

## **Section 7**

### **Care and support**

## Section 7: Experience of care and support

### 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 good 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 good 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 very 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 very 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 help (n=18, 34.62%). This was followed by receiving support through the hospital and clinical setting (n=14, 26.92%), through charities (n=11, 21.15%) and face-to-face peer support (n=8, 15.38%). There were six participants that described not needing any help (11.54%).

## 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.

Overall, the participants in this PEEK study had an average score in the second highest quintile for the **Care coordination: Communication** (mean = 45.75, SD = 9.58), **Care coordination: Navigation** (mean = 26.86, SD = 4.55), and **Care coordination: Total score** (mean = 72.61, SD = 12.86), indicating good communication and navigation of the healthcare system.

Overall, the participants in this PEEK study had an average score in the highest quintile for the **Care coordination: Care coordination global measure** (median = 9.00, IQR = 2.50), and **Care coordination: Quality of care global measure** (median = 9.00, IQR = 2.00) indicating very good care coordination and quality of care.

Comparisons of Care co-ordination have been made based **stage** (Tables 7.2 to 7.3, Figures 7.1 to 7.5), **age** (Tables 7.4 to 7.5, Figures 7.6 to 7.10), **education** (Tables 7.6 to 7.7, Figures 7.11 to 7.15), **year of diagnosis** (Tables 7.8 to 7.9, Figures 7.16 to 7.20), **location** (Tables 7.10 to 7.11, Figures 7.21 to 7.25), and **socioeconomic status** (Tables 7.12 to 7.13, Figures 7.26 to 7.30).

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 good 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 good communication, navigation and overall experience of care coordination.

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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 very good.

**Table 7.1: Care coordination summary statistics**

Care coordination scale (n=51)	Mean	SD	Median	IQR	Possible range	Quintile
Communication*	45.75	9.58	46.00	10.00	13 to 65	4
Navigation*	26.86	4.55	27.00	6.50	7 to 35	4
Total score*	72.61	12.86	75.00	17.50	20 to 100	4
Care coordination global measure	8.12	1.90	9.00	2.50	1 to 10	5
Quality of care global measure	8.80	1.33	9.00	2.00	1 to 10	5

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

## Care coordination by stage

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

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).

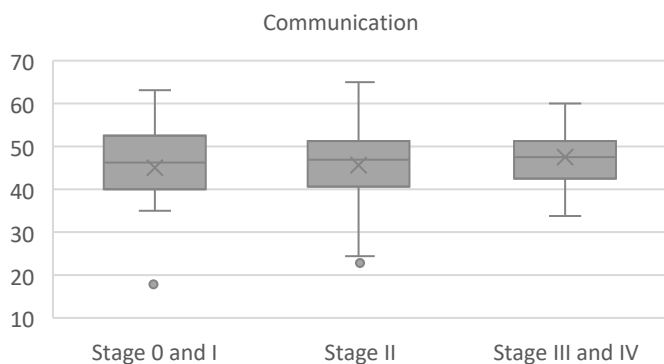
No significant differences were observed between participants by **stage** for any of the Care coordination scales.

**Table 7.2: Care coordination by stage summary statistics and one-way ANOVA**

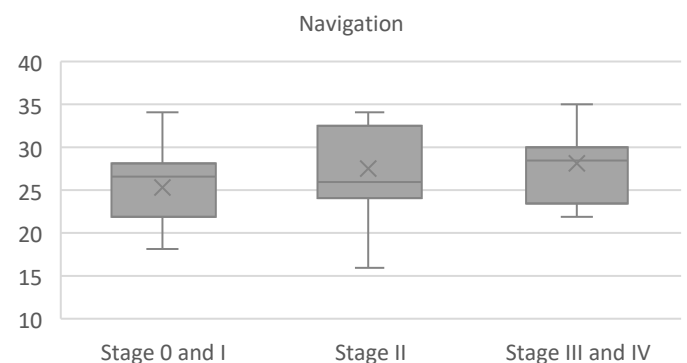
Care coordination scale	Group	Number (n=51)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Communication	Stage 0 and I	18	35.29	45.17	10.19	Between groups	36.00	2	17.99	0.19	0.8280
	Stage II	21	41.18	45.38	10.49	Within groups	4556.00	48	94.91		
	Stage III and IV	12	23.53	47.25	7.33	Total	4592.00	50			
Navigation	Stage 0 and I	18	35.29	25.28	4.21	Between groups	71.30	2	35.64	1.777	0.1800
	Stage II	21	41.18	27.57	4.69	Within groups	962.80	48	20.06		
	Stage III and IV	12	23.53	28.00	4.49	Total	1034.10	50			
Total score	Stage 0 and I	18	35.29	70.44	13.79	Between groups	171.00	2	85.26	0.505	0.6070
	Stage II	21	41.18	72.95	14.23	Within groups	8102.00	48	168.78		
	Stage III and IV	12	23.53	75.25	8.64	Total	8273.00	50			

