

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 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 sources of support and were from their hospital or clinical setting (31.91%), from family and friends (19.15%), domestic services and/or home care (14.89%), and peer support or other patients (8.51%). Almost a third described that they did not receive any formal support (27.66%), others described that they did not need or seek help or support (14.89%), and some described the challenges of finding or accessing support (10.64%).

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 = 44.72, SD = 9.18), **Care coordination: Navigation** (mean = 26.74, SD = 4.80) **Care coordination: Total score** (mean = 71.46, SD = 12.46), 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 = 2.00), and **Care coordination: Quality of care global measure** (median = 9.00, IQR = 1.75). indicating very good care coordination and quality of care.

Comparisons of Care co-ordination have been made based on LP(a) test status, main condition, number of other health conditions, gender, age, location, and socioeconomic status.

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=50)	Mean	SD	Median	IQR	Possible range	Quintile
Communication*	36.86	11.00	38.00	13.00	13 to 65	3
Navigation*	23.84	5.67	23.00	9.50	7 to 35	4
Total score	60.70	13.98	64.00	18.75	20 to 100	3
Care coordination global measure	6.08	2.69	7.00	4.00	1 to 10	4
Quality of care global measure	6.82	2.56	8.00	3.75	1 to 10	4

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

Care coordination by LP(a) test

Comparisons were made by **LP(a) Test status** there were 19 participants (38.00%) that had an LP(a) test and, 31 participants (62.00%) that did not have an LP(a) test.

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

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

No significant differences were observed between participants by **LP(a) test** for any of the Care coordination scales.

Table 7.2: Care coordination by LP(a) test summary statistics and T-test

Care coordination scale	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Communication	Had LP(a) test	19	38.00	36.95	11.03	0.04	48	0.9655
	Not had LP(a) test	31	62.00	36.81	11.17			
Navigation	Had LP(a) test	19	38.00	22.32	5.96	-1.51	48	0.1385
	Not had LP(a) test	31	62.00	24.77	5.37			
Total score	Had LP(a) test	19	38.00	59.26	15.25	-0.57	48	0.5746
	Not had LP(a) test	31	62.00	61.58	13.32			

*Statistically significant at $p < 0.05$

Table 7.3: Care coordination by LP(a) test summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Care coordination global measure	Had LP(a) test	19	38.00	7.00	3.50	300.00	0.9197
	Not had LP(a) test	31	62.00	7.00	4.00		
Quality of care global measure	Had LP(a) test	19	38.00	8.00	3.00	275.00	0.7004
	Not had LP(a) test	31	62.00	8.00	3.50		

*Statistically significant at $p < 0.05$

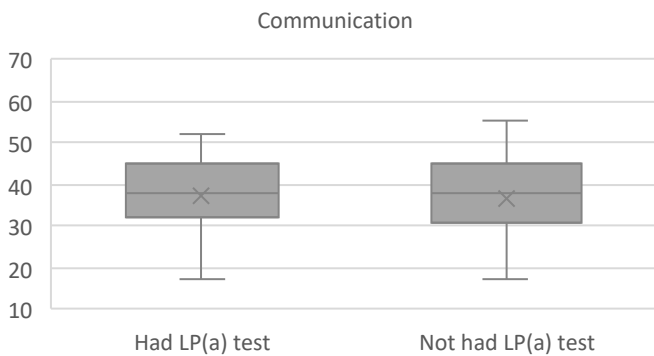


Figure 7.1: Boxplot of Care coordination: Communication by LP(a) test

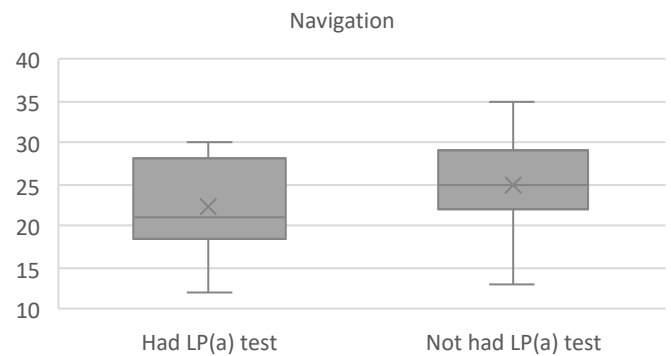


Figure 7.2: Boxplot of Care coordination: Navigation by LP(a) test

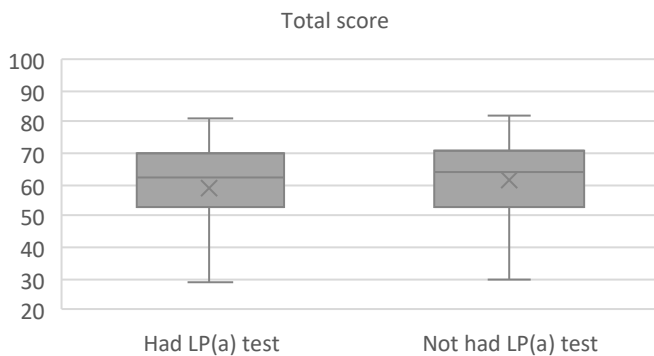


Figure 7.3: Boxplot of Care coordination: Total score by LP(a) test

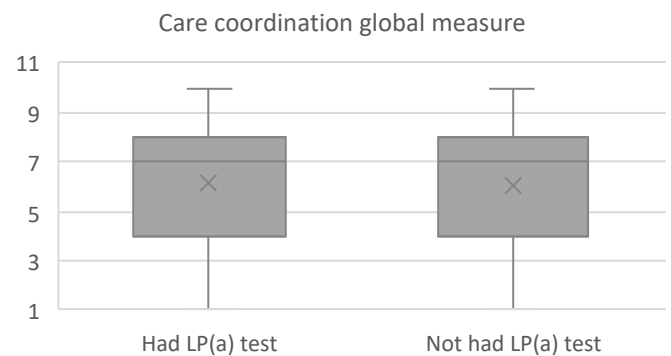


Figure 7.4: Boxplot of Care coordination: Care coordination global measure by LP(a) test

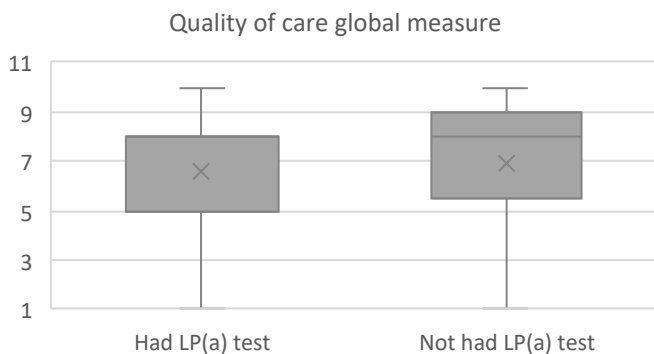


Figure 7.5: Boxplot of Care coordination: Quality of care global measure by LP(a) test

Care coordination by condition

Comparisons were made by the participants' **main condition**. There were 12 participants (24.00%) with high cholesterol aged under 50 years of age, 17 participants (34.00%) with blood vessel conditions, and 21 participants (42.00%) with heart conditions.

