

Section 7 Care and support

Section 7: Experience of care and support**Coordination of care**

- Overall the entire cohort had a mean communication score of 38.06, total score of 64.06, a median score of 5.00 for care co-ordination and 6.00 for care received; these scores fall in the middle of the scale. The median score for navigation was 26.00, this falls in the second highest quintiles indicating good navigation.
- The care coordination navigation scores and total scores were better for those with moderate disease compared to those with either severe or very severe; and the care coordination communication scores were better for those with moderate disease compared to those with very severe disease.
- There was a significant difference between those that live in metropolitan areas compared with those that live in regional/rural areas for care coordination. Those that live in regional/rural areas had a higher score.
- There were no significant differences in care coordination between the comorbid depression and anxiety subgroups or the education status subgroups.

Care and support

- Participants were asked what care and support they had received throughout their experience. The majority of participants described care and support coming from family and friends (n=76; 76.00%), and this was the most common theme followed by care and support accessed from the hospital or clinical setting (n=27; 27.00%). There were also 16 (16.00%) participants that described feeling as though they did not need additional support, however, participants that had severe AD were stated this less frequently (9.09% compared to 16.00% in the general cohort). This was also stated less frequently by participants that had a high school/trade education (7.14 compared to 16.00% in the general cohort).

Experience of coordination of care

A Care Coordination questionnaire was completed. The Care Coordination questionnaire comprises a total score, 2 sub 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 entire cohort had a mean communication score of 38.06, total score of 64.06, a median score of 5.00 for care co-ordination and 6.00 for care received; these scores fall in the middle of the scale. The median score for

navigation was 26.00, this falls in the second highest quintiles indicating good navigation.

Box plots display each of the Care Coordination scores by disease severity, comorbid depression and anxiety, location of participants, and education status (Figures 7.1 to 7.20).

Comparisons of Care Coordination scores have been made based on disease severity (Figures 7.1 to 7.5, Tables 7.2 to 7.5), comorbid depression and anxiety (Figures 7.6 to 7.10, Table 7.6), location (Figures 7.11 to 7.15, Tables 7.7 and 7.8), and education status (Figures 7.16 to 7.20, Tables 7.9 and 7.10).

Table 7.1: Summary statistics Total score - Communication and Navigation

Scale	Mean	SD	Median	IQR	Possible range
Total score*	64.06	11.69	65.50	16.00	20-100
Communication*	38.06	8.49	39.00	11.00	13- 65
Navigation	26.00	5.87	26.00	9.25	7-35
Care co-ordination	5.21	2.35	5.00	4.00	1-10
Care received	5.89	2.18	6.00	4.00	1-10

*Normal distribution, use mean and sd as central measure

Comparisons of Care Coordination scores by disease severity

Comparisons of Care Coordination subscales were made by disease severity. Summary statistics are listed in Table 7.2. A one-way ANOVA test was used when assumptions for normality and variance were met (Table 7.3), or when assumptions for normality and variance were not met, a Kruskal-Wallis test sum correction test was used (Table 7.4).

A one way ANOVA test indicated a significant difference in the care coordination total score between groups [$F(3,96) = 6.53$, $p = 0.0005$], and a difference in the care coordination -navigation scores between groups [$F(3,96) = 5.89$, $p = 0.0010$] (Table 7.3). Post hoc comparisons using the Tukey HSD test indicated that

the mean score for those with moderate disease had a significantly higher score than those with severe or very severe disease for both of these scales (Table 7.4).

A one way ANOVA test indicated a significant difference in the Care coordination - communication score between groups [$F(3,96) = 3.24$, $p = 0.0257$] (Table 7.3). Post hoc comparisons using the Tukey HSD test indicated that the mean score for those with moderate disease had a significantly higher score than those with very severe disease (Table 7.4).

