

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 good 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 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. The average score indicates that participants scored rated their care coordination as good.

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. The average score indicates that participants rated their quality of care as very good.

Experience of care and support

In the structured interview, participants were asked what care and support they had received since their diagnosis. This question aims to investigate what services patients consider to be support and care services. The most common responses were that they found support and care from charities (45.45%), hospital or clinical setting (30.30%), and in the form of accommodation for themselves or their family while having treatment (24.24 %). Other themes included support from family and friends (21.21%), domestic services and/or home care (12.12%), transport to and from hospital appointments (12.12%), and in the form of financial advice and help with Centrelink applications (12.12%). Some participants described the challenges of finding or accessing support (18.18%), not needing or seeking help or support (15.15%), and that they did not receive any formal support (12.12%).

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 highest quintile for Care coordination: Quality of care global measure (median=9.00, IQR=2.00) indicating very good quality of care

The overall scores for the cohort were in the second highest quintile for Care coordination: Communication (mean=45.18, SD=9.53), Care coordination: Navigation (mean=27.09, SD=4.69), Care coordination: Total score (mean=72.27, SD=12.17), Care coordination: Care coordination global measure (median=8.00, IQR=3.00), indicating good communication, good communication, good coordination, good care coordination.

Comparisons of Care co-ordination have been made based on blood cancer type, CAR T-cell therapy, gender, age, location and socioeconomic status.

The **Care coordination: communication** scale measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their

condition, emotional aspects, practical considerations, and financial entitlements. The average score indicates that participants had good 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 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. The average score indicates that participants scored rated their care coordination as good.

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. The average score indicates that participants rated their quality of care as very good.

Table 7.1: Care coordination summary statistics

Care coordination scale (n=33)	Mean	SD	Median	IQR	Possible range	Quintile
Communication*	45.18	9.53	47.00	12.00	13 to 65	4
Navigation*	27.09	4.69	28.00	7.00	7 to 35	4
Total score*	72.27	12.17	72.00	16.00	20 to 100	4
Care coordination global measure	7.94	1.78	8.00	3.00	1 to 10	4
Quality of care global measure	8.85	1.39	9.00	2.00	1 to 10	5

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

Care coordination by blood cancer type

Comparisons were made by type of blood cancer. There were 6 participants (18.18%) with B-cell acute lymphoblastic leukemia (ALL), 10 participants (30.30%) with Diffuse Large B-Cell Lymphoma, and 17 participants (51.52%) with Multiple Myeloma.

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

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

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

Table 7.2: Care coordination blood cancer type summary statistics and one-way ANOVA

Care coordination scale	Group	Number (n=33)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Communication	B-cell acute lymphoblastic leukemia (ALL)	6	18.18	45.00	8.32	Between groups	97.80	2	48.88	0.52	0.5990
	Diffuse Large B-Cell Lymphoma	10	30.30	47.70	10.06	Within groups	2809.20	30	93.64		
	Multiple Myeloma	17	51.52	43.76	9.85	Total	2907.00	32	142.52		
Total score	B-cell acute lymphoblastic leukemia (ALL)	6	18.18	70.67	10.65	Between groups	81.00	2	40.29	0.26	0.7730
	Diffuse Large B-Cell Lymphoma	10	30.30	74.60	12.48	Within groups	4658.00	30	155.27		
	Multiple Myeloma	17	51.52	71.47	12.96	Total	4739.00	32	195.56		
Care coordination global measure	B-cell acute lymphoblastic leukemia (ALL)	6	18.18	7.67	1.86	Between groups	1.97	2	0.99	0.30	0.7460
	Diffuse Large B-Cell Lymphoma	10	30.30	7.70	2.06	Within groups	99.90	30	3.33		
	Multiple Myeloma	17	51.52	8.18	1.67	Total	101.87	32	4.32		

Table 7.3: Care coordination blood cancer type summary statistics and Kruskal-Wallis test

Care coordination scale	Group	Number (n=33)	Percent	Median	IQR	C ²	dF	p-value
Navigation	B-cell acute lymphoblastic leukemia (ALL)	6	18.18	25.00	5.50	1.57	2	0.4553
	Diffuse Large B-Cell Lymphoma	10	30.30	28.00	3.50			
	Multiple Myeloma	17	51.52	29.00	7.00			
Quality of care global measure	B-cell acute lymphoblastic leukemia (ALL)	6	18.18	8.00	1.50	1.32	2	0.5175
	Diffuse Large B-Cell Lymphoma	10	30.30	9.50	1.75			
	Multiple Myeloma	17	51.52	9.00	2.00			

