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 overall scores for the cohort were in the highest quintile for the Care coordination: Quality of care global measure (median = 9.00, IQR = 1.00), scales, indicating very good scores for quality of care.

The overall scores for the cohort were in the second highest quintile for the Care coordination: Communication (mean = 44.64, SD = 7.85), Care coordination: Navigation (mean = 26.55, SD = 3.87), Care coordination: Total score (mean = 71.18, SD = 10.28), Care coordination: Care coordination global measure (median = 8, IQR = 2.25), scales, indicating good scores for care coordination, navigation, and communication.

There we no significant differences between sub-groups within the Care Coordination measure.

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 received support through charities (n=19, 38%). This was followed by receiving support from a hospital or clinical setting (n=11, 22%). There were 15 participants (30.00%) that described not receiving any support. There were five participants (10.00%) who described getting peer support, and the same number described getting support through a psychologist or counselling service (n=5, 10.00%).

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 highest quintile for the **Care coordination: Quality of care global measure** (median = 9.00, IQR = 1.00), scales, indicating very good scores for quality of care.

The overall scores for the cohort were in the second highest quintile for the **Care coordination: Communication** (mean = 44.64, SD = 7.85), **Care coordination: Navigation** (mean = 26.55, SD = 3.87), **Care coordination: Total score** (mean = 71.18, SD = 10.28), **Care coordination: Care coordination global measure** (median = 8, IQR = 2.25), scales, indicating good scores for care coordination, navigation, and communication.

Comparisons of Care co-ordination have been made based **breast cancer stage** (Tables 7.2 to 7.3, Figures 7.1 to 7.5), **physical function** (Tables 7.4 to 7.5, Figures 7.6 to 7.10), e**motional function** (Tables 7.6 to 7.7, Figures 7.11 to 7.15), **education** (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), **socioeconomic status** (Tables 7.12 to 7.13, Figures 7.26 to 7.30), and **age** (Tables 7.14 to 7.15, Figures 7.31 to 7.35).

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 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.

Table 7.1: Care coordination summary statistics

Care coordination scale (n=44)	Mean	SD	Median	IQR	Possible range	Quintile
Communication*	44.64	7.85	45.00	10.25	13 to 65	4
Navigation*	26.55	3.87	27.00	5.00	7 to 35	4
Total score*	71.18	10.28	72.00	12.50	20 to 100	4
Care coordination global measure	7.66	1.72	8.00	2.25	1 to 10	4
Quality of care global measure	8.45	1.21	9.00	1.00	1 to 10	5

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

Care coordination by breast cancer stage

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

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.2), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.3).

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

Table 7.2: Care coordination breast cancer stage summary statistics and T-test

Care coordination scale	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Care coordination global measure	Early breast cancer	20	45.45	8.00	2.25	248.00	0.8570
	Advanced breast cancer	24	54.55	8.00	2.25		
Quality of care global measure	Early breast cancer	20	45.45	8.00	1.00	220.00	0.6345
	Advanced breast cancer	24	54.55	9.00	1.25		

Table 7.3: Care coordination breast cancer stage summary statistics and Wilcoxon rank sum tests

Care coordination scale	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Care coordination global measure	Early breast cancer	20	45.45	8.00	2.25	248.00	0.8570
	Advanced breast cancer	24	54.55	8.00	2.25		
Quality of care global measure	Early breast cancer	20	45.45	8.00	1.00	220.00	0.6345
	Advanced breast cancer	24	54.55	9.00	1.25		

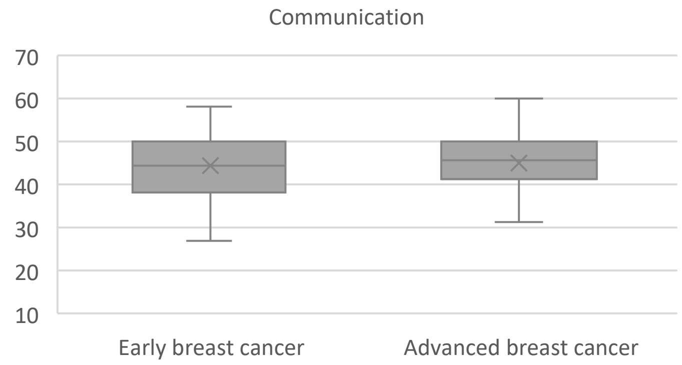


Figure 7.1: Boxplot of Care coordination: Communication by breast cancer stage

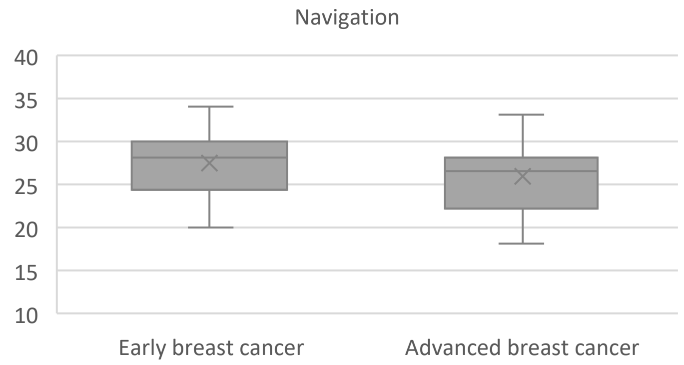


Figure 7.2: Boxplot of Care coordination: Navigation by breast cancer stage

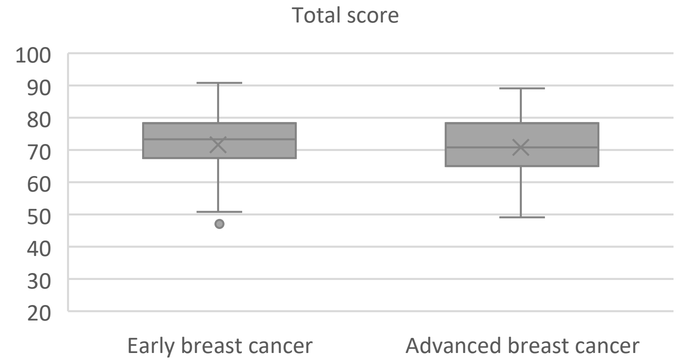


Figure 7.3: Boxplot of Care coordination: Total score by breast cancer stage

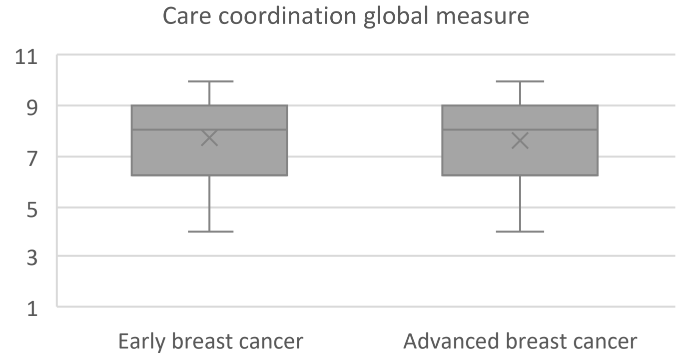


Figure 7.4: Boxplot of Care coordination: Care coordination global measure by breast cancer stage