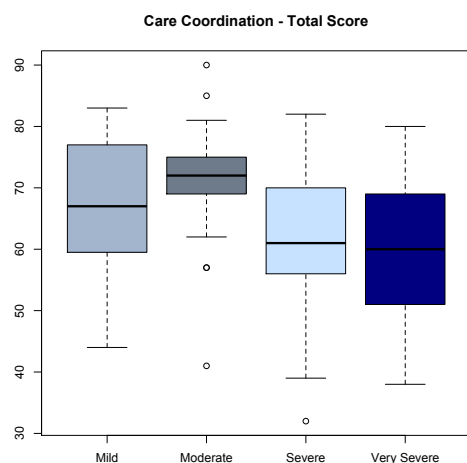


Figure 7.1: Boxplot of Care coordination total score by disease severity

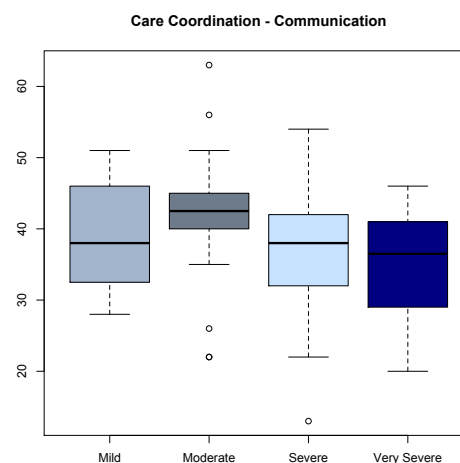


Figure 7.2: Boxplot of Communication sub scale disease severity

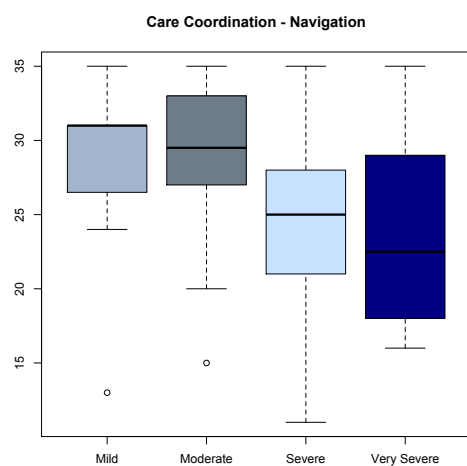


Figure 7.3: Boxplot of Navigation sub scale disease severity

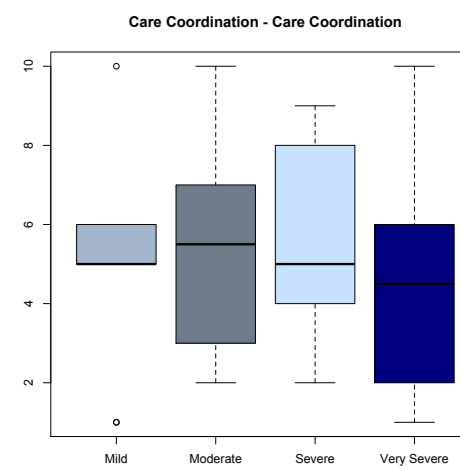


Figure 7.4: Boxplot of Care coordination question disease severity

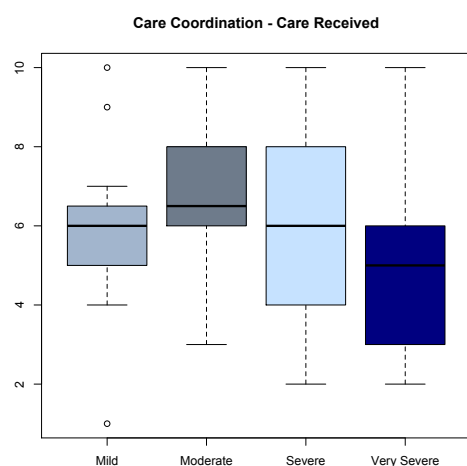


Figure 7.5: Boxplot of Care received disease severity

Table 7.2: Summary statistics by disease severity

Care coordination scale	Group	Count	Mean	Sd
Total score	Mild	11	67.50	11.80
	Moderate	26	71.10	9.52
	Severe	41	61.60	10.70
	Very severe	22	58.70	11.90
Communication	Mild	11	39.20	7.97
	Moderate	26	41.80	8.84
	Severe	41	37.20	8.32
	Very severe	22	34.70	7.34
Navigation	Mild	11	28.30	5.95
	Moderate	26	29.30	5.11
	Severe	41	24.40	5.14
	Very severe	22	24.00	6.23
Care received	Mild	11	5.91	2.39
	Moderate	26	6.62	1.72
	Severe	41	5.88	2.37
	Very severe	22	5.05	2.01

Table 7.3: ANOVA table Care coordination scale by disease severity

Care coordination scale		Sum of squares	Df	Mean square	F	P
Total Score	Between Groups	2294	3	764.80	6.53	0.0005*
	Within Groups	11245	96	117.10		
	Total	13539	99			
Communication	Between Groups	656	3	218.60	3.24	0.0257*
	Within Groups	6488	96	67.58		
	Total	7144	99			
Navigation	Between Groups	529.80	3	176.60	5.886	0.0010*
	Within Groups	2880.20	96	30.00		
	Total	3410.00	99			
Care received	Between Groups	29.40	3	9.80	2.14	0.1010
	Within Groups	440.40	96	4.59		
	Total	469.80	99			

* Statistically significant at $p < 0.05$

