

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 average.

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 average.

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 response was that they did not receive any formal support (41.67%). Others described getting support from peer support or other patients (16.67%), charities (8.33%), community or religious groups (8.33%), family and friends (8.33%), hospital or clinical setting (8.33%), and financial support including financial counselling (8.33%).

Care coordination

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

The overall scores for the cohort were in the second highest quintile for Care coordination: Navigation (mean=24.23, SD=6.75) indicating good communication.

The overall scores for the cohort were in the middle quintile for Care coordination: Communication (mean=37.69, SD=11.14), Care coordination: Total score (mean=61.92, SD=15.24), Care coordination: Care coordination global measure (mean=6.23, SD=3.14), and Care coordination: Quality of care global measure (mean=6.00, SD=2.92) indicating moderate communication, moderate care coordination, moderate care coordination, and moderate quality of care

Comparisons of Care coordination have been made based on gender, age, education, location and socioeconomic status (Tables 7.2 to 7.6 Figures 7.1 to 7.15).

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.

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Table 7.1: Care coordination summary statistics

Care coordination scale (n=13)	Mean	SD	Median	IQR	Possible range	Quintile
Communication*	37.69	11.14	38.00	12.00	13 to 65	3
Navigation*	24.23	6.75	24.00	10.00	7 to 35	4
Total score*	61.92	15.24	65.00	18.00	20 to 100	3
Care coordination global measure*	6.23	3.14	6.00	6.00	1 to 10	3
Quality of care global measure*	6.00	2.92	6.00	5.00	1 to 10	3

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

Care coordination by gender

Comparisons were made by Gender, there were 6 female participants (46.15%), and 7 male participants (53.85%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 7.2).

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

Table 7.2: Care coordination by gender summary statistics and and T-test

Care coordination scale	Group	Number (n=13)	Percent	Mean	SD	T	dF	p-value
Communication	Female	6	46.15	36.50	12.05	-0.34	11	0.7374
	Male	7	53.85	38.71	11.16			
Navigation	Female	6	46.15	26.17	5.81	0.95	11	0.3605
	Male	7	53.85	22.57	7.48			
Total score	Female	6	46.15	62.67	14.53	0.16	11	0.8788
	Male	7	53.85	61.29	16.96			
Care coordination global measure	Female	6	46.15	6.50	3.67	0.27	11	0.7884
	Male	7	53.85	6.00	2.89			
Quality of care global measure	Female	6	46.15	6.17	3.31	0.18	11	0.8581
	Male	7	53.85	5.86	2.79			