**Table 7.3: Care coordination by stage summary statistics and Kruskal-Wallis test**

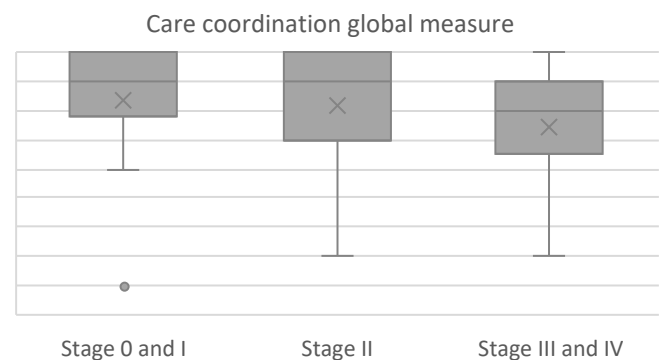
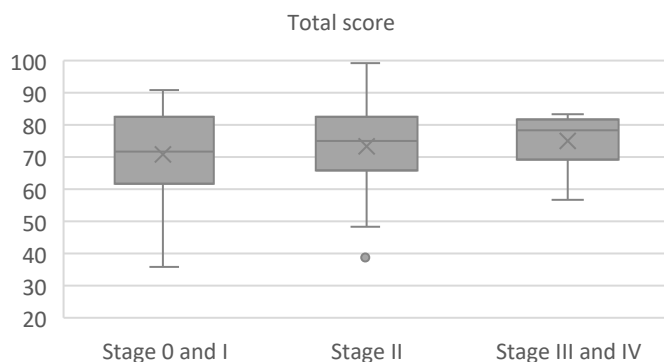
Care coordination scale	Group	Number (n=51)	Percent	Median	IQR	C <sup>2</sup>	dF	p-value
Care coordination global measure	Stage 0 and I	18	35.29	9.00	1.75	1.87	2	0.3924
	Stage II	21	41.18	9.00	3.00			
	Stage III and IV	12	23.53	8.00	2.00			
Quality of care global measure	Stage 0 and I	18	35.29	9.00	2.75	0.01	2	0.9971
	Stage II	21	41.18	9.00	2.00			
	Stage III and IV	12	23.53	9.00	1.25			



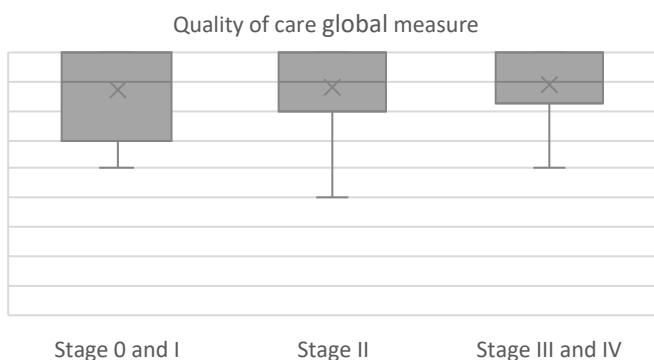
**Figure 7.1: Boxplot of Care coordination: knowledge by stage**



**Figure 7.2: Boxplot of Care coordination: coping by stage**



**Figure 7.3: Boxplot of Care coordination: recognition and management of symptoms by stage**



**Figure 7.5: Boxplot of Care coordination Total score by stage**

**Figure 7.4: Boxplot of Care coordination: adherence to treatment by stage**

### Care coordination by age

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

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.4), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.5).

A two sample t-test indicated that the mean score for the Care coordination Communication scale [t(49) = 2.02 , p = 0.0491\*] was significantly higher for participants in the *Aged 25 to 54* subgroup (Mean =

48.03, SD = 8.32) compared to participants in the *Aged 55 to 74* subgroup (Mean = 42.73, SD = 10.47).

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 *Aged 25 to 54* subgroup scored higher than participants in the *Aged 55 to 74* subgroup. This indicates that healthcare communication was good for participants in the *Aged 25 to 54* subgroup, and average for participants in the *Aged 55 to 74* subgroup.

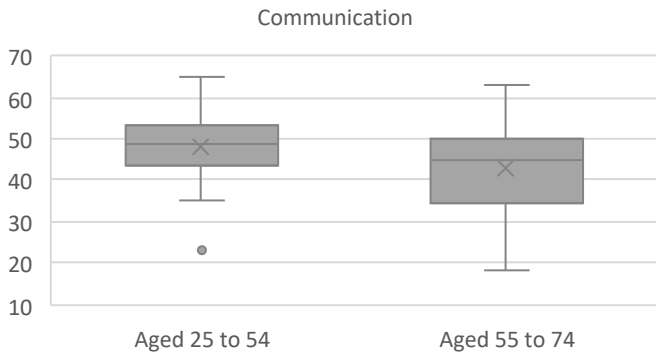
**Table 7.4: Care coordination by age summary statistics and T-test**

Care coordination scale	Group	Number (n=51)	Percent	Mean	SD	T	dF	p-value
Communication	Aged 25 to 54	29	66.00	48.03	8.32	2.02	49	0.0491*
	Aged 55 to 74	22	34.00	42.73	10.47			
Navigation	Aged 25 to 54	29	66.00	27.28	4.90	0.74	49	0.4619
	Aged 55 to 74	22	34.00	26.32	4.09			
Total score	Aged 25 to 54	29	66.00	75.31	11.73	1.76	49	0.0849
	Aged 55 to 74	22	34.00	69.05	13.68			

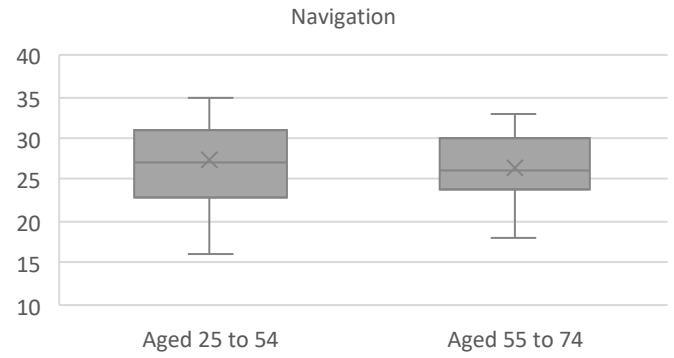
\*Statistically significant at p<0.05

**Table 7.5: Care coordination by age summary statistics and Wilcoxon test**

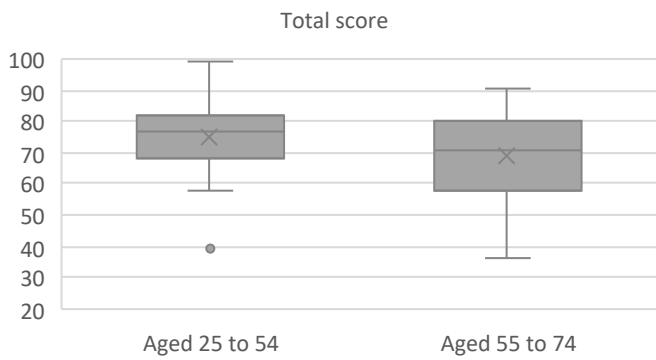
Care coordination scale	Group	Number (n=51)	Percent	Median	IQR	W	p-value
Care coordination global measure	Aged 25 to 54	29	66.00	9.00	2.00	384.50	0.2059
	Aged 55 to 74	22	34.00	8.00	2.75		
Quality of care global measure	Aged 25 to 54	29	66.00	9.00	2.00	345.00	0.6113
	Aged 55 to 74	22	34.00	9.00	2.00		