Table 7.4: Post hoc Tuckey HSD test Care coordination by disease severity

Care coordination scale	Comparison	Mean difference	Lower	Upper	P adjusted
Total score	Moderate -Mild	3.62	-6.56	13.80	0.7886
	Severe-Mild	-5.87	-15.48	3.74	0.3852
	Very severe – Mild	-8.77	-19.22	1.68	0.1320
	Severe-Moderate	-9.49	-16.59	-2.40	0.0039*
	Very Severe-Moderate	-12.40	-20.59	-4.20	0.0008*
	Very Severe-Severe	-2.90	-10.38	4.58	0.7410
Communication	Moderate -Mild	2.63	-5.11	10.36	0.8110
	Severe-Mild	-2.01	-9.31	5.29	0.8887
	Very severe – Mild	-4.45	-12.39	3.48	0.4611
	Severe-Moderate	-4.64	-10.03	0.75	0.1174
	Very Severe-Moderate	-7.08	-13.31	-0.85	0.0192*
	Very Severe-Severe	-2.44	-8.12	3.24	0.6752
Navigation	Moderate -Mild	1.00	-4.15	6.15	0.9575
	Severe-Mild	-3.86	-8.72	1.00	0.1689
	Very severe – Mild	-4.32	-9.61	0.97	0.1495
	Severe-Moderate	-4.85	-8.44	-1.26	0.0035*
	Very Severe-Moderate	-5.31	-9.46	-1.17	0.0063*
	Very Severe-Severe	-0.46	-4.24	3.32	0.9888

* Statistically significant at $p < 0.05$

Table 7.5: Summary statistics and Kruskal-Wallis rank sum test

PIH Scale	Group	Count	Median	IQR	X ²	Df	P
Care coordination	Mild	11	5.00	1.00	3.32	3	0.3445
	Moderate	26	5.50	3.75			
	Severe	41	5.00	4.00			
	Very severe	22	4.50	3.50			

Comparisons of Care Coordination scores by depression and anxiety

Comparisons of Care Coordination scores were made between those that have comorbid depression and anxiety and those that do not. Boxplots for each of the

care coordination scales are displayed in Figures 7.6 to 7.10. Assumptions for normality and variance were met, a two sample t-test was used (Table 7.6). There were no statistically significant differences between these groups.

