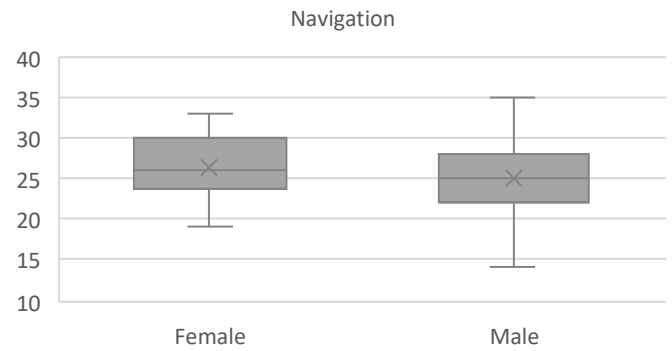


Figure 7.12: Boxplot of Care coordination: Navigation gender

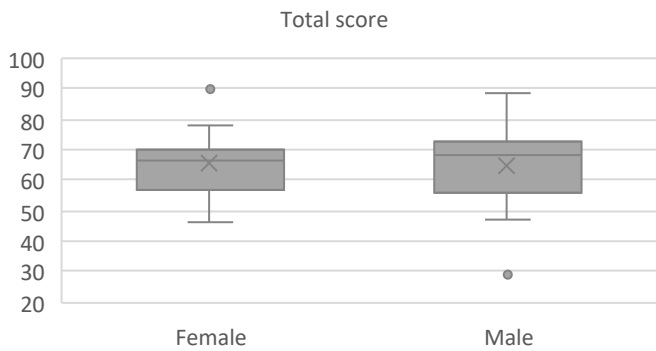


Figure 7.13: Boxplot of Care coordination: Total score gender

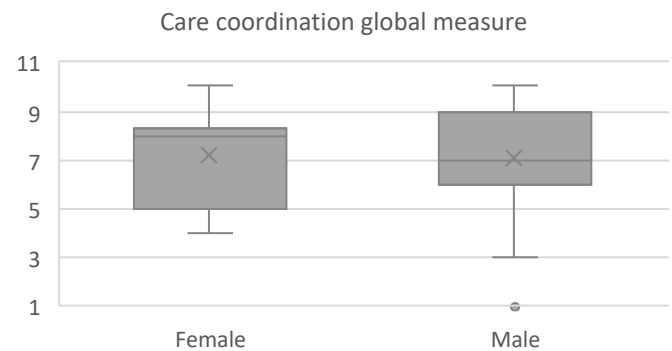


Figure 7.41: Boxplot of Care coordination: Care coordination global measure gender

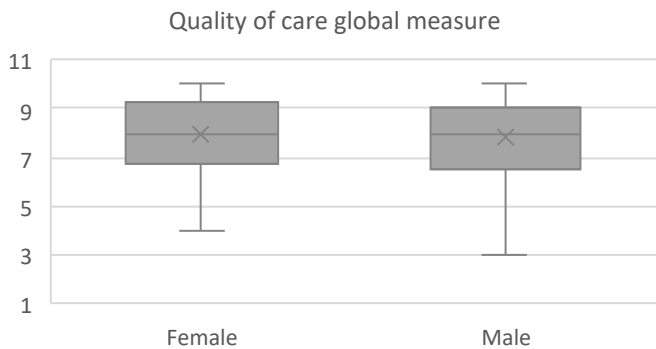


Figure 7.15: Boxplot of Care coordination: Quality of care global measure gender

Care coordination by education

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

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.9), or when

assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.10).

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

Table 7.9: Care coordination by education summary statistics and T-test

Care coordination scale	Group	Number (n=47)	Percent	Mean	SD	T	dF	p-value
Navigation	Trade or high school	29	61.70	24.83	4.88	-1.08	45	0.2854
	University	18	38.30	26.39	4.70			
Total score	Trade or high school	29	61.70	65.45	11.38	0.17	45	0.8664
	University	18	38.30	64.78	15.75			
Care coordination global measure	Trade or high school	29	61.70	6.93	1.85	-0.64	45	0.5258
	University	18	38.30	7.33	2.45			

Table 7.10: Care coordination by education summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=47)	Percent	Median	IQR	W	p-value
Communication	Trade or high school	29	61.70	40	12	291.00	0.5181
	University	18	38.30	39.5	16.5		
Quality of care global measure	Trade or high school	29	61.70	8	2	253.00	0.8674
	University	18	38.30	8.5	3.5		