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

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

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

Table 7.4: Care coordination by main condition summary statistics and one-way ANOVA

Care coordination scale	Group	Number (n=50)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Navigation	High cholesterol under 50 years of age	8	16.33	22.00	5.41	Between groups	62.40	2	31.19	0.97	0.3870
	Blood vessel conditions	19	38.78	23.88	4.28	Within groups	1514.30	47	32.22		
	Heart conditions	22	44.90	24.86	6.70	Total	1576.70	49	63.41		
Care coordination global measure	High cholesterol under 50 years of age	8	16.33	6.50	2.39	Between groups	30.40	2	15.20	2.21	0.1210
	Blood vessel conditions	19	38.78	5.00	2.96	Within groups	323.30	47	6.88		
	Heart conditions	22	44.90	6.71	2.45	Total	353.70	49	22.08		

Table 7.5: Care coordination by main condition summary statistics and Kruskal-Wallis test

Care coordination scale	Group	Number (n=50)	Percent	Median	IQR	C ²	dF	p-value
Communication	High cholesterol under 50 years of age	8	16.33	38.00	12.25	1.48	2	0.4781
	Blood vessel conditions	19	38.78	35.00	13.00			
	Heart conditions	22	44.90	40.00	15.00			
Total score	High cholesterol under 50 years of age	8	16.33	62.50	17.75	1.66	2	0.4364
	Blood vessel conditions	19	38.78	62.00	18.00			
	Heart conditions	22	44.90	67.00	17.00			
Quality of care global measure	High cholesterol under 50 years of age	8	16.33	7.50	1.50	2.87	2	0.2386
	Blood vessel conditions	19	38.78	6.00	4.00			
	Heart conditions	22	44.90	8.00	2.00			

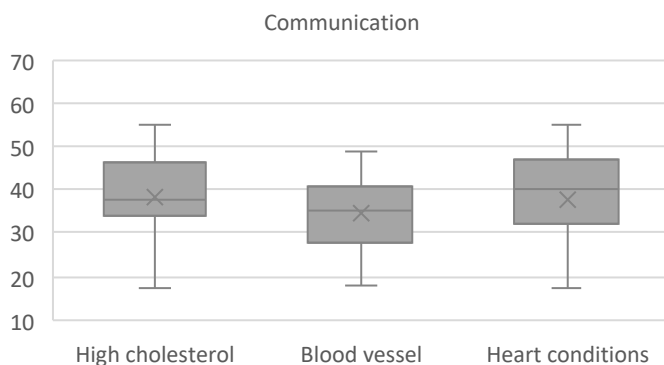


Figure 7.6: Boxplot of Care coordination: Communication by main condition

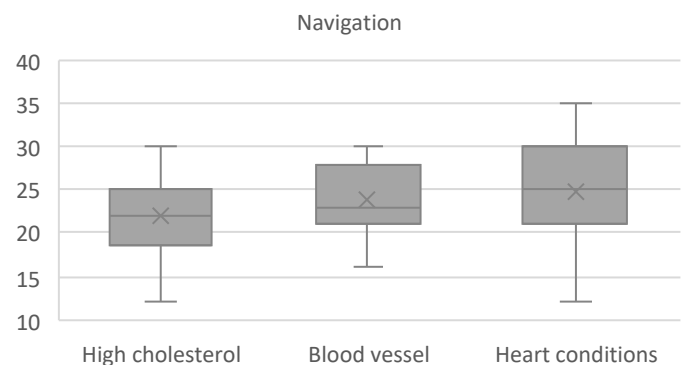


Figure 7.7: Boxplot of Care coordination: Navigation by main condition

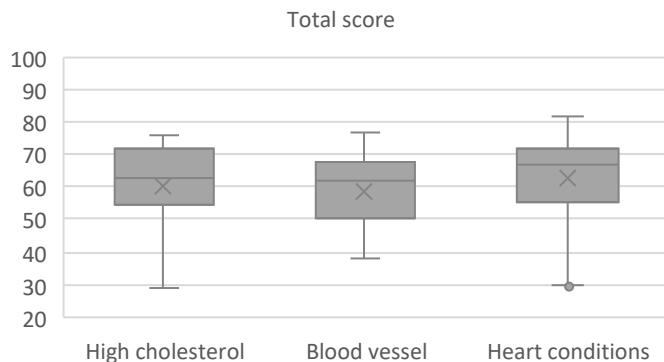


Figure 7.8: Boxplot of Care coordination: Total score by main condition

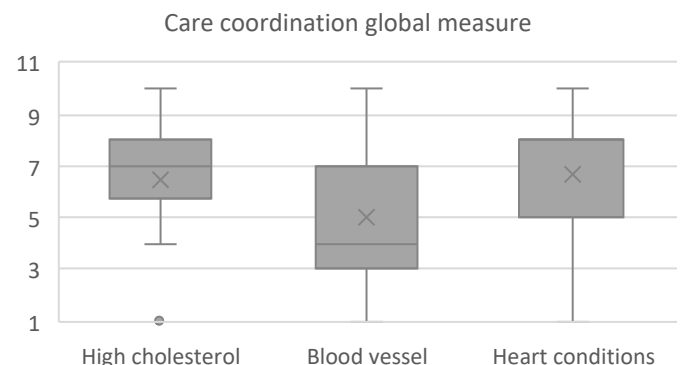


Figure 7.9: Boxplot of Care coordination: Care coordination global measure by main condition

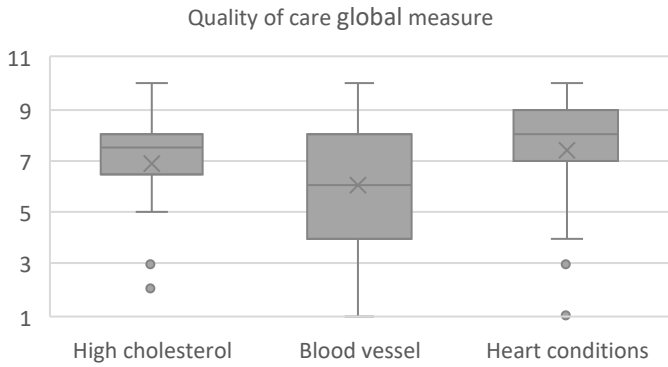


Figure 7.10: Boxplot of Care coordination: Quality of care global measure by main condition

Care coordination by other conditions

Comparisons were made by **number of other health conditions** there were 27 participants (54.00%) with 0 to 5 other conditions and, 23 participants (46.00%) with 6 to 11 other conditions.