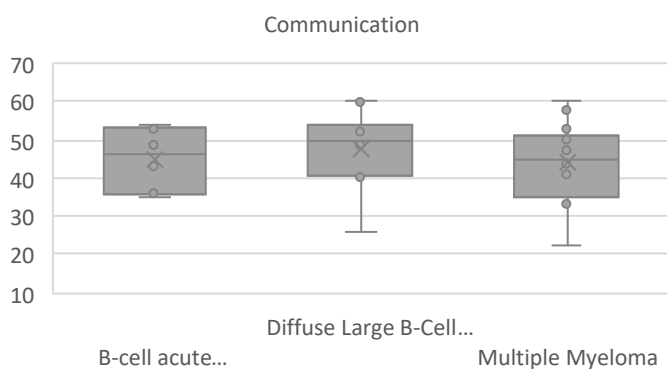


Figure 7.1: Boxplot of Care coordination: Communication by blood cancer type

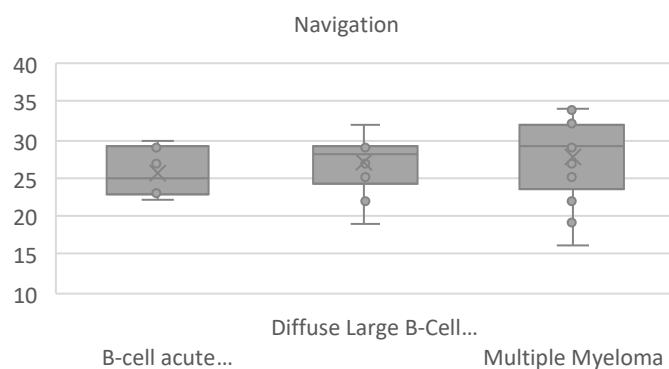


Figure 7.2: Boxplot of Care coordination: Navigation by blood cancer type

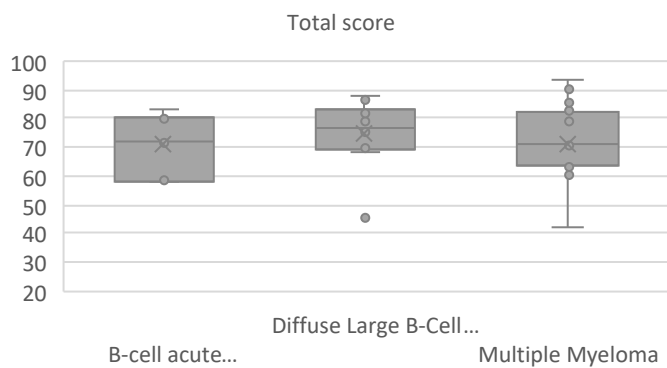


Figure 7.3: Boxplot of Care coordination: Total score by blood cancer type

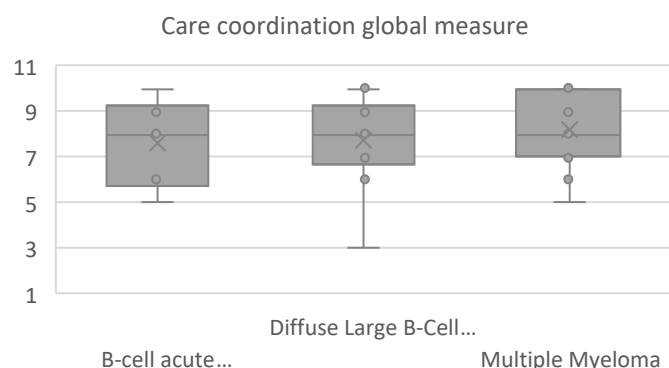


Figure 7.4: Boxplot of Care coordination: Care coordination global measure by blood cancer type

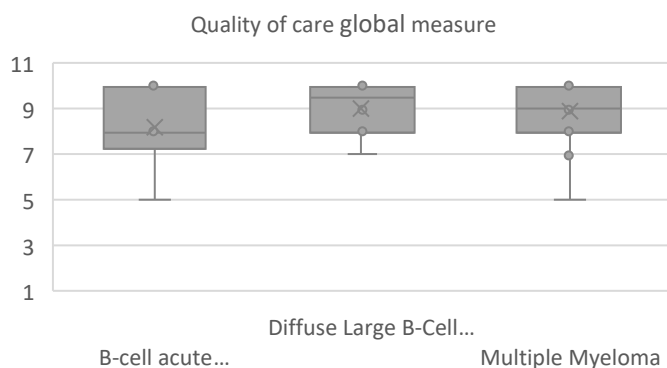


Figure 7.5: Boxplot of Care coordination: Quality of care global measure by blood cancer type

Care coordination by CAR T-cell therapy

Comparisons were made by CAR T-cell therapy there were 25 participants (75.76%) that had treatment with Car T-cell therapy and, 8 participants (24.24%) that did not .

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

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

No significant differences were observed between participants by **CAR T-cell therapy** for any of the Care coordination scales.

Table 7.4: Care coordination by CAR T-cell therapy summary statistics and T-test

Care coordination scale	Group	Number (n=33)	Percent	Mean	SD	T	dF	p-value
Communication	No	25	75.76	45.04	8.36	-0.15	31	0.8827
	Yes	8	24.24	45.63	13.23			
Navigation	No	25	75.76	26.72	4.64	-0.80	31	0.4302
	Yes	8	24.24	28.25	4.95			
Total score	No	25	75.76	71.76	10.90	-0.42	31	0.6757
	Yes	8	24.24	73.88	16.30			

Table 7.5: Care coordination by CAR T-cell therapy summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=33)	Percent	Median	IQR	W	p-value
Care coordination global measure	No	25	75.76	8.00	3.00	121.00	0.3765
	Yes	8	24.24	8.00	2.25		
Quality of care global measure	No	25	75.76	9.00	2.00	80.50	0.3965
	Yes	8	24.24	10.00	1.25		

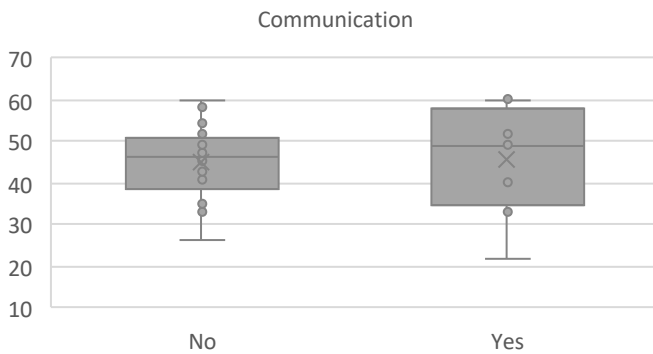


Figure 7.6: Boxplot of Care coordination: Communication by CAR T-cell therapy

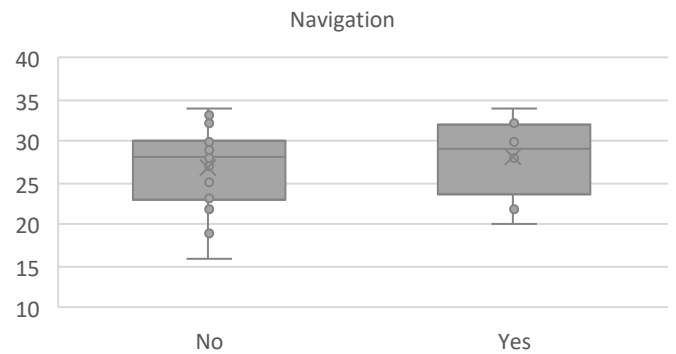


Figure 7.7: Boxplot of Care coordination: Navigation by CAR T-cell therapy

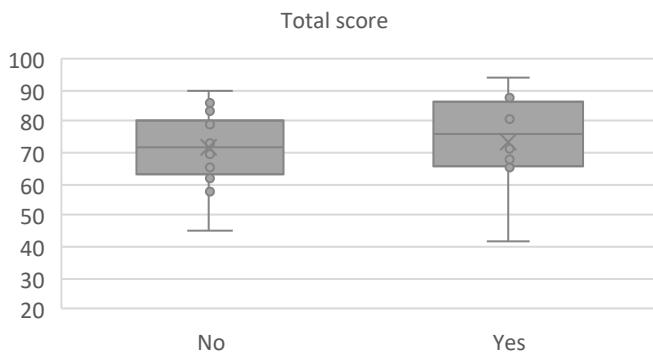


Figure 7.8: Boxplot of Care coordination: Total score by CAR T-cell therapy

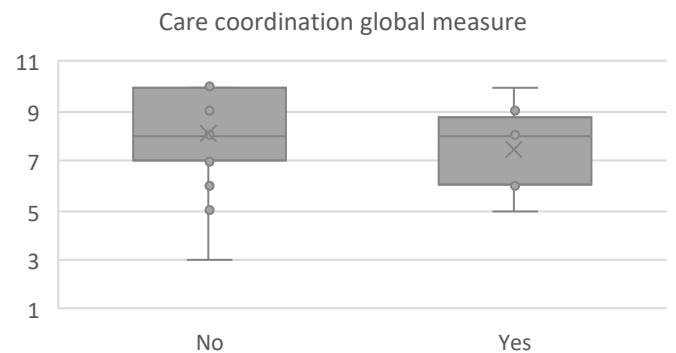


Figure 7.9: Boxplot of Care coordination: Care coordination global measure by CAR T-cell therapy