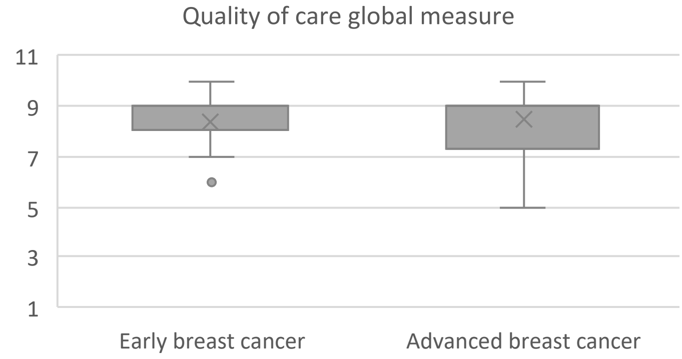


Figure 7.5: Boxplot of Care coordination: Quality of care global measure by breast cancer stage

Care coordination by physical function

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

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(42) = -2.37 , p = 0.0224] was significantly lower for participants in the *Poor physical function* subgroup (Mean = 41.58, SD = 8.03) compared to participants in the *Good physical function* subgroup (Mean = 46.96, SD = 7.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **Care coordination: Quality of care global measure** scale [W = 149.5 , p = 0.0320] was significantly lower for participants in the *Poor physical function* subgroup (Median = 8.00, IQR = 2.00) compared to participants in the *Good physical function* subgroup (Median = 9.00, IQR = 2.00).

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 *Good physical function* subgroup scored higher than participants in the *Poor physical function* subgroup. This indicates that healthcare communication was good for participants in the *Good physical function* subgroup, and average for participants in the *Poor physical function* 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 *Good physical function* subgroup scored higher than participants in the *Poor physical function* subgroup. This indicates that, quality of care was very good for participants in the *Good physical function* subgroup, and good for participants in the *Poor physical function* subgroup.

Table 7.4: Care coordination physical function summary statistics and T-test

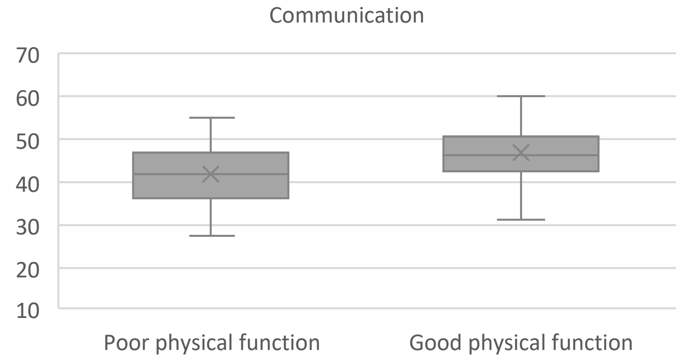
Care coordination scale	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Communication	Poor physical function	19	43.18	41.58	8.03	-2.37	42.00	0.0224*
	Good physical function	25	56.82	46.96	7.00			
Navigation	Poor physical function	19	43.18	26.47	3.27	-0.11	42.00	0.9161
	Good physical function	25	56.82	26.60	4.34			
Total score	Poor physical function	19	43.18	68.05	9.65	-1.81	42.00	0.0783
	Good physical function	25	56.82	73.56	10.30			

*Statistically significant at p<0.05

Table 7.5: Care coordination physical function summary statistics and Wilcoxon rank sum tests

Care coordination scale	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Care coordination global measure	Poor physical function	19	43.18	7.00	2.00	161.00	0.0664
	Good physical function	25	56.82	9.00	1.00		
Quality of care global measure	Poor physical function	19	43.18	8.00	2.00	149.50	0.0320*
	Good physical function	25	56.82	9.00	2.00		

*Statistically significant at p<0.05



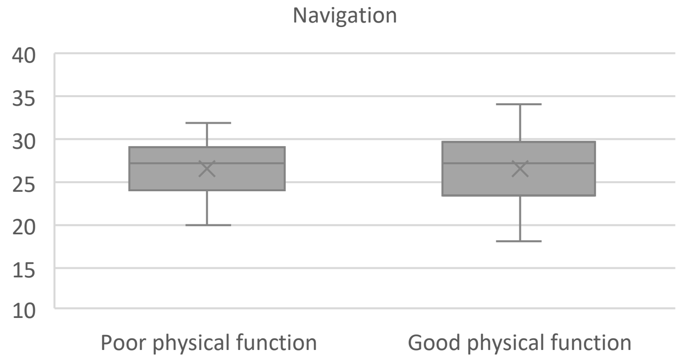


Figure 7.6: Boxplot of Care coordination: Communication by physical function

Figure 7.7: Boxplot of Care coordination: Navigation by physical function

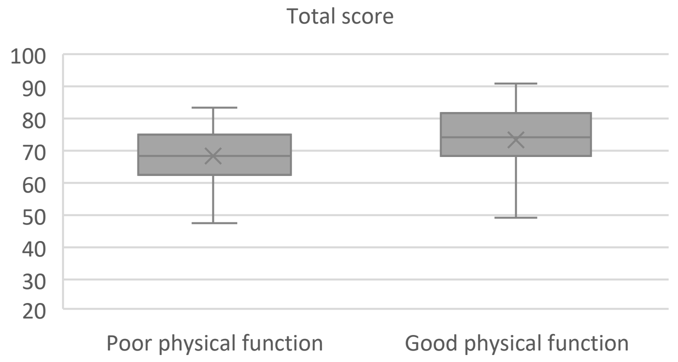


Figure 7.8: Boxplot of Care coordination: Total score by physical function

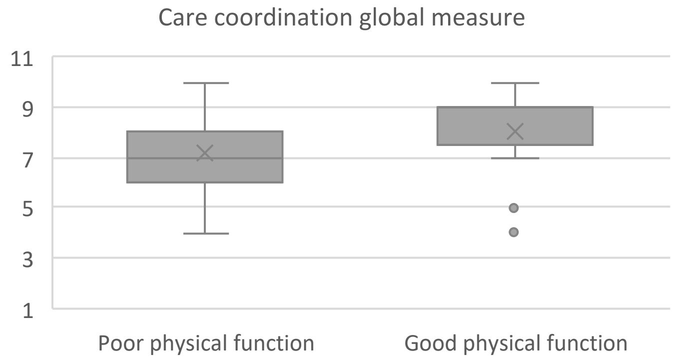


Figure 7.9: Boxplot of Care coordination: Care coordination global measure by physical function

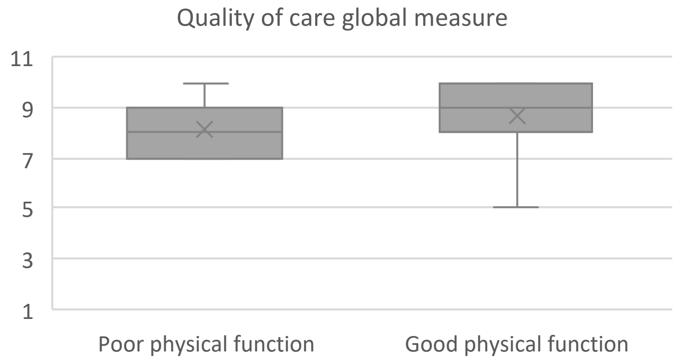


Figure 7.10: Boxplot of Care coordination: Quality of care global measure by physical function

Care coordination by year of diagnosis

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

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 **year of diagnosis** for any of the Care coordination scales.