*Statistically significant at $p < 0.05$

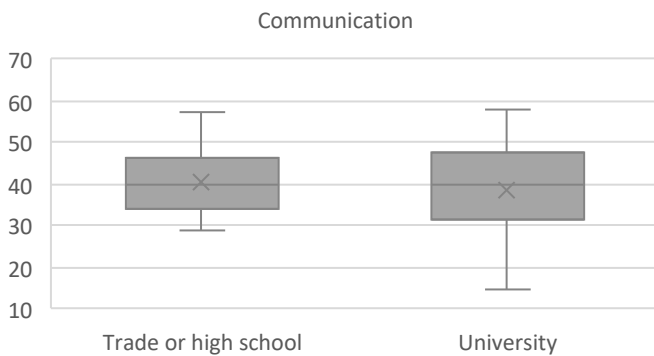


Figure 7.16: Boxplot of Care coordination: Communication education

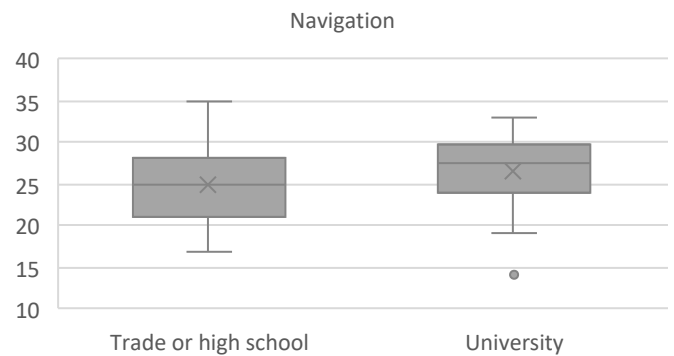


Figure 7.17: Boxplot of Care coordination: Navigation education

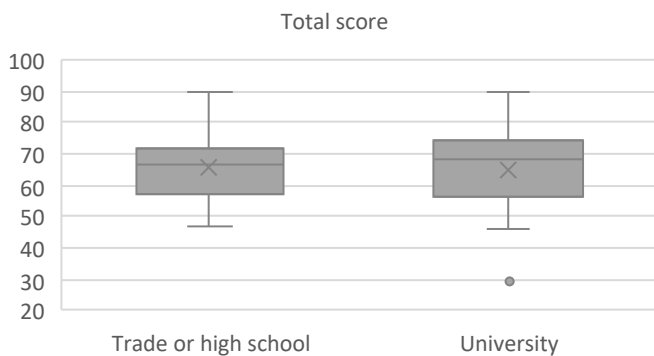


Figure 7.18: Boxplot of Care coordination: Total score education

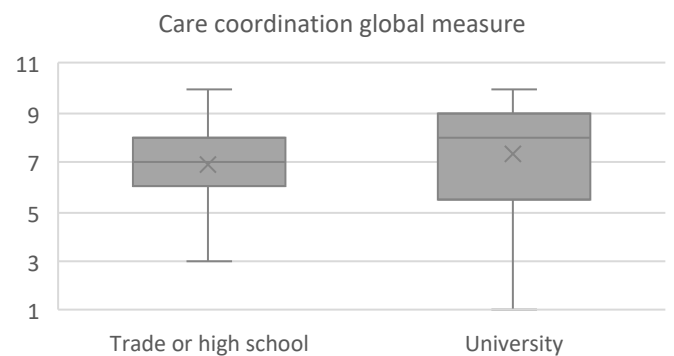


Figure 7.19: Boxplot of Care coordination: Care coordination global measure education

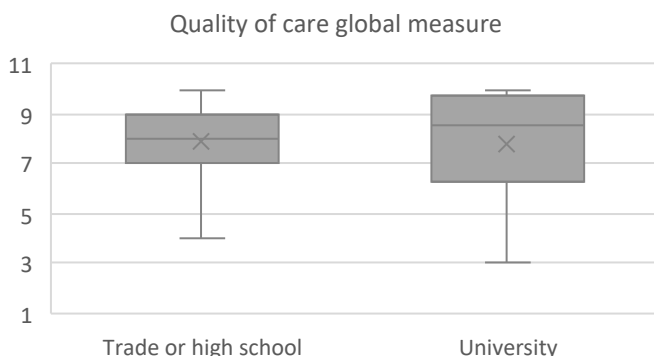


Figure 7.20: Boxplot of Care coordination: Quality of care global measure education

Care coordination by location

The location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. Those living in regional or remote area (n=15, 31.91%) were compared to those living in a metropolitan area (n=32, 68.09%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.11), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.12).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **Care**

coordination Care coordination global measure scale [W = 141.00 , p = 0.0228] was significantly lower for participants in the regional or remote subgroup (Median = 7.00, IQR = 3.00) compared to participants in the metropolitan subgroup (Median = 8.00, IQR = 3.00).