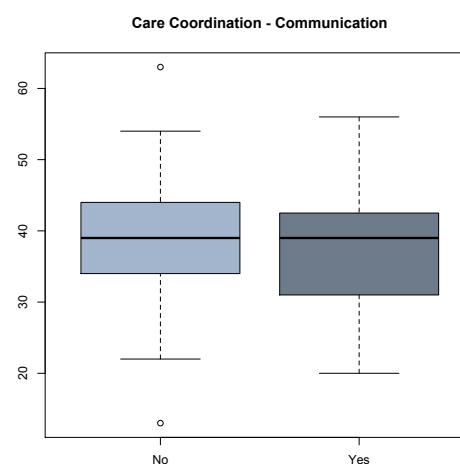
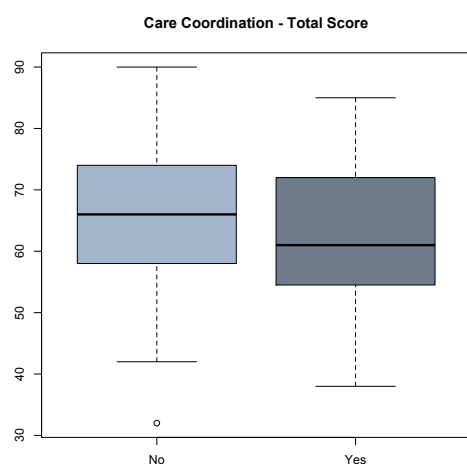
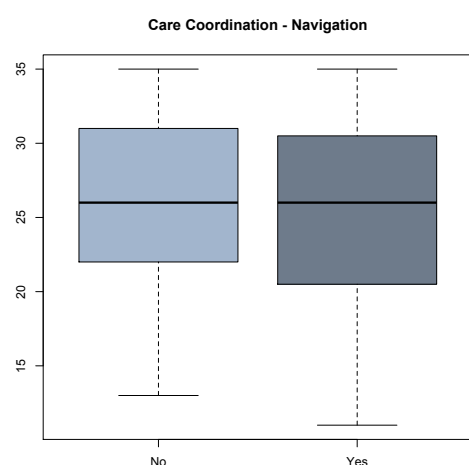


Figure 7.6: Boxplot of Care coordination total score depression and anxiety



7.7: Boxplot of Care coordination Communication depression and anxiety

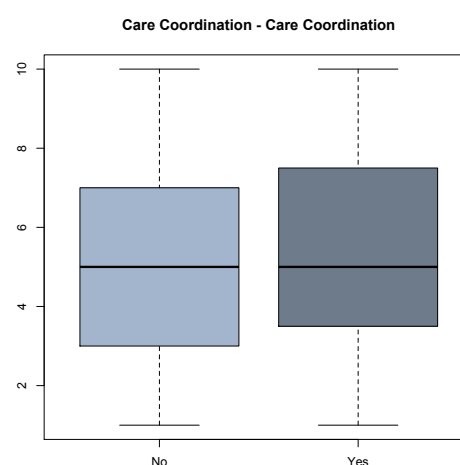


Figure 7.8: Boxplot of Care coordination Navigation depression and anxiety

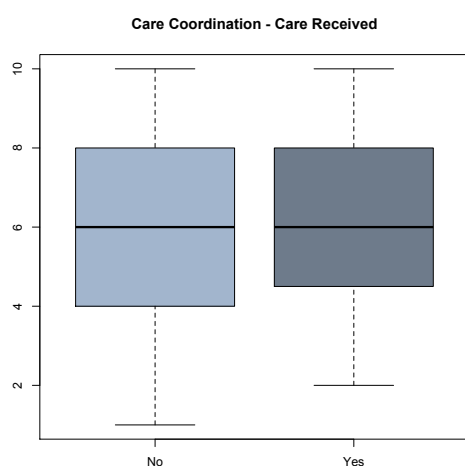


Figure 7.9: Boxplot of Care coordination question depression and anxiety

Figure 7.10: Boxplot of Care Received depression and anxiety

Table 7.6: Summary statistics and two sample t-test care coordination scales by depression and anxiety status

