

Section 7

Care and support

Section 7: Experience of care and support

Care coordination

A Care Coordination questionnaire was completed by participants within the online questionnaire. The Care Coordination questionnaire comprises a total score, two scales (communication and navigation), and a single question for each relating to care-coordination and care received. A higher score denotes better care outcome.

The **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 poor 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 a moderate 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 moderate.

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.

Ability to take medicine as prescribed

Participants were asked about their ability to take medicines as prescribed. The majority of participants with NMOSD responded that they took medicine as prescribed all the time (n=11, 61.11%), and seven participants (38.89%) responded that they took medicines as prescribed most of the time. There were no participants that responded that they sometime, never, or rarely took medicines as prescribed.

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. In the general NMOSD population the most common response was that participants and no received any support (n=8, 44.44%). This was followed by receiving support through domestic services (n=7, 38.89%).

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 **Care coordination: Quality of care global measure** (median=7.00, IQR=3.00) indicating good quality of care.

The average scores for **Care coordination: navigation** (mean = 22.19, SD = 4.68), **Care coordination: Total score** (mean = 55.33, SD = 9.97), and **Care coordination: Care coordination global measure** (mean=5.97, SD=2.13) were in the middle of the scale indicating moderate healthcare navigation and overall experience of care coordination.

The average score for **Care coordination: communication** (median=32.50, IQR=8.00) was in the second lowest quintile, indicating poor healthcare communication.

Comparisons of Care co-ordination have been made based on **participant type** (Tables 7.2 to 7.3, Figures 7.1 to 7.5), **relapse** (Tables 7.4 to 7.5, Figures 7.6 to 7.10), **fear of progression** (Tables 7.6 to 7.7, Figures 7.16 to 7.20), **physical function** (Tables 7.8 to 7.9, Figures 7.16 to 7.20), **education** (Tables 7.10 to 7.11, Figures 7.21 to 7.25), **socioeconomic status** (Tables 7.12 to 7.13, Figures 7.26 to 7.30), **age** (Tables 7.14 to 7.15, Figures 7.31 to 7.35), **gender** (Tables 7.16) and **location** (Table 7.17).

Table 7.1: Care coordination summary statistics

Care coordination scale (n=36)	Mean	SD	Median	IQR	Possible range	Quintile
Communication	33.14	7.31	32.50	8.00	13 to 65	2.00
Navigation*	22.19	4.68	23.00	6.00	7 to 35	3.00
Total score*	55.33	9.97	56.00	11.25	20 to 100	3.00
Care coordination global measure*	5.97	2.13	6.00	2.25	1 to 10	3.00
Quality of care global measure	6.47	2.16	7.00	3.00	1 to 10	4.00

*Normal distribution use mean and SD as average measure

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 poor 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 a moderate 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 moderate.

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.

Comparisons of Care coordination scales by participant type

Participant type were grouped according to diagnosis of NMOSD, MOG, and family and carers; the *NMOSD* group includes participants who had a NMOSD diagnosis, (n=18, 50.00%), participants who had a MOG diagnosis were included in the *MOG* group (n=8, 22.22%), participants in the *NMOSD or MOG* groups were included in the *NMOSD or MOG* subgroup (n=26, 72.22), and family members or carers of people with NMOSD or MOG were included in the *Family and carers* subgroup (n=10, 27.78%).

Boxplots of each Care coordination scale by **participant type** are displayed in Figures 7.1 to 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).

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

Table7.2: Care coordination by participant type ANOVA test

Care coordination scale	Group	Number (n=36)	Percent	Median	IQR	C ²	dF	p-value
Communication	NMOSD	18	50.00	29.50	6.00	6.45	3	0.0917
	MOG	8	22.22	36.50	3.00			
	NMOSD and MOG	26	72.22	31.00	8.75			
	Family and carers	10	27.78	33.00	4.25			

Table7.3: Care coordination by participant type Kruskal-Wallis test

Care coordination scale	Group	Number (n=36)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Navigation	NMOSD	18	50.00	20.56	4.84	Between groups	103.30	3	34.43	1.56	0.2080
	MOG	8	22.22	23.75	4.68	Within groups	1277.30	58	22.02		
	NMOSD and MOG	26	72.22	21.54	4.93	Total	1380.60	61			
	Family and carers	10	27.78	23.90	3.60						
Total score	NMOSD	18	50.00	51.50	11.16	Between groups	590.00	3	196.60	1.88	0.1430
	MOG	8	22.22	61.00	8.86	Within groups	6069.00	58	104.60		
	NMOSD and MOG	26	72.22	54.42	11.25	Total	6659.00	61			
	Family and carers	10	27.78	57.70	5.12						
Care coordination global measure	NMOSD	18	50.00	5.67	2.20	Between groups	11.04	3	3.68	0.85	0.4740
	MOG	8	22.22	7.00	1.31	Within groups	251.95	58	4.34		
	NMOSD and MOG	26	72.22	6.08	2.04	Total	262.99	61			
	Family and carers	10	27.78	5.70	2.45						
Quality of care global measure	NMOSD	18	50.00	6.00	2.50	Between groups	9.49	3	3.16	0.67	0.5770
	MOG	8	22.22	7.25	1.04	Within groups	275.75	58	4.75		
	NMOSD and MOG	26	72.22	6.38	2.21	Total	285.24	61			
	Family and carers	10	27.78	6.70	2.11						