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

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

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

Table 7.6: Care coordination by other conditions summary statistics and T-test

Care coordination scale	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Total score	0 to 5 other conditions	27	54.00	61.89	12.88	0.65	48	0.5202
	6 to 11 other conditions	23	46.00	59.30	15.34			
Care coordination global measure	0 to 5 other conditions	27	54.00	6.11	2.56	0.09	48	0.9304
	6 to 11 other conditions	23	46.00	6.04	2.88			

*Statistically significant at $p < 0.05$

Table 7.7: Care coordination by other conditions summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Communication	0 to 5 other conditions	27	54.00	40.00	11.50	343.00	0.5325
	6 to 11 other conditions	23	46.00	36.00	21.00		
Navigation	0 to 5 other conditions	27	54.00	23.00	10.00	311.50	0.9922
	6 to 11 other conditions	23	46.00	23.00	7.00		
Quality of care global measure	0 to 5 other conditions	27	54.00	8.00	2.50	378.00	0.1864
	6 to 11 other conditions	23	46.00	7.00	3.00		

*Statistically significant at $p < 0.05$

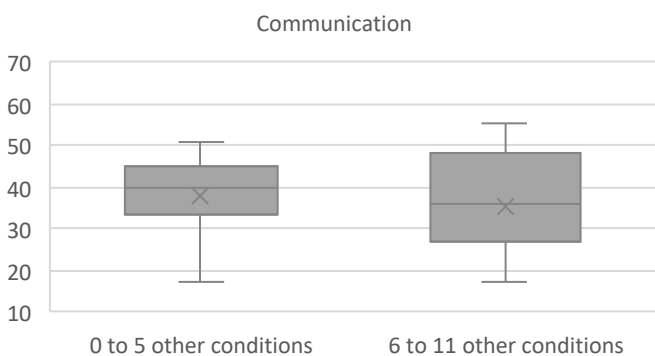


Figure 7.11: Boxplot of Care coordination: Communication by other conditions

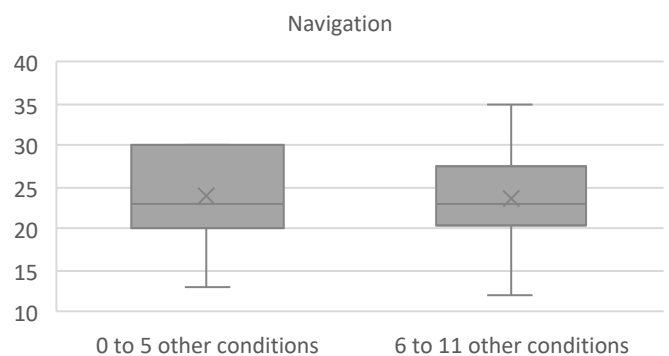


Figure 7.12: Boxplot of Care coordination: Navigation by other conditions

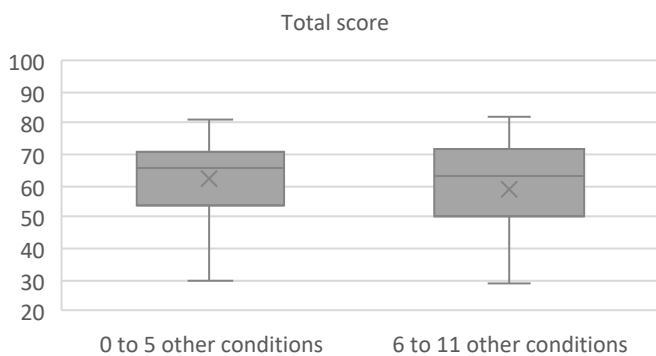


Figure 7.13: Boxplot of Care coordination: Total score by other conditions

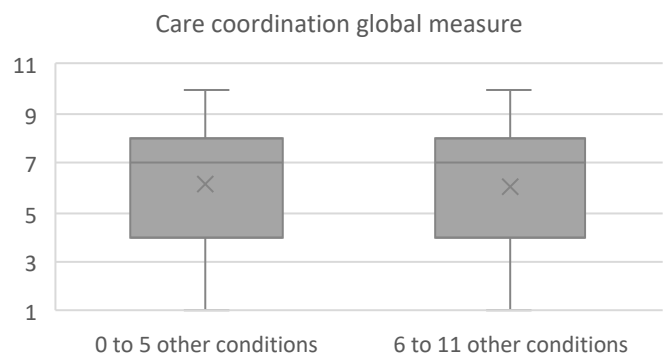


Figure 7.14: Boxplot of Care coordination: Care coordination global measure by other conditions

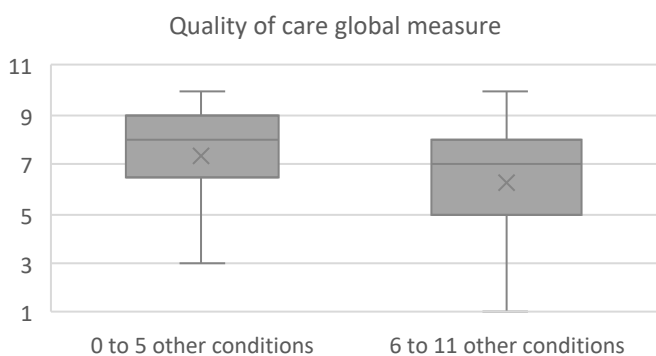


Figure 7.15: Boxplot of Care coordination: Quality of care global measure by other conditions

Care coordination by gender

Comparisons were made by **gender**, there were 28 female participants (56.00%), and 22 male participants (44.00%).

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

a Wilcoxon rank sum test with continuity correction was used.