Care coordination scale	Depression and Anxiety	Count	Mean	SD	t	df	p
Total score	No	61	65.20	11.20	1.18	98	0.2397
	Yes	39	62.30	12.40			
Communication	No	61	38.90	8.64	1.22	98	0.2262
	Yes	39	36.80	8.21			
Navigation	No	61	26.30	5.39	0.59	98	0.5553
	Yes	39	25.60	6.60			
Care coordination	No	61	5.13	2.26	-0.42	98	0.6769
	Yes	39	5.33	2.51			
Care received	No	61	5.84	2.13	-0.31	89	0.7586
	Yes	39	5.97	2.28			

Comparisons of Care Coordination scores by Location

Comparisons of Care Coordination scores were made between participants that live in metropolitan areas compared to those that live in regional/rural. 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). There was a significant difference between those that live in metropolitan areas compared with those that live in regional/rural areas for care coordination [$W=925.00$, $p=0.0445$] with those that live in regional/rural areas having a higher score.

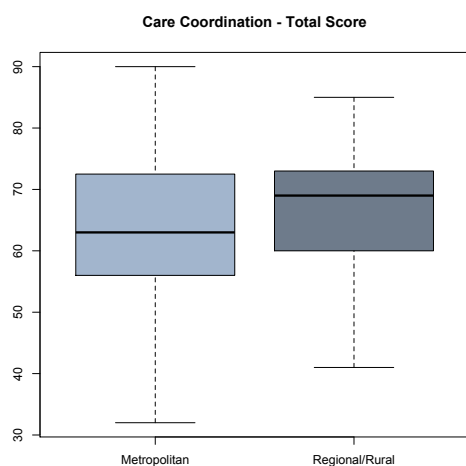
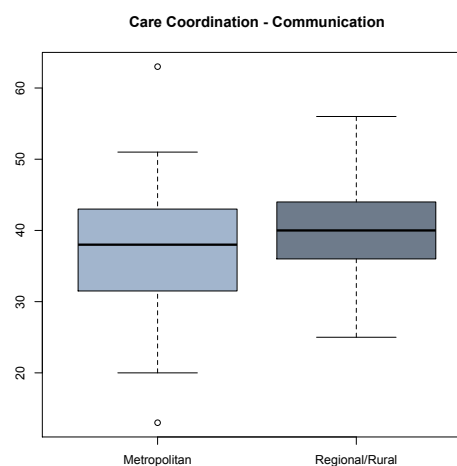