Table 7.6: Care coordination year of diagnosis summary statistics and T-test

Care coordination scale	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Navigation	Diagnosed before 2020	22	50.00	16.64	3.71	0.70	42	0.4856
	Diagnosed in 2020 or 2021	22	50.00	15.73	4.79			
Total score	Diagnosed before 2020	22	50.00	19.86	2.25	0.62	42	0.5394
	Diagnosed in 2020 or 2021	22	50.00	19.36	3.05			
Quality of care global measure	Diagnosed before 2020	22	50.00	77.09	8.56	0.64	42	0.5273
	Diagnosed in 2020 or 2021	22	50.00	75.36	9.40			

*Statistically significant at p<0.05

Table 7.7: Care coordination year of diagnosis summary statistics and Wilcoxon rank sum tests

Care coordination scale	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Communication	Diagnosed before 2020	22	50.00	27.50	6.50	276.50	0.4226
	Diagnosed in 2020 or 2021	22	50.00	25.50	4.50		
Care coordination global measure	Diagnosed before 2020	22	50.00	15.00	2.00	235.00	0.8745
	Diagnosed in 2020 or 2021	22	50.00	15.00	2.00		

*Statistically significant at p<0.05

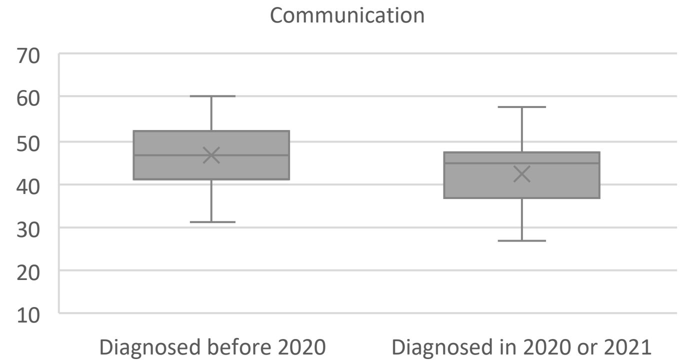


Figure 7.11: Boxplot of Care coordination: Communication by year of diagnosis

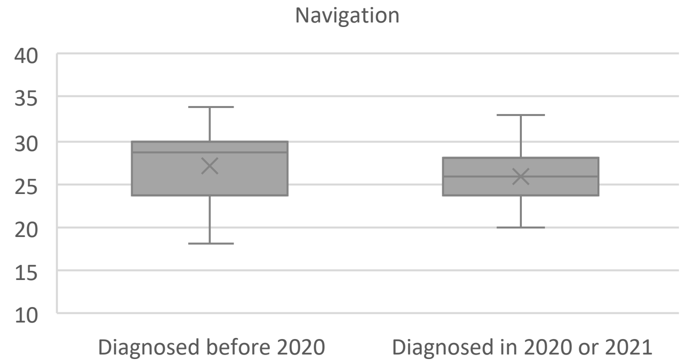


Figure 7.12: Boxplot of Care coordination: Navigation by year of diagnosis

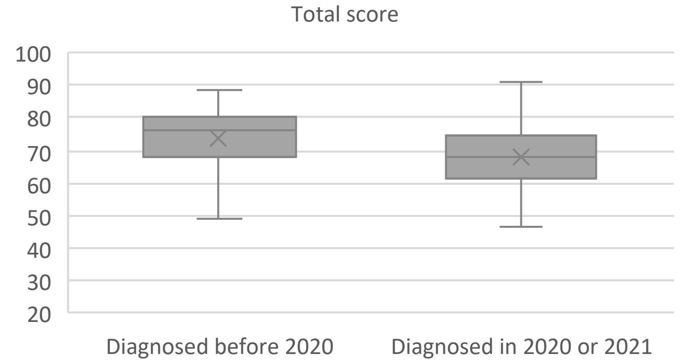


Figure 7.13: Boxplot of Care coordination: Total score by year of diagnosis

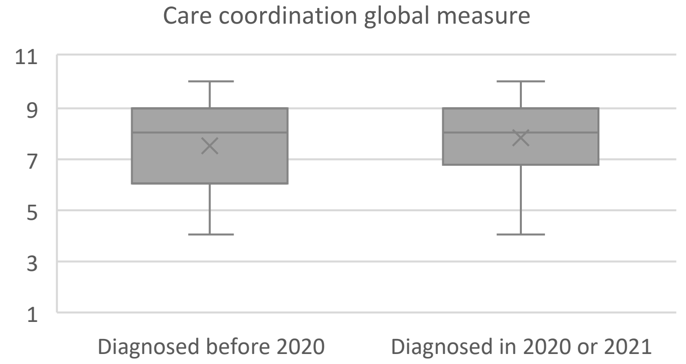


Figure 7.14: Boxplot of Care coordination: Care coordination global measure by year of diagnosis

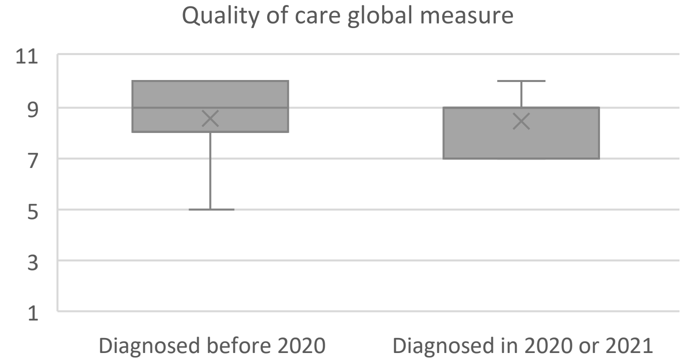


Figure 7.15: Boxplot of Care coordination: Quality of care global measure by year of diagnosis

Care coordination by education

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

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.8), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.9).