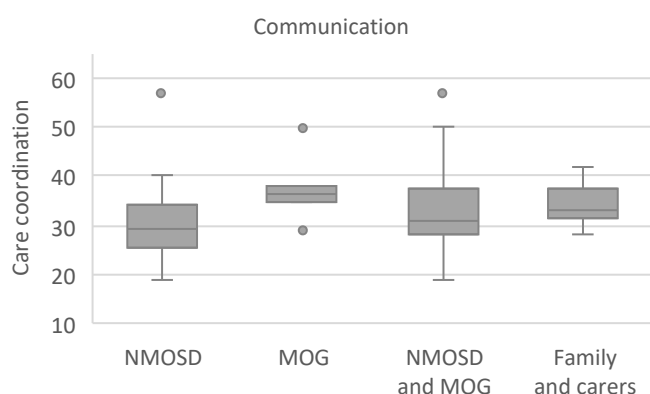


Figure 7.1: Boxplot of Care coordination: Communication by participant type

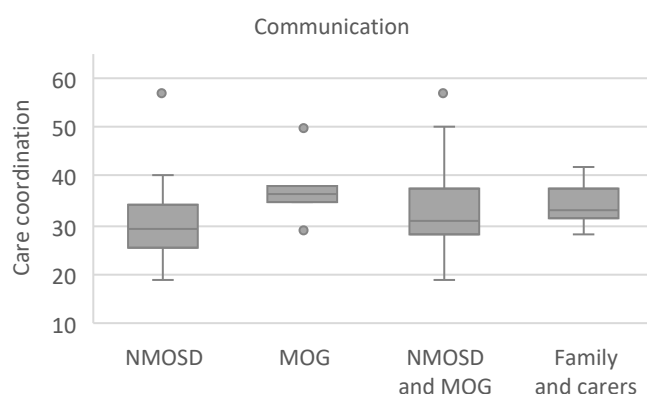


Figure 7.2: Boxplot of Care coordination: Navigation by participant type

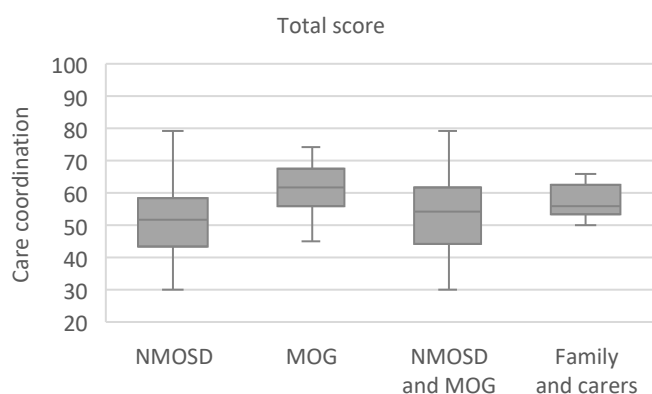


Figure 7.3: Boxplot of Care coordination: Total score by participant type

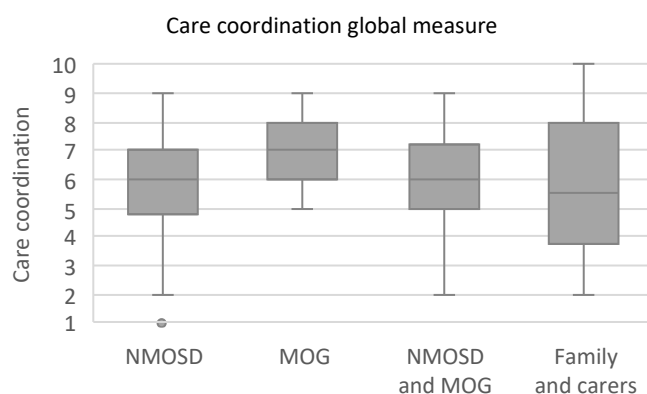


Figure 7.4: Boxplot of Care coordination: Care coordination global measure by participant type

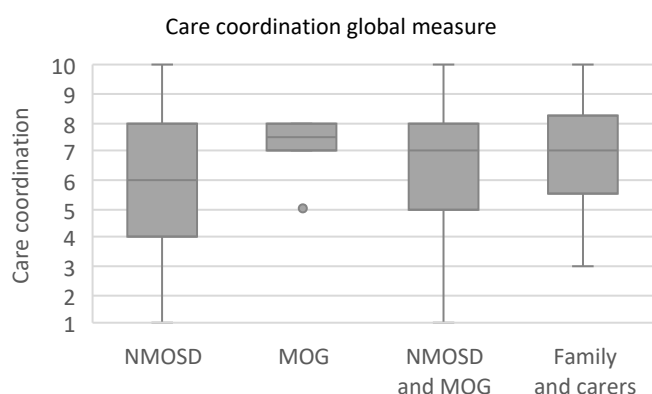


Figure 7.5: Boxplot of Care coordination: Quality of care global measure by participant type

Comparisons of Care coordination scales by relapse

Comparisons were made by NMOSD relapses, those less than two relapses were included in the *fewer relapses* subgroup (n=9, 50.00%), and those that had three or more relapses, in the *more relapses* subgroup (n=9, 50.00%). Only participants with NMOSD were included in this comparison.

Boxplots of each Care coordination scale by **relapse** are displayed in Figures 7.6 to 7.10, summary

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

No significant differences were observed between participants in the *fewer relapses* subgroup compared to those in the *more relapses* subgroup for any of the Care coordination scales.

Table 7.4: Care coordination by relapse summary statistics and two sample t-test

Care coordination scale	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Navigation	<i>Fewer relapses</i>	9	50.00	22.22	4.09	1.52	16	0.1492
	<i>More relapses</i>	9	50.00	18.89	5.18			
Total score	<i>Fewer relapses</i>	9	50.00	52.89	12.30	0.52	16	0.6125
	<i>More relapses</i>	9	50.00	50.11	10.43			
Care coordination global measure	<i>Fewer relapses</i>	9	50.00	5.78	2.11	0.21	16	0.8375
	<i>More relapses</i>	9	50.00	5.56	2.40			
Quality of care global measure	<i>Fewer relapses</i>	9	50.00	6.44	2.13	0.75	16	0.4670
	<i>More relapses</i>	9	50.00	5.56	2.88			

Table 7.5: Care coordination by relapse summary statistics and Wilcoxon rank sum tests with continuity correction

Care coordination scale	Group	Number (n=18)	Percent	Median	IQR	W	p-value
Communication	<i>Fewer relapses</i>	9	50.00	29.00	5.00	33.5	0.5652
	<i>More relapses</i>	9	50.00	30.00	9.00		

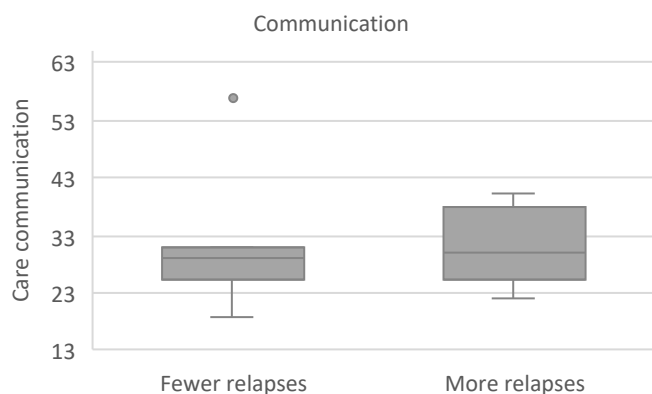


Figure 7.6: Boxplot of Care coordination: Communication by relapse

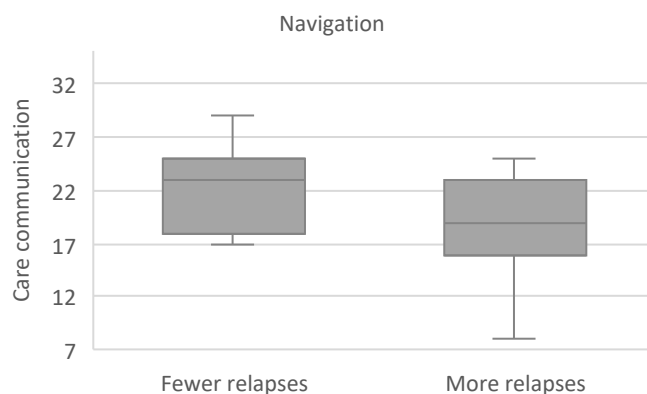


Figure 7.7: Boxplot of Care coordination: Navigation by relapse

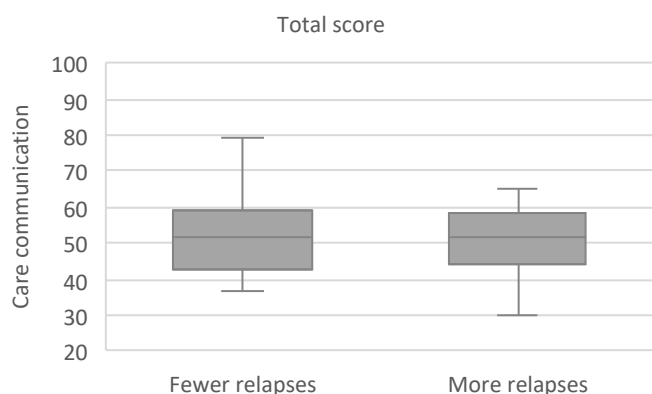


Figure 7.8: Boxplot of Care coordination: Total score by relapse

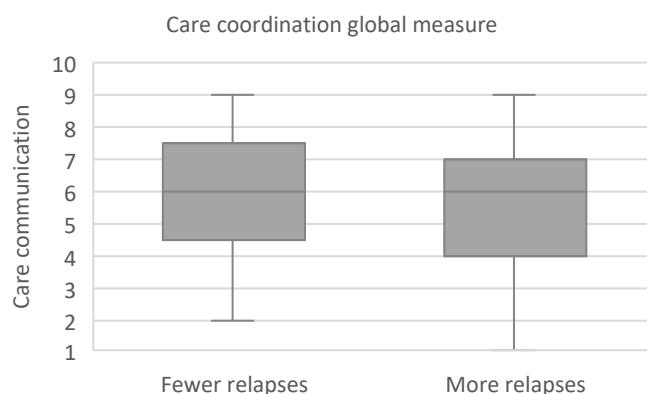


Figure 7.9: Boxplot of Care coordination: Care coordination global measure by relapse