Figure 7.11: Boxplot of Care coordination total score by location



7.12: Boxplot of Care coordination Communication by location

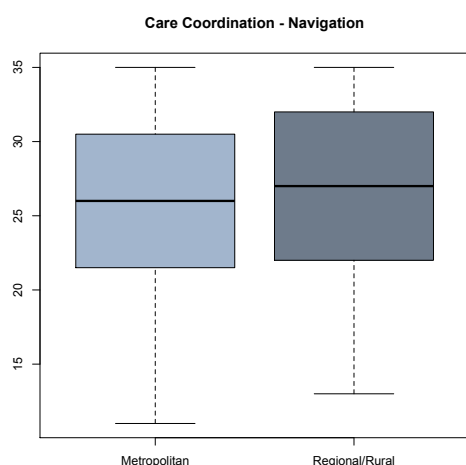


Figure 7.13: Boxplot of Care coordination Navigation by location

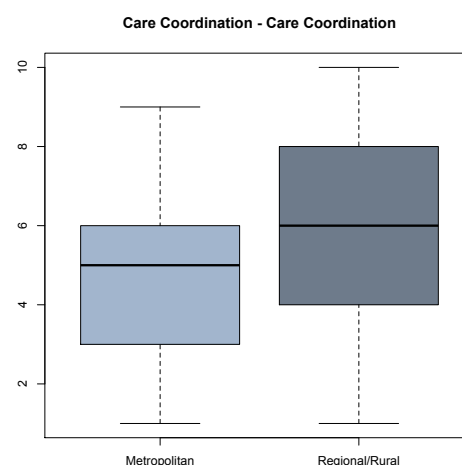


Figure 7.14: Boxplot of Care coordination question by location

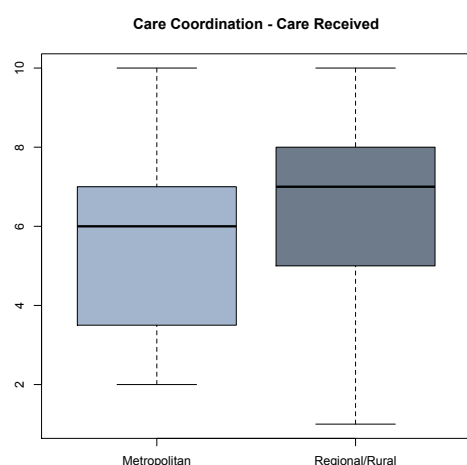


Figure 7.15: Boxplot of Care Received by location

Table 7.7: Summary statistics and Two sample t test by location

Care Coordination	Location	Number	Mean	SD	T	df	P
Total Score	Metropolitan	59	62.90	12.40	-1.18	98	0.2422
	Regional/Rural	41	65.70	10.6			
Communication	Metropolitan	59	37.10	9.13	-1.43	98	0.1551
	Regional/Rural	41	39.50	7.36			
Navigation	Metropolitan	59	25.90	5.86	-0.28	98	0.7832
	Regional/Rural	41	26.20	5.95			

Table 7.8: Summary statistics Wilcoxon rank sum test with continuity correction by location

Care Coordination	Group	Number	Median	IQR	W	P
Care coordination	Metropolitan	59	5.00	3.00	925.00	0.0445*
	Regional/Rural	41	6.00	4.00		
Care received	Metropolitan	59	6.00	3.50	947.50	0.0642
	Regional/Rural	41	7.00	3.00		

Comparisons of Care Coordination scores by education

Comparisons of Care Coordination scores were made between participants education levels, comparing those with high school or trade with those with university education. A two-sample t-test was used

when assumptions for normality and variance were met (Table 7.9), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.10). No statistically significant differences were observed between these two groups for any Care Coordination scores (Tables 7.9 and 7.10).

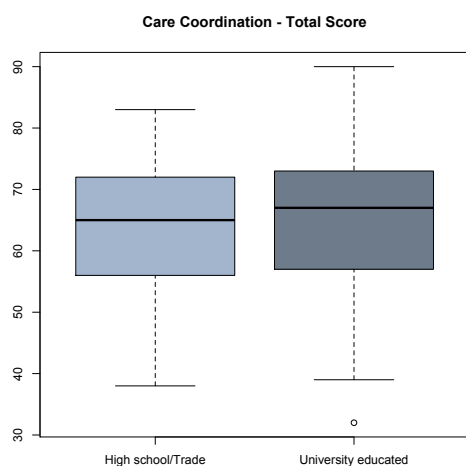
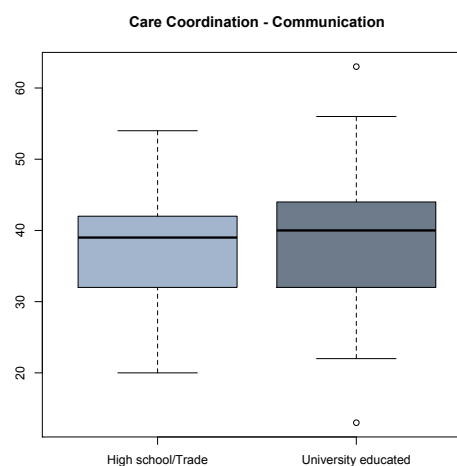