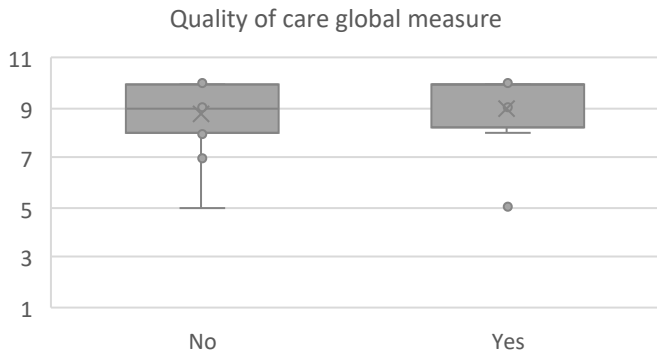


Figure 7.10: Boxplot of Care coordination: Quality of care global measure by CAR T-cell therapy

Care coordination by gender

Comparisons were made by gender, there were 15 female participants (45.45%), and 18 male participants (54.55%).

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

a Wilcoxon rank sum test with continuity correction was used

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

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

Care coordination scale	Group	Number (n=33)	Percent	Mean	SD	T	dF	p-value
Communication	Female	15	45.45	44.73	11.51	-0.24	31.00	0.8095
	Male	18	54.55	45.56	7.85			
Total score	Female	15	45.45	71.33	14.13	-0.40	31.00	0.6923
	Male	18	54.55	73.06	10.62			

Table 7.7: Care coordination by gender summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=33)	Percent	Median	IQR	W	p-value
Navigation	Female	15	45.45	28.00	5.50	118.00	0.5491
	Male	18	54.55	28.00	8.50		
Care coordination global measure	Female	15	45.45	8.00	2.50	112.50	0.4140
	Male	18	54.55	8.00	2.75		
Quality of care global measure	Female	15	45.45	9.00	2.00	127.00	0.7733
	Male	18	54.55	9.00	2.00		

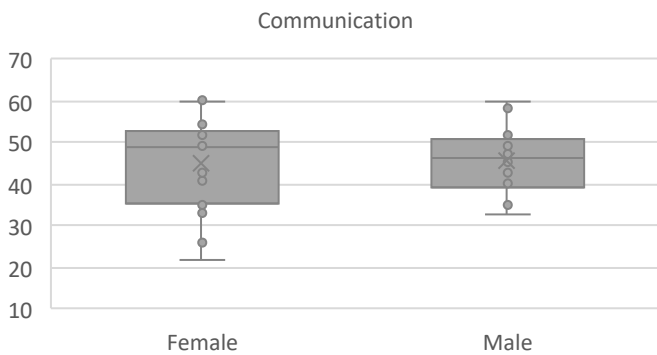


Figure 7.11: Boxplot of Care coordination: Communication by gender

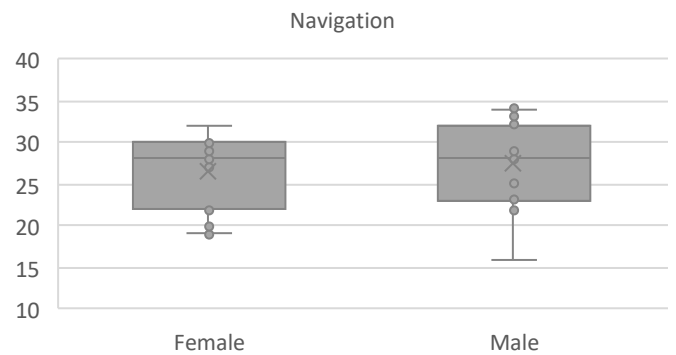


Figure 7.12: Boxplot of Care coordination: Navigation by gender

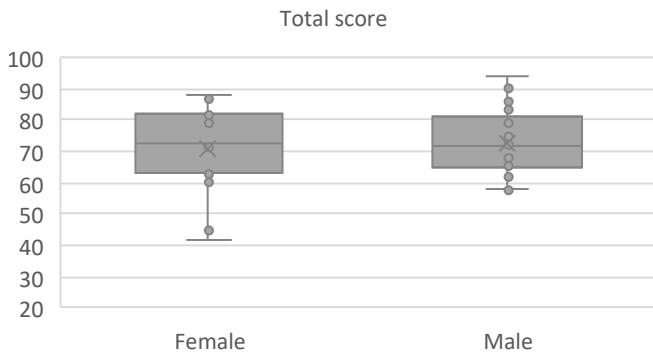


Figure 7.13: Boxplot of Care coordination: Total score by gender

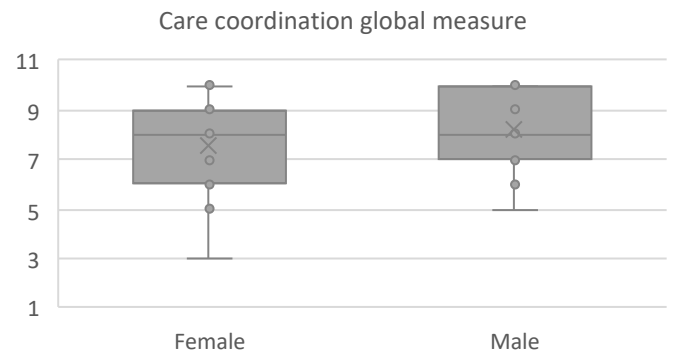


Figure 7.14: Boxplot of Care coordination: Care coordination global measure by gender

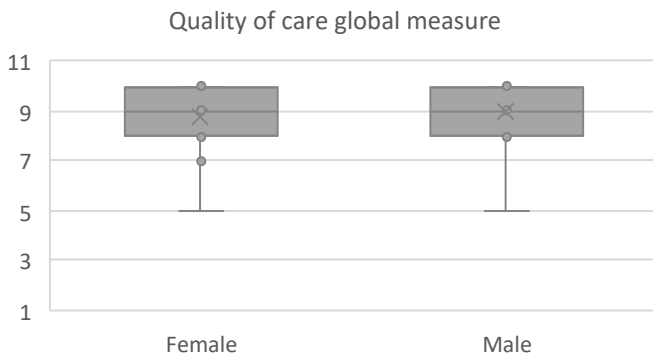


Figure 7.15: Boxplot of Care coordination: Quality of care global measure by gender

Care coordination by age

Participants were grouped according to age, with comparisons made between participants aged 25 to 64 (n=19, 57.58%), and participants aged 65 and older (n=14, 42.42%).