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

Table 7.8: Care coordination education summary statistics and T-test

Care coordination scale	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Communication	Trade or high school	21	47.73	42.86	8.13	-1.46	42	0.1529
	University	23	52.27	46.26	7.38			
Navigation	Trade or high school	21	47.73	26.10	4.28	-0.73	42	0.4677
	University	23	52.27	26.96	3.51			
Total score	Trade or high school	21	47.73	68.95	10.74	-1.39	42	0.1722
	University	23	52.27	73.22	9.63			

Table 7.9: Care coordination education summary statistics and Wilcoxon rank sum tests

Care coordination scale	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Care coordination global measure	Trade or high school	21	47.73	8.00	2.00	227.00	0.7374
	University	23	52.27	8.00	3.00		
Quality of care global measure	Trade or high school	21	47.73	8.00	2.00	183.50	0.1622
	University	23	52.27	9.00	1.50		

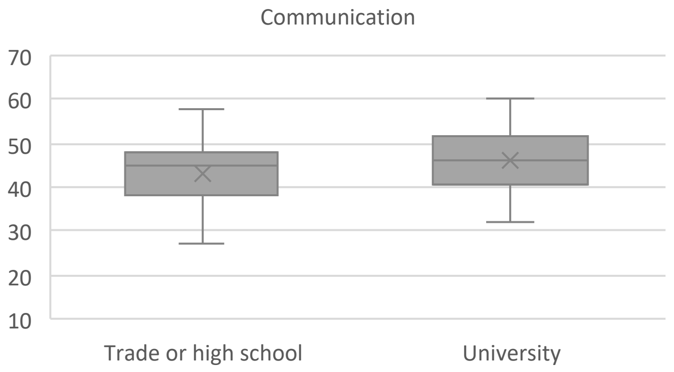


Figure 7.16: Boxplot of Care coordination: Communication by education

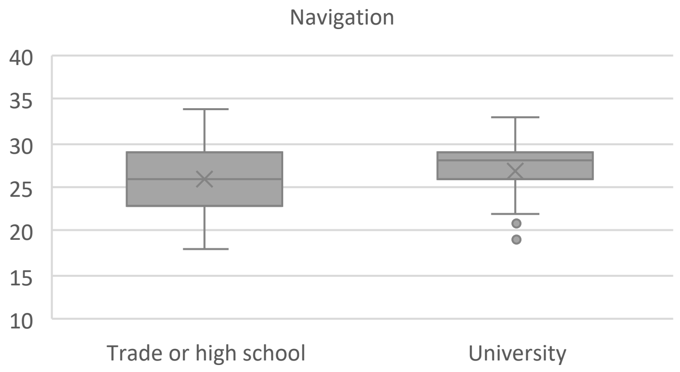


Figure 7.17: Boxplot of Care coordination: Navigation by education

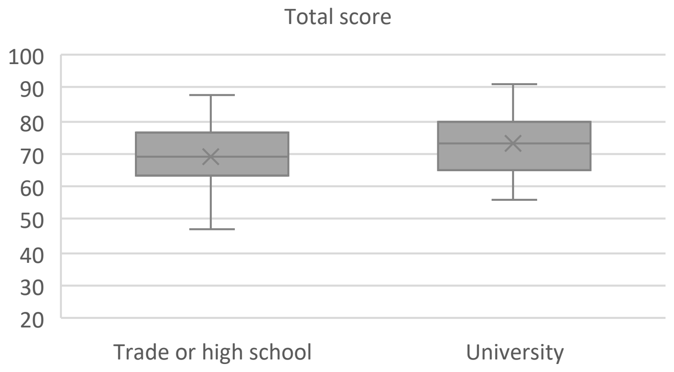


Figure 7.18: Boxplot of Care coordination: Total score by education

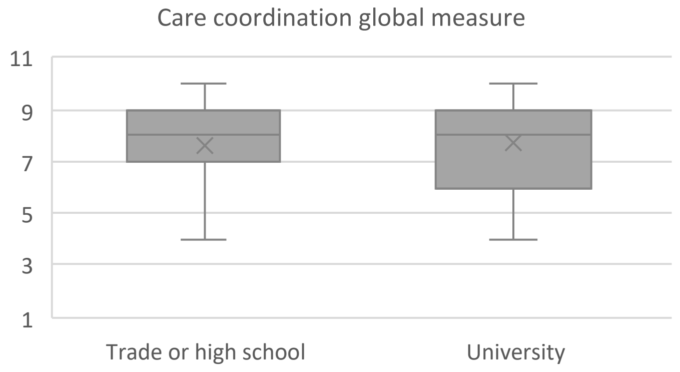


Figure 7.19: Boxplot of Care coordination: Care coordination global measure by education

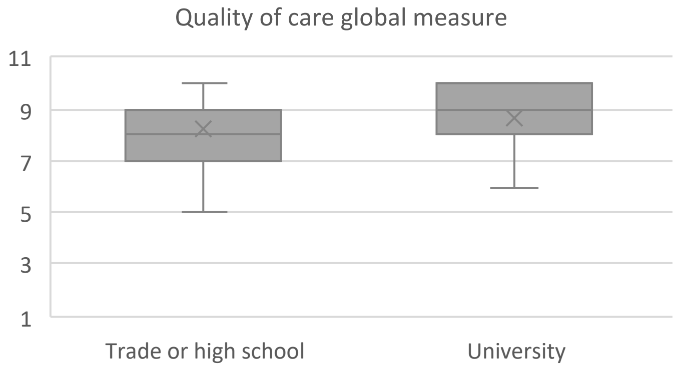


Figure 7.20: Boxplot of Care coordination: Quality of care global measure by education

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/rural areas, *Regional or remote* (n =16, 32.00%) were compared to those living in a major city, *Metropolitan* (n = 34, 68.00%).

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 location summary statistics and T-test

Care coordination scale	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Communication	Regional or remote	14	31.82	43.07	7.11	-0.90	42	0.3724
	Metropolitan	30	68.18	45.37	8.18			
Navigation	Regional or remote	14	31.82	25.57	4.80	-1.14	42	0.2592
	Metropolitan	30	68.18	27.00	3.35			

*Statistically significant at p<0.05

Table 7.11: Care coordination location summary statistics and Wilcoxon rank sum tests

Care coordination scale	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Total score	Regional or remote	14	31.82	69.00	10.25	175.50	0.3908
	Metropolitan	30	68.18	73.00	12.25		
Care coordination global measure	Regional or remote	14	31.82	7.50	2.75	159.50	0.1990
	Metropolitan	30	68.18	8.00	2.00		
Quality of care global measure	Regional or remote	14	31.82	9.00	1.00	225.00	0.7055
	Metropolitan	30	68.18	8.50	1.75		