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

Table 7.8: Care coordination by gender summary statistics and T-test

Care coordination scale	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Communication	Female	28	56	36.7142857	10.6765827	-0.10456	48	0.9172
	Male	22	44	37.0454545	11.6597691			
Navigation	Female	28	56	23.4285714	5.85901377	-0.57462	48	0.5682
	Male	22	44	24.3636364	5.51660225			

*Statistically significant at $p < 0.05$

Table 7.9: Care coordination by gender summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Total score	Female	28	56.00	64.50	18.50	294.50	0.7993
	Male	22	44.00	63.50	18.50		
Care coordination global measure	Female	28	56.00	6.50	4.25	261.00	0.3590
	Male	22	44.00	7.00	3.75		
Quality of care global measure	Female	28	56.00	7.00	4.25	281.50	0.6067
	Male	22	44.00	8.00	1.75		

*Statistically significant at $p < 0.05$

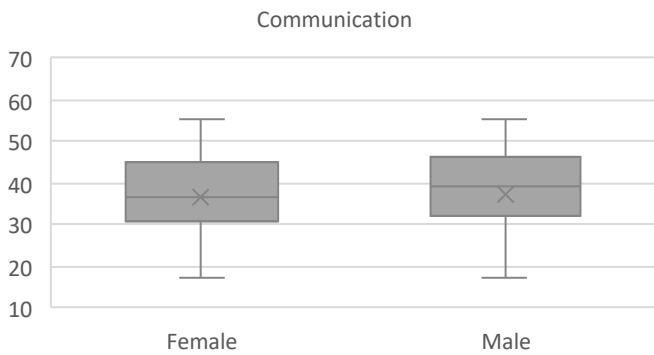


Figure 7.16: Boxplot of Care coordination: Communication by gender

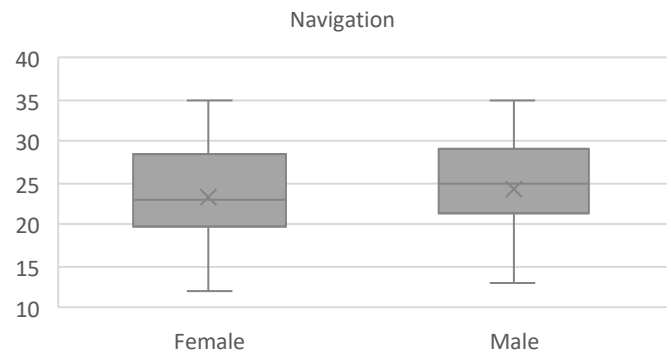


Figure 7.17: Boxplot of Care coordination: Navigation by gender

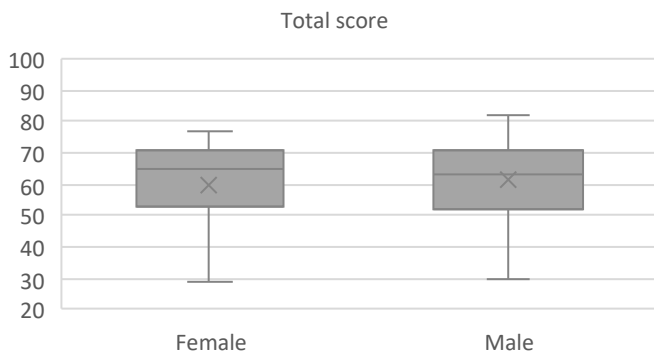


Figure 7.18: Boxplot of Care coordination: Total score by gender

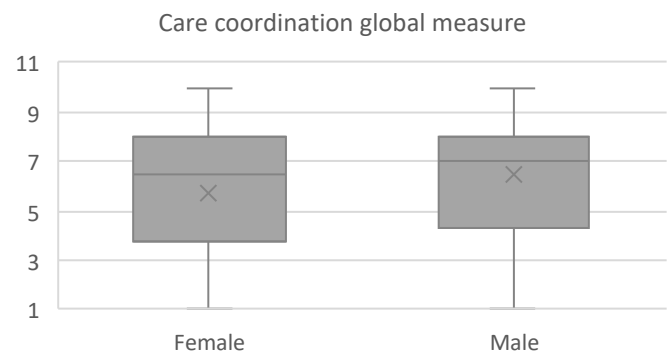


Figure 7.19: Boxplot of Care coordination: Care coordination global measure by gender

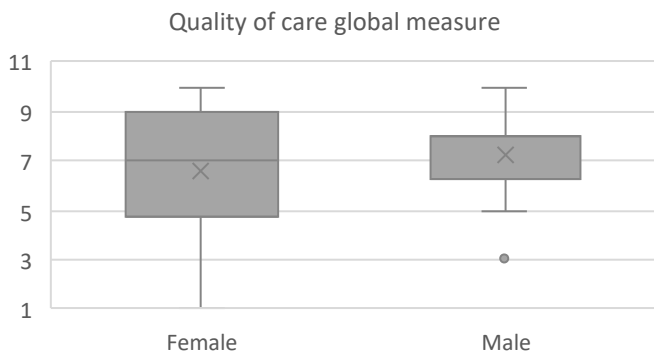


Figure 7.20: Boxplot of Care coordination: Quality of care global measure by gender

Care coordination by age

Participants were grouped according to **age**, with comparisons made between participants aged 25 to 44 (n=27, 54.00%), and participants aged 45 and older (n=23, 46.00%).

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

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

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

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

Care coordination scale	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Navigation	Aged 25 to 44	27	54.00	23.30	5.90	-0.73	48	0.4684
	Aged 45 and older	23	46.00	24.48	5.45			
Total score	Aged 25 to 44	27	54.00	60.30	15.08	-0.22	48	0.8275
	Aged 45 and older	23	46.00	61.17	12.88			

*Statistically significant at $p < 0.05$

Table 7.11: Care coordination by age summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Communication	Aged 25 to 44	27	54.00	40.00	15.50	333.50	0.6608
	Aged 45 and older	23	46.00	37.00	12.50		
Care coordination global measure	Aged 25 to 44	27	54.00	7.00	4.00	344.00	0.5167
	Aged 45 and older	23	46.00	7.00	4.00		
Quality of care global measure	Aged 25 to 44	27	54.00	8.00	3.50	341.50	0.5475
	Aged 45 and older	23	46.00	8.00	3.00		