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. On average, participants in the metropolitan subgroup scored higher than participants in the regional or remote subgroup. This indicates that, quality of care was good for participants in the metropolitan subgroup, and average for participants in the regional or remote subgroup.

Table 7.11: Care coordination by location summary statistics and T-test

Care coordination scale	Group	Number (n=47)	Percent	Mean	SD	T	dF	p-value
Communication	Regional or remote	15	31.91	37.27	10.38	-1.24	45	0.2217
	Metropolitan	32	68.09	40.94	9.02			
Navigation	Regional or remote	15	31.91	24.40	5.69	-1.00	45	0.3235
	Metropolitan	32	68.09	25.91	4.37			
Total score	Regional or remote	15	31.91	61.67	15.30	-1.28	45	0.2089
	Metropolitan	32	68.09	66.84	11.78			

Table 7.12: Care coordination by location summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=47)	Percent	Median	IQR	W	p-value
Care coordination global measure	Regional or remote	15	31.91	7.00	3.00	141.00	0.0228*
	Metropolitan	32	68.09	8.00	3.00		
Quality of care global measure	Regional or remote	15	31.91	8.00	3.50	178.00	0.1533
	Metropolitan	32	68.09	9.00	2.25		

*Statistically significant at p<0.05

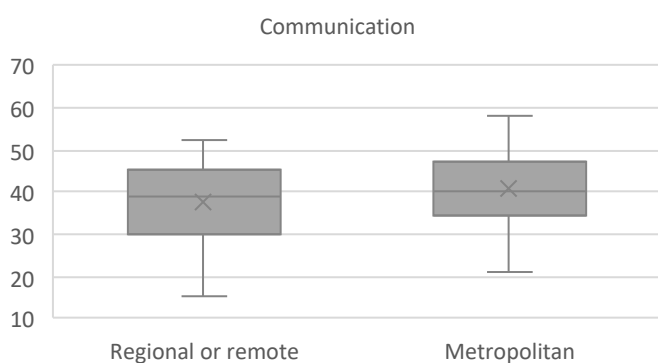


Figure 7.21: Boxplot of Care coordination: Communication location

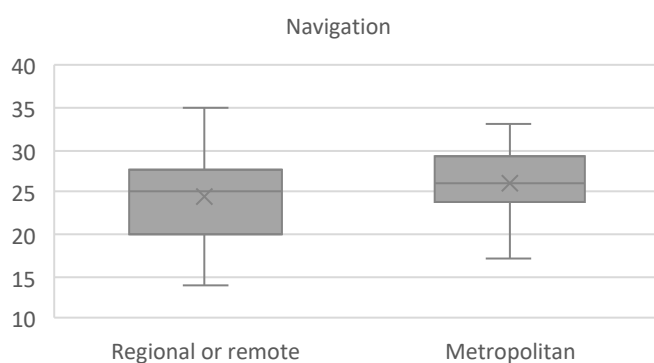


Figure 7.22: Boxplot of Care coordination: Navigation location

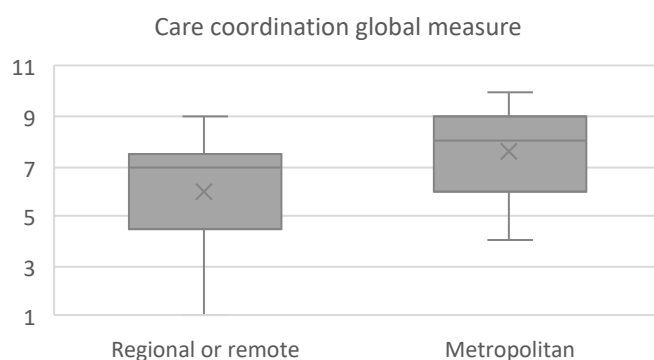
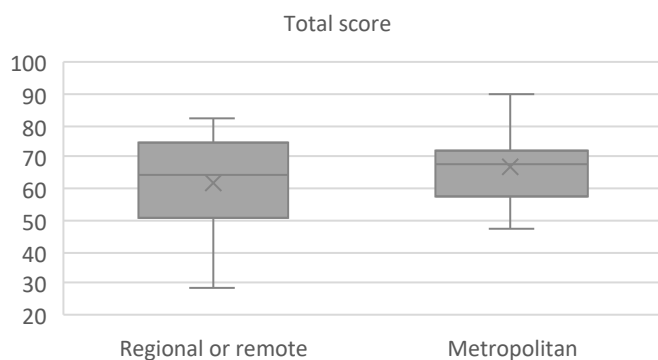