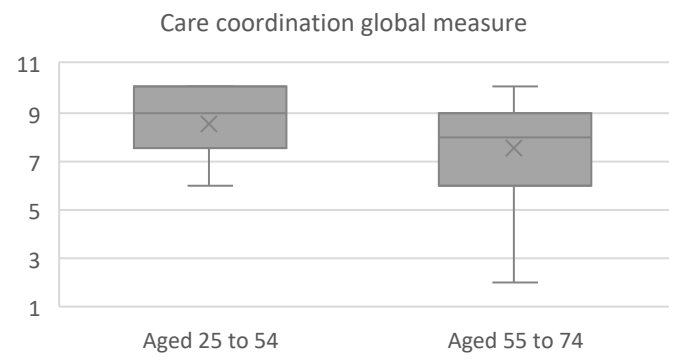
**Figure 7.6: Boxplot of Care coordination: knowledge by age**



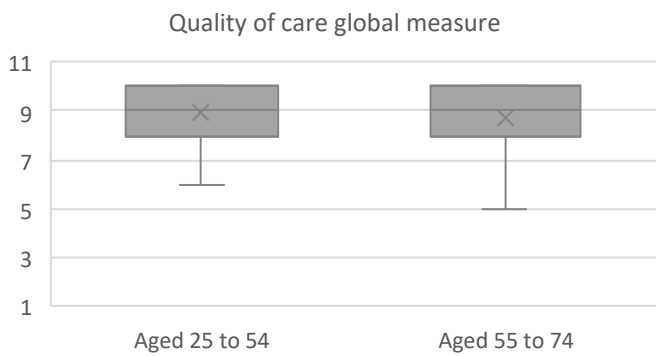
**Figure 7.7: Boxplot of Care coordination: coping by age**



**Figure 7.8: Boxplot of Care coordination: recognition and management of symptoms by age**



**Figure 7.9: Boxplot of Care coordination: adherence to treatment by age**



**Figure 7.10: Boxplot of Care coordination Total score by age**

## Care coordination by education

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

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.6), or when

assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.7).

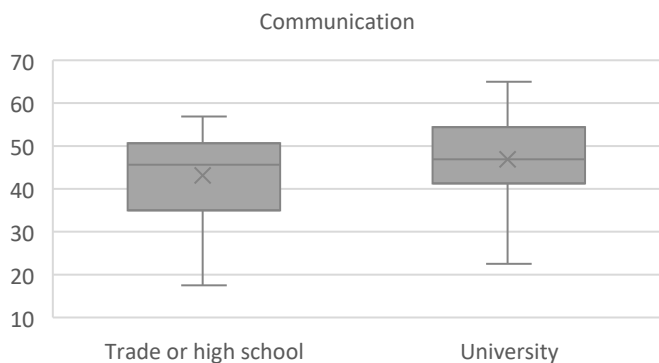
No significant differences were observed between participants by **education** for any of the Care coordination scales.

**Table 7.6: Care coordination by education summary statistics and T-test**

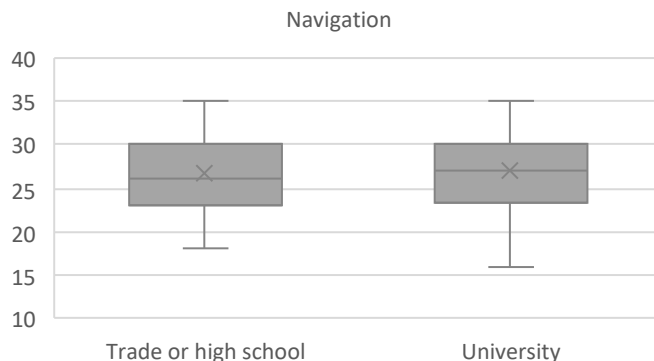
Care coordination scale	Group	Number (n=51)	Percent	Mean	SD	T	dF	p-value
Navigation	Trade or high school	19	37.25	26.58	4.68	-0.34	49	0.7350
	University	32	62.75	27.03	4.53			
Total score	Trade or high school	19	37.25	69.89	13.83	-1.16	49	0.2497
	University	32	62.75	74.22	12.19			

**Table 7.7: Care coordination by education summary statistics and Wilcoxon test**

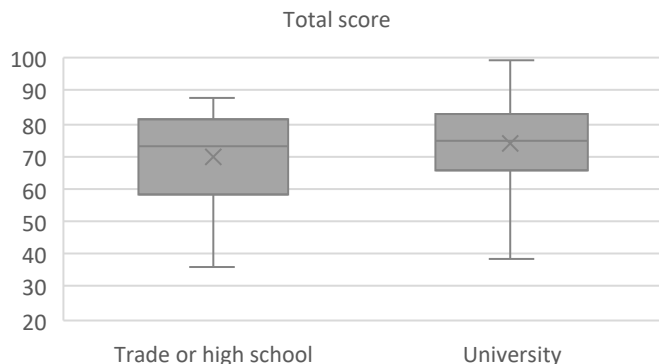
Care coordination scale	Group	Number (n=51)	Percent	Median	IQR	W	p-value
Communication	Trade or high school	19	37.25	46.00	12.50	260.00	0.3961
	University	32	62.75	47.00	12.50		
Care coordination global measure	Trade or high school	19	37.25	8.00	2.50	284.00	0.6975
	University	32	62.75	9.00	1.50		
Quality of care global measure	Trade or high school	19	37.25	9.00	2.00	287.50	0.7440
	University	32	62.75	9.00	2.00		