*Statistically significant at p<0.05

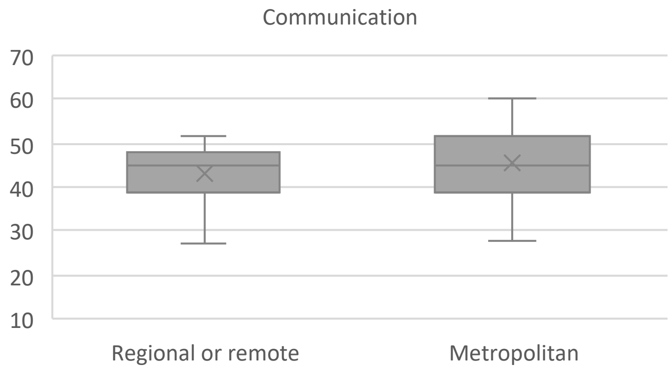


Figure 7.21: Boxplot of Care coordination: Communication by location

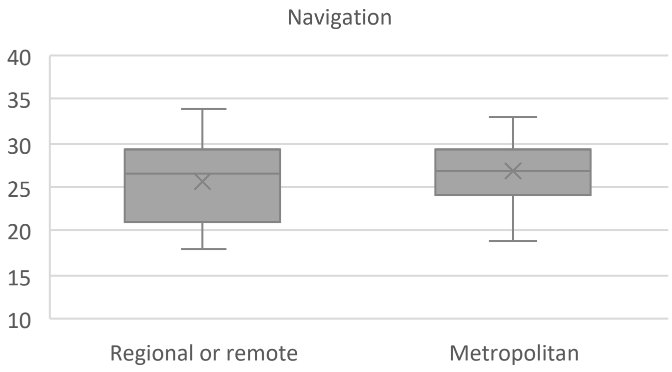


Figure 7.22: Boxplot of Care coordination: Navigation by location

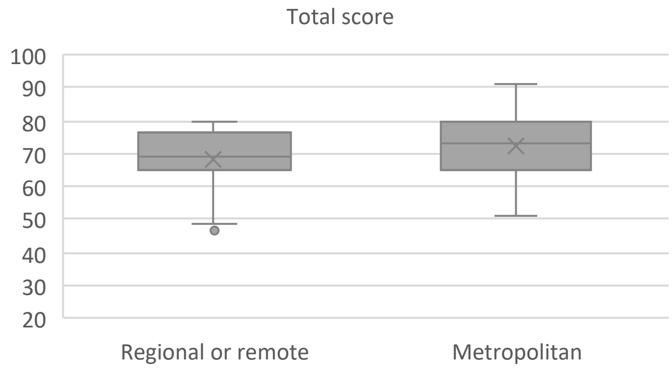


Figure 7.23: Boxplot of Care coordination: Total score by location

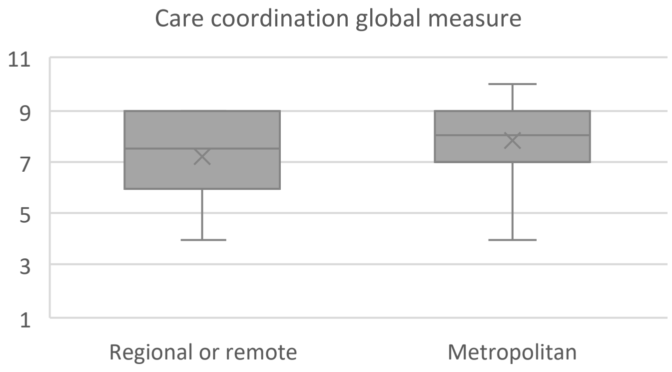


Figure 7.24: Boxplot of Care coordination: Care coordination global measure by location

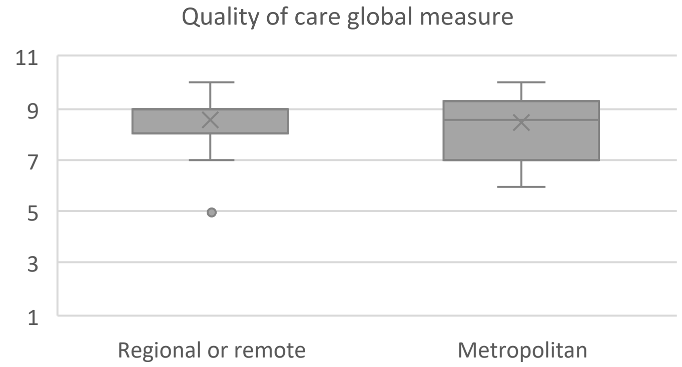


Figure 7.25: Boxplot of Care coordination: Quality of care global measure by location

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

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 socioeconomic status summary statistics and T-test

Care coordination scale	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Communication	Mid to low status	17	38.64	43.88	7.77	-0.50	42	0.6188
	Higher status	27	61.36	45.11	8.01			
Navigation	Mid to low status	17	38.64	25.59	4.24	-1.31	42	0.1967
	Higher status	27	61.36	27.15	3.57			
Total score	Mid to low status	17	38.64	69.47	10.57	-0.87	42	0.3875
	Higher status	27	61.36	72.26	10.15			

Table 7.13: Care coordination socioeconomic status summary statistics and Wilcoxon rank sum tests

Care coordination scale	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Care coordination global measure	Mid to low status	17	38.64	8.00	1.00	180.50	0.2334
	Higher status	27	61.36	8.00	2.50		
Quality of care global measure	Mid to low status	17	38.64	8.00	1.00	181.00	0.2314
	Higher status	27	61.36	9.00	2.00		

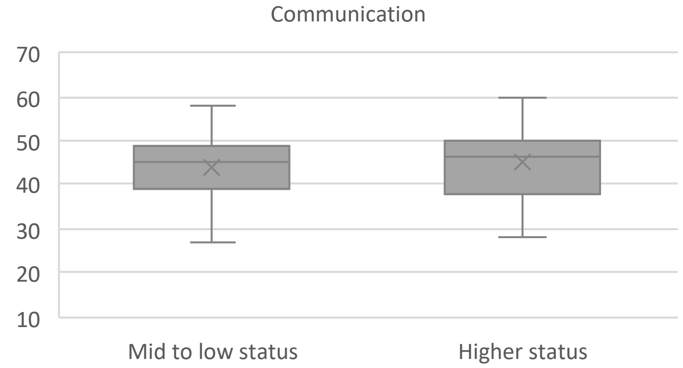


Figure 7.26: Boxplot of Care coordination: Communication by socioeconomic status

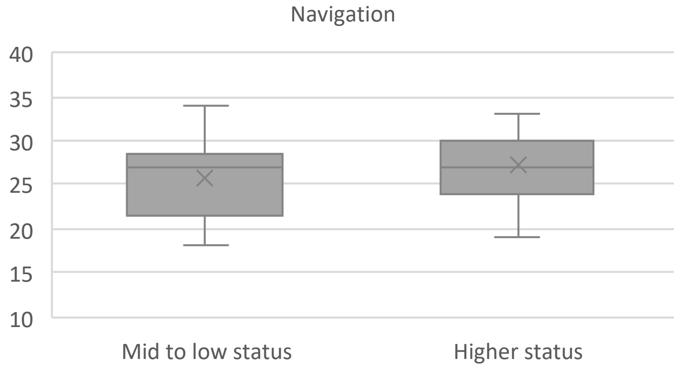


Figure 7.27: Boxplot of Care coordination: Navigation by socioeconomic status

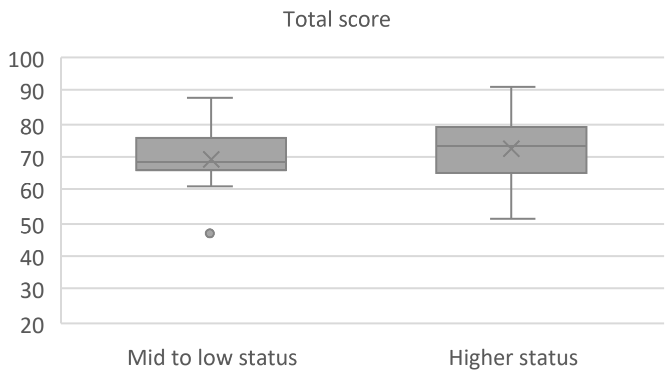


Figure 7.28: Boxplot of Care coordination: Total score by socioeconomic status

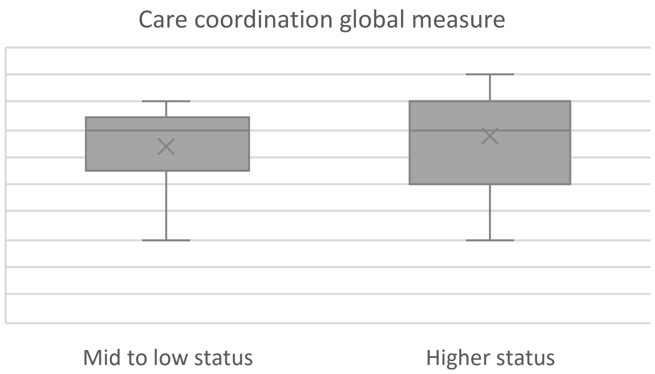


Figure 7.29: Boxplot of Care coordination: Care coordination global measure by socioeconomic status