Figure 7.23: Boxplot of Care coordination: Total score location

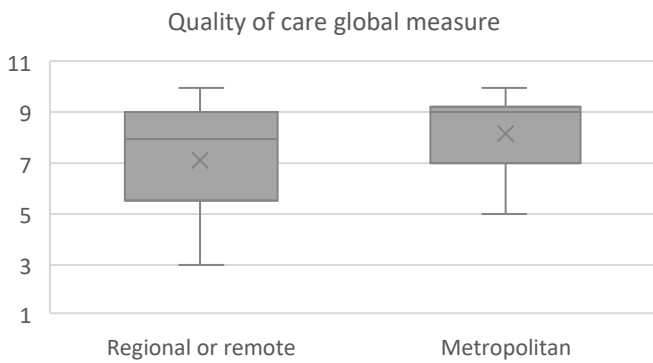


Figure 7.24: Boxplot of Care coordination: Care coordination global measure location

Figure 7.25: Boxplot of Care coordination: Quality of care global measure location

Care coordination by socioeconomic status

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

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.13), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.14).

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

Table 7.13: Care coordination by socioeconomic status summary statistics and T-test

Care coordination scale	Group	Number (n=47)	Percent	Mean	SD	T	dF	p-value
Communication	Mid to low status	20	42.55	38.50	10.39	-0.78	45	0.4388
	Higher status	27	57.45	40.70	8.91			
Navigation	Mid to low status	20	42.55	25.00	5.42	-0.52	45	0.6080
	Higher status	27	57.45	25.74	4.41			
Total score	Mid to low status	20	42.55	63.50	14.42	-0.76	45	0.4510
	Higher status	27	57.45	66.44	12.09			
Care coordination global measure	Mid to low status	20	42.55	6.70	2.39	-1.09	45	0.2802
	Higher status	27	57.45	7.37	1.82			

Table 7.14: Care coordination by socioeconomic status summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=47)	Percent	Median	IQR	W	p-value
Quality of care global measure	Mid to low status	20	42.55	8.50	3.50	249.00	0.6536
	Higher status	27	57.45	8.00	2.00		

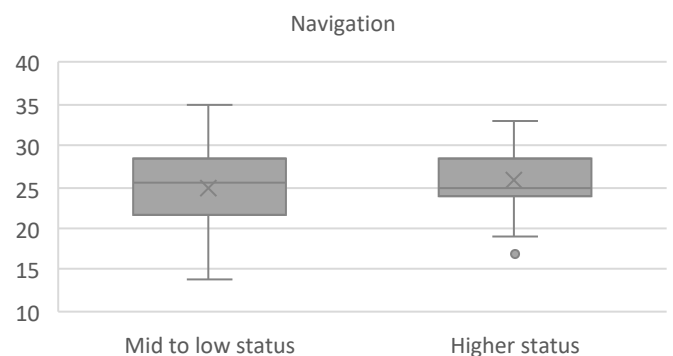
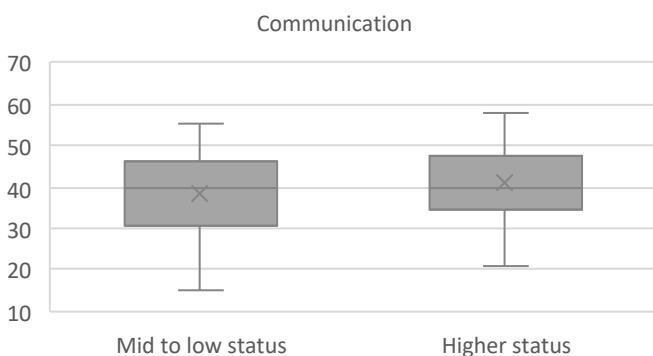