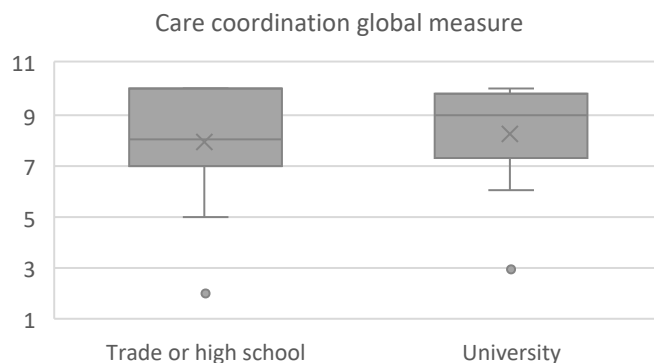
**Figure 7.11: Boxplot of Care coordination: knowledge by education**



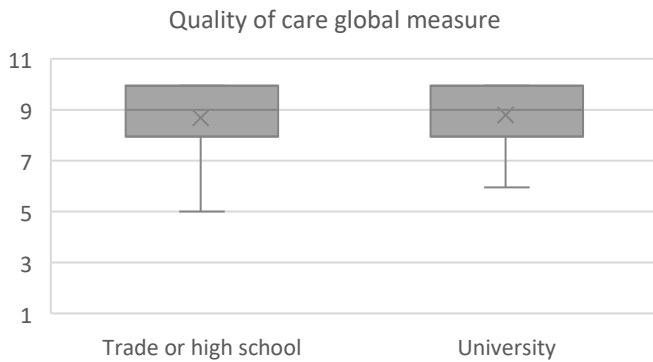
**Figure 7.12: Boxplot of Care coordination: coping by education**



**Figure 7.13: Boxplot of Care coordination: recognition and management of symptoms by education**



**Figure 7.14: Boxplot of Care coordination: adherence to treatment by education**



**Figure 7.15: Boxplot of Care coordination Total score by education**

**Care coordination by year of breast cancer diagnosis**

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

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

normally distributed and variances of populations were equal (Table 7.8). When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 7.9).

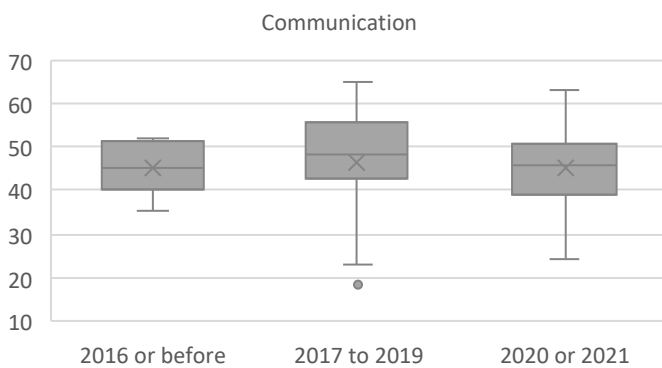
No significant differences were observed between participants by **year of breast cancer diagnosis** for any of the Care coordination scales.

**Table 7.8: Care coordination by year of breast cancer diagnosis summary statistics and one-way ANOVA**

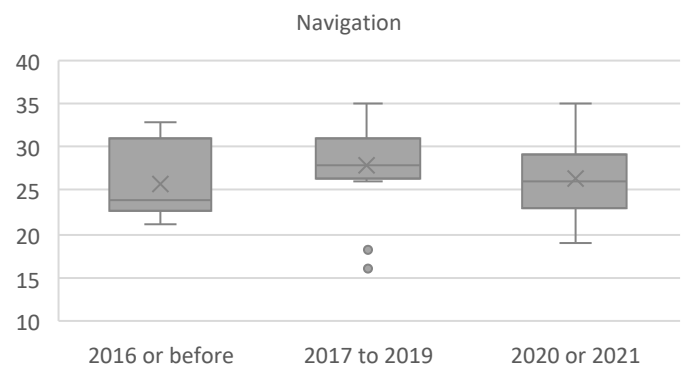
Care coordination scale	Group	Number (n=51)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Communication	Diagnosed in 2016 or before	9	17.65	45.22	6.02	Between groups	16.00	2	7.92	0.083	0.9200
	Diagnosed in 2017 to 2019	16	31.37	46.56	12.10	Within groups	4576.00	48	95.33		
	Diagnosed in 2020 or 2021	26	50.98	45.42	9.14	Total	4592.00	50			
Navigation	Diagnosed in 2016 or before	9	17.65	25.89	4.54	Between groups	32.70	2	16.32	0.783	0.4630
	Diagnosed in 2017 to 2019	16	31.37	28.00	5.18	Within groups	1001.40	48	20.86		
	Diagnosed in 2020 or 2021	26	50.98	26.50	4.17	Total	1034.10	50			

**Table 7.9: Care coordination by year of breast cancer diagnosis summary statistics and Kruskal-Wallis test**

Care coordination scale	Group	Number (n=51)	Percent	Median	IQR	C <sup>2</sup>	dF	p-value
Total score	Diagnosed in 2016 or before	9	17.65	70.00	15.00	1.87	2	0.3918
	Diagnosed in 2017 to 2019	16	31.37	77.00	12.75			
	Diagnosed in 2020 or 2021	26	50.98	73.50	18.50			
Care coordination global measure	Diagnosed in 2016 or before	9	17.65	7.00	3.00	0.81	2	0.6675
	Diagnosed in 2017 to 2019	16	31.37	8.50	1.25			
	Diagnosed in 2020 or 2021	26	50.98	9.00	1.00			
Quality of care global measure	Diagnosed in 2016 or before	9	17.65	8.00	2.00	4.81	2	0.0902
	Diagnosed in 2017 to 2019	16	31.37	10.00	1.00			
	Diagnosed in 2020 or 2021	26	50.98	9.00	1.75			