*Statistically significant at $p < 0.05$

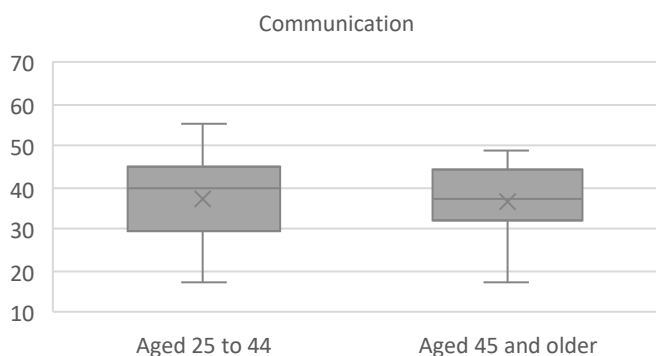


Figure 7.21: Boxplot of Care coordination: Communication by age

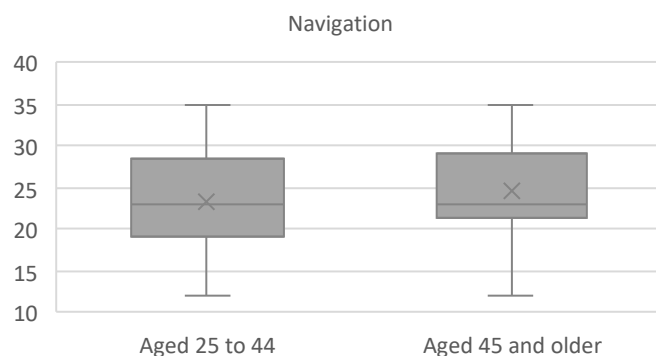


Figure 7.22: Boxplot of Care coordination: Navigation by age

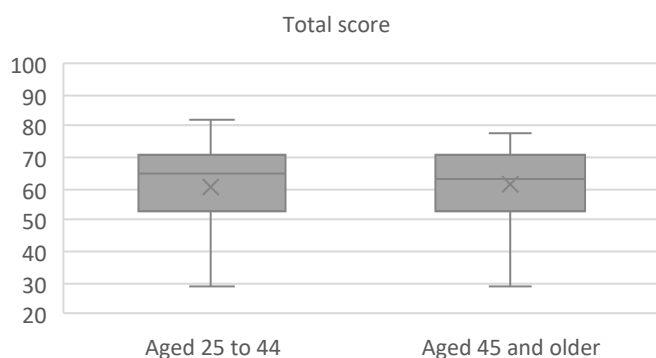


Figure 7.23: Boxplot of Care coordination: Total score by age

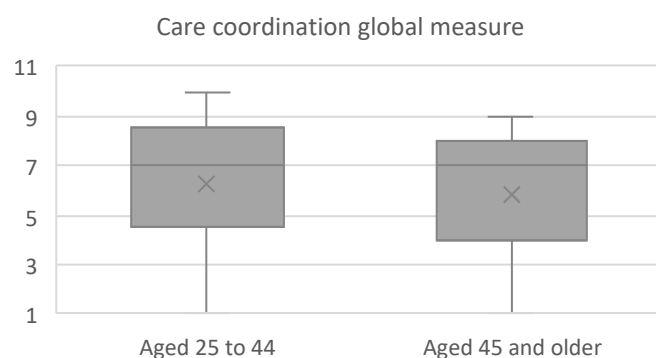


Figure 7.24: Boxplot of Care coordination: Care coordination global measure by age

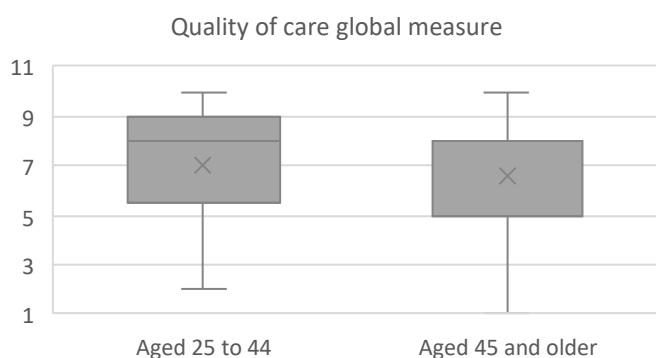


Figure 7.25: Boxplot of Care coordination: Quality of care global measure by age

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 areas (n=15, 30.00%) were compared to those living in metropolitan areas (n=35, 70.00%).

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

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

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

Table 7.12: Care coordination by location summary statistics and T-test

Care coordination scale	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Communication	Regional or remote	15	30.00	40.20	10.53	1.42	48	0.1622
	Metropolitan	35	70.00	35.43	11.04			
Navigation	Regional or remote	15	30.00	23.40	5.30	-0.36	48	0.7235
	Metropolitan	35	70.00	24.03	5.89			

*Statistically significant at p<0.05

Table 7.13: Care coordination by location summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Total score	Regional or remote	15	30.00	67.00	14.00	320.50	0.2230
	Metropolitan	35	70.00	62.00	18.50		
Care coordination global measure	Regional or remote	15	30.00	5.00	4.00	224.00	0.4168
	Metropolitan	35	70.00	7.00	3.00		
Quality of care global measure	Regional or remote	15	30.00	8.00	4.50	281.50	0.6915
	Metropolitan	35	70.00	8.00	2.50		

*Statistically significant at p<0.05

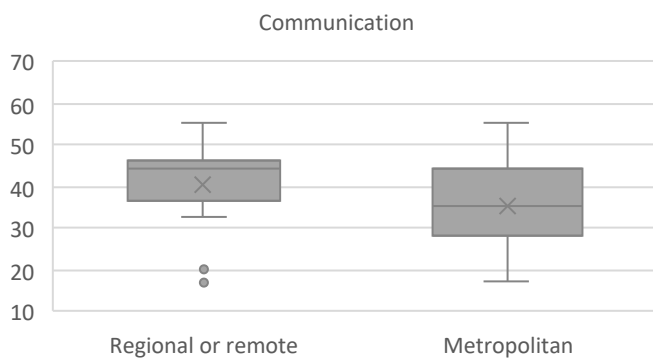


Figure 7.26: Boxplot of Care coordination: Communication by location

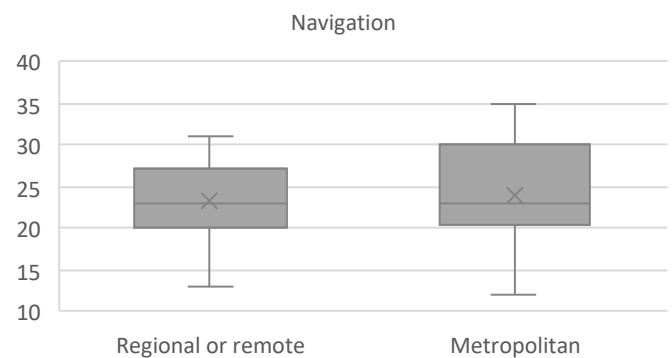


Figure 7.27: Boxplot of Care coordination: Navigation by location

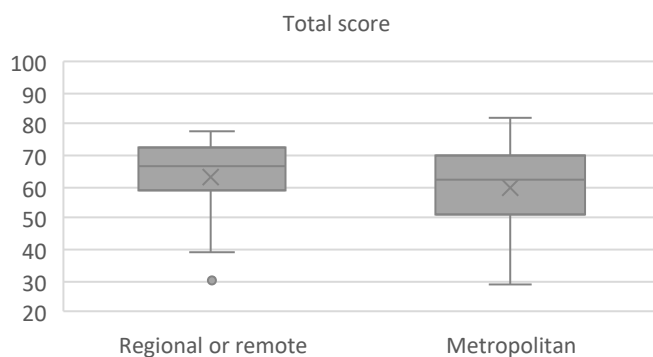


Figure 7.28: Boxplot of Care coordination: Total score by location

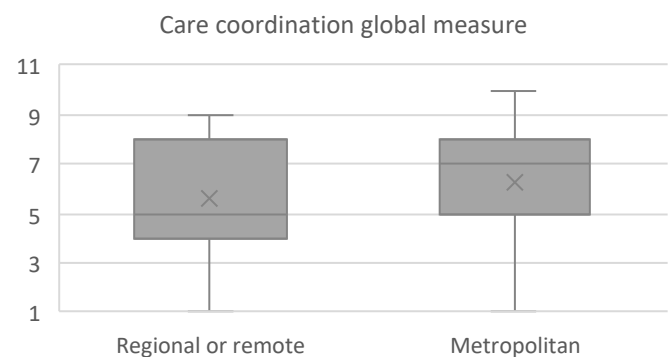


Figure 7.29: Boxplot of Care coordination: Care coordination global measure by location

