Section 7

Care and support

Section 7 Summary: 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. On average, the participants in this study scored in the middle of the scale, indicating 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. On average, the participants in this study had good navigation of the healthcare system.

- The **"Care coordination: total score"** scale measures communication, navigation and overall experience of care coordination. On average, participants in this study had very 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. On average, participants in this study 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. On average, participants in this study rated their quality of care as excellent.

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 frequent description of care and support was family and friends (n=19, 52.78%). This was followed by receiving support through a hospital or clinical setting (n=14, 38.89%); through face-to-face peer support (n=10, 27.78%); through charities (n=7, 19.44%). There were seven participants that described finding or accessing support as challenging (19.44%).

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 highest quintile for **"Care coordination: Quality of care global measure"** (Median = 9.00, IQR = 1.00) indicating excellent quality of care.

On average, the scores for **"Care coordination: Navigation"** (Mean = 27.56, SD = 3.78), "**Care coordination: total score"** (Mean **=** 69.72, SD = 9.15), **"Care coordination: care coordination global measure"** (Median = 8.00, IQR = 2.00), were in the second highest quintile, indicating good navigation of the healthcare system, and overall care coordination.

On average, the score for "**Care coordination: communication"** (Mean = 42.17, SD = 7.11) was in the middle of the scale, indicating moderate communication.

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, the participants in this study scored in the middle of the scale, indicating 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. On average, the participants in this study had good navigation of the healthcare system.

The **"Care coordination: total score"** scale measures communication, navigation and overall experience of care coordination. On average, participants in this study had very 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. On average, participants in this study 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. On average, participants in this study rated their quality of care as excellent.

Table 7.1: Care coordination summary statistics

Care coordination scale (n=36)	Mean	SD	Median	IQR	Possible range	Quintile
Communication*	42.17	42.17	42.00	11.00	13 to 65	3
Navigation*	27.56	27.56	27.00	5.00	7 to 35	4
Total score*	69.72	69.72	72.00	12.50	20 to 100	4
Care coordination global measure	7.92	7.92	8.00	2.00	1 to 10	4
Quality of care global measure	8.44	8.44	9.00	1.00	1 to 10	5

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

Comparisons of Care coordination scales by Participant type

Participant type were grouped according to diagnosis. The *ATTR-cardiac* group includes participants diagnosed with hereditary or wild type ATTR (n=18, 50.00%). *All cardiac* includes all participants diagnosed with amyloidosis that have cardiac involvement, this group includes participants diagnosed with AL amyloidosis and ATTR (n=25, 64.44%). The *AL amyloidosis* group includes all participants diagnosed with AL amyloidosis, including any organ involvement (n=10, 27.78%). The final participant type are *Carers* to people with any type of amyloidosis (n=8, 22.22%).

Boxplots of each Care coordination scale by **Participant type** are displayed in Figures 7.1-7.5, summary statistics are displayed in Tables 7.2 and 7.3.

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 7.2).

When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 7.3). Post hoc pairwise comparisons using Wilcoxon rank sum test was used to identify the source of any differences identified in the Kruskal-Wallis test (Table 7.4).

A Kruskal-Wallis test indicated a statistically significant difference in the **"Care coordination: Navigation"** scale between groups, $\chi^2(3) = 9.05$, p = 0.0287. Wilcoxon rank sum tests between groups indicated that participants in the *All cardiac* subgroup (Median = 28.00, IQR = 5.00), scored significantly higher than participants in the *Carer* subgroup (Median = 24.00, IQR = 1.75, p = 0.0300), and participants in the *AL amyloidosis* subgroup (Median = 29.00, IQR = 3.50), scored significantly higher than participants in the *Carer* subgroup (Median = 24.00, IQR = 1.75, p = 0.0250).

A Kruskal-Wallis test indicated a statistically significant difference in the **"Care coordination: Total score"** scale between groups, $\chi^2(3) = 8.95$, p = 0.0220. Wilcoxon rank sum tests between groups indicated that participants in the *AL amyloidosis* subgroup (Median = 74.00, IQR = 3,25), scored significantly higher than participants in the *Carer* subgroup (Median = 61.00, IQR = 3.50, p = 0.0220).

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. On average, participants in the *All cardiac* and *AL amyloidosis* subgroups scored higher than participants in the *Carer* subgroup. However, all participants scored in the same range, this 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. On average, participants in the *AL amyloidosis* subgroup scored higher than participants in the *Carer* subgroup. This indicates that participants in the *AL amyloidosis* subgroup, had very good communication, navigation and overall experience of care coordination, compared to moderate communication and navigation for participants in the *Carer* subgroup.

Table7.2: Care coordination by Participant type ANOVA test and summary statistics

Care coordination scale	Group	Number (n=36)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Communication	ATTR-cardiac	18	50.00	42.17	8.49	Between groups	278.60	3	92.88	1.87	0.1440
	All-cardiac	25	69.44	43.12	7.42	Within groups	2826.40	57	49.59		
	AL amyloidosis	10	27.78	45.60	3.44	Total	3105.00	60			
	Carer	8	22.22	37.88	4.97						

Table 7.3: Care coordination by Participant type Kruskal-Wallis test and summary statistics

Care coordination scale	Group	Number (n=36)	Percent	Median	IQR	c^2	dF	p-value
Navigation	ATTR-cardiac	18	50.00	27.50	5.25	9.05	3	0.0287*
	All-cardiac	25	69.44	28.00	5.00			
	AL amyloidosis	10	27.78	29.00	3.50			
	Carer	8	22.22	24.00	1.75			
Total score	ATTR-cardiac	18	50.00	72.00	12.25	8.95	3	0.0299*
	All-cardiac	25	69.44	73.00	5.00			
	AL amyloidosis	10	27.78	74.00	3.25			
	Carer	8	22.22	61.00	3.50			
Care coordination global measure	ATTR-cardiac	18	50.00	8.50	1.00	5.02	3	0.1706
	All-cardiac	25	69.44	8.00	1.00			
	AL amyloidosis	10	27.78	8.50	1.00			
	Carer	8	22.22	6.50	2.50			
Quality of care global measure	ATTR-cardiac	18	50.00	9.00	1.00	0.06	2	0.9691
	All-cardiac	25	69.44	9.00	1.00			
	AL amyloidosis	10	27.78	9.00	1.50			
	Carer	8	22.22	8.00	2.00			

Table 7.4: Care coordination by Participant type post hoc pairwise Wilcoxon rank sum test