Figure 7.26: Boxplot of Care coordination: Communication socioeconomic status

Figure 7.27: Boxplot of Care coordination: Navigation socioeconomic status

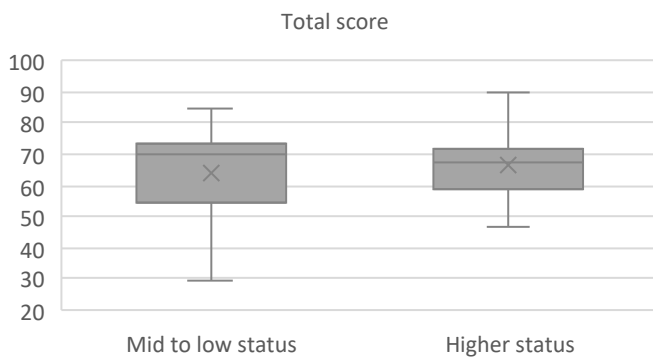


Figure 7.28: Boxplot of Care coordination: Total score socioeconomic status

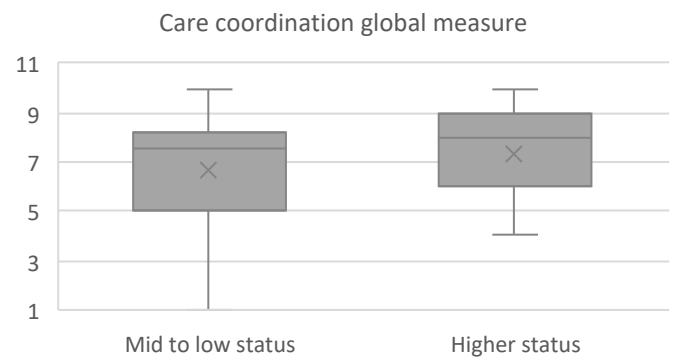


Figure 7.29: Boxplot of Care coordination: Care coordination global measure socioeconomic status

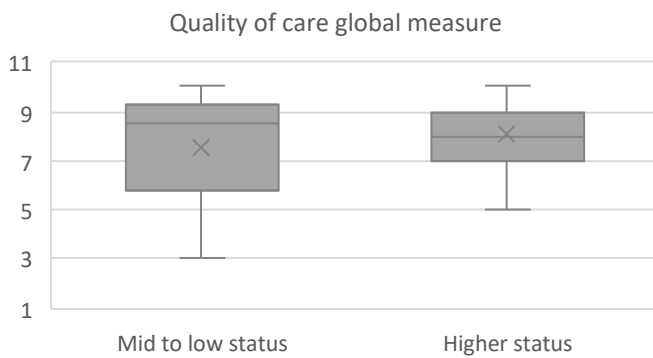


Figure 7.30: Boxplot of Care coordination: Quality of care global measure socioeconomic status

Experience of care and support

In the structured interview, participants were asked what care and support they had received since their diagnosis. This question aims to investigate what services patients consider to be support and care services. The most common theme was that participant did not receive any support (n=18, 36.73%). This was followed by receiving support through charities (n=15, 30.61%), hospital and clinical setting (including nurse support) (n=14, 28.57%), online, phone or social media peer support (n=12, 24.49%), and face-to-face peer support (n=8, 16.33%). There were 5 participants (10.20%) that described not needing any help or support.

Participant describes not receiving any support

*No one. No one's even spoken about it.
Participant 007_2022AUBLC*

*No. Never been offered. Yeah. Yeah. No discussion from the surgeons.
Participant 008_2022AUBLC*

No, because private patients don't get offered anything. If you're, like if I had gone to PUBLIC

*HOSPITAL, they might have offered something or seen to work or something, but not in the private. You really got to see things yourself and yeah, I mean and I don't really need it because I'm still working.
Participant 018_2022AUBLC*

Participant describes receiving support through charities (General support and information)

*We were we were put in touch with Palliative Care Australia. So we've had them pretty much, you know, from. Once he started palliative care in hospital, right through to coming home and even continuing now with my own grief counselling, bereavement counselling that my daughter, my youngest, just sort of had a dabble with some art therapy and music therapy through Palliative Care Australia. We were put in touch with health, community and health services. He also was offered a social worker in hospital, which he declined.
Carer 002_2022AUBLC*

PARTICIPANT: Oh yes, support from BEAT. Also I had trouble. Well, this is a couple years ago. I had trouble with with a garden. And I had one Cancer STATE or Cancer Australia, not sure who, offered, offered a, um uh, well, I don't know whether it was 3 or \$600, but they offered a one off come and clean up type of thing. I got to a gardener to come in and fix my garden for me.

INTERVIEWER: Excellent. Okay.

PARTICIPANT: All right. Look at that. That was about two years ago now.

INTERVIEWER: And now other important things like transport, maybe help with that.

PARTICIPANT: But that's that's part of the DVA. I used theiir transport. They transport the go to clinic all the time.