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

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

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

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

Care coordination scale	Group	Number (n=33)	Percent	Mean	SD	T	dF	p-value
Communication	Aged 25 to 64	19	57.58	45.21	8.94	0.02	31.00	0.9843
	Aged 65 and older	14	42.42	45.14	10.63			
Navigation	Aged 25 to 64	19	57.58	26.37	4.37	-1.03	31.00	0.3097
	Aged 65 and older	14	42.42	28.07	5.08			
Total score	Aged 25 to 64	19	57.58	71.58	11.12	-0.38	31.00	0.7092
	Aged 65 and older	14	42.42	73.21	13.84			

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

Care coordination scale	Group	Number (n=33)	Percent	Median	IQR	W	p-value
Care coordination global measure	Aged 25 to 64	19	57.58	8.00	2.50	139.00	0.8370
	Aged 65 and older	14	42.42	8.00	3.50		
Quality of care global measure	Aged 25 to 64	19	57.58	9.00	2.00	103.00	0.2537
	Aged 65 and older	14	42.42	10.00	1.75		

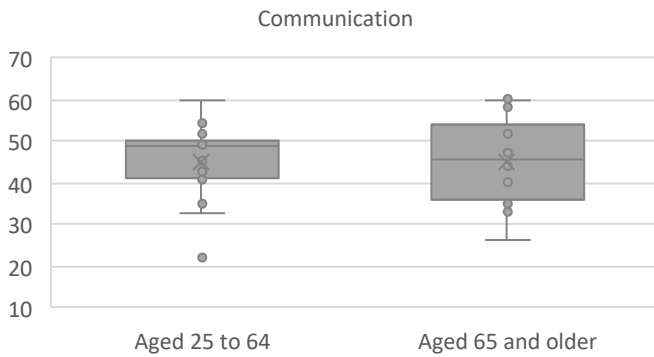


Figure 7.16: Boxplot of Care coordination: Communication by age

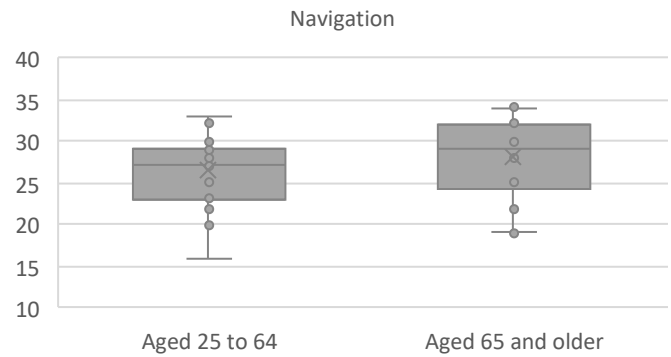


Figure 7.17: Boxplot of Care coordination: Navigation by age

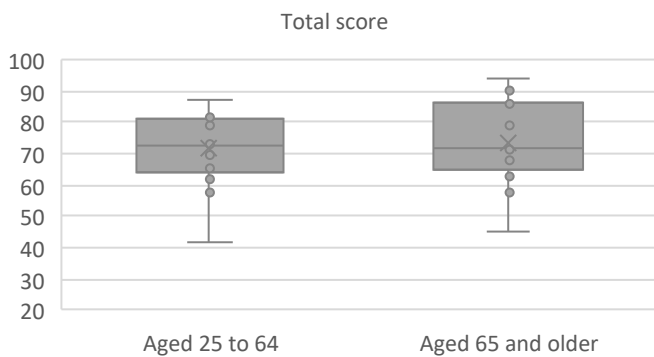


Figure 7.18: Boxplot of Care coordination: Total score by age

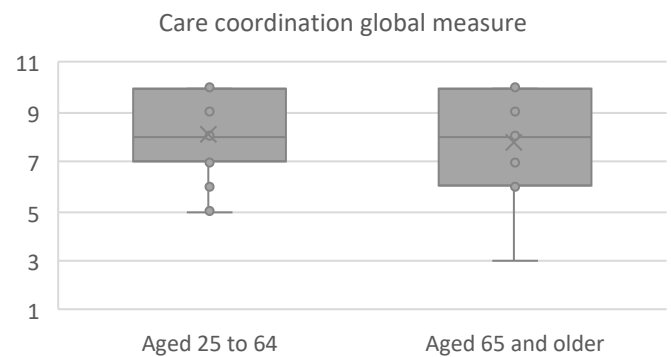


Figure 7.19: Boxplot of Care coordination: Care coordination global measure by age

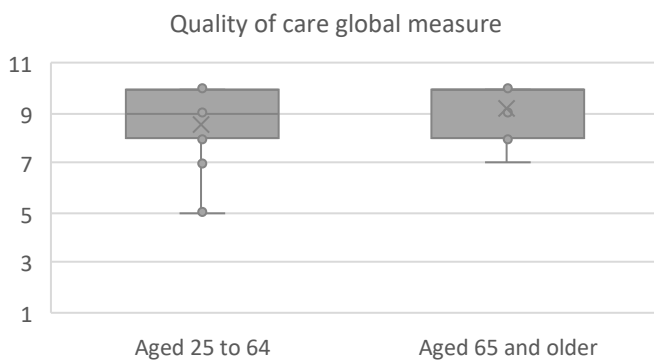


Figure 7.20: Boxplot of Care coordination: Quality of care global measure by age

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 (n=15, 45.45%) were compared to those living in a major city (n=18, 54.55%).

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

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

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

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

Care coordination scale	Group	Number (n=33)	Percent	Mean	SD	T	dF	p-value
Communication	Metropolitan	15	45.45	41.93	8.00	-1.85	31.00	0.0733
	Regional or remote	18	54.55	47.89	10.06			
Navigation	Metropolitan	15	45.45	26.80	3.90	-0.32	31.00	0.7504
	Regional or remote	18	54.55	27.33	5.36			
Total score	Metropolitan	15	45.45	68.73	9.90	-1.56	31.00	0.1292
	Regional or remote	18	54.55	75.22	13.34			

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

Care coordination scale	Group	Number (n=33)	Percent	Median	IQR	W	p-value
Care coordination global measure	Metropolitan	15	45.45	8.00	2.00	99.00	0.1875
	Regional or remote	18	54.55	8.00	2.00		
Quality of care global measure	Metropolitan	15	45.45	9.00	2.00	99.00	0.1727
	Regional or remote	18	54.55	10.00	1.75		