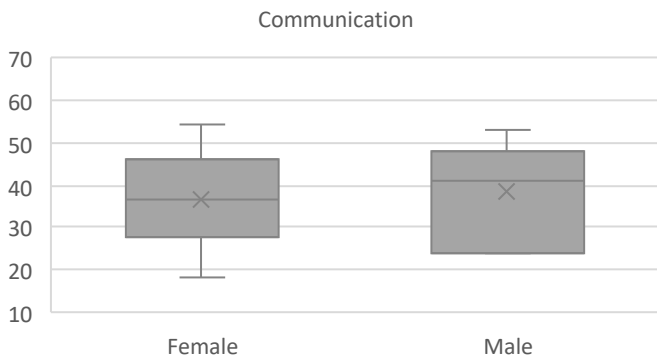


Figure 7.1: Boxplot of Care coordination: Communication by gender

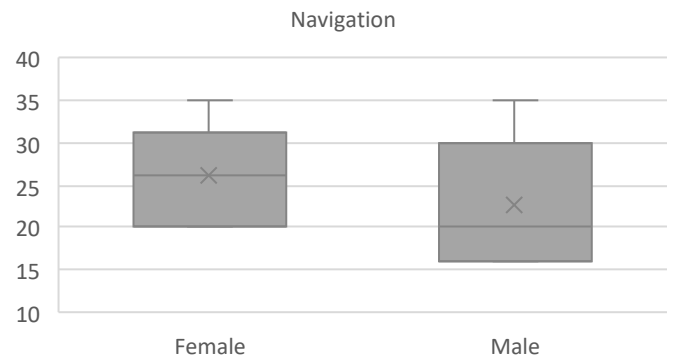


Figure 7.2: Boxplot of Care coordination: Navigation by gender

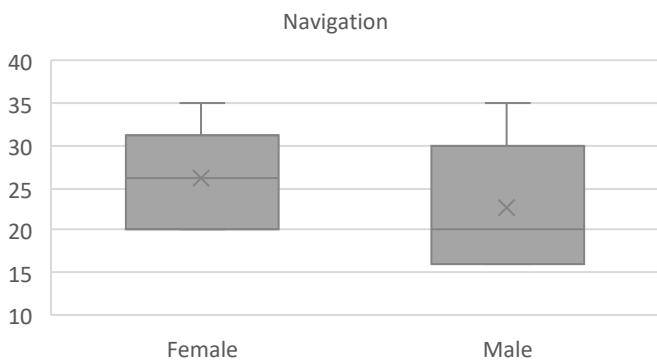


Figure 7.3: Boxplot of Care coordination: Total score by gender

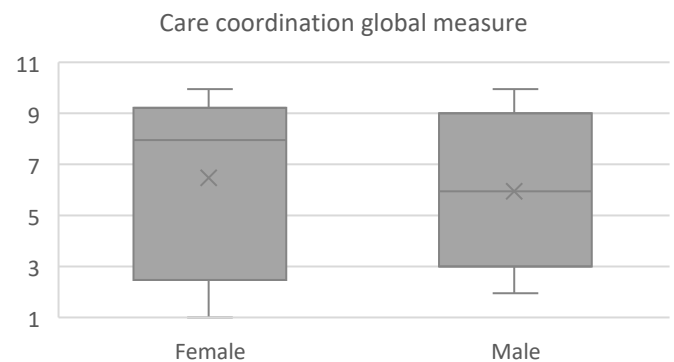


Figure 7.4: Boxplot of Care coordination: Care coordination global measure by gender

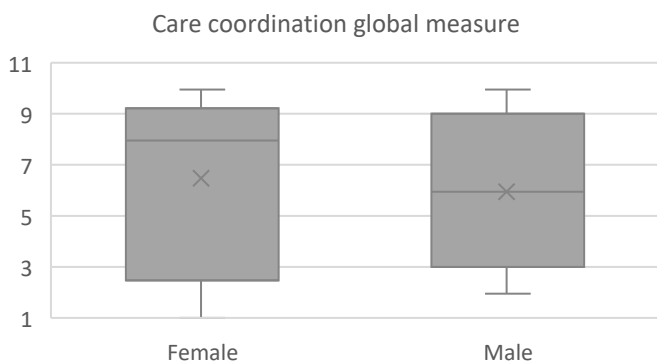


Figure 7.5: Boxplot of Care coordination: Quality of care global measure by gender

Care coordination by age

Participants were grouped according to age, with comparisons made between participants aged under 44 (n=7, 53.85%), and participants aged 45 and older (n=6, 46.15%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 7.3).

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

Table 7.3: Care coordination by age summary statistics and and T-test

Care coordination scale	Group	Number (n=13)	Percent	Mean	SD	T	dF	p-value
Communication	Aged 18 to 44	7	53.85	37.29	9.48	-0.14	11	0.8941
	Aged 45 and older	6	46.15	38.17	13.76			
Navigation	Aged 18 to 44	7	53.85	24.57	6.32	0.19	11	0.8539
	Aged 45 and older	6	46.15	23.83	7.81			
Total score	Aged 18 to 44	7	53.85	61.86	9.03	-0.02	11	0.9874
	Aged 45 and older	6	46.15	62.00	21.44			
Care coordination global measure	Aged 18 to 44	7	53.85	5.86	3.34	-0.45	11	0.6631
	Aged 45 and older	6	46.15	6.67	3.14			
Quality of care global measure	Aged 18 to 44	7	53.85	5.00	2.94	-1.39	11	0.1932
	Aged 45 and older	6	46.15	7.17	2.64			