Participant 037_2022AUBLC

Well, the main support of that is basically from via Facebook and ZOOM some some of the bladder cancer groups. BEAT's been a big help they had an open forum, I was on a Zoom meeting I was on that last night they had a chap on, and I'm glad I didn't do it prior to the operation to be honest, he showed a few gory pictures. One of the urologist or gentleman's he's been in the field for quite a few years 40 years or something urology. There was a few, but answered questions and describing operations for various people. So I thought it was fairly good, I went down to a bladder cancer walk on Sunday and a walk in CITY, in Memory of The young lass that died with bladder cancer died from bladder cancer. And people there, it's a registered charity, BEAT they were very supportive. And, you know, all of the family members plus members of the medical association are medical, they were there. So, you know, just general chit chat and no one got too personal about anything, but it was a yes. Good supportive environment.

Participant 011_2022AUBLC

Participant describes receiving support through the hospital or clinical setting

No. Like I said, just like the government. Free counselling services at the hospital. Um, but I have more done my own research and found BEAT bladder cancer. I'm like, I've just come across them on Facebook page, which is obviously where all this interview is actually come from. That's how I heard about it. Um. But if I'm being honest, I've signed up for

the support groups, but I've never once attended because I'm too anxious about it.

Participant 009_2022AUBLC

It was during the BCG therapy stage, the nurse did reach out with some very good information on what BCG therapy was and would be involved in it. And, they were always, every nurse and registrar was always excellent with explaining the process and making sure you knew what was going to happen that day when you went into a hospital and even had one of the sessions was on my birthday and the registrar offered to sing Happy Birthday right at the right time, but I said, no, thank you. Afterwards, there was none really by professionals. There was no care that really needed when I was at the hospital.

Participant 019_2022AUBLC

Yeah, I've found that they've been awesome. When I had a problem there maybe six months ago, I was having problems withwhere around the stoma. it was pretty red. And yeah, when seen the nurse and she told me to change the bag like daily instead of, you know, it was doing two or three days and things like that. So I've found that if I have any problems, I can ring her up, you know. And she's been great to ring up. I actually should, I save having to go into the hospital. I was taking pictures of me stoma and I'll send it to her and she was sending messages back and try this or try that. So didn't actually have to come to the hospital. So I was having like telephone consults with her. And I found it really good support.

Participant 044_2022AUBLC

Only the support group. Yeah, his GP has been very caring of him. So I think the GP having put everything in place. You know, my husband used to think, oh, I can see any doctor, you know. But now he's, he's really, realised that his GP is very important and also we've had to shop health care professionals. And when I said we've had to shop for care professionals, we've had to shop around for the ones that have empathy, the ones who have ethics, the ones who have time, and the ones who have your interests at heart. Those four elements is what we've had to shop for. Oh, and and then the other most important thing is our private health. You know, having a caring and empathetic private health insurer has been amazing.

Carer 004_2022AUBLC

Participant describes receiving support through peer support: Online, online/phone groups and social media

*Well, the main support of that is basically from via Facebook and ZOOM some some of the bladder cancer groups. BEAT's been a big help they had an open forum, I was on a Zoom meeting I was on that last night they had a chap on, and I'm glad I didn't do it prior to the operation to be honest, he showed a few gory pictures. One of the urologist or gentleman's he's been in the field for quite a few years 40 years or something urology. There was a few, but answered questions and describing operations for various people. So I thought it was fairly good, I went down to a bladder cancer walk on Sunday and a walk in CITY, in Memory of The young lass that died with bladder cancer died from bladder cancer. And people there, it's a registered charity, BEAT they were very supportive. And, you know, all of the family members plus members of the medical association are medical, they were there. So, you know, just general chit chat and no one got too personal about anything, but it was a yes. Good supportive environment.
Participant 011_2022AUBLC*

*So I don't really know. I did I did go to a couple of those things, the bladder cancer forums. I have it at night, they do that once every month or two months, but that's the only thing I'll just. I've been on it twice, I think. Might have only been once, about a year ago. Apart from that, there's been nothing.
Participant 021_2022AUBLC*

*And think the only support I got is from this bladder cancer group. Oh, right. On Facebook. So that was very helpful. I if I had any question or, you know, just learning about other people's experiences, that was pretty good.
Participant 028_2022AUBLC*

Participant describes receiving support through peer support: Face-to-face (or unspecified support group)

Well, this the support group we are a member of that is based in Melbourne. Bladder Cancer Australia. It was run by two young women that lost their father to bladder cancer a few years ago. So and then we've been, you know. They have meetings and Zoom meetings and we've just been down and had a conference in Melbourne just February. So it's, it's good to see people in person and be able to talk to them about their experiences. Participant 027_2022AUBLC

PARTICIPANT: Yes BEAT, B E A T.