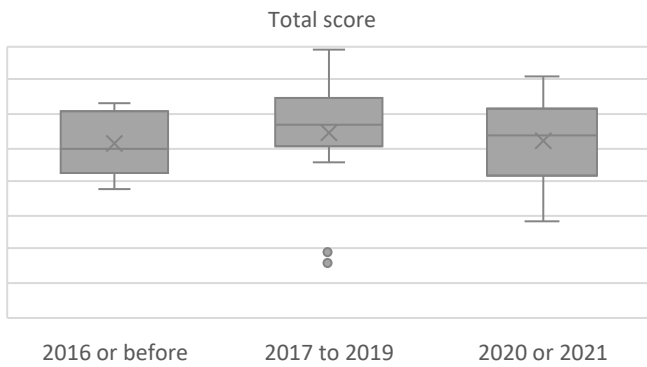


**Figure 7.16: Boxplot of Care coordination: knowledge by year of breast cancer diagnosis**

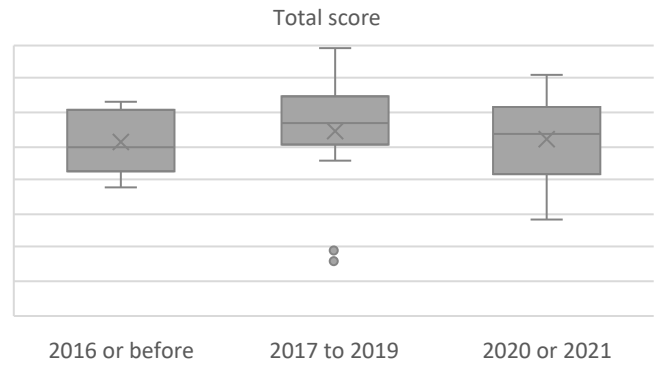


**Figure 7.17: Boxplot of Care coordination: coping by year of breast cancer diagnosis**

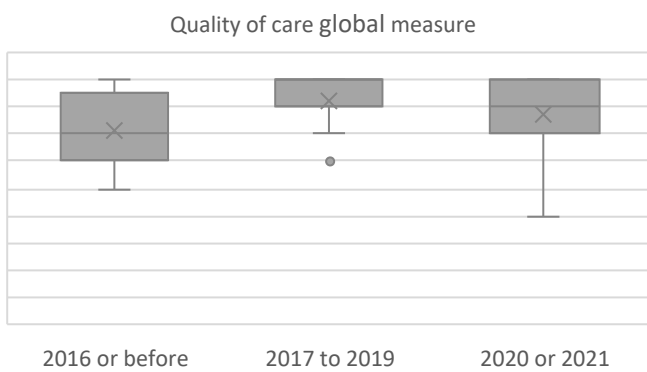




**Figure 7.18: Boxplot of Care coordination: recognition and management of symptoms by year of breast cancer diagnosis**



**Figure 7.19: Boxplot of Care coordination: adherence to treatment by year of breast cancer diagnosis**



**Figure 7.20: Boxplot of Care coordination Total score by year of breast cancer diagnosis**

### 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/rural areas, *Regional or remote* (n=10, 19.61%) were compared to those living in a major city, *Metropolitan* (n=41, 80.39%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.10), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.11).

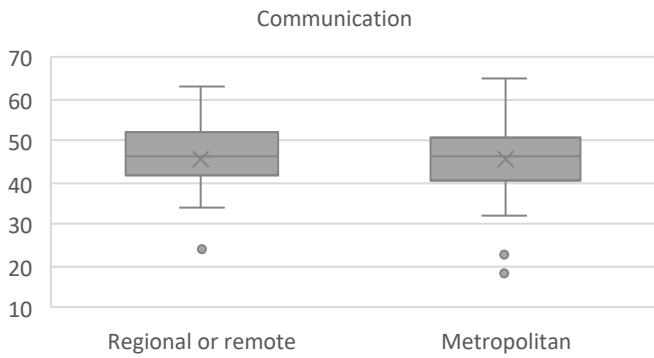
No significant differences were observed between participants by **location** for any of the Care coordination scales.

**Table 7.10: Care coordination by location summary statistics and T-test**

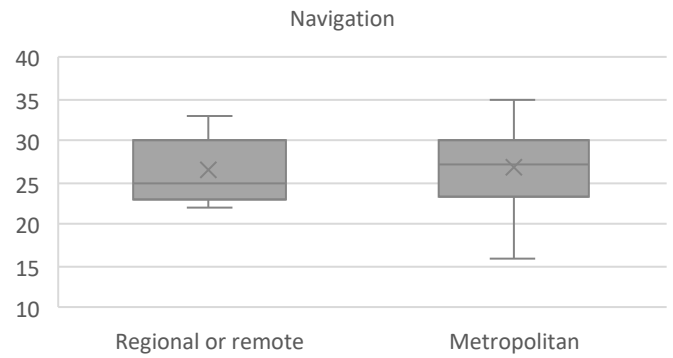
Care coordination scale	Group	Number (n=51)	Percent	Mean	SD	T	dF	p-value
Communication	Regional or remote	10	19.61	45.82	10.20	0.03	49	0.9776
	Metropolitan	41	80.39	45.73	9.54			
Navigation	Regional or remote	10	19.61	26.55	3.86	-0.26	49	0.7968
	Metropolitan	41	80.39	26.95	4.76			
Total score	Regional or remote	10	19.61	72.36	11.83	-0.07	49	0.9442
	Metropolitan	41	80.39	72.68	13.27			

**Table 7.11: Care coordination by location summary statistics and Wilcoxon test**

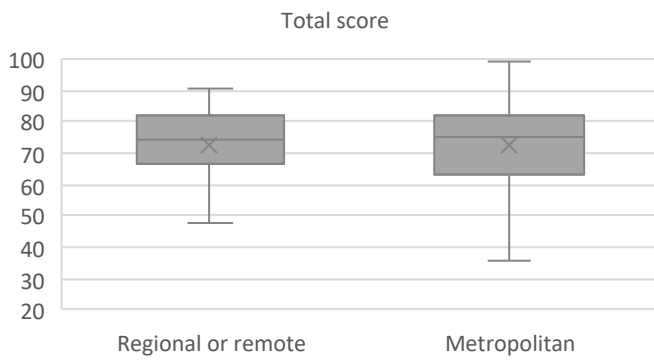
Care coordination scale	Group	Number (n=51)	Percent	Median	IQR	W	p-value
Care coordination global measure	Regional or remote	10	19.61	9.00	2.50	265.00	0.2970
	Metropolitan	41	80.39	8.00	2.00		
Quality of care global measure	Regional or remote	10	19.61	9.00	1.00	263.50	0.3022
	Metropolitan	41	80.39	9.00	2.00		