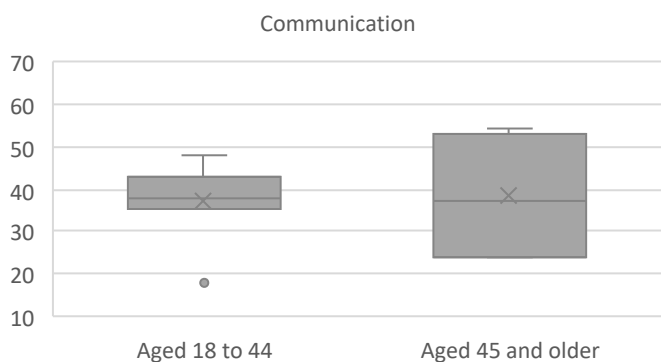


Figure 7.6: Boxplot of Care coordination: Communication by age

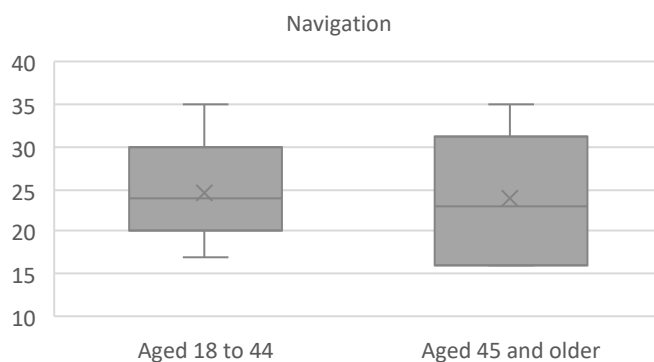


Figure 7.7: Boxplot of Care coordination: Navigation by age

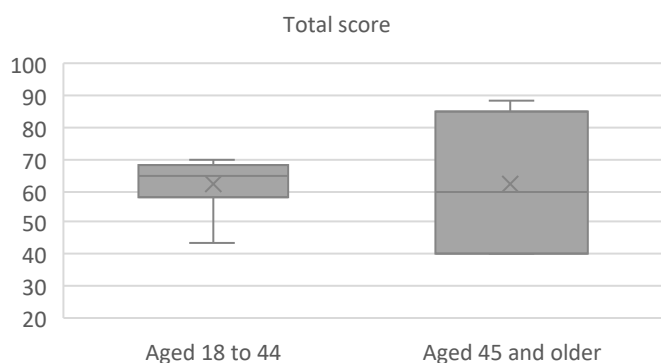


Figure 7.8: Boxplot of Care coordination: Total score by age

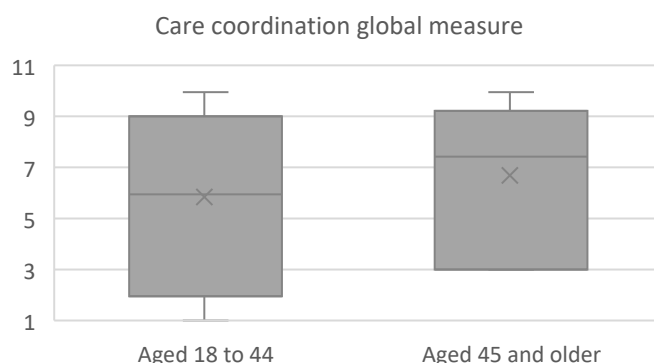


Figure 7.9: Boxplot of Care coordination: Care coordination global measure by age

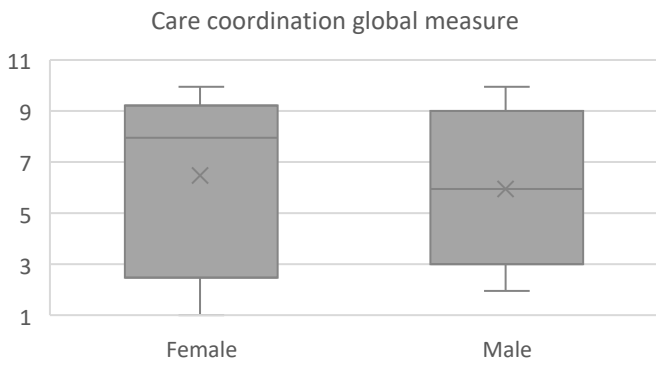


Figure 7.10: Boxplot of Care coordination: Quality of care global measure by age

Care coordination by education

Comparisons were made by education status, between those with trade or high school qualifications, Trade or high school (n=5, 38.46%), and those with a university qualification, University (n=8, 64.54%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 7.4).