INTERVIEWER: Yes. Are there other are there other groups that you've you've accessed any sort of community support from? If so, what kind of support and where from?

PARTICIPANT: No, no. There'd been nothing else that I could think of. I mean, I belong to a social group. It's called Progress, but it's got nothing to do with health. It's it's about fun, friendship and frivolity, basically. And it's we we organise a lot of retirees activities, days out, lunches, that sort of thing. And that has been a means of support for me, but not the community support health wise. Participant 036_2022AUBLC

**Okay. So the psychiatric help or the psychological help that I've just recently gotten onto it was put into place two years ago by HOSPITAL and they, they put me down on their programme to have access to somebody to help me there. I've had access through to community groups, bladder cancer community groups. Um, that, yeah, we actively take part in and meet with and raise funds for.
Participant 035_2022AUBLC**

Participant describes not needing and help or support

No, not really. And I haven't, I don't think I've needed it as such. You know I'm I'm still ,you know, not is a people sort of a surprise when I told them because I was oh you don't look sick and I don't I don't feel sick. It didn't get to that point of it being debilitating or anything like that. So I haven't required any. Community care or anything like that. Participant 014_2022AUBLC

No, I'm living normal lives. I'm lucky. Yes. Participant 015_2022AUBLC

**Well, no, not really. I don't think because. As I say, I am fiercely independent. So, you know, like I had a major op and they told me I'd have to have three months of work and I'm like, Well, I don't think I will. So, you know, I said, I'll have a month and. And then I will work because I don't like sitting around doing nothing. And so I need to be busy. So. So yes, I didn't kind of really. Really need it. And when I'm you know, when I had the last op my son wanted to come and I'm like, you know, it might be a time when I feel good actually like to be just on my own when I feel shit. So I actually don't want people around. I'd rather just. Take my time to do what I'm going to do and manage.
Participant 026_2022AUBLC**

Participant describes receiving support through a psychologist or counselling services

So the psychiatric help or the psychological help that I've just recently gotten onto it was put into place two years ago by HOSPITAL and they, they put me down on their programme to have access to somebody to

help me there. I've had access through to community groups, bladder cancer community groups. Um, that, yeah, we actively take part in and meet with and raise funds for. Um. Well, what else? No, that that's probably that is. Yeah, I think we've covered up on most of that.

Participant 035_2022AUBL

Table 7.15: Experience of care and support

Care and support received	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 not receiving any support	18	36.73	12	60.00	2	20.00	3	21.43	17	38.64	1	20.00	7	41.18	11	34.38
Participant describes receiving support through charities (General support and information)	15	30.61	4	20.00	2	20.00	7	50.00	13	29.55	2	40.00	5	29.41	10	31.25
Participant describes receiving support through the hospital or clinical setting	14	28.57	3	15.00	2	20.00	6	42.86	11	25.00	3	60.00	2	11.76	12	37.50
Participant describes receiving support through peer support: Online, online/phone groups and social media	12	24.49	3	15.00	4	40.00	4	28.57	11	25.00	1	20.00	3	17.65	9	28.13
Participant describes receiving support through peer support: Face-to-face (or unspecified support group)	8	16.33	1	5.00	2	20.00	3	21.43	6	13.64	2	40.00	2	11.76	6	18.75
Participant describes not needing and help or support	5	10.20	3	15.00	2	20.00	0	0.00	5	11.36	0	0.00	3	17.65	2	6.25
Participant describes receiving support through a psychologist or counselling services	3	6.12	1	5.00	0	0.00	1	7.14	2	4.55	1	20.00	1	5.88	2	6.25

Care and support received	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 not receiving any support	18	36.73	8	27.59	10	52.63	5	33.33	13	39.39	8	40.00	10	35.71
Participant describes receiving support through charities (General support and information)	15	30.61	12	41.38	2	10.53	4	26.67	10	30.30	5	25.00	9	32.14
Participant describes receiving support through the hospital or clinical setting	14	28.57	10	34.48	3	15.79	4	26.67	9	27.27	6	30.00	7	25.00
Participant describes receiving support through peer support: Online, online/phone groups and social media	12	24.49	9	31.03	2	10.53	3	20.00	8	24.24	4	20.00	7	25.00
Participant describes receiving support through peer support: Face-to-face (or unspecified support group)	8	16.33	5	17.24	2	10.53	3	20.00	4	12.12	3	15.00	4	14.29
Participant describes not needing and help or support	5	10.20	1	3.45	4	21.05	2	13.33	3	9.09	2	10.00	3	10.71
Participant describes receiving support through a psychologist or counselling services	3	6.12	3	10.34	0	0.00	1	6.67	2	6.06	1	5.00	2	7.14