Care coordination scale	Type	ATTR-cardiac	All-cardiac	AL amyloidosis
Navigation	All-cardiac	0.8530	-	-
	AL amyloidosis	0.5830	0.5830	-
	Carer	0.0550	0.0300*	0.0250*
Total score	All-cardiac	0.6570	-	-
	AL amyloidosis	0.3030	0.3540	-
	Carer	0.1170	0.0550	0.0220*

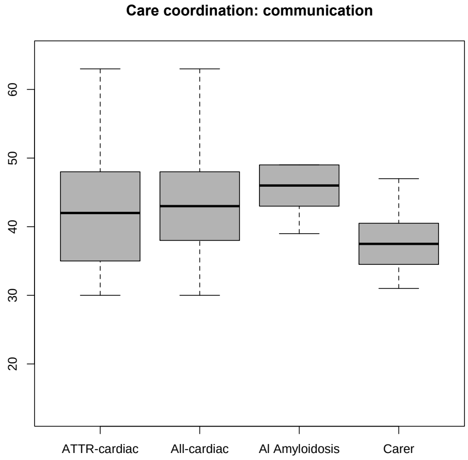


Figure 7.1: Boxplot of "Care coordination: Communication" by Participant type

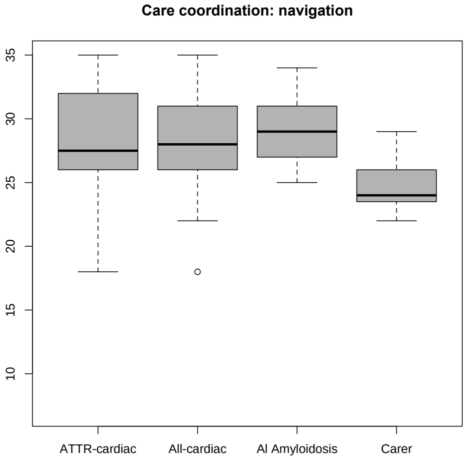


Figure 7.2: Boxplot of "Care coordination: Navigation" by Participant type

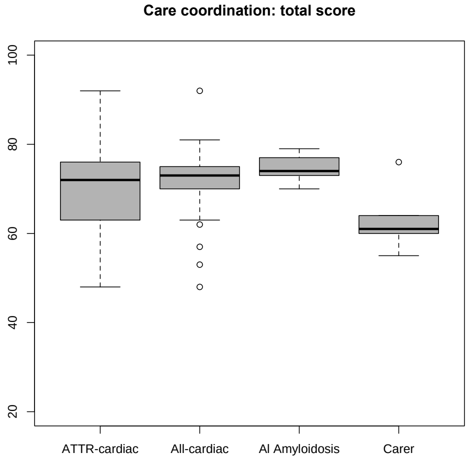


Figure 7.3: Boxplot of "Care coordination: Total score" by Participant type

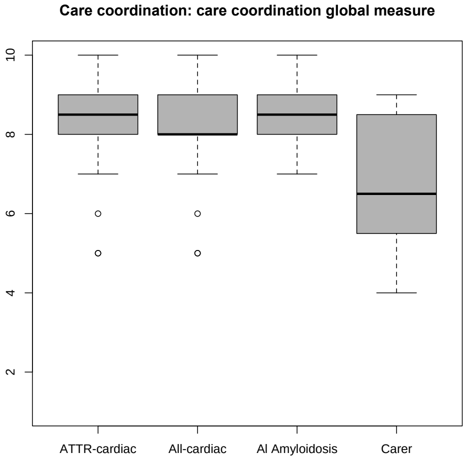


Figure 7.4: Boxplot of "Care coordination: Care coordination global measure" by Participant type

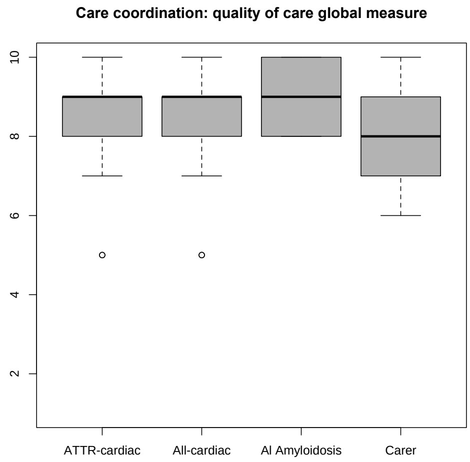


Figure 7.5: Boxplot of "Care coordination: Quality of care global measure" by Participant type

Comparisons of Care coordination scales by Gender

Comparisons were made by **Gender**, between *Males* (n=22, 61.11) and *Females* (n=14, 38.89%).

Boxplots of each Care coordination scale by **Gender** are displayed in Figures 7.6 to 7.10, summary statistics are displayed in Tables 7.5 to 7.6. A two-sample t-test was used when assumptions for normality and variance were met (Table 7.5), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.6).

A two sample t-test indicated that the mean score for the **"Care coordination Total score"** [t(34) = 2.21 p = 0.0341] was significantly higher for *Male* participants (Mean = 72.72, SD = 9.15) compared to *Female* participants (Mean = 65.71, SD = 7.88).

The "Care coordination: total score" scale measures communication, navigation and overall experience of care coordination. On average, *Male* participants in the scored higher than participants in the *Female* participants. This indicates that *Male* participants, had very good communication, navigation and overall experience of care coordination, compared to moderate communication and navigation for *Female* participants.