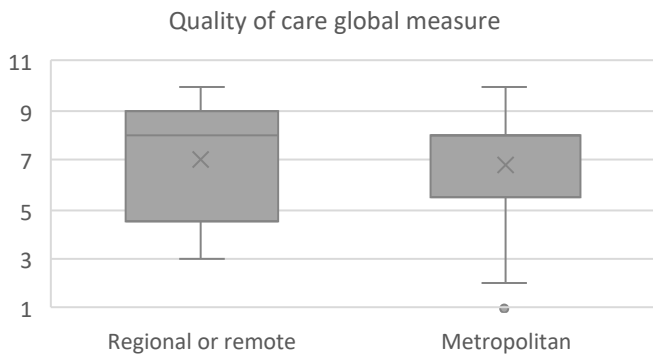


Figure 7.30: Boxplot of Care coordination: Quality of care global measure by location

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=25, 50.00%) compared to those with a higher SEIFA score of 7-10, Higher status (n=25, 50.00%).

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

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

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

Care coordination scale	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Navigation	Mid to low socioeconomic status	25	50.00	24.00	5.16	0.20	48	0.8443
	Higher socioeconomic status	25	50.00	23.68	6.24			

*Statistically significant at p<0.05

Table 7.15: Care coordination by socioeconomic status summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Communication	Mid to low socioeconomic status	25	50.00	40.00	15.00	386.50	0.1530
	Higher socioeconomic status	25	50.00	35.00	9.00		
Total score	Mid to low socioeconomic status	25	50.00	70.00	18.00	376.50	0.2175
	Higher socioeconomic status	25	50.00	62.00	15.00		
Care coordination global measure	Mid to low socioeconomic status	25	50.00	7.00	4.00	314.00	0.9844
	Higher socioeconomic status	25	50.00	6.00	4.00		
Quality of care global measure	Mid to low socioeconomic status	25	50.00	8.00	4.00	323.50	0.8365
	Higher socioeconomic status	25	50.00	7.00	3.00		

*Statistically significant at p<0.05

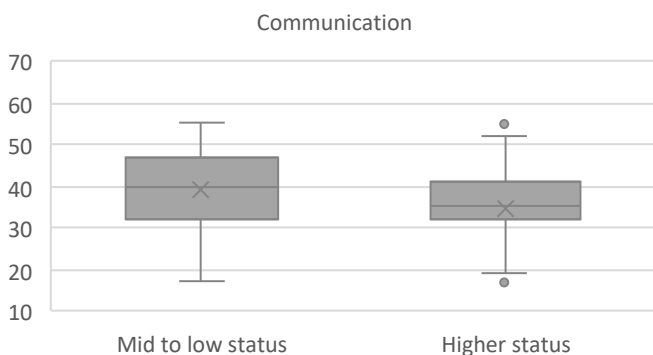


Figure 7.31: Boxplot of Care coordination: Communication by socioeconomic status

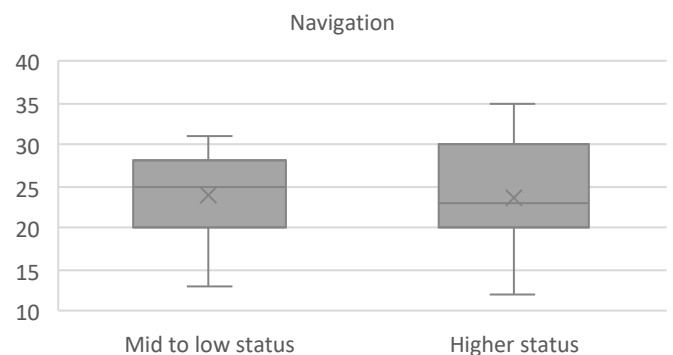


Figure 7.32: Boxplot of Care coordination: Navigation by socioeconomic status

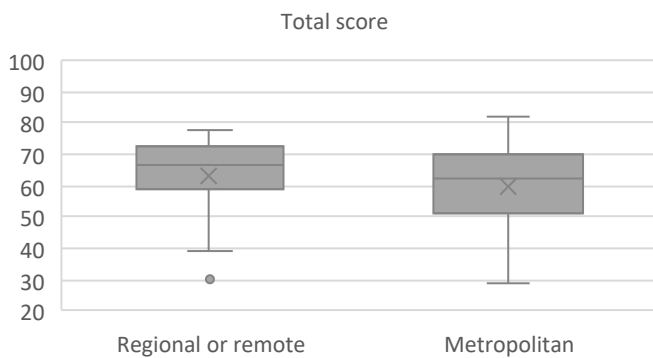


Figure 7.33: Boxplot of Care coordination: Total score by socioeconomic status

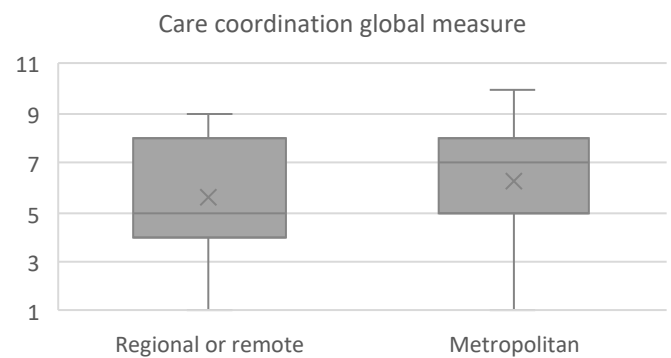


Figure 7.34: Boxplot of Care coordination: Care coordination global measure by socioeconomic status

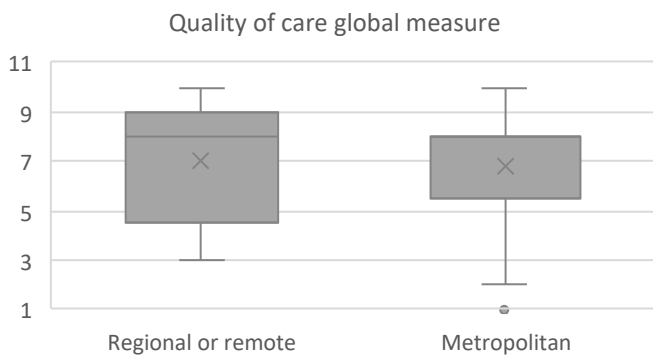


Figure 7.35: Boxplot of Care coordination: Quality of care global measure by socioeconomic status

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 sources of support and were from their hospital or clinical setting (31.91%), from family and friends (19.15%), domestic services and/or home care (14.89%), and peer support or other patients (8.51%). Almost a third described that they did not receive any formal support (27.66%), others described that they did not need or seek help or support (14.89%), and some described the challenges of finding or accessing support (10.64%).