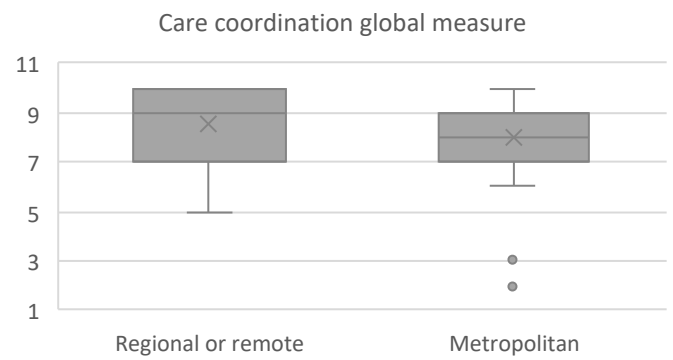
**Figure 7.21: Boxplot of Care coordination: knowledge by location**



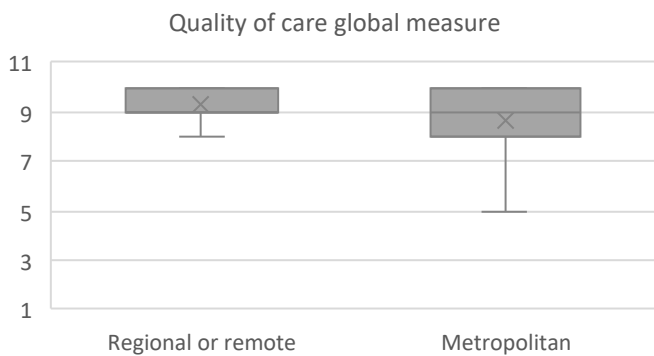
**Figure 7.22: Boxplot of Care coordination: coping by location**



**Figure 7.23: Boxplot of Care coordination: recognition and management of symptoms by location**



**Figure 7.24: Boxplot of Care coordination: adherence to treatment by location**



**Figure 7.25: Boxplot of Care coordination Total score by 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, *Mid to low status* (n=17, 33.33%) compared to those with a higher SEIFA score of 7-10, *Higher status* (n=34, 66.67%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.12), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.13).

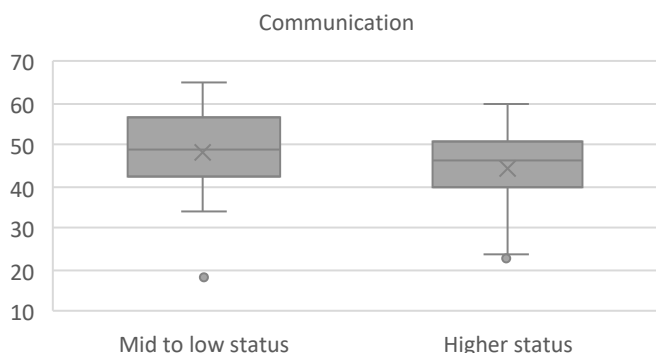
No significant differences were observed between participants by **socioeconomic status** for any of the Care coordination scales.

**Table 7.12:** Care coordination by **socioeconomic status** summary statistics and T-test

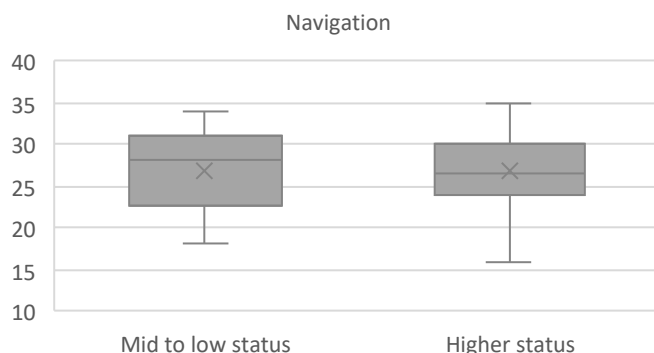
Care coordination scale	Group	Number (n=51)	Percent	Mean	SD	T	dF	p-value
Communication	Mid to low status	17	33.33	48.00	11.27	1.19	49	0.2385
	Higher status	34	66.67	44.62	8.58			
Navigation	Mid to low status	17	33.33	26.88	5.04	0.02	49	0.9829
	Higher status	34	66.67	26.85	4.36			
Total score	Mid to low status	17	33.33	74.88	14.91	0.89	49	0.3772
	Higher status	34	66.67	71.47	11.78			

**Table 7.13:** Care coordination by **socioeconomic status** summary statistics and Wilcoxon test

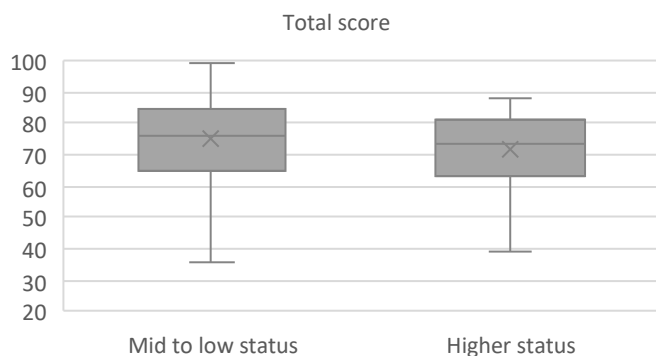
Care coordination scale	Group	Number (n=51)	Percent	Median	IQR	W	p-value
Care coordination global measure	Mid to low status	17	33.33	9.00	2.00	358.00	0.1613
	Higher status	34	66.67	8.00	2.00		
Quality of care global measure	Mid to low status	17	33.33	10.00	2.00	345.50	0.2410
	Higher status	34	66.67	9.00	2.00		