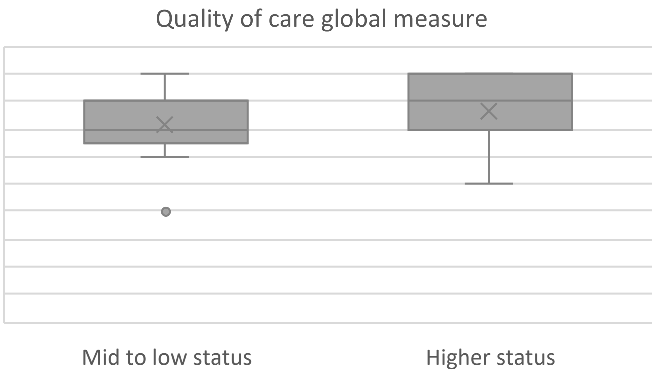


Figure 7.30: Boxplot of Care coordination: Quality of care global measure by socioeconomic status

Care coordination by age

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

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 7.14). When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 7.15).

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

Table 7.14: Care coordination age summary statistics and one-way ANOVA

Care coordination scale	Group	Number (n=44)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Communication	Aged 25 to 44	16	36.36	45.75	7.00	Between groups	133.50	2	66.76	1.09	0.3460
	Aged 45 to 54	19	43.18	42.68	8.81	Within groups	2514.70	41	61.33		
	Aged 55 to 74	9	20.45	46.78	6.91	Total	2648.20	43			
Navigation	Aged 25 to 44	16	36.36	26.13	2.63	Between groups	40.90	2	20.47	1.39	0.2610
	Aged 45 to 54	19	43.18	26.00	4.91	Within groups	604.00	41	14.73		
	Aged 55 to 74	9	20.45	28.44	2.88	Total	644.90	43			
Total score	Aged 25 to 44	16	36.36	71.88	8.57	Between groups	273.00	2	136.60	1.31	0.2810
	Aged 45 to 54	19	43.18	68.68	11.94	Within groups	4275.00	41	104.30		
	Aged 55 to 74	9	20.45	75.22	8.73	Total	4548.00	43			
Quality of care global measure	Aged 25 to 44	16	36.36	8.56	0.96	Between groups	2.26	2	1.13	0.76	0.4730
	Aged 45 to 54	19	43.18	8.21	1.47	Within groups	60.65	41	1.48		
	Aged 55 to 74	9	20.45	8.78	0.97	Total	62.91	43			

Table 7.15: Care coordination age summary statistics and Kruskal-Wallis test

Care coordination scale	Group	Number (n=44)	Percent	Median	IQR	C^2	dF	p-value
Care coordination global measure	Aged 25 to 44	16	36.36	8.00	2.00	1.62	2	0.4459
	Aged 45 to 54	19	43.18	8.00	3.00			
	Aged 55 to 74	9	20.45	8.00	1.00			

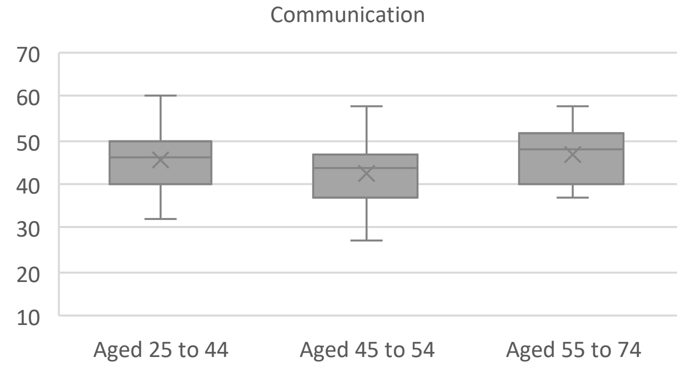


Figure 7.31: Boxplot of Care coordination: Communication by age

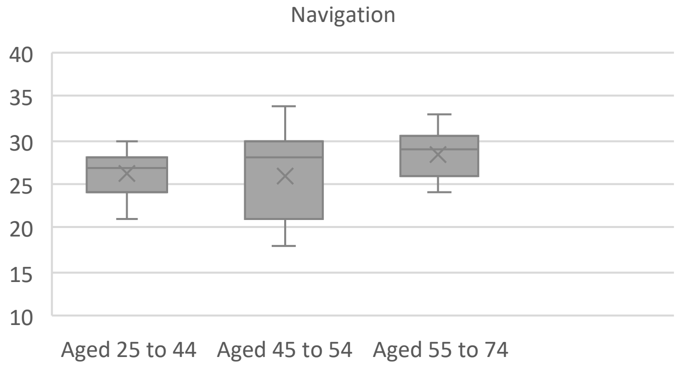


Figure 7.32: Boxplot of Care coordination: Navigation by age

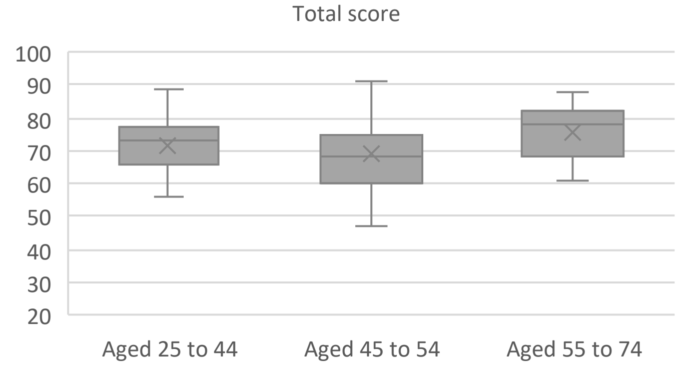


Figure 7.33: Boxplot of Care coordination: Total score by age

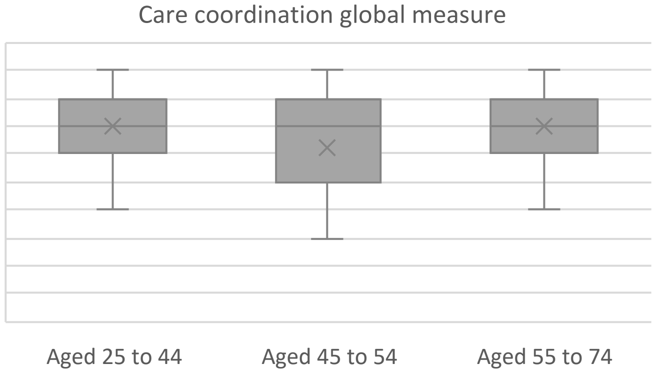


Figure 7.34: Boxplot of Care coordination: Care coordination global measure by age