Table 7.5: Care coordination by Gender summary statistics and two sample t-test

Care coordination scale	Group	Number (n=36)	Percent	Mean	SD	t	dF	p-value
Communication	Female	14	38.89	39.29	5.70	2.02	34.00	0.0509
	Male	22	61.11	44.00	7.42			
Navigation	Female	14	38.89	26.43	3.50	1.45	34.00	0.1559
	Male	22	61.11	28.27	3.84			
Total score	Female	14	38.89	65.71	7.88	2.21	34.00	0.0341*
	Male	22	61.11	72.27	9.15			

Table 7.6: Care coordination by Gender summary statistics and Wilcoxon rank sum tests with continuity correction

Care coordination scale	Group	Number (n=36)	Percent	Median	IQR	W	p-value
Care coordination global measure	Female	14	38.89	8.00	2.75	181.00	0.3725
	Male	22	61.11	8.00	1.00		
Quality of care global measure	Female	14	38.89	8.50	1.75	171.50	0.5684
	Male	22	61.11	9.00	1.00		

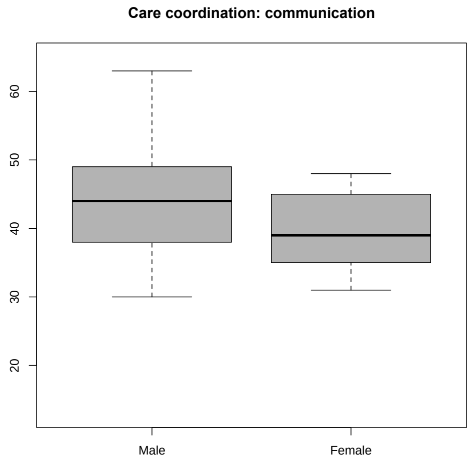


Figure 7.6: Boxplot of "Care coordination: Communication" by gender

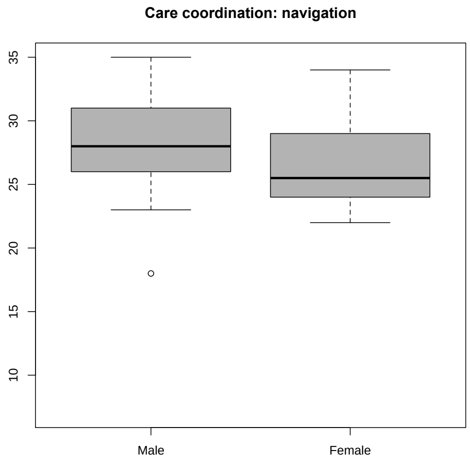


Figure 7.7: Boxplot of "Care coordination: Navigation" by gender

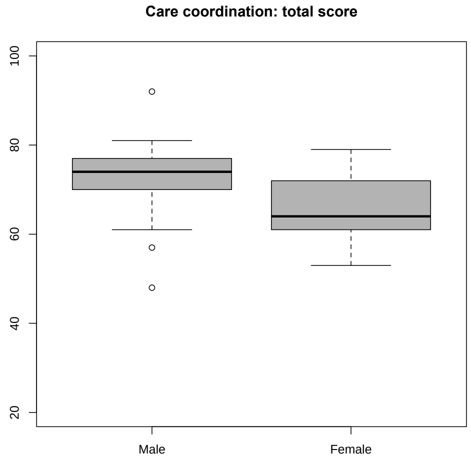


Figure 7.8: Boxplot of "Care coordination: Total score" by gender

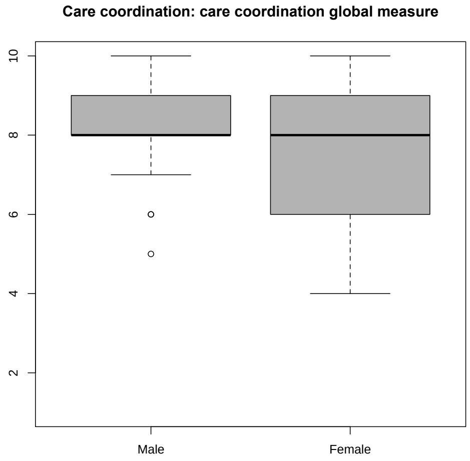


Figure 7.9: Boxplot of "Care coordination: Care coordination global measure" by gender

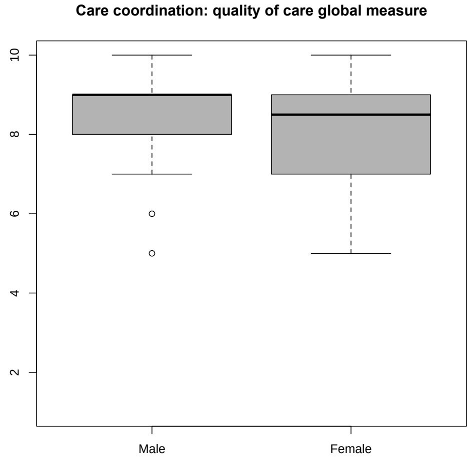


Figure 7.10: Boxplot of "Care coordination: Quality of care global measure" by gender

Comparisons of Care coordination scales 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 a major city, *Metropolitan* (n=27, 75.00%) were compared to those living in regional/rural areas, *Regional or remote* (n=9, 25.00%).

Boxplots of each Care coordination scale by **location** are displayed in Figures 7.11 to 7.15, summary statistics are displayed in Tables 7.7 to 7.8.

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.7), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.8).

No significant differences were observed between participants in the *Regional or remote* subgroup compared to those in the *Metropolitan* subgroup for any of the Care coordination scales.

Table 7.7: Care coordination by location summary statistics and two sample t-test

Care coordination scale	Group	Number (n=36)	Percent	Mean	SD	T	dF	p-value
Communication	Regional or remote	9	25.00	41.67	6.00	-0.24	34	0.8115
	Metropolitan	27	75.00	42.33	7.54			
Navigation	Regional or remote	9	25.00	26.67	3.00	-0.81	34	0.4227
	Metropolitan	27	75.00	27.85	4.01			
Total score	Regional or remote	9	25.00	68.33	7.58	-0.52	34	0.6064
	Metropolitan	27	75.00	70.19	9.71			

Table 7.8: Care coordination by location summary statistics and Wilcoxon rank sum tests with continuity correction

Care coordination scale	Group	Number (n=36)	Percent	Median	IQR	W	p-value
Care coordination global measure	Regional or remote	9	25.00	8.00	3.00	83.00	0.1500
	Metropolitan	27	75.00	8.00	1.00		
Quality of care global measure	Regional or remote	9	25.00	8.00	2.00	91.50	0.2652
	Metropolitan	27	75.00	9.00	1.50		