Participant describes getting care and support from hospital or clinical setting

Healthcare workers have been wonderful, as I've said. I had to change GPs because I wasn't happy with one of my GP. The current GP, I had a good chat to him, and we started from the base, and that's when we discovered that I had severe hypertension and thus I had severe left ventricular hypertrophy. I'm very happy with what he's done. Support from my family, my immediate family is always very good. They make sure I don't -- sometimes they're just a bit too much

and make sure I'm not carrying stuff or -- they're gushing a bit much. I think before the AF, my immediate family kind of thought she's okay, she'll be fine, and that's how it's always been done. I think that's why my brother was so devastated when I got sick, I would say, because he didn't actually realise how serious -- although, yeah. Yeah, so no. I don't know. Everyone's great.

Participant 034_2023AUHBV

No. Other than no. No other than the allied health dietitian No.

Participant 001_2023AUHBV

PARTICIPANT: My GP.

INTERVIEWER: Yup.

PARTICIPANT: My cardiologist.

INTERVIEWER: Yup.

PARTICIPANT: The team at NAME HOSPITAL.

Participant 033_2023AUHBV

Participant describes that they did not receive any formal support

No, not yet.

Participant 003_2023AUHBV

*No. I can't say I have received any. No.
Participant 039_2023AUHBV*

Participant describes getting care and support from family and friends

*Only from my wife. My wife and children, but that's just normal love and affection, but no, nothing else.
Participant 038_2023AUHBV*

*No. Nothing. The only support I've really got is my daughter. It's just basically what I've got.
Participant 042_2023AUHBV*

Well it's my immediate family have been my main support and carers. I stayed with my parents for a week and a half, I think it was after I had the open-heart surgery. I've got a daughter who's 26 so she came around and helped me do quite a few things when I couldn't do them. Carers. I've never had a carer. Paid care or anything like that. Just my family really. They've been my support group. My friends. Health workers I've had the cardiac nurse just after surgery so that was good. I don't think there's anyone else. Participant 036_2023AUHBV

Participant describes that they did not need or seek help or support

*So only the initial cardiac rehab which which like I said earlier, I didn't find that in any way helpful or. More supportive? No. So other than that, no, no, not really. And I, but I also haven't gone and thought any. I haven't gone and thought the support either.
Participant 009_2023AUHBV*

*Nothing really. I mean my GP has been fantastic. We don't talk about it much. I just go there and he gives me the scripts and off I go. And family and friends, I think some of my friends don't even know. So I think it's been a non-event with everybody really.
Participant 037_2023AUHBV*

Participant describes getting care and support from domestic services and/or home care

*I did receive home help for about six weeks once I got home from hospital to assist with cleaning. It was very frustrating because they could vacuum most of the house but not my children's bedrooms because that didn't really impact. They were there for me and not the kids. I found that very frustrating because I would have to still vacuum after they left.
Participant 047_2023AUHBV*

INTERVIEWER: My next question is, have you received any support from health and community services to help manage the impact of your stroke since getting home? PARTICIPANT: Yes.

*INTERVIEWER: Where did you have that support from? PARTICIPANT: Homecare.
Participant 040_2023AUHBV*

Participant describes the challenges of finding or accessing support

That's a really good question, because I haven't asked for any care, as such, and I'll tell you why. Because I'm too embarrassed, and I really feel that I should do this by myself or with my wife. We're at the stage where we have been offered home care and all that sort of stuff. But we haven't accepted it, mainly because of embarrassment. As I see it, we're in this transition period of being totally dependent, or independent, rather, independent, and it looks like we're gonna have to move across to be dependent on other people. We're in that period where -- I mean, I'm flat out cleaning the shower, and I can run around with a vacuum cleaner, but to clean the shower is a bit challenging. But then I can call on a family member and they're probably gonna do it for me.

Participant 031_2023AUHBV

I currently see a psychologist and it's NDIS. She's an amazing woman. I call it giggle therapy because I don't know how, but we manage to just sit there and giggle for nearly an hour once a fortnight, which is amazing within itself because laughter makes you feel better. She's also a listening ear. Things are a bit tough for us. The cardiologist just let me down because he hasn't rung or because the neurologist was unable to give me any new advice or thoughts and just told me, "Yes, all good. See you in another six months." Whatever the case, she's been a good ear. Apart from that, no, I've just really had to advocate for myself and really speak clearly to the professionals about what I want, how I plan on achieving it, and what I need from them.

Participant 050_2023AUHBV

Participant describes getting care and support from peer support or other patients

PARTICIPANT: Yes, the cardiomyopathy association of Australia.

INTERVIEWER: Okay. And is that all online?

PARTICIPANT: No, we have meetings

INTERVIEWER: Yeah? That's great.

PARTICIPANT: And a seminar, I've been to some.
INTERVIEWER: Yeah.

PARTICIPANT: It's really good, and through that I've met two other women my age with defibrillators, and they're good mates, so we catch up every month or so.

INTERVIEWER: Wonderful.

Participant 032_2023AUHBV

Yeah, so I think from healthcare workers, patient groups have provided support, friends and family. So, after surgery usually, the church organised a meal

also. People bring around meals for us, or just come round and do the folding, or do something like that. I have a cleaner coming every fortnight, or sorry, once a month now, because I don't need them once a fortnight anymore, and so once a month, just to do the big clean of the house- --and then we just maintain it in between, which is a great help. So yeah, and they're the main supports I've had. I've never had community services in or nursing services in to help me after any of the surgeries or anything.