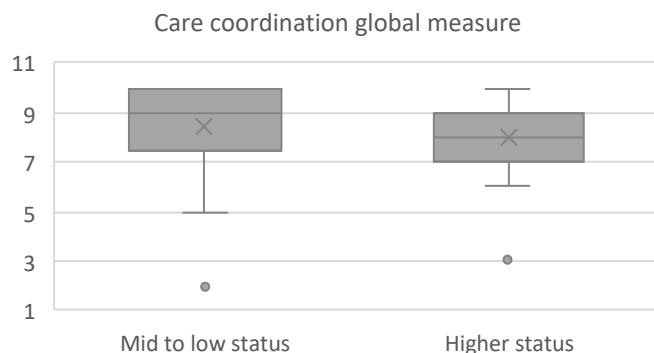
**Figure 7.26:** Boxplot of Care coordination: knowledge by socioeconomic status



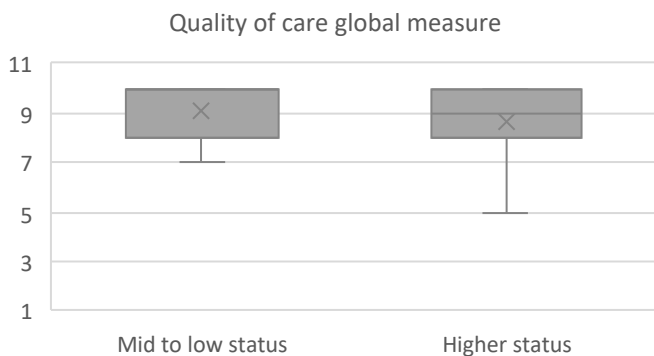
**Figure 7.27:** Boxplot of Care coordination: coping by socioeconomic status



**Figure 7.28:** Boxplot of Care coordination: recognition and management of symptoms by socioeconomic status



**Figure 7.29:** Boxplot of Care coordination: adherence to treatment by socioeconomic status



**Figure 7.30: Boxplot of Care coordination Total score by 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 help (n=18, 34.62%). This was followed by receiving support through the hospital and clinical setting (n=14, 26.92%), through charities (n=11, 21.15%) and face-to-face peer support (n=8, 15.38%). There were six participants that described not needing any help (11.54%).

#### Participant describes not receiving any support

*No, nope. Nope. And I've asked for it. Participant 003\_2021AUHRP*

*The public hospital said a McGrath breast care nurse will be in contact with you. And before I go home, and that was meant to be day surgery, I didn't see her I didn't go home and I didn't see her the next day and there was another breast lumpectomy patient as well breast cancer patient and she didn't see anyone either. And when I was discharged I was given her number if I, in case I'd needed her but I also felt that I'm only stage one probably other people that need her more or she busy with people that need her more than me so I didn't feel right contacting her and I thought now maybe in a couple of weeks she'll ring me anyway but nup.*

**INTERVIEWER:** *And yeah, have you had any community engagement?*

**PARTICIPANT:** *Nup. Participant 014\_2021AUHRP*

*No. I actually wasn't eligible for home help when I had the mastectomy, because I was the wrong age and I'd had the operation in a private hospital. Participant 031\_2021AUHRP*

#### Participant describes receiving support from a hospital or clinical setting

*I guess the only support I have is my GP has me on, I'm trying to think of the proper name of it, but some care plan. With that, I get five, I think it is, five treatments a year, and that's where I use the occupational therapist to do the lymphatic training. I get five treatments paid for, and then I pay for all the rest. That's the only government help that I have. Participant 004\_2021AUHRP*

*Just when my GP would frequently check in on me. She would actually call me to check in on me quite often. Participant 008\_2021AUHRP*

*The breast cancer nurse at my oncology unit was amazing. She told me about all the charities that were available, all the support that was available. If I wanted counseling it was available. She was my main go-to if I needed something to help with something, she was just a breast care nurse. Participant 024\_2021AUHRP*

*It was there if I needed it. I remember one day when I was having radiation, I was a complete mess and I was just lying there crying. When I finished, the social worker came and sat down and had a cup of tea with me. I think I just gave myself a good virtual kick in the pants and got back on track. If I needed help, I'm sure that could have been arranged. Participant 039\_2021AUHRP*

## Participant describes receiving support through charities

*Not a lot. I think when I was going for radiation there was a community group who gave us a fuel voucher to get to and from hospital to help with the petrol side of things, but that's about it. Participant 018\_2021AUHRP*

*And I think I've got a \$500 thing from Cancer Council that went towards some bills that that, and I went to it a feel better program. Yep. And I went to an I did the life, the life program, that's the Cancer Council, the exercise program that they run that as well. So that's it's really. Participant 033\_2021AUHRP*

*I've received some support from a charity called Mummy's Wish. They gave me a grocery voucher, which was really lovely and just the materials and things for my daughter. Look Good Feel Better Foundation. They sent me through that little pack that they sent your information. I know BCNA, one of the nurses just called me to check in and see how I was going. That was really good in terms of just mental health, particularly, at the beginning of things. That would be the three things. Participant 052\_2021AUHRP*

## Participant describes receiving support through peer support (Face-to-face)

*No. I've reached out to a couple of other mothers that have had breast cancer. So wait to see first of all, we should put a team together and walked around, look like we've done bikes and stuff like that. No, no. That's all the stuff. Participant 002\_2021AUHRP*

*Yes, it was the early breast cancer group at the HOSPITAL. Even now, I'm a peer mentor. Peer mentors meet up regularly for coffee. We've become our own little support group as well. Participant 043\_2021AUHRP*

*Breast care nurses, they put me in touch with some support groups, which were good, but weren't really good because I was always the youngest, [chuckles] and I went through a support group with the hospital where we used to live, and it was a cancer support group, and it's just to get you doing some exercise and they have guest speakers in that, and unfortunately, a lot of it was geared towards the older people, so 50, 60 plus. I didn't get a lot out of it that way, and it's hard because there's not necessarily a lot of people that I know of that have been my age and gone through it, but they did try, so that was really good. Participant 025\_2021AUHRP*