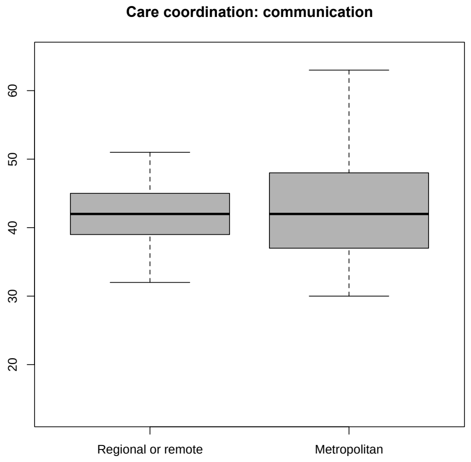


Figure 7.11: Boxplot of "Care coordination: Communication" by location

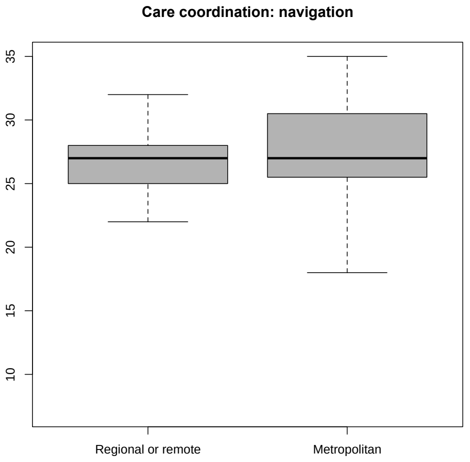


Figure 7.12: Boxplot of "Care coordination: Navigation" by location

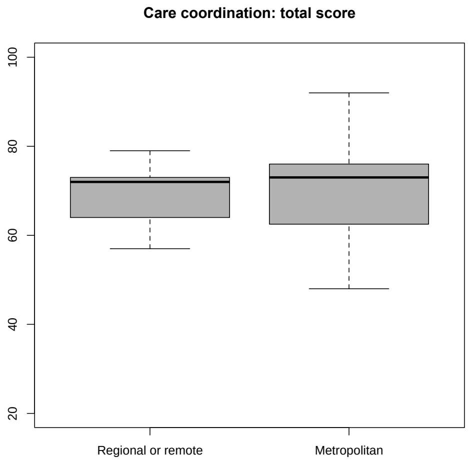


Figure 7.13: Boxplot of "Care coordination: Total score" by location

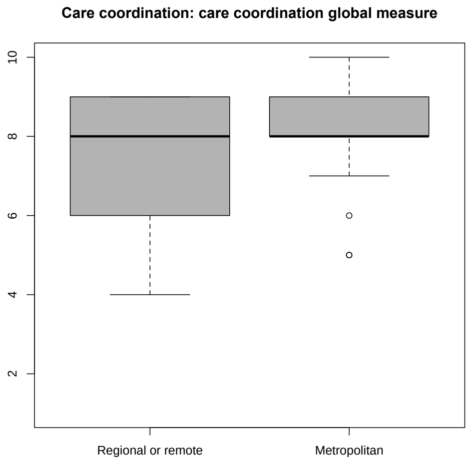


Figure 7.14: Boxplot of "Care coordination: Care coordination global measure" by location

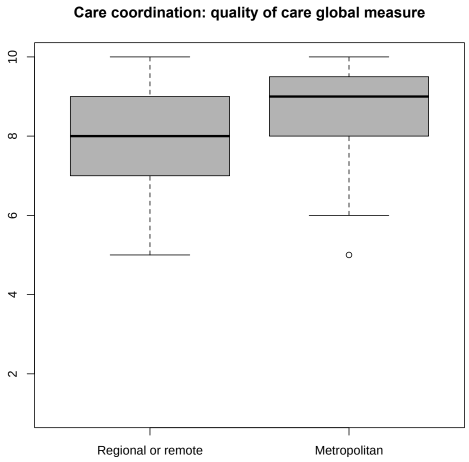


Figure 7.15: Boxplot of "Care coordination: Quality of care global measure" by location

Comparisons of Care coordination scales by age

Participants were groups according to **age,** with comparisons made between participants *Aged 55 to 64* (n=8, 22.86%), *Aged 65 to 74* (n=19, 54.29%), and *Aged 75 or older* (n=8, 22.86%). One participant was aged in the 25 to 34 year old age bracket and was excluded from age comparisons.

Boxplots of each Care coordination scale by **age** are displayed in Figures 7.16 to 7.20, summary statistics are displayed in Tables 7.9 and 7.10.

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 7.9).

When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 7.10).

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

Table 7.9: Care coordination by Age ANOVA test and summary statistics

Care coordination scale	Group	Number (n=35)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Navigation	Aged 55 to 64	8	22.86	25.63	5.42	Between groups	45.90	2	22.93	1.63	0.2120
	Aged 65 to 74	19	54.29	27.89	3.33	Within groups	450.50	32	14.08		
	Aged 75 or older	8	22.86	28.88	2.53	Total	496.40	34			

Table 7.10: Care coordination by Age Kruskal-Wallis test and summary statistics

Care coordination scale	Group	Number (n=35)	Percent	Mean	SD	c^2	dF	p-value
Navigation	*Aged 55 to 64*	8	22.86	33.50	11.00	5.69	2	0.0581
	Aged 65 to 74	19	54.29	43.00	9.50			
	Aged 75 or older	8	22.86	46.00	9.25			
Total score	*Aged 55 to 64*	8	22.86	60.50	16.00	5.10	2	0.0779
	Aged 65 to 74	19	54.29	73.00	12.50			
	Aged 75 or older	8	22.86	73.00	6.75			
Care coordination global measure	*Aged 55 to 64*	8	22.86	8.00	1.50	0.80	2	0.6705
	Aged 65 to 74	19	54.29	8.00	1.50			
	Aged 75 or older	8	22.86	8.50	1.25			
Quality of care global measure	*Aged 55 to 64*	8	22.86	8.00	1.50	0.24	2	0.8884
	Aged 65 to 74	19	54.29	9.00	1.00			
	Aged 75 or older	8	22.86	8.50	2.25			