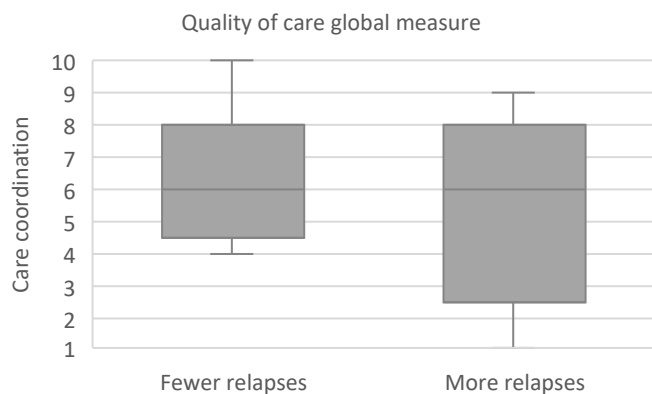


Figure 7.10: Boxplot of Care coordination: Quality of care global measure by relapse

Comparisons of Care coordination scales by fear of progression

The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their conditions. The Fear of Progression questionnaire comprises a total score, between 12 and 60, with a higher score denoting increased anxiety. Participants that scored over 41 in the Fear of progression questionnaire were included in the High to very high fear subgroup (n=10, 55.56%), and those that scored less than 41 were included in the

Low to moderate fear subgroup (n=8, 44.44%). Only participants with NMOSD were included in this comparison.

Boxplots of each Care coordination scale by **fear of progression** are displayed in Figures 7.11 to 7.15, summary statistics are displayed in Tables 7.6 to 7.7. A two-sample t-test was used when assumptions for normality and variance were met (Table 7.6), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.7).

No significant differences were observed between participants in the *Low to moderate fear* subgroup

compared to those in the *High to very high fear* subgroup for any of the Care coordination scales.

Table 7.6: Care coordination by fear of progression summary statistics and two sample t-test

Care coordination scale	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Navigation	Low to moderate fear	8	44.44	21.75	4.37	0.93	16	0.3649
	High to very high fear	10	55.56	19.60	5.21			
Total score	Low to moderate fear	8	44.44	53.00	7.09	0.50	16	0.6248
	High to very high fear	10	55.56	50.30	13.87			
Care coordination global measure	Low to moderate fear	8	44.44	6.25	2.49	1.01	16	0.3283
	High to very high fear	10	55.56	5.20	1.93			
Quality of care global measure	Low to moderate fear	8	44.44	6.88	1.96	1.36	16	0.1918
	High to very high fear	10	55.56	5.30	2.75			

Table 7.7: Care coordination by fear of progression summary statistics and Wilcoxon rank sum tests with continuity correction

Care coordination scale	Group	Number (n=18)	Percent	Median	IQR	W	p-value
Communication	Low to moderate fear	8	44.44	31.00	6.50	49.50	0.4229
	High to very high fear	10	55.56	29.00	5.75		

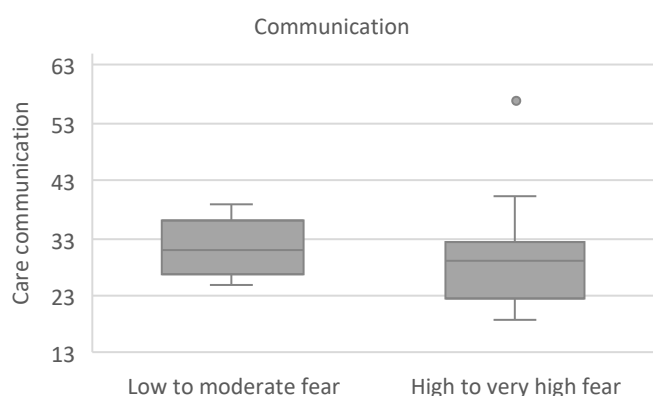


Figure 7.11: Boxplot of Care coordination: Communication by fear of progression

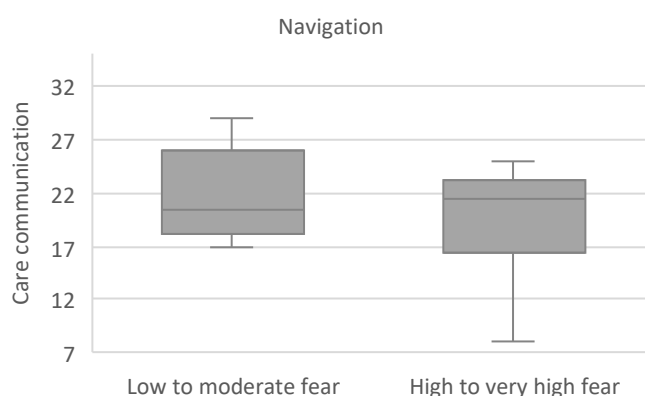


Figure 7.12: Boxplot of Care coordination: Navigation by fear of progression

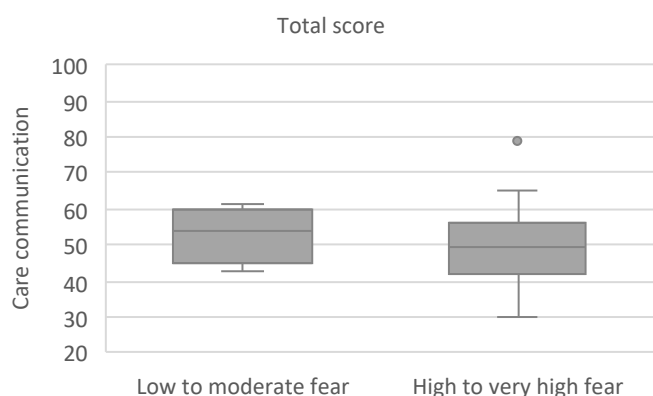


Figure 7.13: Boxplot of Care coordination: Total score by fear of progression

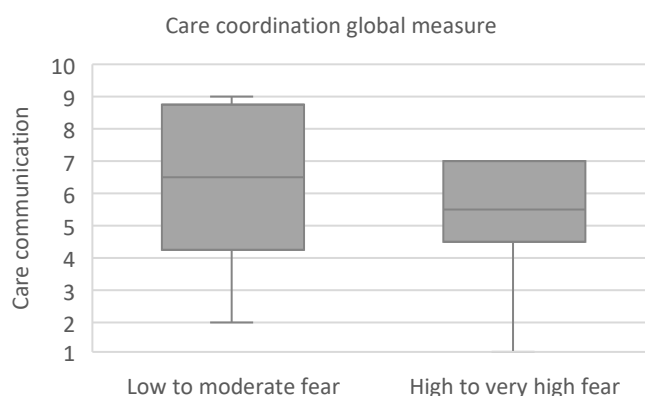


Figure 7.14: Boxplot of Care coordination: Care coordination global measure by fear of progression

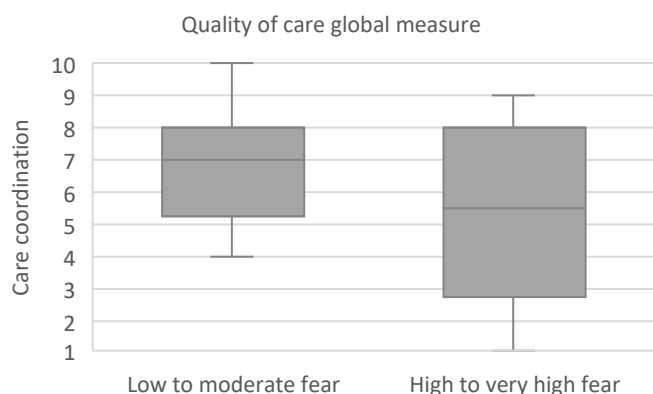


Figure 7.15: Boxplot of Care coordination: Quality of care global measure by fear of progression

Comparisons of Care coordination scales by physical function

The SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. Comparisons were made by **physical function**, participants that scored in the lowest three quintiles of the SF36 Physical functioning scale were included in the *Moderate to very poor physical function* subgroup (n=9, 50.00%), and participants that scored in the highest two quintiles were included in the *Good to very good physical function* subgroup (n=9, 50.00%). Only participants with NMOSD were included in this comparison.