## Participant describes not needing any support

*Other than, like breast care nurse, and doctors. I haven't really thought anything outside of that, because I didn't really feel like I needed that. Participant Okay. 020\_2021AUHRP*

*I'm trying to think what that would, what that would involve, but no, I don't think so. Because I haven't really needed it. Participant 034\_2021AUHRP*

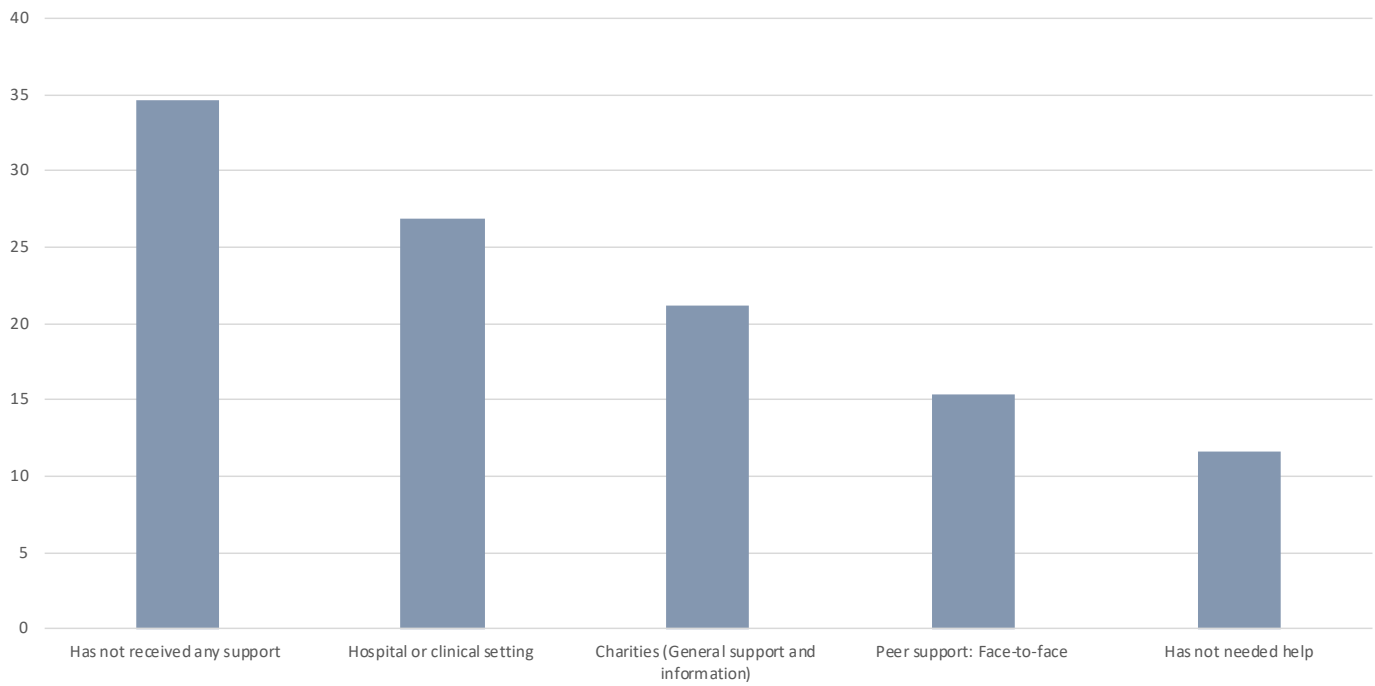
*No. I haven't really needed anything...My family is in LOCATION, but my sisters send care packages. Participant 011\_2021AUHRP*

**Table 7.14: Experience of care and support**

Experience of care and support	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes not receiving any support	18	34.62	5	26.32	8	38.10	5	41.67	12	41.38	6	26.09	7	36.84	11	33.33
Participant describes receiving support from a hospital or clinical setting	14	26.92	7	36.84	6	28.57	1	8.33	6	20.69	8	34.78	7	36.84	7	21.21
Participant describes receiving support through charities	11	21.15	4	21.05	5	23.81	2	16.67	3	10.34	8	34.78	3	15.79	8	24.24
Participant describes receiving support through peer support (Face-to-face)	8	15.38	3	15.79	2	9.52	3	25.00	5	17.24	3	13.04	1	5.26	7	21.21
Participant describes not needing help	6	11.54	2	10.53	3	14.29	1	8.33	4	13.79	2	8.70	1	5.26	5	15.15

Experience of care and support	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes not receiving any support	18	34.62	5	50.00	6	37.50	7	26.92	5	45.45	13	31.71	6	33.33	12	35.29
Participant describes receiving support from a hospital or clinical setting	14	26.92	3	30.00	5	31.25	6	23.08	2	18.18	12	29.27	6	33.33	8	23.53
Participant describes receiving support through charities	11	21.15	1	10.00	2	12.50	8	30.77	4	36.36	7	17.07	6	33.33	5	14.71
Participant describes receiving support through peer support (Face-to-face)	8	15.38	1	10.00	3	18.75	4	15.38	0	0.00	8	19.51	2	11.11	6	17.65
Participant describes not needing help	6	11.54	0	0.00	3	18.75	3	11.54	1	9.09	5	12.20	1	5.56	5	14.71



**Figure 7.31: Experience of care and support**

**Table 7.15: Experience of care and support – subgroup variations**

Experience of care and support	Reported less frequently	Reported more frequently
Participant describes not receiving any support	-	Diagnosed in 2016 or before Regional or remote
Participant describes receiving support from a hospital or clinical setting	Stage III and IV	
Participant describes receiving support through charities	Aged 25 to 54 Diagnosed in 2016 or before	Aged 55 to 74 Regional or remote Mid to low status
Participant describes receiving support through peer support (Face-to-face)	Trade or high school Regional or remote	-
Participant describes not needing help	Diagnosed in 2016 or before	-