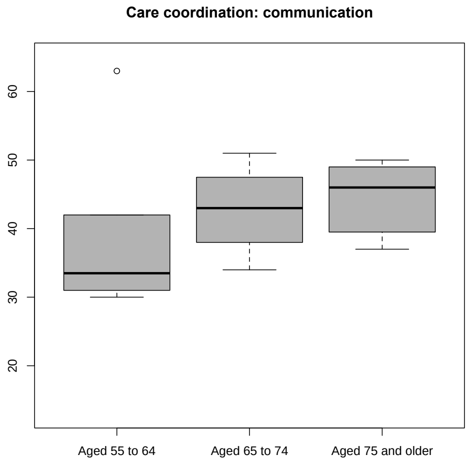


Figure 7.16: Boxplot of "Care coordination: Communication" by age

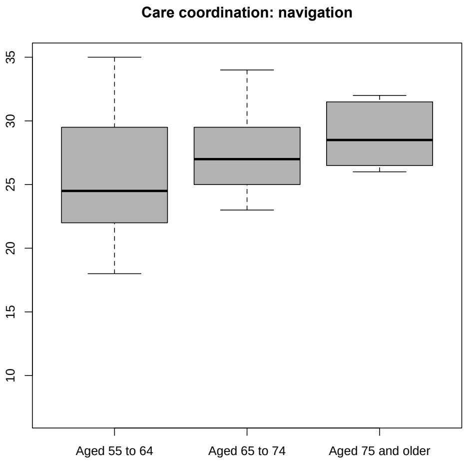


Figure 7.17: Boxplot of "Care coordination: Navigation" by age

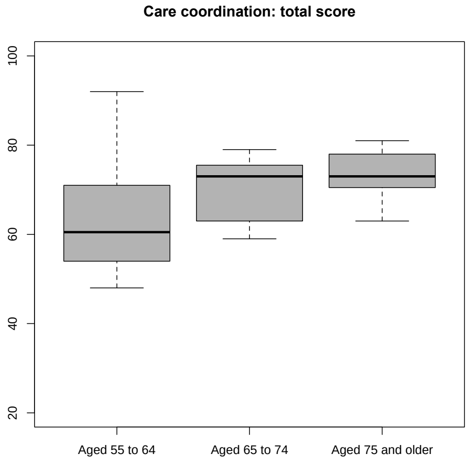


Figure 7.18: Boxplot of "Care coordination: Total score" by age

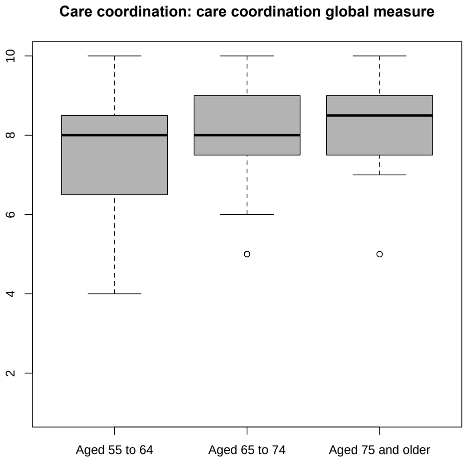


Figure 7.19: Boxplot of "Care coordination: Care coordination global measure" by age

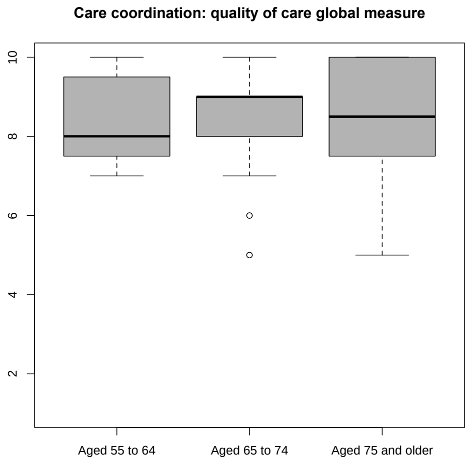


Figure 7.20: Boxplot of “Care coordination: Quality of care global measure” by age

Comparisons of Care coordination scales by education

Education status was collected only for participants diagnosed with amyloidosis (n=28). Comparisons were made by **education** status, between those with a university qualification, *University* (n= 14, 50.00%), and those with trade or high school qualifications, *Trade or high school* (n=14, 50.00%).

Boxplots of each Care coordination scale by **education** are displayed in Figures 7.21 to 7.25, summary statistics are displayed in Tables 7.11 to 7.12.

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

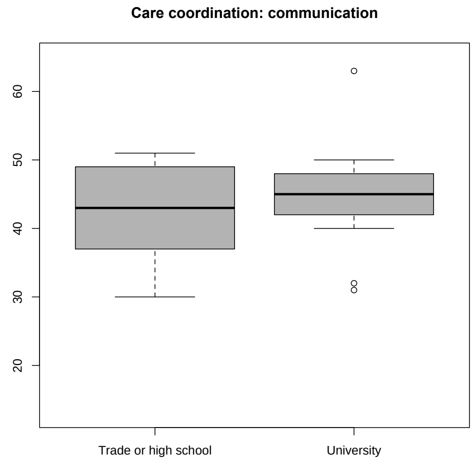
No significant differences were observed between participants in the *Trade or high school* subgroup compared to those in the university subgroup for any of the Care coordination scales.

Table 7.11: Care coordination by education summary statistics and two sample t-test

Care coordination scale	Group	Number (n=28)	Percent	Mean	SD	T	dF	p-value
Communication	Trade or high school	14	50.00	42.21	6.60	-0.86	26	0.3977
	University	14	50.00	44.57	7.85			
Navigation	Trade or high school	14	50.00	27.71	4.03	-0.90	26	0.3760
	University	14	50.00	29.00	3.51			

Table 7.12: Care coordination by education summary statistics and Wilcoxon rank sum tests with continuity correction

Care coordination scale	Group	Number (n=28)	Percent	Median	IQR	W	p-value
Total score	Trade or high school	14	50.00	71.50	7.75	66.00	0.1463
	University	14	50.00	74.50	6.00		
Care coordination global measure	Trade or high school	14	50.00	9.00	1.00	112.00	0.5144
	University	14	50.00	8.00	1.00		
Quality of care global measure	Trade or high school	14	50.00	9.00	1.75	91.50	0.7742
	University	14	50.00	9.00	1.00		



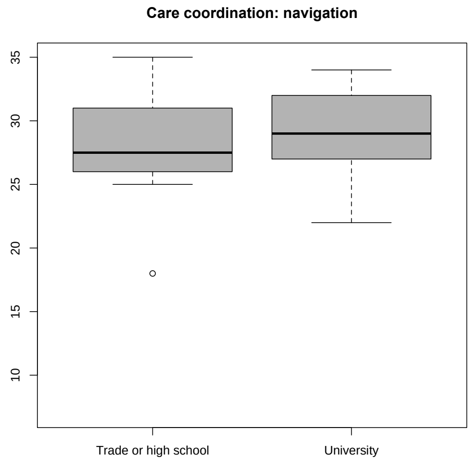
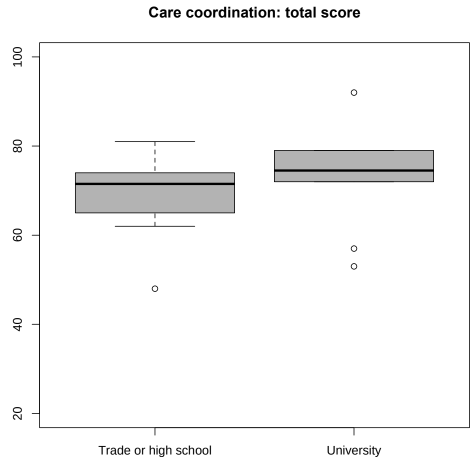