Participant 030_2023AUHBV

Table 7.16: Experience of care and support

Care and support received	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes getting care and support from hospital or clinical setting	15	31.91	5	27.78	10	34.48	3	33.33	4	23.53	8	38.10	10	37.04	5	25.00
Participant describes that they did not receive any formal support	13	27.66	8	44.44	5	17.24	4	44.44	4	23.53	5	23.81	7	25.93	6	30.00
Participant describes getting care and support from family and friends	9	19.15	2	11.11	7	24.14	2	22.22	1	5.88	6	28.57	4	14.81	5	25.00
Participant describes that they did not need or seek help or support	7	14.89	2	11.11	5	17.24	1	11.11	3	17.65	3	14.29	5	18.52	2	10.00
Participant describes getting care and support from domestic services and/or home care	7	14.89	3	16.67	4	13.79	1	11.11	4	23.53	2	9.52	4	14.81	3	15.00
Participant describes the challenges of finding or accessing support	5	10.64	0	0.00	5	17.24	0	0.00	4	23.53	1	4.76	3	11.11	2	10.00
Participant describes getting care and support from peer support or other patients	4	8.51	1	5.56	3	10.34	1	11.11	1	5.88	2	9.52	3	11.11	1	5.00
Participant describes getting care and support from charities	3	6.38	0	0.00	3	10.34	0	0.00	0	0.00	3	14.29	2	7.41	1	5.00
Participant describes getting care and support from psychologist or counselling service	3	6.38	1	5.56	2	6.90	0	0.00	1	5.88	2	9.52	2	7.41	1	5.00
Participant describes getting care and support from public or private health subsidies	3	6.38	1	5.56	2	6.90	1	11.11	1	5.88	1	4.76	2	7.41	1	5.00

Care and support received	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes getting care and support from hospital or clinical setting	15	31.91	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes that they did not receive any formal support	13	27.66	8	30.77	7	33.33	7	29.17	8	34.78	6	40.00	9	28.13	7	28.00	8	36.36
Participant describes getting care and support from family and friends	9	19.15	8	30.77	5	23.81	8	33.33	5	21.74	2	13.33	11	34.38	8	32.00	5	22.73
Participant describes that they did not need or seek help or support	7	14.89	3	11.54	6	28.57	4	16.67	5	21.74	3	20.00	6	18.75	4	16.00	5	22.73
Participant describes getting care and support from domestic services and/or home care	7	14.89	2	7.69	5	23.81	4	16.67	3	13.04	4	26.67	3	9.38	5	20.00	2	9.09
Participant describes the challenges of finding or accessing support	5	10.64	2	7.69	5	23.81	3	12.50	4	17.39	2	13.33	5	15.63	2	8.00	5	22.73
Participant describes getting care and support from peer support or other patients	4	8.51	4	15.38	1	4.76	1	4.17	4	17.39	2	13.33	3	9.38	3	12.00	2	9.09
Participant describes getting care and support from charities	3	6.38	3	11.54	1	4.76	1	4.17	3	13.04	1	6.67	3	9.38	1	4.00	3	13.64
Participant describes getting care and support from psychologist or counselling service	3	6.38	1	3.85	2	9.52	1	4.17	2	8.70	0	0.00	3	9.38	0	0.00	3	13.64
Participant describes getting care and support from public or private health subsidies	3	6.38	2	7.69	1	4.76	1	4.17	2	8.70	1	6.67	2	6.25	2	8.00	1	4.55

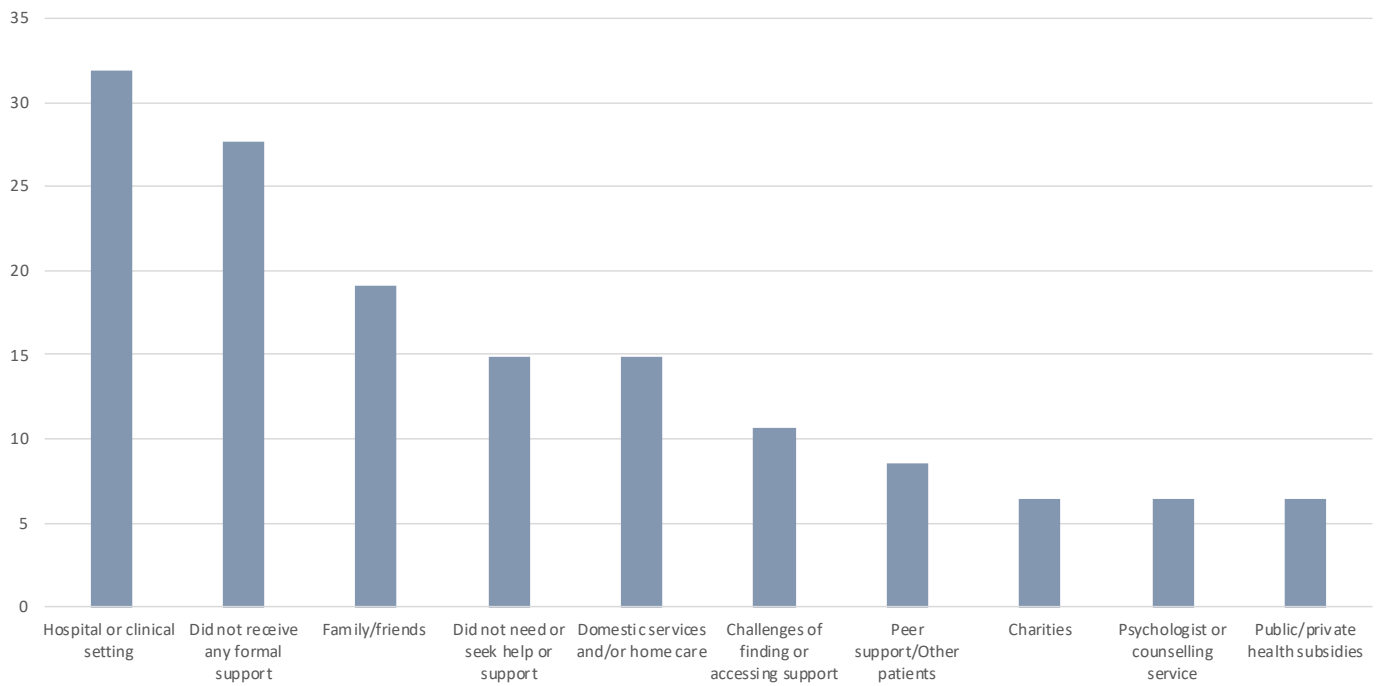


Figure 7.36: Experience of care and support

Table 7.17: Experience of care and support – subgroup variations

Care and support received	Reported less frequently	Reported more frequently
Participant describes that they did not receive any formal support	Did not had LP(a) test Regional or remote	Had LP(a) test High cholesterol under 50 years of age
Participant describes getting care and support from family and friends	Blood vessel conditions	-
Participant describes that they did not need or seek help or support	-	Regional or remote
Participant describes the challenges of finding or accessing support	Had LP(a) test High cholesterol under 50 years of age	Blood vessel conditions