Boxplots of each Care coordination scale by **physical function** are displayed in Figures 7.16 to 7.20, summary statistics are displayed in Tables 7.8 to 7.9.

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

No significant differences were observed between participants in the *Moderate to very poor physical function* subgroup compared to those in the *Good to very good physical function* subgroup for any of the care coordination scales.

Table 7.8: Care coordination by physical function summary statistics and two sample t-test

Care coordination scale	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Navigation	Moderate to very poor physical function	9	50.00	20.89	5.82	0.28	16	0.7800
	Good to very good physical function	9	50.00	20.22	3.96			
Care coordination global measure	Moderate to very poor physical function	9	50.00	5.78	2.49	0.21	16	0.8375
	Good to very good physical function	9	50.00	5.56	2.01			
Quality of care global measure	Moderate to very poor physical function	9	50.00	6.56	2.30	0.94	16	0.3608
	Good to very good physical function	9	50.00	5.44	2.70			

Table 7.9: Care coordination by physical function summary statistics and Wilcoxon rank sum tests with continuity correction

Care coordination scale	Group	Number (n=18)	Percent	Median	IQR	W	p-value
Communication	Moderate to very poor physical function	9	50.00	30.00	10.00	39.5	0.9647
	Good to very good physical function	9	50.00	29.00	3.00		
Total score	Moderate to very poor physical function	9	50.00	52.00	16.00	43.5	0.8247
	Good to very good physical function	9	50.00	52.00	12.00		

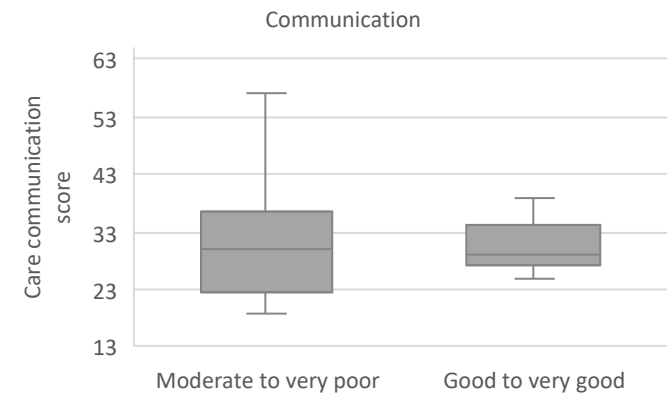


Figure 7.16: Boxplot of Care coordination: Communication by physical function

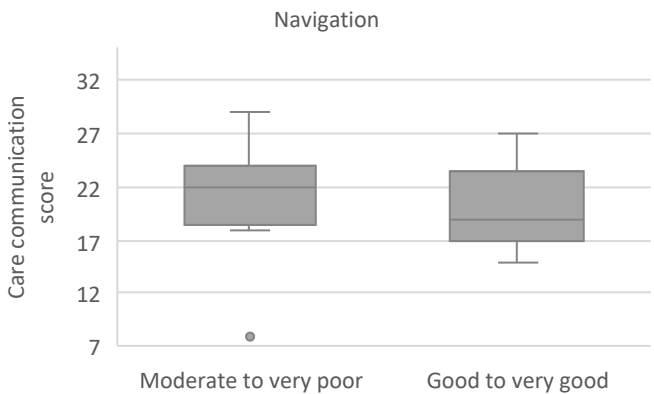


Figure 7.17: Boxplot of Care coordination: Navigation by physical function

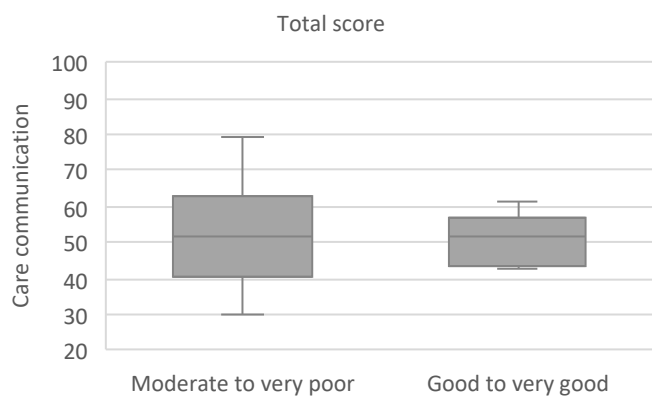


Figure 7.18: Boxplot of Care coordination: Total score by physical function

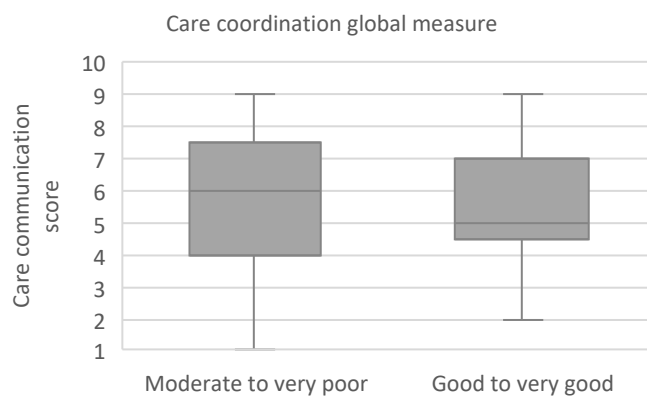


Figure 7.19: Boxplot of Care coordination: Care coordination global measure by physical function

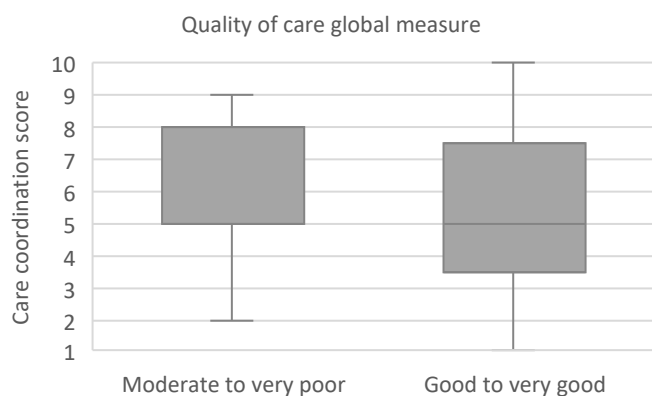


Figure 7.20: Boxplot of Care coordination: Quality of care global measure by physical function

Comparisons of Care coordination scales by education

Comparisons were made by Education status, between those with trade or high school qualifications, *trade or high school* (n=10, 55.56%), and those with a university qualification, *University* (n= 8, 44.44%). Only participants with NMOSD were included in this comparison.