Figure 7.21: Boxplot of "Care coordination: Communication" by education

Figure 7.22: Boxplot of "Care coordination: Navigation" by education



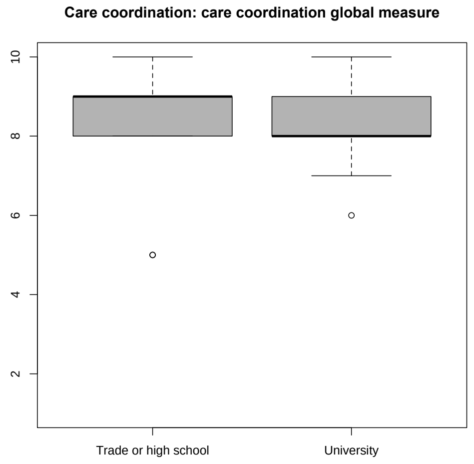


Figure 7.23: Boxplot of "Care coordination: Total score" by education

Figure 7.24: Boxplot of "Care coordination: Care coordination global measure" by education

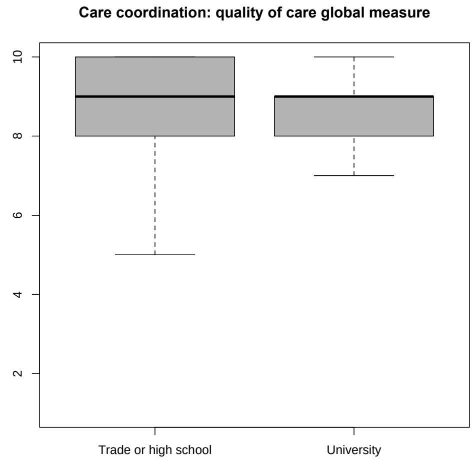


Figure 7.25: Boxplot of "Care coordination: Quality of care global measure" by education

Comparisons of Care coordination scales by SEIFA

Comparisons were made by 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 higher SEIFA score of 7-10, *Higher SEIFA* (n=25, 69.44%) compared to those with a mid to low SEIFA score of 1-6, *Mid to low SEIFA* (n=11, 30.56%).

Boxplots of each Care coordination scale by **SEIFA** are displayed in Figures 7.26 to 7.30, summary statistics are displayed in Tables 7.13 to 7.14.

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

No significant differences were observed between participants in the *Mid to low SEIFA* subgroup compared to those in the *Higher SEIFA* subgroup for any of the Care coordination scales.

Table 7.13: Care coordination by SEIFA summary statistics and two sample t-test

Care coordination scale	Group	Number (n=36)	Percent	Mean	SD	T	dF	p-value
Communication	Mid to low SEIFA	11	30.56	42.55	5.99	0.21	34	0.8356
	Higher SEIFA	25	69.44	42.00	7.66			
Navigation	Mid to low SEIFA	11	30.56	28.27	4.13	0.75	34	0.4576
	Higher SEIFA	25	69.44	27.24	3.65			
Total score	Mid to low SEIFA	11	30.56	70.82	7.41	0.47	34	0.6405
	Higher SEIFA	25	69.44	69.24	9.93			

Table 7.14: Care coordination by SEIFA summary statistics and Wilcoxon rank sum tests with continuity correction

Care coordination scale	Group	Number (n=36)	Percent	Median	IQR	W	p-value
Care coordination global measure	Mid to low SEIFA	11	30.56	9.00	3.00	135.50	0.9574
	Higher SEIFA	25	69.44	8.00	1.00		
Quality of care global measure	Mid to low SEIFA	11	30.56	9.00	1.50	123.00	0.6191
	Higher SEIFA	25	69.44	9.00	1.00		

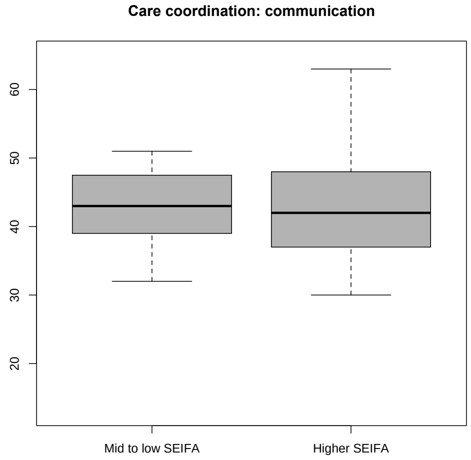


Figure 7.26: Boxplot of "Care coordination: Communication" by SEIFA

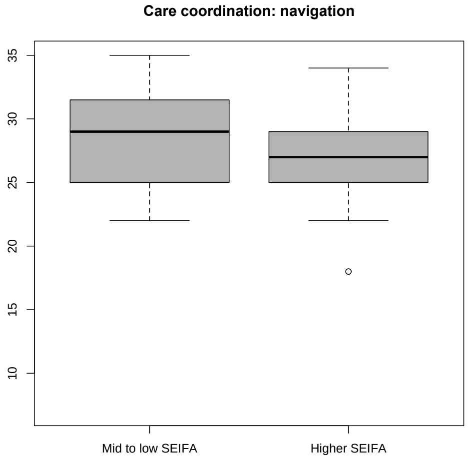


Figure 7.27: Boxplot of "Care coordination: Navigation" by SEIFA

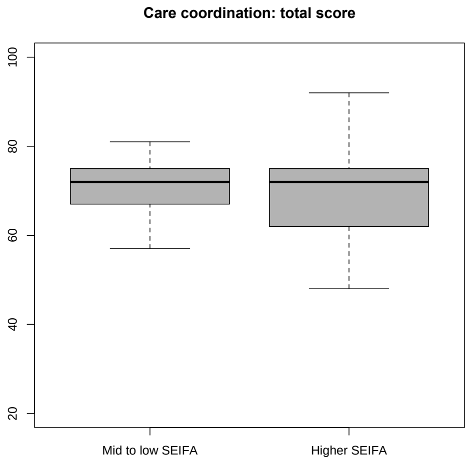


Figure 7.28: Boxplot of "Care coordination: Total score" by SEIFA

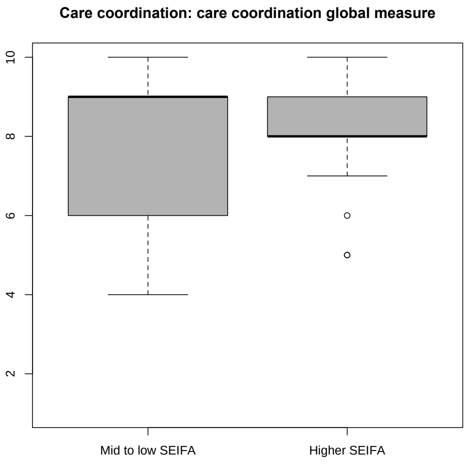


Figure 7.29: Boxplot of "Care coordination: Care coordination global measure" by SEIFA