Figure 7.16: Boxplot of Care coordination total score by education



7.17: Boxplot of Care coordination Communication by education

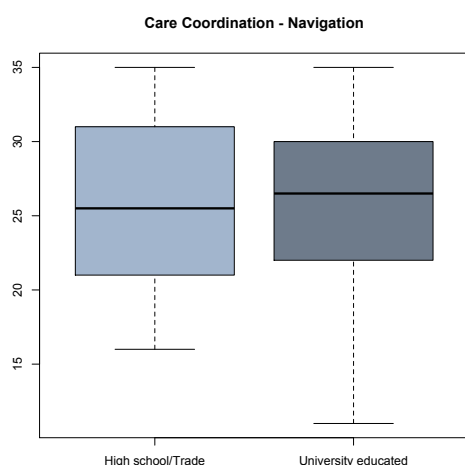


Figure 7.18: Boxplot of Care coordination Navigation by education

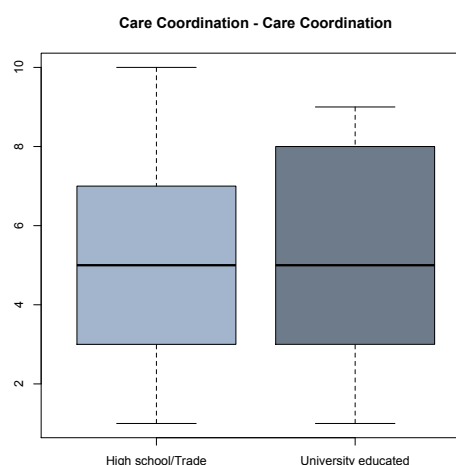


Figure 7.19: Boxplot of Care coordination question by education

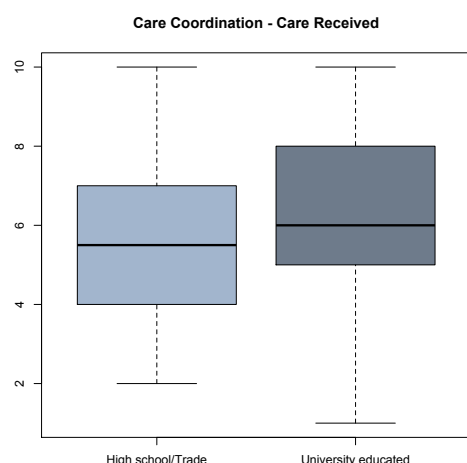


Figure 7.20: Boxplot of Care Received by education

Table 7.9: Summary statistics and Two sample t test by education status

Care Coordination	Group	Number	Mean	SD	T	df	P
Total Score	High school/Trade	42	64.00	11.10	-0.04	98	0.9654
	University	58	64.10	12.20			
Communication	High school/Trade	42	38.00	7.45	-0.11	98	0.9148
	University	58	38.10	9.24			

Table 7.10: Summary statistics Wilcoxon rank sum test with continuity correction by education status

Care Coordination	Group	Number	Median	IQR	W	P
Navigation	High school/Trade	42	25.50	9.75	1204	0.9247
	University	58	26.50	8.00		
Care coordination	High school/Trade	42	5.00	3.50	1193	0.8629
	University	58	5.00	4.75		
Care received	High school/Trade	42	5.50	3.00	1078	0.3251
	University	58	6.00	3.00		

Experience of care and support

Participants were asked what care and support they had received throughout their experience. The majority of participants described care and support coming from family and friends (n=76; 76.00%), and this was the most common theme followed by care and support accessed from the hospital or clinical setting (n=27; 27.00%). There were also 16 (16.00%) participants that described feeling as though they did

not need additional support, however, participants that had severe AD were stated this less frequently (9.09% compared to 16.00% in the general cohort). This was also stated less frequently by participants that had a high school/trade education (7.14 compared to 16.00% in the general cohort).