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

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

Care coordination scale	Group	Number (n=13)	Percent	Mean	SD	T	dF	p-value
Communication	Aged 18 to 44	7	53.85	37.29	9.48	-0.14	11	0.8941
	Aged 45 and older	6	46.15	38.17	13.76			
Navigation	Aged 18 to 44	7	53.85	24.57	6.32	0.19	11	0.8539
	Aged 45 and older	6	46.15	23.83	7.81			
Total score	Aged 18 to 44	7	53.85	61.86	9.03	-0.02	11	0.9874
	Aged 45 and older	6	46.15	62.00	21.44			
Care coordination global measure	Aged 18 to 44	7	53.85	5.86	3.34	-0.45	11	0.6631
	Aged 45 and older	6	46.15	6.67	3.14			
Quality of care global measure	Aged 18 to 44	7	53.85	5.00	2.94	-1.39	11	0.1932
	Aged 45 and older	6	46.15	7.17	2.64			

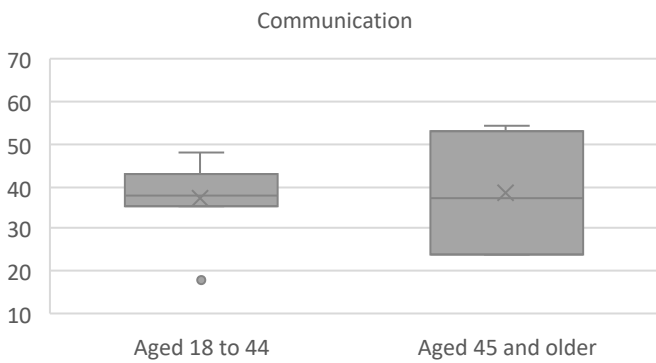


Figure 7.11: Boxplot of Care coordination: Communication by education

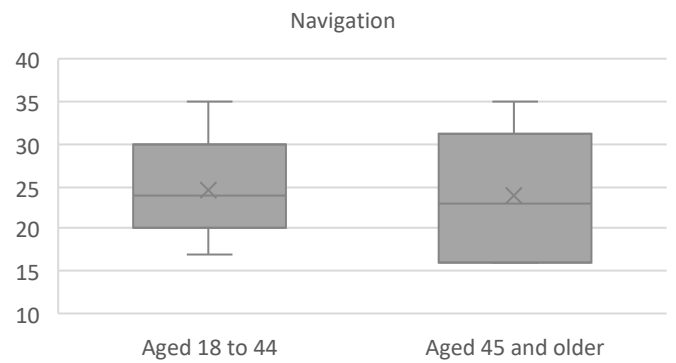


Figure 7.12: Boxplot of Care coordination: Navigation by education

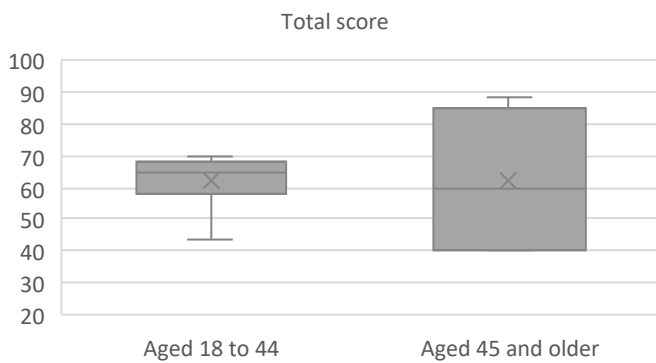


Figure 7.13: Boxplot of Care coordination: Total score by education

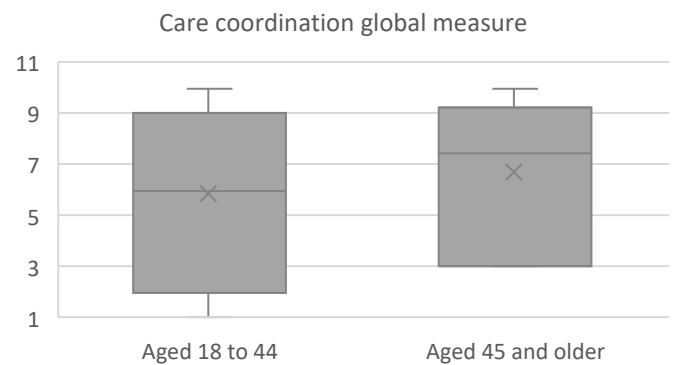


Figure 7.14: Boxplot of Care coordination: Care coordination global measure by education