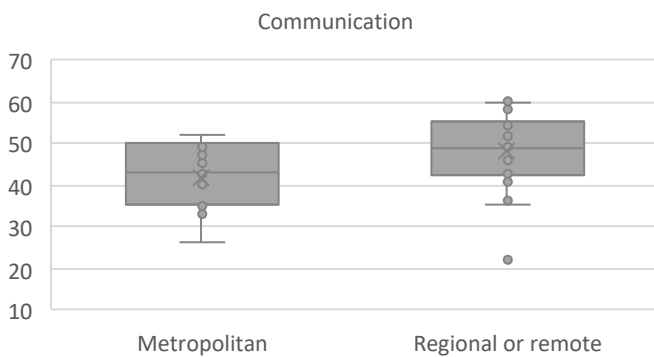


Figure 7.21: Boxplot of Care coordination: Communication by location

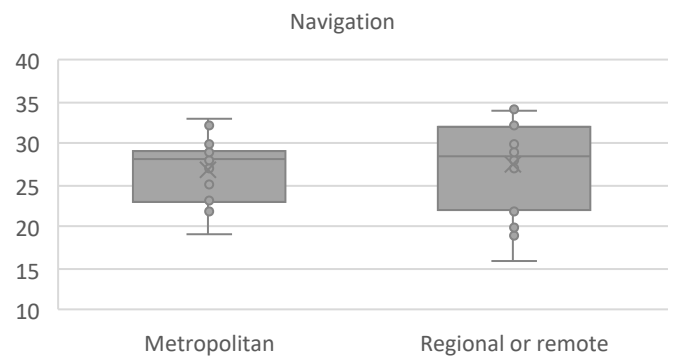


Figure 7.22: Boxplot of Care coordination: Navigation by location

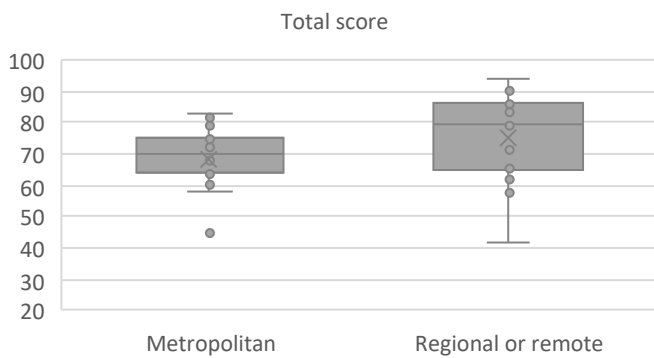


Figure 7.23: Boxplot of Care coordination: Total score by location

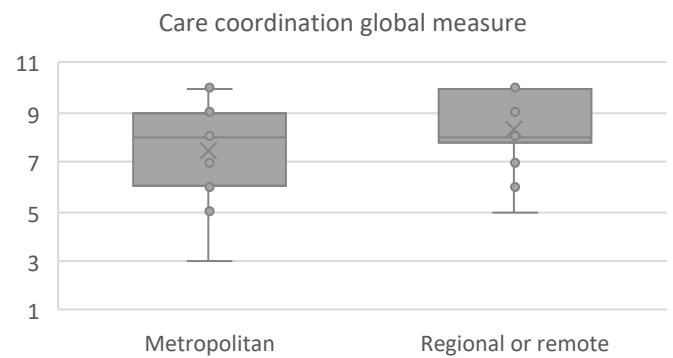


Figure 7.24: Boxplot of Care coordination: Care coordination global measure by location

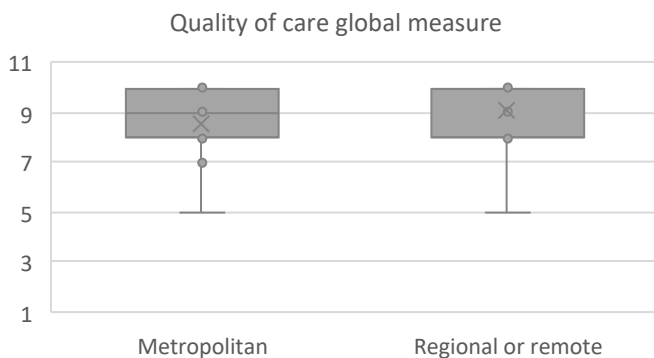


Figure 7.25: Boxplot of Care coordination: Quality of care global measure by location

Care coordination by socioeconomic status

Comparisons were made by socioeconomic status, using the Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a mid to low SEIFA score of 1-6 (n=16, 48.48%) compared to those with a higher SEIFA score of 7-10 (n=17, 51.52%).

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

A two sample t-test indicated that the mean score for the Care coordination Communication scale [t(31) = -2.77 , p = 0.0094*] was significantly lower for participants in the Higher advantage subgroup (Mean = 40.88, SD = 8.71) compared to participants in the Mid to low advantage subgroup (Mean = 49.24, SD = 8.64.)

A two sample t-test indicated that the mean score for the Care coordination Total score scale [t(31) = -2.78 , p = 0.0091*] was significantly lower for participants in the Higher advantage subgroup (Mean = 66.75, SD = 11.08) compared to participants in the Mid to low advantage subgroup (Mean = 77.47, SD = 11.03.)

Wilcoxon rank sum tests with continuity correction indicated that the median score for the Care coordination Quality of care global measure scale [W = 67.00 , p = 0.0088*] was significantly lower for participants in the Higher advantage subgroup (Median = 8.00, IQR = 1.50) compared to participants in the Mid

to low advantage subgroup (Median = 10.00, IQR = 1.00).

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, participants in the Mid to low advantage subgroup scored higher than participants in the Higher advantage subgroup. This indicates that healthcare communication was good for participants in the Mid to low advantage subgroup, and average for participants in the Higher advantage subgroup.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. On average, participants in the Mid to low advantage subgroup scored higher than participants in the Higher advantage subgroup. This indicates that communication, navigation and overall experience of care coordination was good for participants in the Mid to low advantage subgroup, and average for participants in the Higher advantage subgroup.

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. On average, participants in the Mid to low advantage subgroup scored higher than participants in the Higher advantage subgroup. This indicates that, quality of care was very good for participants in the Mid to low advantage subgroup, and good for participants in the Higher advantage subgroup.

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

Care coordination scale	Group	Number (n=33)	Percent	Mean	SD	T	dF	p-value
Communication	Higher advantage	16	48.48	40.88	8.71	-2.77	31.00	0.0094*
	Mid to low advantage	17	51.52	49.24	8.64			
Total score	Higher advantage	16	48.48	66.75	11.08	-2.78	31.00	0.0091*
	Mid to low advantage	17	51.52	77.47	11.03			

*Statistically significant at p<0.05

Table 7.13: Care coordination by socioeconomic status summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=33)	Percent	Median	IQR	W	p-value
Navigation	Higher advantage	16	48.48	26.00	6.25	91.50	0.1114
	Mid to low advantage	17	51.52	29.00	5.00		
Care coordination global measure	Higher advantage	16	48.48	8.00	2.00	107.00	0.2917
	Mid to low advantage	17	51.52	8.00	2.00		
Quality of care global measure	Higher advantage	16	48.48	8.00	1.50	67.00	0.0088*
	Mid to low advantage	17	51.52	10.00	1.00		