Boxplots of each Care coordination scale by education are displayed in Figures 7.21 to 7.25,

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

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

Table 7.10: Care coordination by education summary statistics and two sample t-test

Care coordination scale	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Navigation	Trade or high school	10	55.56	18.70	4.90	-1.97	16	0.0670
	University	8	44.44	22.88	3.87			
Care coordination global measure	Trade or high school	10	55.56	5.30	2.26	-0.78	16	0.4451
	University	8	44.44	6.13	2.17			
Quality of care global measure	Trade or high school	10	55.56	5.70	2.83	-0.56	16	0.5844
	University	8	44.44	6.38	2.13			

Table 7.11: Care coordination by education summary statistics and Wilcoxon rank sum tests with continuity correction

Care coordination scale	Group	Number (n=18)	Percent	Median	IQR	W	p-value
Communication	Trade or high school	10	55.56	28.50	8.75	29.50	0.3733
	University	8	44.44	30.50	3.75		
Total score	Trade or high school	10	55.56	45.50	8.75	24.50	0.1812
	University	8	44.44	54.50	6.75		

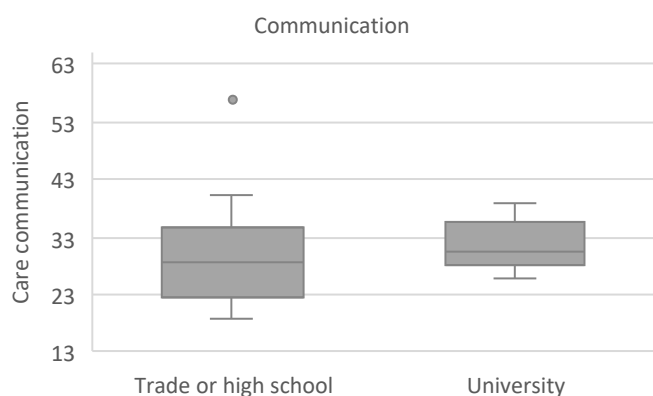


Figure 7.21: Boxplot of Care coordination: Communication by education

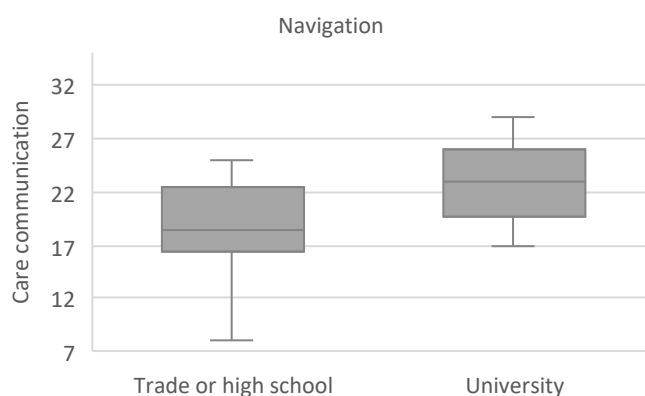


Figure 7.22: Boxplot of Care coordination: Navigation by education

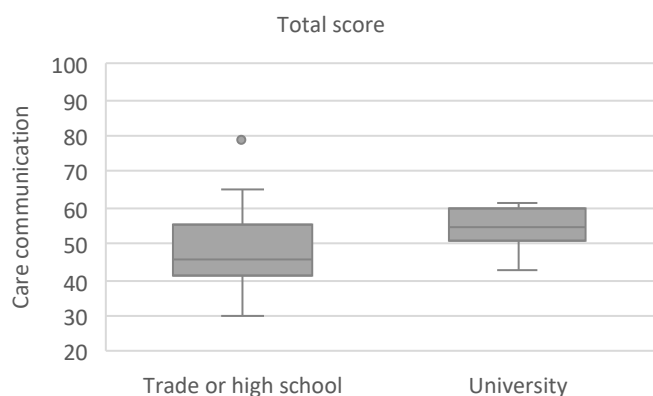


Figure 7.23: Boxplot of Care coordination: Total score by education

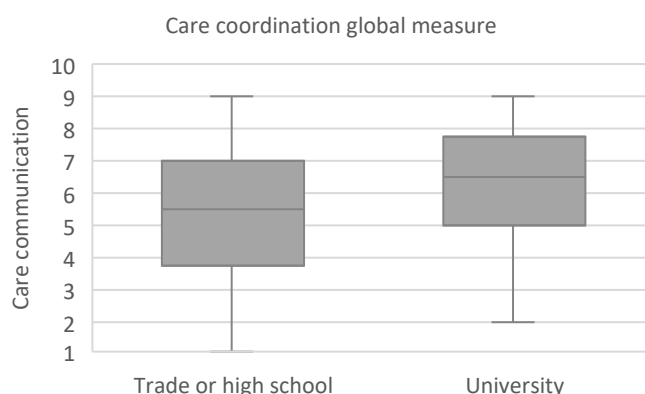


Figure 7.24: Boxplot of Care coordination: Care coordination global measure by education

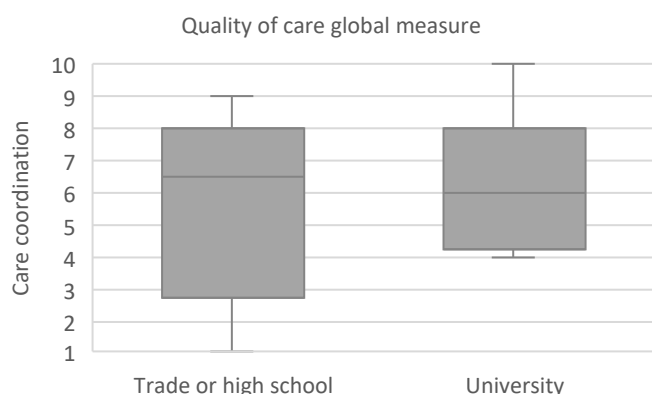


Figure 7.25: Boxplot of Care coordination: Quality of care global measure by education

Comparisons of Care coordination scales by 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=6, 33.33%) compared to those with a higher SEIFA score of 7-10, *higher status* (n=12, 66.67%). Only participants with NMOSD were included in this comparison.

Boxplots of each Care coordination scale by **socioeconomic status** are displayed in Figures 7.26 to 7.30, summary statistics are displayed in Tables 7.12 to 7.13. A two-sample t-test was used when assumptions for normality and variance were met (Table 7.12), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.13).

A two sample t-test indicated that the mean score for the **Care coordination: navigation** scale [$t(16) = -2.37$ $p=0.0309$] was significantly higher for participants in the *Higher status* subgroup (Mean = 22.25, SD = 3.96) compared to participants in the *Mid to low status* subgroup (Mean = 17.17, SD = 4.96).

A two sample t-test indicated that the mean score for the **Care coordination: total score** scale [$t(16) = -2.45$, $p=0.0264$] was significantly higher for

participants in the *Higher status* subgroup (Mean = 55.50, SD = 10.26) compared to participants in the *Mid to low status* subgroup (Mean = 43.50, SD = 8.73).

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 *Higher status* subgroup scored higher than participants in the *Mid to low status* subgroup. This indicates that participants in the *Higher status* subgroup, had moderate navigation of the healthcare system, compared to poor navigation for participants in the *Mid to low status* subgroup.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. On average, participants in the *Higher status* subgroup scored higher than participants in the *Mid to low status* subgroup. On average, participants in the *Higher status* subgroup scored higher than participants in the *Mid to low status* subgroup. This indicates that participants in the *High status* subgroup, had moderate communication, navigation and overall experience of care coordination, compared to poor communication and navigation and overall experience of care coordination for participants in the *Mid to low status* subgroup.

Table 7.12: Care coordination by socioeconomic status summary statistics and two sample t-test

Care coordination scale	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Navigation	Mid to low status	6	33.33	17.17	4.96	-2.37	16	0.0309*
	Higher status	12	66.67	22.25	3.96			
Total score	Mid to low status	6	33.33	43.50	8.73	-2.45	16	0.0264*
	Higher status	12	66.67	55.50	10.26			
Care coordination global measure	Mid to low status	6	33.33	5.00	2.61	-0.91	16	0.3785
	Higher status	12	66.67	6.00	2.00			
Quality of care global measure	Mid to low status	6	33.33	4.83	2.93	-1.45	16	0.1675
	Higher status	12	66.67	6.58	2.15			

*Significant at $p < 0.05$

Table 7.13: Care coordination by socioeconomic status summary statistics and Wilcoxon rank sum tests with continuity correction

Care coordination scale	Group	Number (n=18)	Percent	Median	IQR	W	p-value
Communication	Mid to low status	6	33.33	27.00	7.00	19.00	0.1215
	Higher status	12	66.67	30.50	9.50		