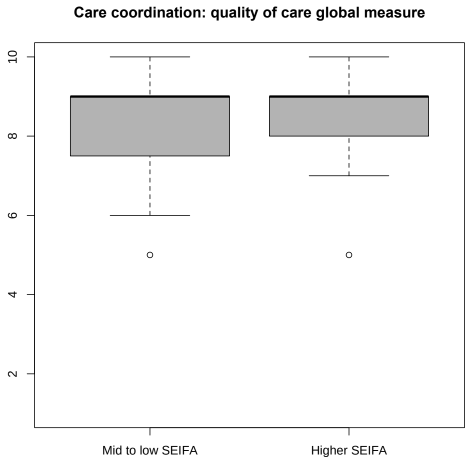


Figure 7.30: Boxplot of "Care coordination: Quality of care global measure" by SEIFA

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 description of care and support was family and friends (n=19, 52.78%). This was followed by receiving support through a hospital or clinical setting (n=14, 38.89%); through face-to-face peer support (n=10, 27.78%); through charities (n=7, 19.44%). There were seven participants described the challenges of finding or accessing support (19.44%).

In relation to subgroup variations, participants in the *Carer* (37.50%), and *Aged 65 to 74* (42.11%) subgroups described receiving support from family and/or friends less frequently than the general population (52.78%), while those in the *Aged 75 or older* (75.00%), *Trade or high school* (64.29%), and *Mid to low SEIFA* (63.64%) subgroups described this more frequently.

Participants in the *Aged 65 to 74* (52.63%), *University* (57.14%), and *Regional or remote* (55.56%) subgroups described receiving support from a hospital or clinical setting more frequently than the general population (38.89%), while those in the subgroups *Aged 55 to 64* (25.00%), *Aged 75 or older* (12.50%) and *Trade or high school* (21.43%) described this less frequently.

Participants in the *AL amyloidosis* (70.00%) subgroup described receiving support through peer support more frequently than the general population (27.78%), while those in the subgroups *ATTR-cardiac* (5.56%), *Aged 55 to 64* (12.50%), and *Regional or remote* (11.11%) described this less frequently.

Participants in the *AL amyloidosis* (30.00%), *Regional or remote* (44.44%), and *Mid to low SEIFA* (45.45%) described receiving support through charities more frequently than the general population (19.44%), while those in the *Higher SEIFA* (8.00%) subgroup described it less frequently.

Participants in the *University* (35.71%) subgroup described the challenged of finding or accessing support more frequently than the general population (19.44%), while those in the *Trade or high school* (7.14%), and *Mid to low SEIFA* (9.09%) subgroups described this less frequently.

Family/friends

Well, I haven't needed any support or care from the outside. I just generally got my normal family support. My family is concerned, and they're a little bit in the dark about the long-term situation as well. But it's like any illness, terminal or chronic. It's just what life deals out to you sometimes. So, I haven't required any external help and support because I've not needed it because I'm early in the diagnosis. Participant 001ATR

Most of it's been from my wife. Certainly, the church I attended in LOCATION considered me to be their miracle. I had tremendous support from the people there, I've had great support from friends and family in that period. Participant 002ALX

Since I have been diagnosed, I've gotten support mainly from many friends and family. Friends that we got a long relationship with or some new as well that are like-minded in terms of helping me out. Participant 002ATR

Charities

Friends of Amyloid, that we call it-- I look after NAME HOSPITAL Friends of Amyloid. We've got a couple of sub—I ORGANISE EVENTS for NAME HOSPITAL. I wouldn't be going over my head by saying that. There's another lady who organises three-monthly morning tea. We have, let's see, Leukaemia Foundation, who also have amyloid patients. We have a morning tea combined with every three months, and we all-- It's for patients and carers, husbands and wives. Participant 005AL

The Amyloidosis Association has been our biggest support when we need something. Like what I had said, my family has been brilliant. Participant 009ATR

Only in as much as participating workshops and events and talking to other people with similar conditions. Participant 011ATR

Hospital or clinical setting

NAME CLINIC, they have various seminars, et cetera, that I attend and also help organise or coordinate the support group which we meet every two months under the banner of NAME CLINIC. I find that helpful just talking to people without doing specifics, just talk to see how we're going, et cetera. Participant 001ALX

No, we haven't had any extra really. It's really been specialists and he's had to occasionally have a GP visit, but no, we haven't resorted to any other care at this stage at all. Participant 001CA

Well, medical that's really it. Participant 002CA

Peer support (Face-to-face)

Both of wife and myself have been going to things, morning teas usually by the Leukaemia Foundation. Also, our own group where we just have the amyloidosis group. As I said, we have morning teas in various places. We have 20, 30 people turn up to those. People have got different problems and that's done as a round table. A few lies are told and a few laughs and [unintelligible 00:41:18] as well or had. It's quite a supportive group really and we send the emails to one another. My wife's involved with all of those things. The kids, obviously, aren't because they're working and they're not here in LOCATION REGIONAL. Participant 003AL

My husband is supportive. It's just the two of us at home now. With the support group I've maybe been to two of them I suppose. The social support group has been incredibly supportive. Really wonderful. I'll come away feeling quite uplifted really just the camaraderie is amazing really, the general sort of we're in this together, we'll support each other, we'll pull through somehow or rather and those who eventually won't pull through, the support is amazing. It's lovely. It's just really lovely.