*Statistically significant at p<0.05

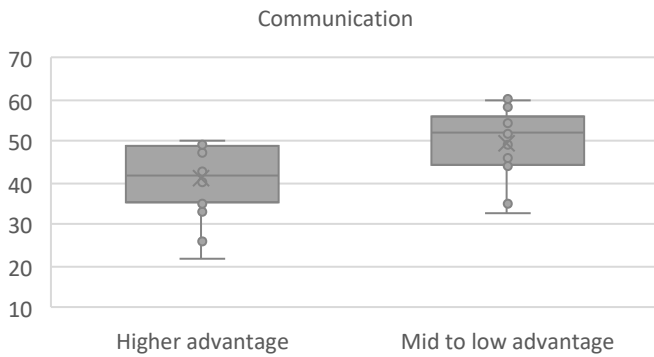


Figure 7.26: Boxplot of Care coordination: Communication by socioeconomic

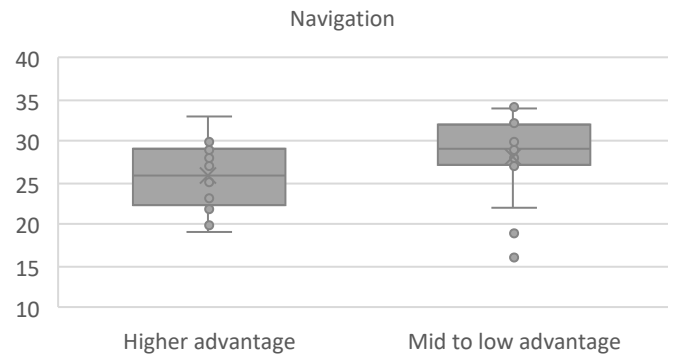


Figure 7.27: Boxplot of Care coordination: Navigation by socioeconomic

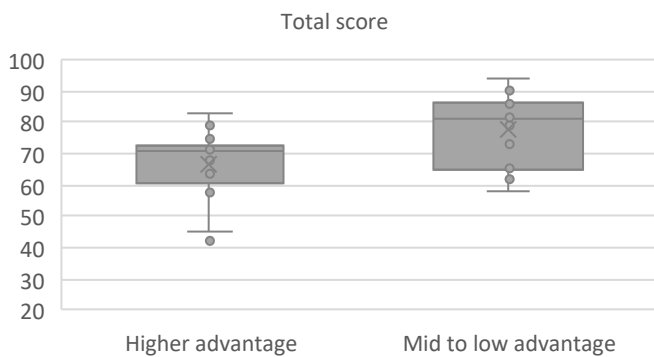


Figure 7.28: Boxplot of Care coordination: Total score by socioeconomic

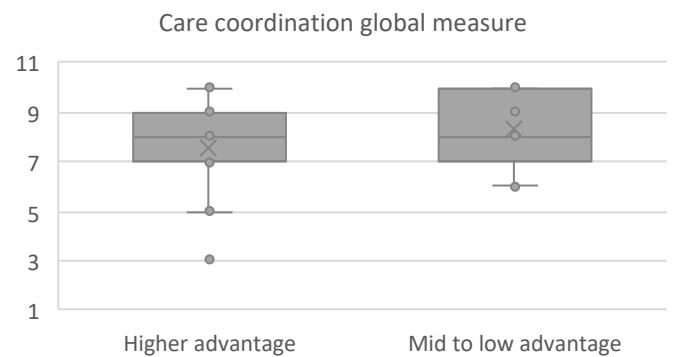


Figure 7.29: Boxplot of Care coordination: Care coordination global measure by socioeconomic

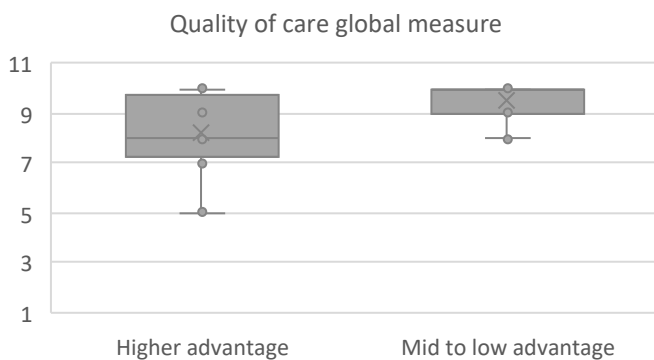


Figure 7.30: Boxplot of Care coordination: Quality of care global measure by socioeconomic

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 responses were that they found support and care from charities (45.45%), hospital or clinical setting (30.30%), and in the form of accommodation for themselves or their family while having treatment (24.24 %). Other themes included support from family and friends (21.21%), domestic services and/or home care (12.12%), transport to and from hospital appointments (12.12%), and in the form of financial advice and help with Centrelink applications (12.12%). Some participants described the

challenges of finding or accessing support (18.18%), not needing or seeking help or support (15.15%), and that they did not receive any formal support (12.12%).

Participant describes getting care and support from charities

We've got a local Vinnie's here. Handout vouchers. The local church, he financially helped us out. Yeah, had a fundraiser here for me, like a football club. 037_2023AUCRT

Leukemia Foundation would be the key one. I had some legal advice through the Cancer Council to sort

out my will. The Cancer Council, they provided, I mean, Leukemia Foundation, were amazing. They provided accommodation for NAME and I, when we had to be in LOCATION, I would have backed out of my transplant because I got so scared without there counsellors. The counsellors were amazing and their ongoing social support post transplant has been great. I came across your study through them. I've joined the Leukemia Foundation consumer group. So yeah, those two would be the main two, I think.
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PARTICIPANT: No, I haven't used any support no at all. But I've been. I know when you say support, I've been to a thing where they have, like they have trials, they have tests or studies with the Brain and Mind Institute and things like that. And I've always joined up with that. And they give you good results. Yeah, you get a bit of feedback.

INTERVIEWER: Mentioned earlier the multiple Myeloma association, is that right?

PARTICIPANT: Yeah, that's right. They put, they put, they put a webinar on or they put sessions on, they come to LOCATION. So I get invited. We always go to those but we don't use their services. Oh, they did a cooking thing once we went to that one because that was worthwhile. But then really they I haven't had to use them, you know, for they offer a lot of services that really they don't apply to me, They apply to other people and probably sicker than me. So yeah, I'm. I'm fine, yeah.
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When you say health community, you talk about overall, because the biggest support I've received was from the Leukemia Foundation. But yeah I have had help from I don't think it was but local charities just in like support I think they I mean I'm trying to get their name but any they're but they they just provided I think what they did they part of it something probably just cheap alternatives but they just I think it was like a yeah moderate just like they spoke to NAME and my wife and just showed her where and how to access sort of services with the government and cheap sort of options available to to us and that sort of stuff. I don't know I think there's no million yet doesn't it. And then blue meals maybe. Yeah. Blue meals maybe it was. Yeah, sorry. And then I said Leukemia Foundation was one that provided this accommodation with LOCATION while doing a transplant. But also there was a lady there that was like support for my wife, just through the emotional turmoil of the transplant. That was huge. The Leukemia Foundation, I'm totally grateful for because they've done a lot that way plus

providing information. The there was lady at the hospital who's like a coordinator I suppose back in the day she helped my wife a little bit with actually going through the process with Centrelink. 019_2023AUCRT