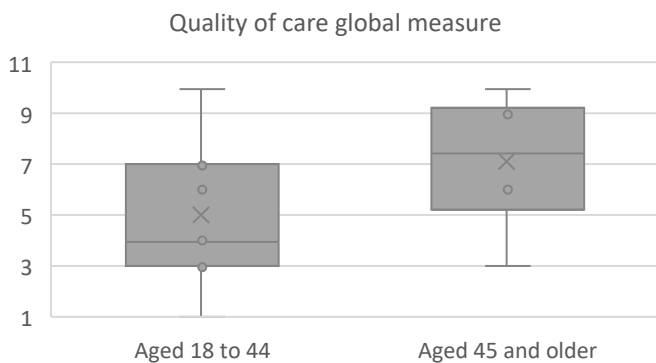


Figure 7.15: Boxplot of Care coordination: Quality of care global measure by education

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=3, 23.08%) were compared to

those living in a major city, Metropolitan (n=10, 76.92%).

There were too few participants in the regional and remote subgroup to make comparison. Summary statistics are displayed in Table 7.5.

Table 7.5: Care coordination by location summary statistics

Care coordination scale	Group	Number (n=13)	Percent	Mean	SD	T	dF	p-value
Communication	Trade or high school	5	38.46	36.20	12.66	-0.37	11	0.7199
	University	8	61.54	38.63	10.89			
Navigation	Trade or high school	5	38.46	21.20	5.93	-1.32	11	0.2139
	University	8	61.54	26.13	6.88			
Total score	Trade or high school	5	38.46	57.40	18.51	-0.84	11	0.4213
	University	8	61.54	64.75	13.36			
Care coordination global measure	Trade or high school	5	38.46	6.00	3.54	-0.20	11	0.8444
	University	8	61.54	6.38	3.11			
Quality of care global measure	Trade or high school	5	38.46	5.20	2.95	-0.77	11	0.4583
	University	8	61.54	6.50	2.98			

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=2, 15.38%) compared to those with a

higher SEIFA score of 7-10, Higher status (n=11, 84.62%).

There were too few participants in the mid to low status subgroup to make comparison. Summary statistics are displayed in Table 7.6.

Table 7.6: Care coordination by socioeconomic status stage summary statistics

Care coordination scale	Group	Number (n=13)	Percent	Mean	SD	Median	IQR
Communication	Rural or remote	3	23.08	40.00	14.73	43.00	14.50
	Metropolitan	10	76.92	37.00	10.72	38.00	10.50
Navigation	Rural or remote	3	23.08	25.67	9.50	26.00	9.50
	Metropolitan	10	76.92	23.80	6.30	22.00	9.00
Total score	Rural or remote	3	23.08	65.67	24.17	69.00	24.00
	Metropolitan	10	76.92	60.80	13.18	62.50	15.25
Care coordination global measure	Rural or remote	3	23.08	8.00	1.73	9.00	1.50
	Metropolitan	10	76.92	5.70	3.33	6.00	5.50
Quality of care global measure	Rural or remote	3	23.08	8.00	1.73	9.00	1.50
	Metropolitan	10	76.92	5.40	2.99	5.00	3.50

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 response was that they did not receive any formal support (41.67%). Others described getting support from peer support or other patients (16.67%), charities (8.33%), community or religious groups (8.33%), family and friends (8.33%), hospital or clinical setting (8.33%), and financial support including financial counselling (8.33%).

Participant describes that they did not receive any formal support

No, I've never get any support. Never, never. It's just my doctor advice from doctor when I go to for my blood test.

Participant 001_2023AUHDV

No, not really. Yeah. I mean, when I when I when I had the interferon treatment, it was all through the hospital. So no, I wasn't aware of any other community support services that were available and none, none was made was they didn't tell me about anything else was available. So, no, not not throughout.

Participant 011_2023AUHDV

Participant describes the challenges of finding or accessing support

Not really, but I would love to see there is something available, especially in the language I guess

Participant 003_2023AUHDV

Participant describes getting care and support from community or religious groups

PARTICIPANT: Not really. I haven't. Apart from it, I would say the church. I haven't really received much from the community.

INTERVIEWER: Or from church.

PARTICIPANT: Yeah, that's correct.

INTERVIEWER: OK. All right. So, So what kind of support is that? Is it like? Yeah.

PARTICIPANT: Well, it's financial and, you know, spiritual support.