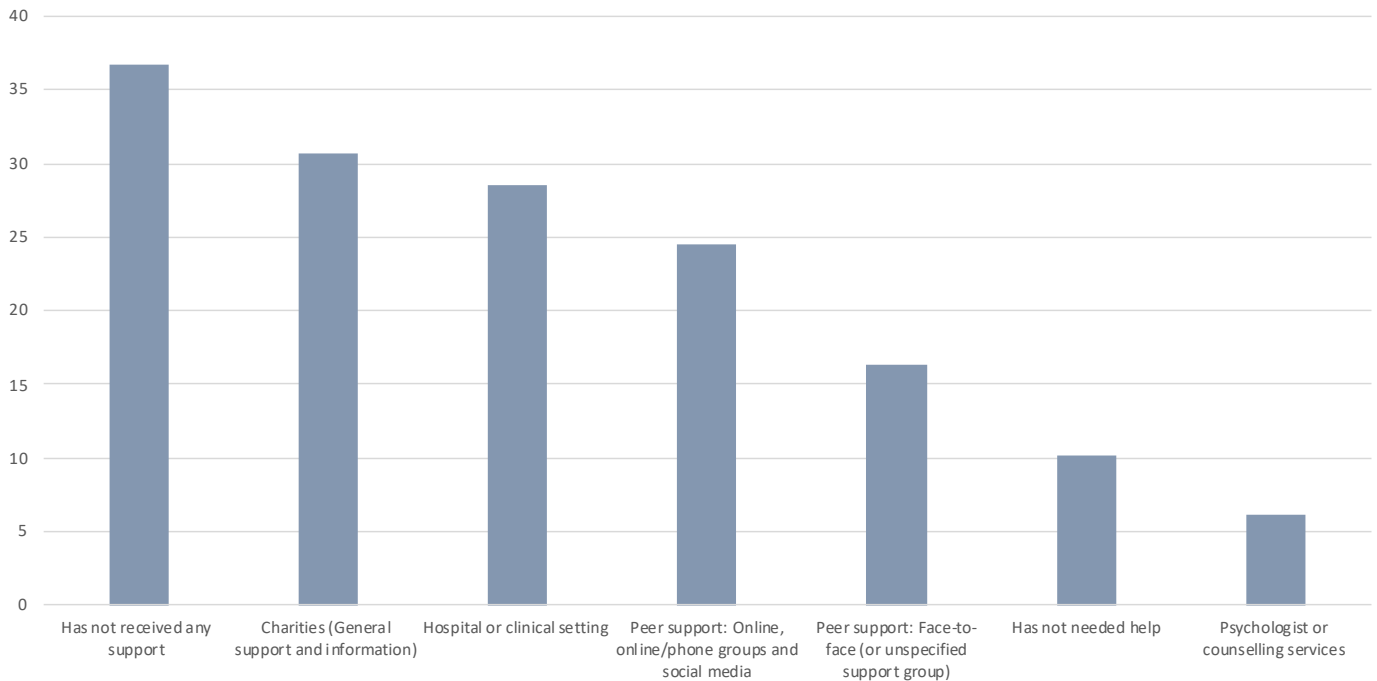


Figure 7.31: Experience of care and support

Table 7.16: Experience of care and support – subgroup variations

Care and support received	Reported less frequently	Reported more frequently
Participant describes not receiving any support	Invasive (Stage III) Advanced (Stage IV) Carer to someone with bladder cancer	Early (Stages 0 and I) University
Participant describes receiving support through charities (General support and information)	Early (Stages 0 and I) Invasive (Stage III) University	Advanced (Stage IV) Trade or high school
Participant describes receiving support through the hospital or clinical setting	Early (Stages 0 and I) Female University	Advanced (Stage IV) Carer to someone with bladder cancer
Participant describes receiving support through peer support: Online, online/phone groups and social media	University	Invasive (Stage III)
Participant describes receiving support through peer support: Face-to-face (or unspecified support group)	Early (Stages 0 and I)	Carer to someone with bladder cancer
Participant describes not needing and help or support	Advanced (Stage IV) Carer to someone with bladder cancer	University