Participant describes getting care and support from hospital or clinical setting

Yes, I have telehealth appointments too every six to eight weeks so that's good to just check-in and have the hematologist reviewing my blood. It's a little bit of peace of mind, I guess.
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Community Nursing would attend when I needed that. Let me think just the the General Medical and nursing staff at the hospital throughout the treatment was, as I said before, just awesome. Let me think. No, I think that that that's about about it and friends and family, particularly in the the middle of the bad time.
009_2023AUCRT

Participant describes getting care and support in the form of accomodation for themselves or their family while having treatment

We came your foundation are very supportive as well I there if it wasn't for them like people in the country of remote people in remote areas wouldn't would have a great deal of expense staying in the cities to get treatment because some of the some of them leukemia pay like to stay for three months you know close to the hospital So that's that would be very expensive if they didn't have the the support of the government subsidised scheme where which then the leukemia foundation only charge what the government gives you as an allowance for their accommodation so it doesn't cost you anything to stay the leukemia lodge. So that's a big benefit for us people outside, people outside, you know, in the rural areas.
032_2023AUCRT

Participant describes getting care and support from family and friends

The main support for me has been my family, just with taking me to appointments and to the clinic and when I had to go to hospital and things like that. I haven't had any help from outside organizations. I've had a few good friends that have come over to help me when I needed help, but other than that, we pretty much looked after ourselves.
002_2023AUCRT

So obviously family and friends have been supportive as far as sending me messages or and either coming to visit in hospital when they can or if they can't, sending things so people would get, you know, nice, just nice little things like warm socks or a nice spray to spray on your face when you're feeling uncomfortable and those sorts of things

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Participant describes the challenges of finding or accessing support

PARTICIPANT: I've had a chat with a social worker.

INTERVIEWER: Okay.

PARTICIPANT: And it was only one chat.

PARTICIPANT: And then and she sort of said, look I don't think you need any any support NAME and I see at the hospital sometimes you know you know walk and say G'day, but I've never had any any sort of sit down. Yeah, it was a just sort of a general. I think every patient, they go along and see them and they, I think they make a decision on whether this person needs ongoing support or whether he's able to cope with life without a social worker. So they made that decision, not me.

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There was Leukemia Foundation. When I was on treatment, when I wasn't working, they did give me some vouchers for food and fuel, fuel for when I'm traveling up and things like that. It was a little bit difficult as well, because I'm on the border of STATE 1, I'm literally minutes from STATE 2. The Leukemia Foundation were from STATE 2, they said I wasn't eligible for all of the funding that they normally would give to a patient because I'm a STATE 1 patient going into STATE 2. Even with their assistance with drivers and things like that, if I ever needed them, they could only meet me at the border. They weren't allowed to come to my house, so I still had to arrange for someone to drive me to the boarder, and then getting a vehicle at the boarder and go into STATE 2. If anything could be fixed, that would be a big one for me, border residency. I think it should be an Australian-wide thing. Money's Wish, they provided six weeks of house cleaning. That was amazing, because you came home after treatment, you had a nice clean house. The last thing you felt like you had energy for. I got to pick what I wanted. It was either that or the canteen lunches for X amount of weeks for the kids, the school had already arranged that for me. That's why I went with the cleaning. Those two helped. The five dollars off that the hospital offered did help.

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I could get some help contact from the Leukemia Foundation one One of the problems with that was I live I live on the border with STATE 1 and STATE 2 and I live in in LOCATION which is STATE 2 and there was a I was I suppose transport was an issue and I couldn't access transport so I had to get my own transport that's the only but they were very supportive they they did help with some of the accommodation which which was really really appreciated but the transport from well it's bloody living over the border. If I lived in STATE 1 I could access transport, but living in new STATE 2 I was unable to do that. And I suppose my experience was that when I went down for my transplant I had to catch the train and I had a unfortunate incident on the train where this, oh, I wasn't feeling that good. Someone decided that they wanted my seat....but lucky enough for someone else there to help me out, send them off kind of thing. So that was possibly the only kind of problem I, you know, had with all that. 015_2023AUCRT

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

But I haven't reached out for it either. Yeah, I'm managing it.

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No, not really. I haven't asked for it.

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No, I didn't ask for it. No one, didn't look for it. 034_2023AUCRT

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

Okay. When I was first diagnosed and I couldn't do all the things that I normally would do, I did approach the council and the lady come in and help do some cleaning because my husband at that stage was working full time as well. And you know, I had, I'm just trying to remember now I didn't have any children living at home. No, I didn't have any children living at home. They'd all flown by then. Oh, I didn't have the support from them that I because they were working as well. So yeah. So I okay help. Yeah.

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I get help through the local council here, home care, so I have a cleaner. He comes in, he comes in once a fortnight and does some cleaning for me, which is

which is good. That's only a that's only a cost to me. I think it's \$6.20 an hour or something subsidized, obviously so and apart from that I haven't had, I haven't had to rely, I haven't had to rely on any other sort of support from other organizations or other people at this stage.

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Participant describes getting care and support in the form of financial aid

Yeah, there's a place in in in LOCATION next to the hospital called NAME. It's a building that is funded by some farmers from the LOCATION region, I believe, and without that support I don't know what I've done. It was provided free, so when I was able to leave the hospital once, I had some immunity. I was able to stay there free of charge as a government patient. This and travel scheme was a huge help. Instead of forking out three to \$500.00 for an air flight, I could get one for \$50. Things like that. Yeah, social workers with access to government funding, I suppose, to support us financially during that period of time.

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Participant describes getting care and support in the form of transport to and from hospital appointments

When I got the the cancer back the second time in 2020, you know, I couldn't drive. So there's a volunteer transport service near where I live. And so I contacted them and a few times they took me to appointments and picked me up and took me home. And I found a lovely taxi driver who took me to hospital for my radiotherapy and took me home. But you know, a very caring man, Pakistani man, who stopped and bought food for me on the way home and things like that, you know, So and some of the volunteer work I used to do, like the community garden and exercise classes at the Community Center, those people have come around and visited me and you know, brought me pot, planted Christmas and things like that just to sort of show I haven't been forgotten.