Participant 006_2023AUHDV

Participant describes getting care and support from family and friends

So far I haven't actually received any stuff...support, but my family have been good.
Participant 009_2023AUHDV

Participant describes getting care and support from hospital or clinical setting

I guess the hepatitis nurse and the association, the psychologist and the sexual health clinic.
Participant 004_2023AUHDV

Table 7.7: Experience of care and support

Care and support received	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes that they did not receive any formal support	5	41.67	3	50.00	2	33.33	5	62.50	0	0.00	3	50.00	2	33.33	0	0.00	5	45.45	0	0.00	5	45.45
Participant describes getting care and support from peer support or other patients	2	16.67	0	0.00	2	33.33	0	0.00	2	50.00	1	16.67	1	16.67	1	100.00	1	9.09	1	100.00	1	9.09
Participant describes the challenges of finding or accessing support	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes getting care and support from charities	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes getting care and support from community or religious groups	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes getting care and support from family and friends	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes getting care and support from hospital or clinical setting	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes getting care and support in the form of financial support including financial counselling	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
No particular comment (Other/no response)	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09

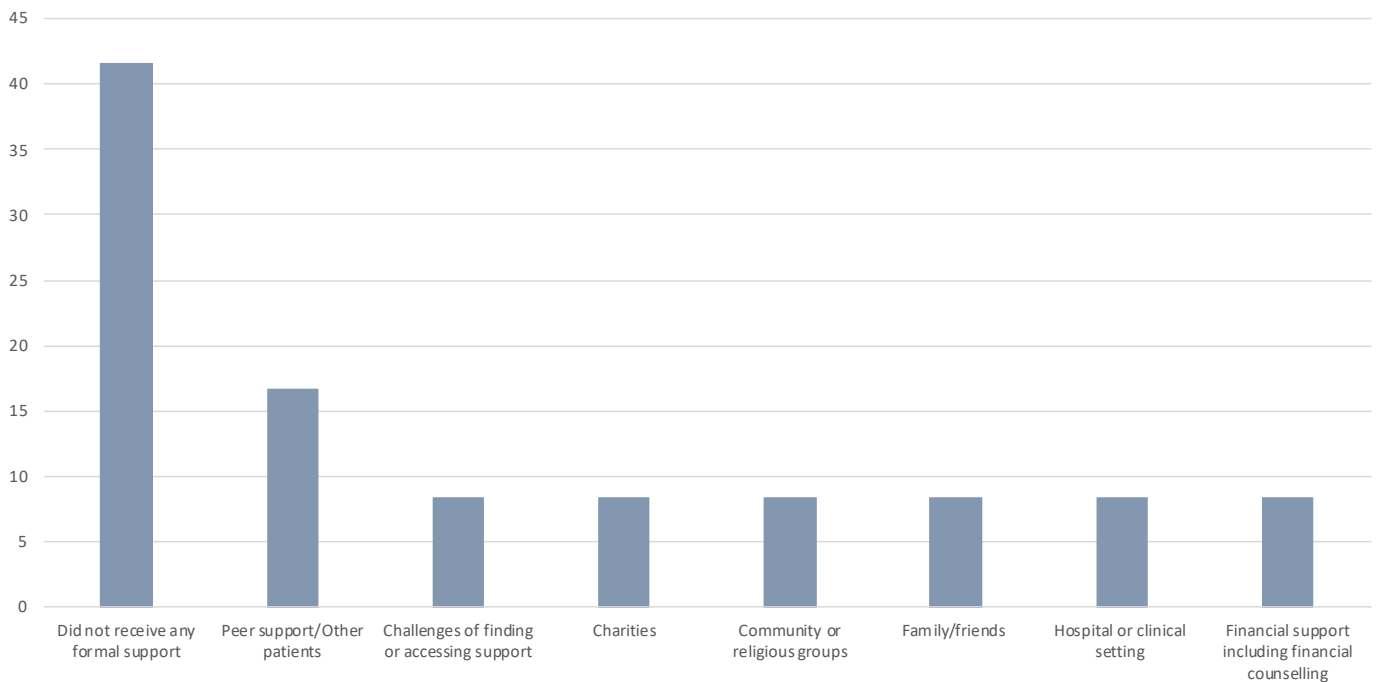


Figure 7.16: Experience of care and support

Table 7.8: 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	Aged 45 and older	Aged 18 to 44