Table 7.14: Care and support received

	Total Participants (n=100)		Mild Atopic Dermatitis (n=11)		Moderate Atopic Dermatitis (n=26)		Severe Atopic Dermatitis (n=41)		Very Severe Atopic Dermatitis (n=22)	
Participant describes primarily receiving support and care from family and friends	76	76.00	9	81.82	21	80.77	29	70.73	17	77.27
Participant describes only receiving care from health professionals/clinical setting	27	27.00	2	18.18	6	23.08	12	29.27	7	31.82
Participant describes not needing or approaching any kind of support	16	16.00	2	18.18	4	15.38	8	19.51	2	9.09
Participant describes receiving support from support groups (online pages like Facebook)	8	8.00	0	0.00	0	0.00	3	7.32	5	22.73
	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
Participant describes primarily receiving support and care from family and friends	30	76.92	31	75.61	45	76.27	39	67.24	37	88.10
Participant describes only receiving care from health professionals/clinical setting	10	25.64	14	34.15	13	22.03	16	27.59	11	26.19
Participant describes not needing or approaching any kind of support	6	15.38	5	12.20	11	18.64	13	22.41	3	7.14
Participant describes receiving support from support groups (online pages like Facebook)	2	5.13	5	12.20	3	5.08	3	5.17	5	11.90

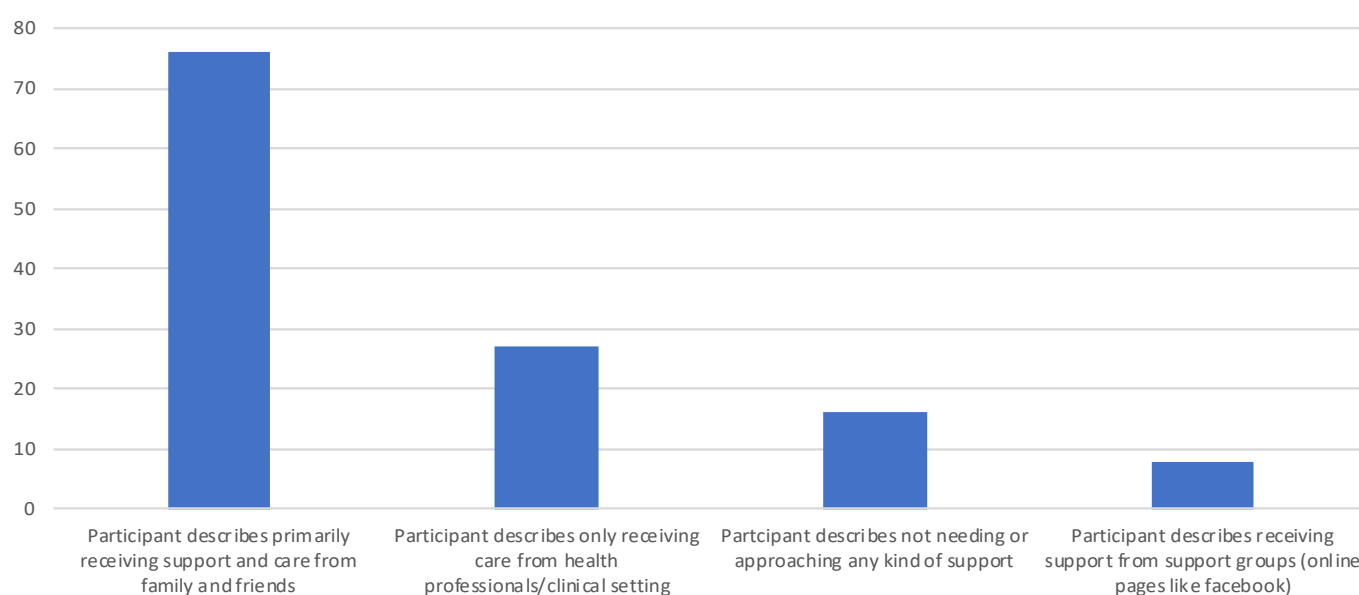


Figure 7.36: Care and support received (% of all participants)