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Table 7.14: Experience of care and support

Care and support received	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7	%	n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes getting care and support from charities	15	45.45	4	57.14	3	30.00	8	50.00	14	53.85	1	14.29	6	40.00	9	50.00
Participant describes getting care and support from hospital or clinical setting	10	30.30	1	14.29	5	50.00	4	25.00	7	26.92	3	42.86	5	33.33	5	27.78
Participant describes getting care and support in the form of accommodation for themselves or their family while having treatment	8	24.24	3	42.86	1	10.00	4	25.00	8	30.77	0	0.00	3	20.00	5	27.78
Participant describes getting care and support from family and friends	7	21.21	2	28.57	4	40.00	1	6.25	6	23.08	1	14.29	7	46.67	0	0.00
Participant describes the challenges of finding or accessing support	6	18.18	2	28.57	2	20.00	2	12.50	6	23.08	0	0.00	4	26.67	2	11.11
Participant describes that they did not need or seek help or support	5	15.15	0	0.00	2	20.00	3	18.75	2	7.69	3	42.86	1	6.67	4	22.22
Participant describes that they did not receive any formal support	4	12.12	1	14.29	1	10.00	2	12.50	3	11.54	1	14.29	2	13.33	2	11.11
Participant describes getting care and support from domestic services and/or home care	4	12.12	2	28.57	0	0.00	2	12.50	4	15.38	0	0.00	3	20.00	1	5.56
Participant describes getting care and support in the form of financial advice and help with Centrelink applications	4	12.12	2	28.57	1	10.00	1	6.25	4	15.38	0	0.00	2	13.33	2	11.11
Participant describes getting care and support in the form of transport to and from hospital appointments	4	12.12	3	42.86	0	0.00	1	6.25	4	15.38	0	0.00	4	26.67	0	0.00

Care and support received	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes getting care and support from charities	15	45.45	11	57.89	4	28.57	6	42.86	9	47.37	9	64.29	6	31.58
Participant describes getting care and support from hospital or clinical setting	10	30.30	6	31.58	4	28.57	5	35.71	5	26.32	5	35.71	5	26.32
Participant describes getting care and support in the form of accommodation for themselves or their family while having treatment	8	24.24	7	36.84	1	7.14	4	28.57	4	21.05	4	28.57	4	21.05
Participant describes getting care and support from family and friends	7	21.21	5	26.32	2	14.29	3	21.43	4	21.05	3	21.43	4	21.05
Participant describes the challenges of finding or accessing support	6	18.18	4	21.05	2	14.29	2	14.29	4	21.05	3	21.43	3	15.79
Participant describes that they did not need or seek help or support	5	15.15	1	5.26	4	28.57	2	14.29	3	15.79	1	7.14	4	21.05
Participant describes that they did not receive any formal support	4	12.12	1	5.26	3	21.43	1	7.14	3	15.79	1	7.14	3	15.79
Participant describes getting care and support from domestic services and/or home care	4	12.12	2	10.53	2	14.29	1	7.14	3	15.79	2	14.29	2	10.53
Participant describes getting care and support in the form of financial advice and help with Centrelink applications	4	12.12	4	21.05	0	0.00	1	7.14	3	15.79	2	14.29	2	10.53
Participant describes getting care and support in the form of transport to and from hospital appointments	4	12.12	3	15.79	1	7.14	0	0.00	4	21.05	2	14.29	2	10.53

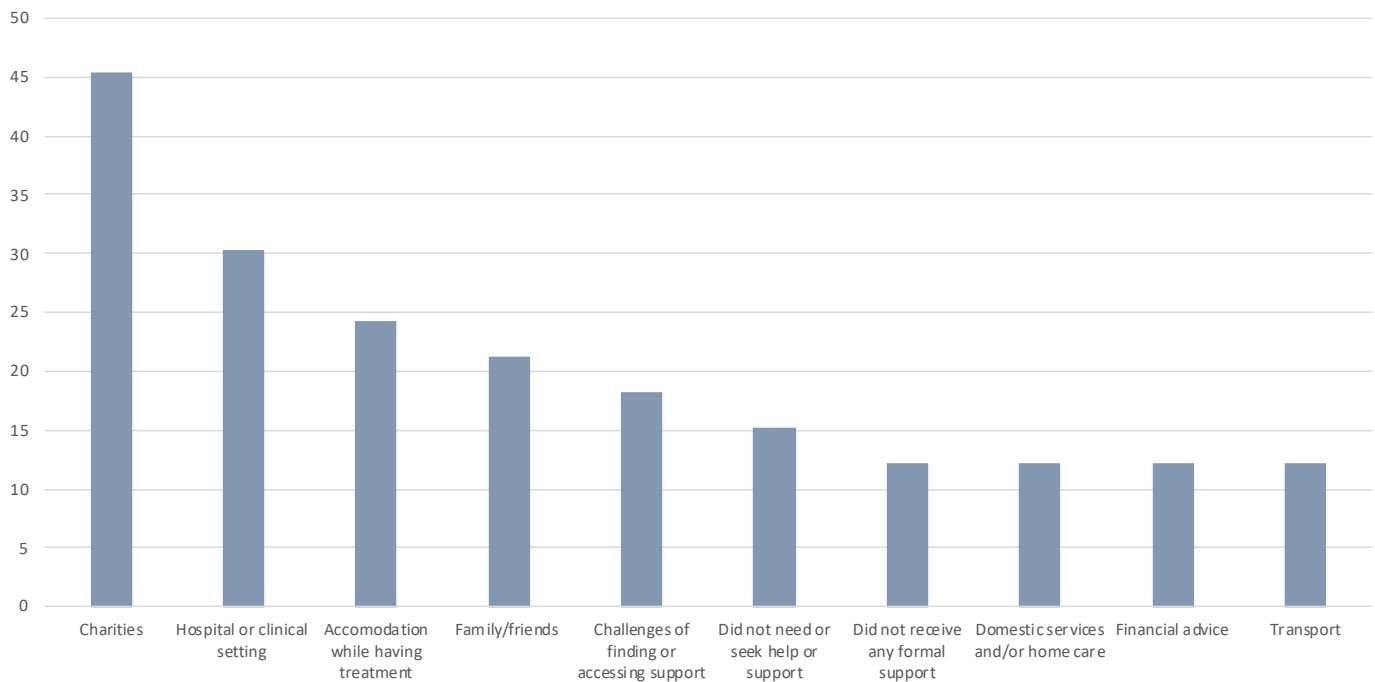


Figure 7.31: Experience of care and support

Table 7.15: Experience of care and support – subgroup variations

Care and support received	Reported less frequently	Reported more frequently
Participant describes getting care and support from charities	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Aged 65 or older Higher status	B-cell acute lymphoblastic leukaemia (ALL) Aged 25 to 64 Mid to low status
Participant describes getting care and support from hospital or clinical setting	B-cell acute lymphoblastic leukaemia (ALL)	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy
Participant describes getting care and support in the form of accommodation for themselves or their family while having treatment	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Aged 65 or older	B-cell acute lymphoblastic leukaemia (ALL) Aged 25 to 64
Participant describes getting care and support from family and friends	Multiple Myeloma Male	Diffuse Large B-Cell Lymphoma Female
Participant describes the challenges of finding or accessing support	CAR T-Cell therapy	B-cell acute lymphoblastic leukaemia (ALL)
Participant describes that they did not need or seek help or support	B-cell acute lymphoblastic leukaemia (ALL)	CAR T-Cell therapy Aged 65 or older
Participant describes getting care and support from domestic services and/or home care	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy	B-cell acute lymphoblastic leukaemia (ALL)
Participant describes getting care and support in the form of financial advice and help with Centrelink applications	CAR T-Cell therapy Aged 65 or older	B-cell acute lymphoblastic leukaemia (ALL)
Participant describes getting care and support in the form of transport to and from hospital appointments	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Male Regional or remote	B-cell acute lymphoblastic leukaemia (ALL) Female