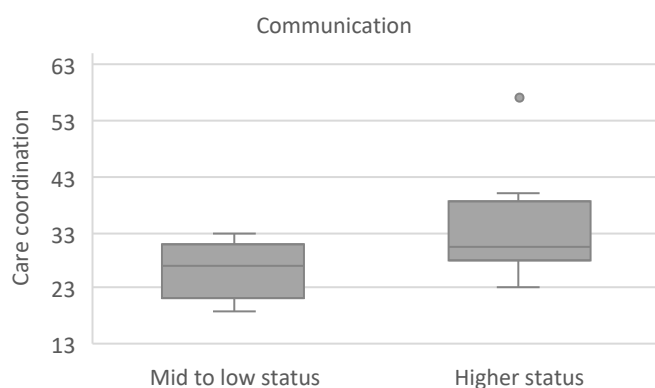


Figure 7.26: Boxplot of Care coordination: Communication by socioeconomic status

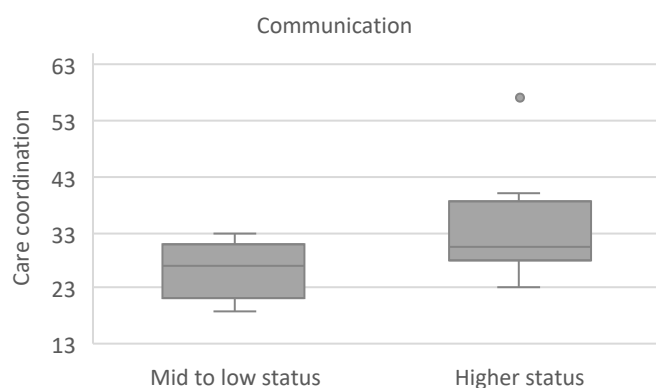


Figure 7.27: Boxplot of Care coordination: Navigation by socioeconomic status

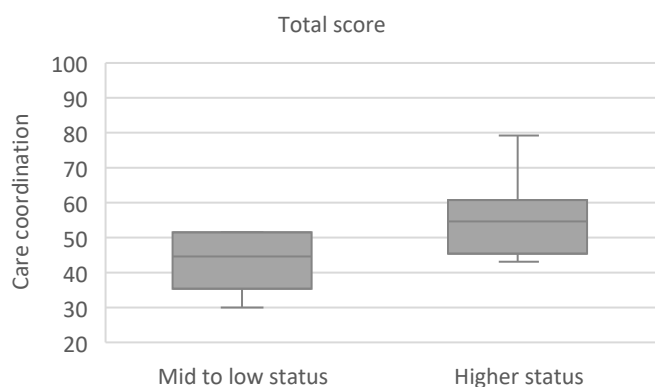


Figure 7.28: Boxplot of Care coordination: Total score by socioeconomic status

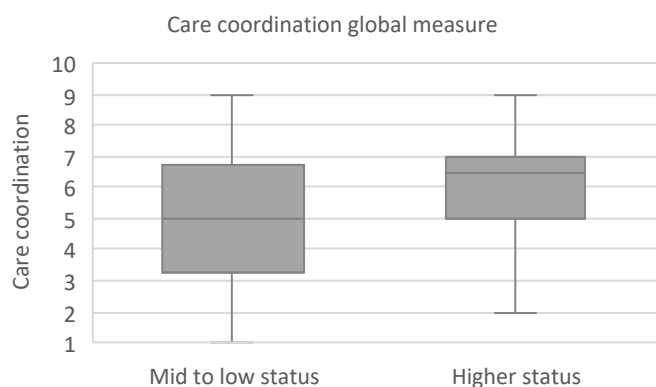


Figure 7.29: Boxplot of Care coordination: Care coordination global measure by socioeconomic status

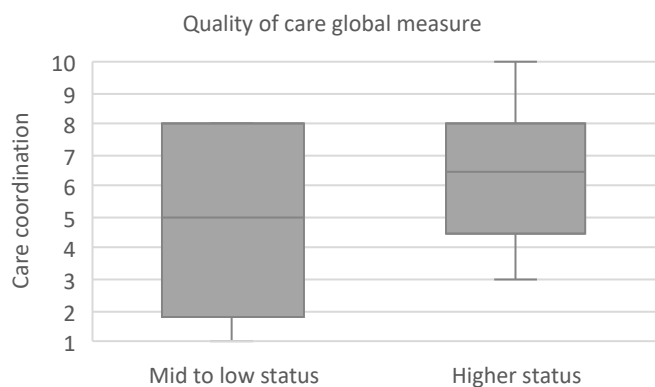


Figure 7.30: Boxplot of Care coordination: Quality of care global measure by socioeconomic status

Comparisons of Care coordination scales by age

Participants were grouped according to **age**, with comparisons made between participants *Aged 18 to 44* (n=7, 38.89%), and *Aged 45 or older* (n=11, 61.11%). Only participants with NMOSD were included in this comparison.

Boxplots of each Care coordination scale by **age** are displayed in Figures 7.31 to 7.35, summary statistics are displayed in Tables 7.14 to 7.15.

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.14), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.15).

No significant differences were observed between participants in the *Aged 18 to 44* subgroup compared to those in the *Aged 45 or older* subgroup for any of the care coordination scales.

Table 7.14: Care coordination by age summary statistics and two sample t-test

Care coordination scale	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Total score	<i>Aged 18 to 44</i>	7	38.89	49.57	11.18	-0.57	16	0.5744
	<i>Aged 45 or older</i>	11	61.11	52.73	11.51			
Care coordination global measure	<i>Aged 18 to 44</i>	7	38.89	5.14	2.67	-0.80	16	0.4362
	<i>Aged 45 or older</i>	11	61.11	6.00	1.90			
Quality of care global measure	<i>Aged 18 to 44</i>	7	38.89	5.00	2.38	-1.39	16	0.1829
	<i>Aged 45 or older</i>	11	61.11	6.64	2.46			

Table 7.15: Care coordination by age summary statistics and Wilcoxon rank sum tests with continuity correction

Care coordination scale	Group	Number (n=18)	Percent	Median	IQR	W	p-value
Communication	<i>Aged 18 to 44</i>	7	38.89	30.00	6.50	41.5	0.8205
	<i>Aged 45 or older</i>	11	61.11	29.00	5.50		
Navigation	<i>Aged 18 to 44</i>	7	38.89	19.00	6.50	27.5	0.3396
	<i>Aged 45 or older</i>	11	61.11	22.00	5.00		