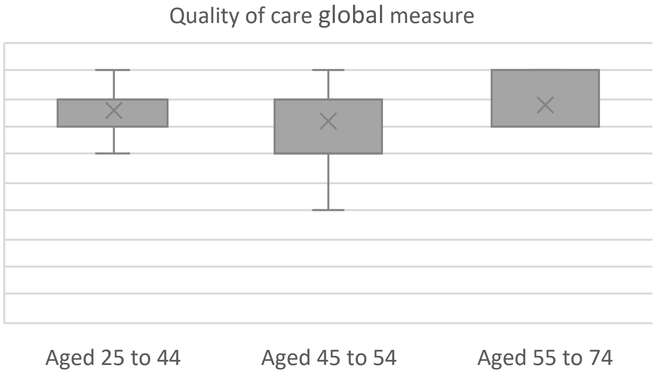


Figure 7.35: Boxplot of Care coordination: Quality of care global measure by age

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 received support through charities (n=19, 38%). This was followed by receiving support from a hospital or clinical setting (n=11, 22%). There were 15 participants (30.00%) that described not receiving any support. There were five participants (10.00%) who described care through accessing peer support, and the same number described getting support through a psychologist or counselling service (n=5, 10.00%).

Participant describes receiving support through charities

I received some support from, again, that organization called Mummy's Wish. Through them, I came to know I can have access to something called in-home care for my child. There was a point when my family, they were feeling the burden of having to take time off, especially my mum. She'd exhausted along, obviously. Then I came to know of the service. I was able to organize a caretaker to come and look after my son and at least maintain the environment for him as positively as possible while I could go and get my treatment and rest up. That was through Centrelink. We got ACCS, which is complete subsidy, so we didn't have to pay for it either. That really, really helped me because I was relieved someone looked after my son. The service continued right up until I reintegrated with the workforce. Participant_016

PARTICIPANT: I did one of those Look Good Feel Better workshops online. I had the Cancer Council booklets, and I did look up some of their info online and that sort of thing in the Breast Cancer Network. My GP was fantastic. She would give me a call every few months just to see how I was. That was really amazing. I saw my breast care nurse pretty much every week when I was at chemo, so I had easy access to her as I needed it which was great. That's probably really the main things that I would have accessed.
INTERVIEWER: Did you find the Look Good Feel Better program helpful?
PARTICIPANT: I did the make up one. I don't generally wear makeup. I'm not sure that I was the right kind of person for that particular thing. Friends just said to me, "Oh, this thing you can do. Why don't you enrol?" I didn't get that much out of it, but that's because I don't wear makeup normally, anyway. I didn't end up doing the one for..They do another one for wigs and stuff, because I ended up just not wearing anything. I just went bald because it was too hot. In the end, I realized that that probably wouldn't be for me either, so I didn't bother to do the second one…The friend who recommended it to me was really concerned about losing her hair, and she did the ice caps and the whole thing. For her, that was probably a really useful thing, but for me, it was just not. That's not me. Participant_011

Not really. The social worker referred me to a charity, a local charity in Brisbane called Be Uplifted who were amazing. They came over and gave me a food hamper, a basket full of goodies and a couple of blankets. One was crocheted, one was a quilt. They're able to bring in a cleaner for me to help with my floors. They're getting someone to help me my yard…The social worker also referred me to another charity. Oh, what is it called? Look Good, Feel Better, I think they're called. I did a skin and makeup tutorial and got the most amazing thing of makeup from them. Other than that, I really haven't had much assistance or support Participant_014

Participant describes not receiving any support

No I didn't get any. Participant_006

I haven't, that's my choice. I think there are those support services out there, but I haven't really needed that. Participant_019

No. I haven't had any. Participant_035

Participant describes receiving support through a community service program

Oh, really? I mean, the only, you know, my friends like the six times that I had my chemo. Yeah. I had a friend who made sure that dinner was cooked for my family, that not because I'm was too tired to do it, but other people think I think I recall there being you know I think they were saying, don't you get told don't hesitate to ask to help me write down. Many times I hope. But the other people I'm sure I know there is community life and the home and community care programme that I has that is usually aimed at older people and sick people say, know when you're having cancer, it's only short term, but something like that where you have someone coming into your bathroom, all those services would be good. And if I could have got that first six or seven dollars an hour, I probably would have taken it up knowing that it was just for the short term while I went through my chemo. Participant_003

Yes. There's a local one in LOCATION called Reacher. They're a community group that's been put together. I think they've been there for a couple of years, charity group. They have offered me counselling. I've had two sessions with a counsellor through them. They have offered to assist with gardening with my home in LOCATION because I'm in LOCATION. I'm not there to look after it. They've offered that. They've also offered memberships…They've offered me that and I'm just going to actually just go through that now. Then you've got Breast Care LOCATION who assisted me with counselling services. Participant_017

Yes, I have. I suppose you call it community service, a breast care nurse has probably put me in touch with a few. I have reached out to what's called Mummy's Wish which has got some support components in there as well. What else is there? There's not much community-wise in that sense that isn't through our local cancer centre. There's a support network group that they've finally been able to get going again after all the COVID stuff. That's one we just started so that's something I'll actively participate in. Other than that, a lot of it's just online. Participant_030

Participant describes receiving support from a hospital or clinical setting

I think the main support would be the the breast care nurse, even during treatment, very busy person. In our regional town, it's a point five position. She's run off her feet, but she made regular contact, just to see how I was going. Like I said, she still maintains that contact through our support group. Other than that, I guess, no. That was the main impetus for the group of women that set up our support group. That was the main reason that we did come together and set that support group up and have maintained that because we felt that there wasn't that support out there in the community. While we initially set it up for women that were going through that breast cancer diagnosis, we've opened that up to other women that are going through a cancer diagnosis to come along as well. I've found that the most beneficial. We've also, most of us are like, one to two years, down the track of finishing treatment. We've gone on to set up our own charity, to fundraise, to support people within our community financially that are struggling with treatment. I think, in that regard, we found our own support. Participant_013

I had the hospital group, which was good, the Cancer Council, the peer support group, our breast reconstruction group. It's just support from professionals, isn't it? Participant_040

I got a food voucher from a private hospital on the LOCATION, which was nice because I told them I was struggling with money. LOCATION is a partially funded service, the Cancer Wellness Center that I go to. I only pay very small amount of out-of-pockets. They even have drivers to pick you up and all that kind of stuff. I find that very supportive. That's probably about it. That's all I can think of right now. That's another thing when they're raising money for women with breast cancer, I'm like, "Where's this money going?" [laughs] Participant_008