Probably my main support would be those groups, amyloid groups. Participant 003ALX

Now, I know that NAME HUSBAND really enjoys the amyloid group that gets together and that's really important to him. It's really important that he didn't feel alone because it is rare, it's hard to find anybody that knows anything about it. I know that if ever we went to a doctor, we'd have to explain to them what it was all about because at that stage, they had no idea. That group has been really, really important to NAME HUSBAND. Participant 003CA

Challenges of finding or accessing support

I think the answer is that there is almost more that could be done to assist us. Just to provide better assistance. Because life always has to explain to different aspects in the situation and everybody also is different will be affected in different ways. Just a matter, again, to discover what is going on inside and also doctor patients may we require further assistance. Participant 005ATR

The trouble with accessing psychological services in this country is they're extremely expensive. I think NAME HUSBAND might have said when he was speaking to you that he's a psychologist. Actually, when I told him that I wanted to speak to a psychologist, he said, 'Oh, you can speak to me.' He's completely missing the point that it was him I needed to talk about. I think that's the main barrier, is that the cost barrier and it takes a long time to-- I saw somebody at the very beginning and then I didn't feel I was getting anywhere, so, I was fine, then I went through another difficult patch. I guess as you adjust to the changes in your relationship because that changes completely, it's not husband or wife anymore. Your physical relationship has changed because one of you is telling the other all the time what to do and what they shouldn't do. Participant 002CA

Yes, care is a really important thing. I think the system is there, but I don't think there's enough money in it to allow people to do the things that they need to do. I've been assessed by the aged care people. Once I-- she walked in and looked at me like, 'I could tell. What's wrong with you? You're just looking for some handouts.' Participant 013ATR

Table 7.15: Experience of care and support

Care and support received	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes receiving support from family/friends	19	52.78	11	61.11	14	56.00	5	50.00	**3**	**37.50**	11	50.00	8	57.14	5	55.56	14	51.85
Participant describes receiving support from a hospital or clinical setting	14	38.89	7	38.89	10	40.00	4	40.00	3	37.50	9	40.91	5	35.71	**5**	**55.56**	9	33.33
Participant describes receiving support through peer support (Face-to-face)	10	27.78	**1**	**5.56**	5	20.00	**7**	**70.00**	2	25.00	6	27.27	4	28.57	**1**	**11.11**	9	33.33
Participant describes receiving support through charities	7	19.44	3	16.67	6	24.00	**3**	**30.00**	1	12.50	5	22.73	2	14.29	**4**	**44.44**	3	11.11
Participant describes challenges of finding or accessing support	7	19.44	5	27.78	6	24.00	1	10.00	1	12.50	5	22.73	2	14.29	1	11.11	6	22.22

Care and support received	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes receiving support from family/friends	19	52.78	5	62.50	**8**	**42.11**	**6**	**75.00**	**9**	**64.29**	7	50.00	**7**	**63.64**	12	48.00
Participant describes receiving support from a hospital or clinical setting	14	38.89	**2**	**25.00**	**10**	**52.63**	**1**	**12.50**	**3**	**21.43**	**8**	**57.14**	5	45.45	9	36.00
Participant describes receiving support through peer support (Face-to-face)	10	27.78	**1**	**12.50**	6	31.58	3	37.50	3	21.43	5	35.71	2	18.18	8	32.00
Participant describes receiving support through charities	7	19.44	1	12.50	5	26.32	1	12.50	4	28.57	2	14.29	**5**	**45.45**	**2**	**8.00**
Participant describes challenges of finding or accessing support	7	19.44	2	25.00	3	15.79	2	25.00	**1**	**7.14**	**5**	**35.71**	**1**	**9.09**	6	24.00

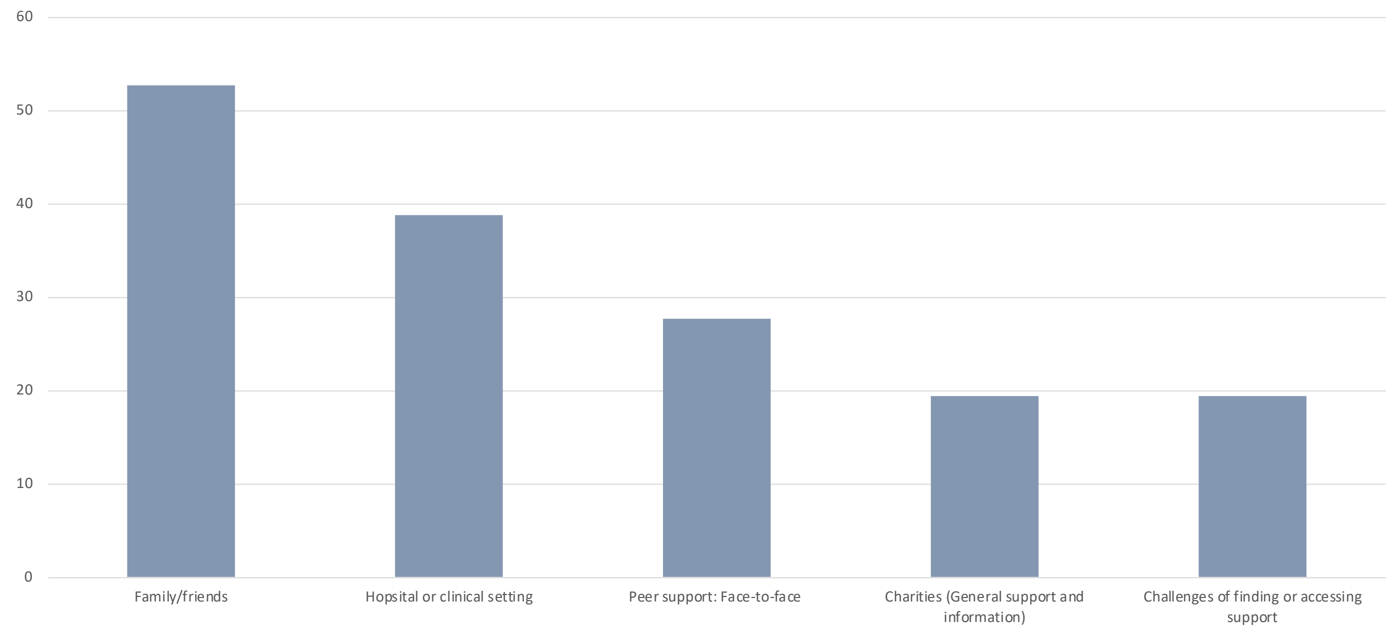


Figure 7.31: Experience of care and support