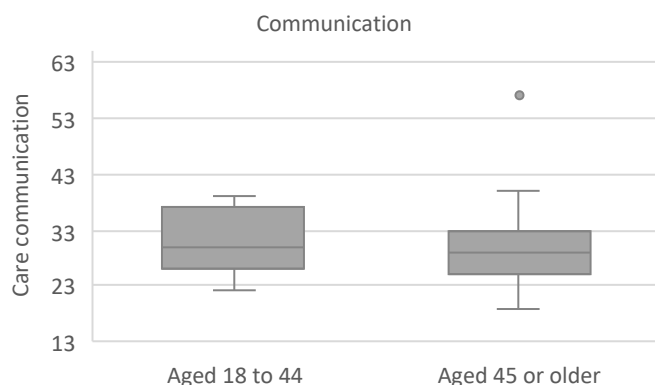


Figure 7.31: Boxplot of Care coordination: Communication by age

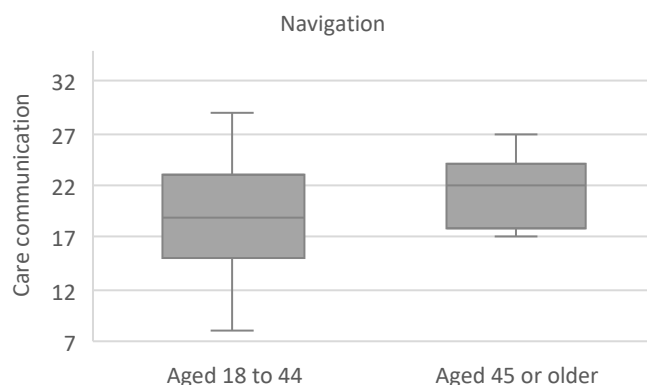


Figure 7.32: Boxplot of Care coordination: Navigation by age

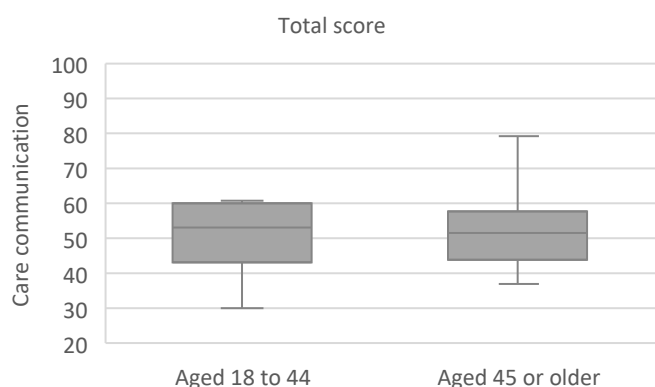


Figure 7.33: Boxplot of Care coordination: Total score by age

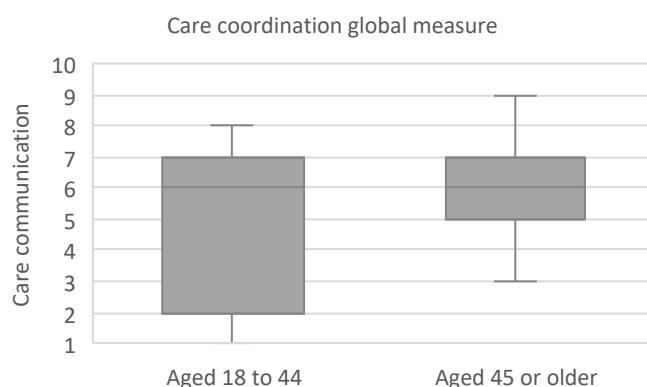


Figure 7.34: Boxplot of Care coordination: Care coordination global measure by age

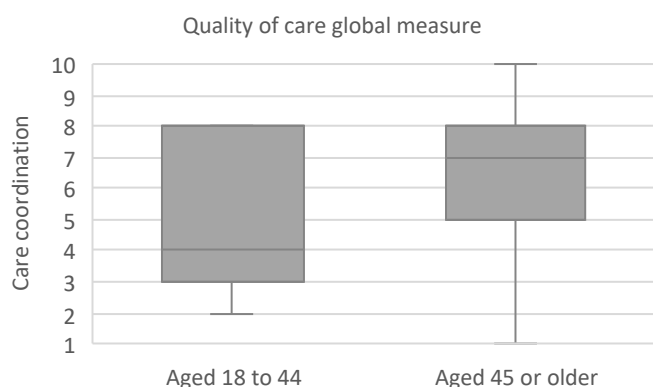


Figure 7.35: Boxplot of Care coordination: Quality of care global measure by age

Comparisons of Care coordination scales by gender

There were 16 females (n=16, 88.89%) with NMOSD, however, there were too few males (n=2, 11.11%)

for comparisons to be made. Data by gender is displayed for NMOSD participants in Table 7.16, but no analysis conducted.

Table 7.16: Care coordination by gender summary statistics

Care coordination scale	Group	Number (n=18)	Percent	Mean	SD	Median	IQR
Communication	Female	16	88.89	31.13	8.22	29.50	4.00
	Male	2	11.11	29.50	14.85	29.50	10.50
Navigation	Female	16	88.89	20.44	4.98	21.50	5.25
	Male	2	11.11	21.50	4.95	21.50	3.50
Total score	Female	16	88.89	51.56	10.72	52.00	12.50
	Male	2	11.11	51.00	19.80	51.00	14.00
Care coordination global measure	Female	16	88.89	5.56	2.31	5.50	2.25
	Male	2	11.11	6.50	0.71	6.50	0.50
Quality of care global measure	Female	16	88.89	5.69	2.47	6.00	4.00
	Male	2	11.11	8.50	0.71	8.50	0.50

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. There were 15

participants with NMOSD (83.33%) that lived in Metropolitan areas, however, too few participants with NMOSD lived in Regional or remote areas (16.67%) for comparisons to be made. Data by location is displayed for NMOSD participants in Table 6.17, but no analysis conducted.

Table 7.17: Care coordination by location summary statistics

Care coordination scale	Group	Number (n=18)	Percent	Mean	SD	Median	IQR
Communication	Regional or remote	3	16.67	27.33	7.37	30.00	7.00
	Metropolitan	15	83.33	31.67	8.80	29.00	7.00
Navigation	Regional or remote	3	16.67	18.00	1.00	18.00	1.00
	Metropolitan	15	83.33	21.07	5.16	22.00	5.00
Total score	Regional or remote	3	16.67	45.33	7.64	47.00	7.50
	Metropolitan	15	83.33	52.73	11.54	52.00	15.00
Care coordination global measure	Regional or remote	3	16.67	6.67	2.08	6.00	2.00
	Metropolitan	15	83.33	5.47	2.23	6.00	2.50
Quality of care global measure	Regional or remote	3	16.67	5.67	4.04	8.00	3.50
	Metropolitan	15	83.33	6.07	2.28	6.00	3.50

Ability to take medicine as prescribed

Participants were asked about their ability to take medicines as prescribed. There were no participants that responded that they sometime, never, or rarely took medicines as prescribed (Table 7.18, Figure 7.36).

NMOSD

The majority of participants with NMOSD responded that they took medicine as prescribed all the time (n=11, 61.11%), and seven participants (38.89%) responded that they took medicines as prescribed most of the time.

MOG

The majority of participants with MOG responded that they took medicine as prescribed most of the time(n=6, 75.00%), and two participants (25.00%) responded that they took medicines as prescribed all the time

NMOSD or MOG

Overall, half of the participants with NMOSD or MOG, took medicine as prescribed all of the time, and the other half took medicine as prescribed most of the time.

Table 7.18: Ability to take medicine as prescribed

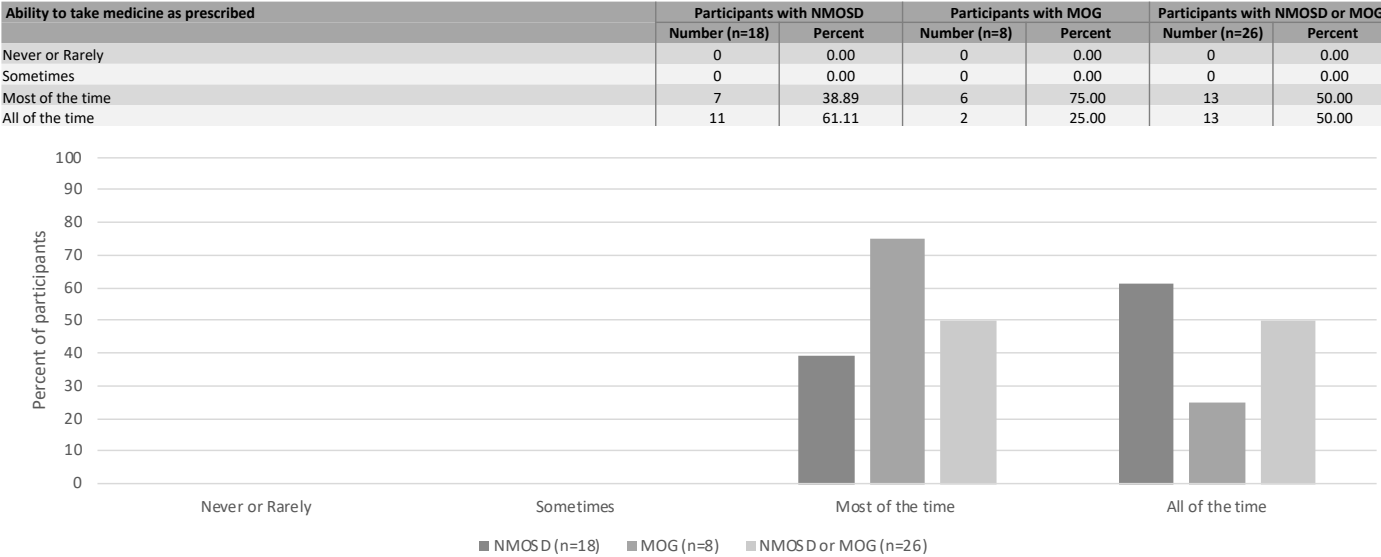


Figure 7.36: Ability to take medicine as prescribed

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. In the general NMOSD population the most common response was that participants and no received any support (n=8, 44.44%). This was followed by receiving support through domestic services (n=7, 38.89%).