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

I think the main support would be the, the breast care nurse, even during treatment, very busy person. In our regional town, it's a point five position. She's run off her feet, but she made regular contact, just to see how I was going. Like I said, she still maintains that contact through our support group. Other than that, I guess, no. That was the main impetus for the group of women that set up our support group. That was the main reason that we did come together and set that support group up and have maintained that because we felt that there wasn't that support out there in the community. While we initially set it up for women that were going through that breast cancer diagnosis, we've opened that up to other women that are going through a cancer diagnosis to come along as well. I've found that the most beneficial. We've also, most of us are like, one to two years, down the track of finishing treatment. We've gone on to set up our own charity, to fundraise, to support people within our community financially that are struggling with treatment. I think, in that regard, we found our own support. Participant_013

I had the hospital group, which was good, the Cancer Council, the peer support group, our breast reconstruction group. It's just support from professionals, isn't it? Participant_040

Participant describes receiving support through a psychologist or counselling service

I had two telephone counselling sessions with a psychologist who's specialized in breast cancer. After I was diagnosed with the gene, I had an in-person counselling session through the breast cancer organization, I can't remember which one. I had one in-person session. The biggest help, at the time, was the first cancer nurse. I could ring her. I met with her a few times, and I could call her any time. She totally understood what I was going through. Participant_037

> *The support I've had from Cancer Council, once I had contacted them, they gave me some financial support at the beginning of the breast to me so she could be in contact with me at any time, or I could contact her at any time to talk through things. Also, I supplied a counsellor where we had monthly meetings and she would facilitate it. And then I'd seen her on a personal basis over the years. I then joined another support group, which was a group of ladies where we did activities together once every quarter sort of thing, and then we started doing monthly catch up and now we're doing catch up to talk to various professional. We had a person coming to talk to us about exercise therapy. Participant_049*

Table 7.16: Experience of care and support

Experience of care and support	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes receiving support through charities	19	38.00	10	43.48	9	33.33	7	36.84	10	40.00	11	42.31	8	33.33	8	33.33	11	42.31
Participant describes not receiving any support	15	30.00	6	26.09	9	33.33	4	21.05	9	36.00	4	15.38	11	45.83	8	33.33	7	26.92
Participant describes receiving support through a community service program	12	24.00	9	39.13	3	11.11	5	26.32	7	28.00	6	23.08	6	25.00	4	16.67	8	30.77
Participant describes receiving support from a hospital or clinical setting	11	22.00	6	26.09	5	18.52	5	26.32	5	20.00	9	34.62	2	8.33	4	16.67	7	26.92
Participant describes receiving support through peer support (Face-to-face)	5	10.00	2	8.70	3	11.11	1	5.26	4	16.00	3	11.54	2	8.33	2	8.33	3	11.54
Participant describes receiving support through a psychologist or counselling service	5	10.00	2	8.70	3	11.11	3	15.79	1	4.00	4	15.38	1	4.17	3	12.50	2	7.69

Experience of care and support	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes receiving support through charities	19	38.00	6	37.50	13	38.24	6	30.00	13	43.33	8	42.11	7	31.82	4	44.44
Participant describes not receiving any support	15	30.00	6	37.50	9	26.47	6	30.00	9	30.00	4	21.05	7	31.82	4	44.44
Participant describes receiving support through a community service program	12	24.00	5	31.25	7	20.59	2	10.00	10	33.33	6	31.58	5	22.73	1	11.11
Participant describes receiving support from a hospital or clinical setting	11	22.00	3	18.75	8	23.53	3	15.00	8	26.67	4	21.05	5	22.73	2	22.22
Participant describes receiving support through peer support (Face-to-face)	5	10.00	2	12.50	3	8.82	2	10.00	3	10.00	2	10.53	1	4.55	2	22.22
Participant describes receiving support through a psychologist or counselling service	5	10.00	1	6.25	4	11.76	0	0.00	5	16.67	1	5.26	2	9.09	2	22.22

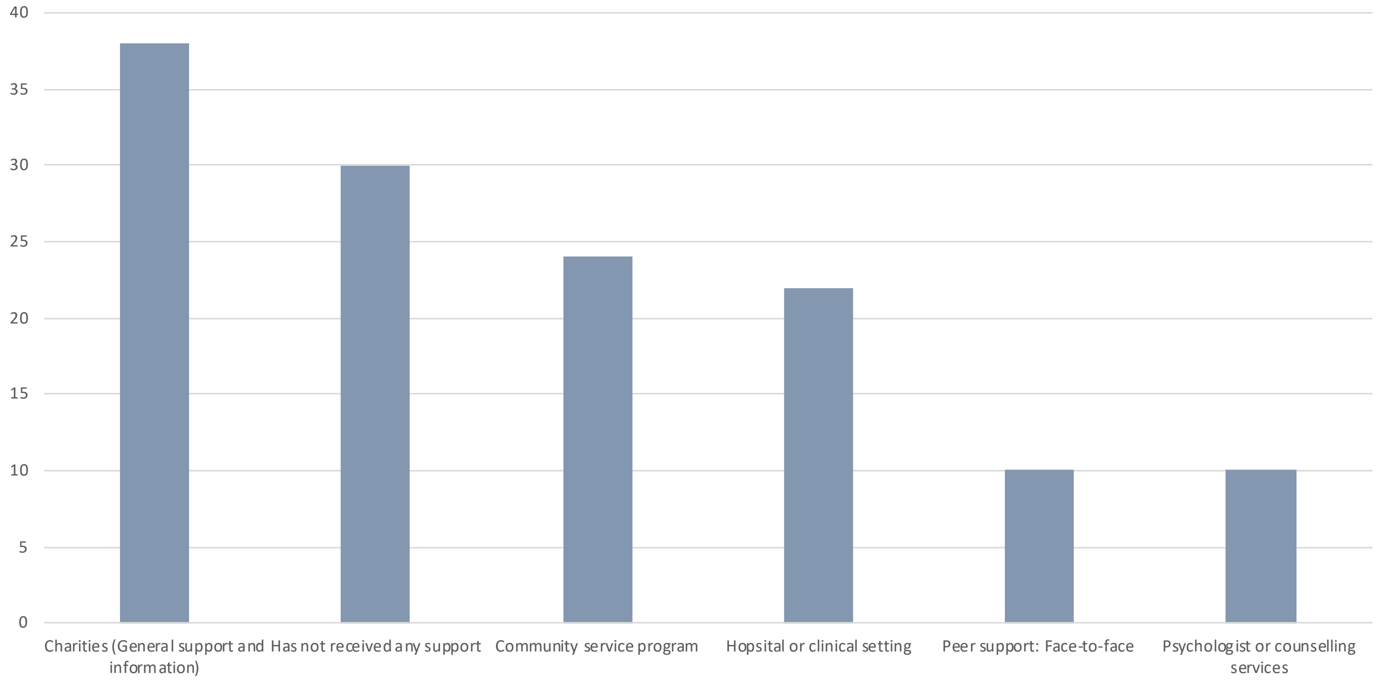


Figure 7.36: Experience of care and support – percent of all participants

Table 7.18: Experience of care and support – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes not receiving any support	Diagnosed before 2020	Diagnosed in 2020 or 2021 Aged 55 to 74
Participant describes receiving support through a community service program	Advanced breast cancer Mid to low status Aged 55 to 74	Early breast cancer
Participant describes receiving support from a hospital or clinical setting	Diagnosed in 2020 or 2021	Diagnosed before 2020