Participant describes not receiving any support

No, I haven't received any. Participant NMO_008

No, I haven't had any. Participant NMO_009

None, from nowhere. Participant NMO_003

Participant describes receiving support through domestic services

In December, when it gets reassessed, there's going to be a couple of changes, I would say. Maybe around the home or that kind of stuff, because I can't do as much as I could last year, if that makes any sense. They will help me with my grocery shopping, because I don't want to push the trolley, because I could take something out. Participant NMO_012

Only through NDIS. I get a gardener, I get a cleaner once a fortnight. I get my exercise physiology

through NDIS. NDIS has really been my lifesaver. Participant NMO_004

Yes, I don't know if it falls under community services. Someone comes to my home once a week and prepares the meals for the week. I also have someone come to the home that helps with domestic tasks like she changes the linen on the bed, and she hangs out some washing and stuff like that. Participant NMO_010

Participant describes receiving support for transport

I have access to transport because I had to go quite a way to my physio and if I have to go to hospital appointments and stuff, I can get a taxi. I have funding for that now. I could take a support worker, like when I go to swimming. I've been going to the pool and that's an amazing, because I'm normal in the pool. I can take somebody there if I need. The NDIS gave me the opportunity of getting somebody to help me cook meals for the week. Participant NMO_006

About three years ago, I went through NAME Care type thing. I used to go there and they have their

meetings and talks. Virtually, they'd come out, do the housework for me, they would do transport the whole thing, but then I think they were taken over by another company. Participant NMO_013

They have been quite good, but seeing that we've had COVID, I only had one to two weeks of going out shopping and feeling like I was normal again, and then COVID hit. [laughs] I haven't really been able to get out and about, but they have been taking me to my hospital appointments and doctors' appointments. The transport, it's really good having that service there. Participant NMO_012

Participant describes receiving support from a hospital or clinical setting

It will be from my GP. GP and also my psychologist, because I've known my GP for more than 10 years. Participant NMO_001

That was a huge thing. It was just brilliant to be able to see doctors that actually knew about the condition and a whole panel of them, not just one. That was fantastic. Participant NMO_016

Table 7.19: Experience of care and support

Care and support	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very good physical function	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes not receiving any support	8	44.44	3	33.33	5	55.56	3	37.50	5	50.00	2	22.22	6	66.67
Participant describes receiving support through domestic services	7	38.89	3	33.33	4	44.44	3	37.50	4	40.00	5	55.56	2	22.22
Participant describes receiving support for transport	3	16.67	1	11.11	2	22.22	0	0.00	3	30.00	2	22.22	1	11.11
Participant describes receiving support from a hospital or clinical setting	2	11.11	1	11.11	1	11.11	1	12.50	1	10.00	2	22.22	0	0.00

Care and support	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or older	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes not receiving any support	8	44.44	5	50.00	3	37.50	3	50.00	5	41.67	3	42.86	5	45.45
Participant describes receiving support through domestic services	7	38.89	5	50.00	2	25.00	3	50.00	4	33.33	3	42.86	4	36.36
Participant describes receiving support for transport	3	16.67	3	30.00	0	0.00	1	16.67	2	16.67	1	28.57	2	18.18
Participant describes receiving support from a hospital or clinical setting	2	11.11	1	10.00	1	12.50	1	16.67	1	8.33	2	28.57	0	0.00

Care and support	NMOSD		MOG		NMOSD and MOG		Family and carers		Female		Male		Regional or remote		Metropolitan	
	n=18	%	n=8	%	n=26	%	n=10	%	n=16	%	n=2	%	n=3	%	n=11	%
Participant describes not receiving any support	8	44.44	2	25.00	10	38.46	3	30.00	6	37.50	2	100.00	1	33.33	7	46.67
Participant describes receiving support through domestic services	7	38.89	1	12.50	8	30.77	1	10.00	7	43.75	0	0.00	2	66.67	5	33.33
Participant describes receiving support for transport	3	16.67	1	12.50	4	15.38	1	10.00	3	18.75	0	0.00	1	33.33	2	13.33
Participant describes receiving support from a hospital or clinical setting	2	11.11	1	12.50	3	11.54	2	20.00	2	12.50	0	0.00	0	0.00	2	13.33

Table 7.20: Experience of care and support (Subgroup variations)

Care and support	More frequent	Less frequent
Participant describes not receiving any support	More relapses Good to very good physical function	Fewer relapses Moderate to very poor physical function
Participant describes receiving support through domestic services	Moderate to very poor physical function Trade or high school Mid to low socioeconomic status	Good to very good physical function University

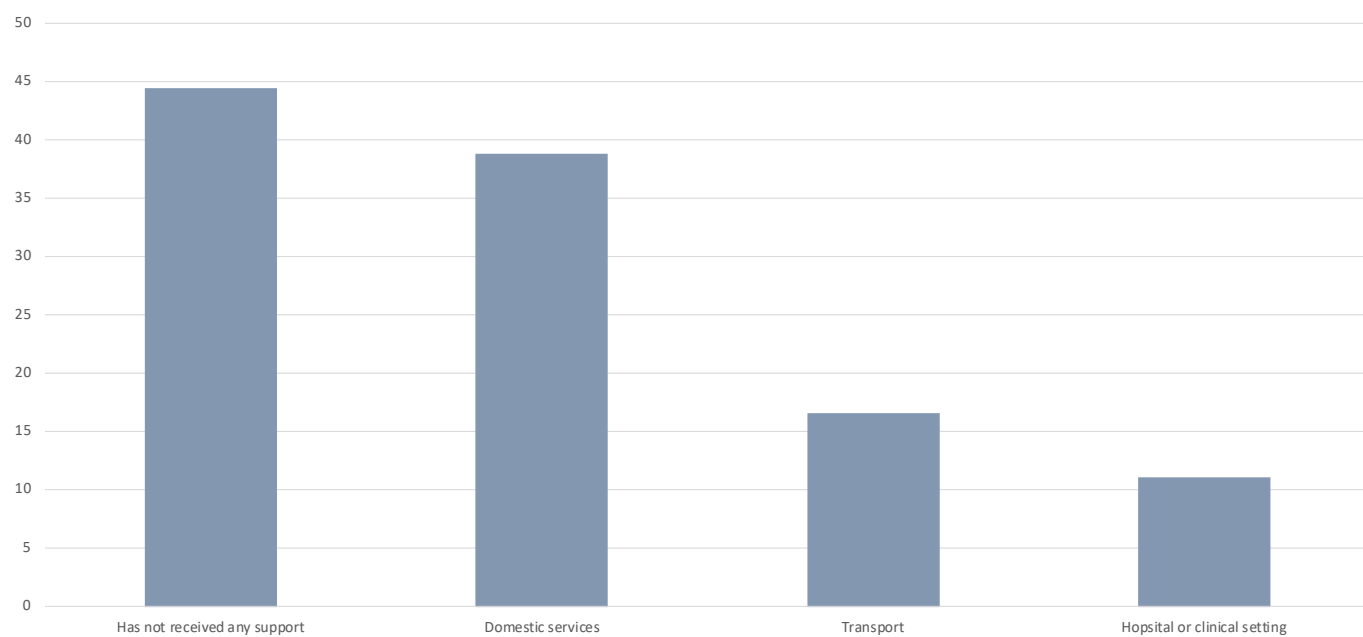


Figure 7.37: Experience of care and support