

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 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 poor 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 poor 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 poor.

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 poor.

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 did not receive any formal support (50.00%), or that they found support from the hospital or clinical setting (15.00%). Other themes included peer support or other patients (10.00%), and psychologist or counselling service (5.00%).

Care coordination scale	Mean	SD	Median	IQR
Care coordination: communication*	34.40	9.31	35.00	11.25
Care coordination: navigation*	24.72	4.76	25.00	6.00
Care coordination: total score*	59.12	12.54	60.00	16.00
Care coordination: care coordination global measure	6.46	2.27	7.00	3.00
Care coordination: quality of care global measure	7.31	1.91	8.00	1.25

Care coordination

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

The overall scores for the cohort were in the second lowest quintile for Care coordination: Communication (mean=29.21, SD=9.26), Care coordination: Navigation (mean=18.11, SD=5.52), Care coordination: Total score (mean=47.32, SD=10.48), Care coordination: Care coordination global measure (mean=3.53, SD=2.01), Care coordination: Quality of care global measure (mean=3.95, SD=2.09) indicating poor communication, poor communication, poor coordination, poor care coordination, poor quality of care.

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 poor 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 poor 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 poor.

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 poor.

Table 7.1: Care coordination summary statistics

Care coordination scale (n=20)	Mean	SD	Median	IQR	Possible range	Quintile
Communication*	29.21	9.26	31.00	14.50	13 to 65	2
Navigation*	18.11	5.52	18.00	5.50	7 to 35	2
Total score*	47.32	10.48	44.00	17.50	20 to 100	2
Care coordination global measure*	3.53	2.01	3.00	3.50	1 to 10	2
Quality of care global measure*	3.95	2.09	4.00	4.00	1 to 10	2

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

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 did not receive any formal support (50.00%), or that they found support from the hospital or clinical setting (15.00%). Other themes included peer support or other patients (10.00%), and psychologist or counselling service (5.00%).

Participant describes that they did not receive any formal support

No, because it's not a recognized condition. Nobody knows about it. It's not on any of their lists at any of their foundations or their centers. Never heard of it. So it's not something they'll come and help out with. It's not on the list. All these joints are run by the government and the government gives them a list and if it's not on the list then you know and I feel like that's. You know that one of the things with this too, it's just like nobody knows about it hurt. No one's heard of it. So yeah, yeah for it.

Participant 006_2023AUHIS

No, not really. Participant 004_2023AUHIS

Participant describes getting care and support from hospital or clinical setting

Didn't have community health. Yeah they they oh, sorry, you're right. So when I like post surgery they were coming to, they actually came back to the house to pack the wounds and but it was like hospital at home. Yes. So the release here from hospital and then they send you home and then the community nurse that's come to the house and do the packings and then I can access community health for the winds, but they only operate from like 9:00 in the morning until 5:00 at night. And I would have to stop working to be able to access them because I need great things every day.

Participant 005_2023AUHIS

The most support, probably the only support I've really received has been from. My GP and and my clinicians, they my GP especially, he has been really good at trying to help me manage my pain. He's been really good at trying to he he tries to get me dressings and supplies and and where he can he'll bulk on my appointments even though he's a private practice so that I can. Use the money I would have used on the appointment to go get medications or dressing so that way instead all.

Participant 012_2023AUHIS

Participant describes getting care and support from peer support or other patients

PARTICIPANT: Not really. I am in a support group on Facebook, so I'm not sure if that counts.

INTERVIEWER: Well, you've mentioned it, so that's good that you've got support. So is there anything else you want to add? What kind of support is that?

PARTICIPANT: It's just people sharing their experience with HS. It's just something that makes me feel like, you know, I'm not alone with what I'm dealing with. I don't know anyone in my personal life who has this. So I joined a group where other people have it and we all kind of share our thoughts and experience and inspirational quotes and stuff like that to make sure that we're all okay, I guess.

Participant 010_2023AUHIS

Just through the Facebook group and my friendships that forwards that all who are aware of the condition I have.

Participant 011_2023AUHIS

Table 7.17: Experience of care and support

Care and support received	All participants	
	n=20	%
Participant describes that they did not receive any formal support	10	50.00
Participant describes getting care and support from hospital or clinical setting	3	15.00
Participant describes getting care and support from peer support or other patients	2	10.00
Participant describes getting care and support from psychologist or counselling service	1	5.00
No particular comment	4	20.00

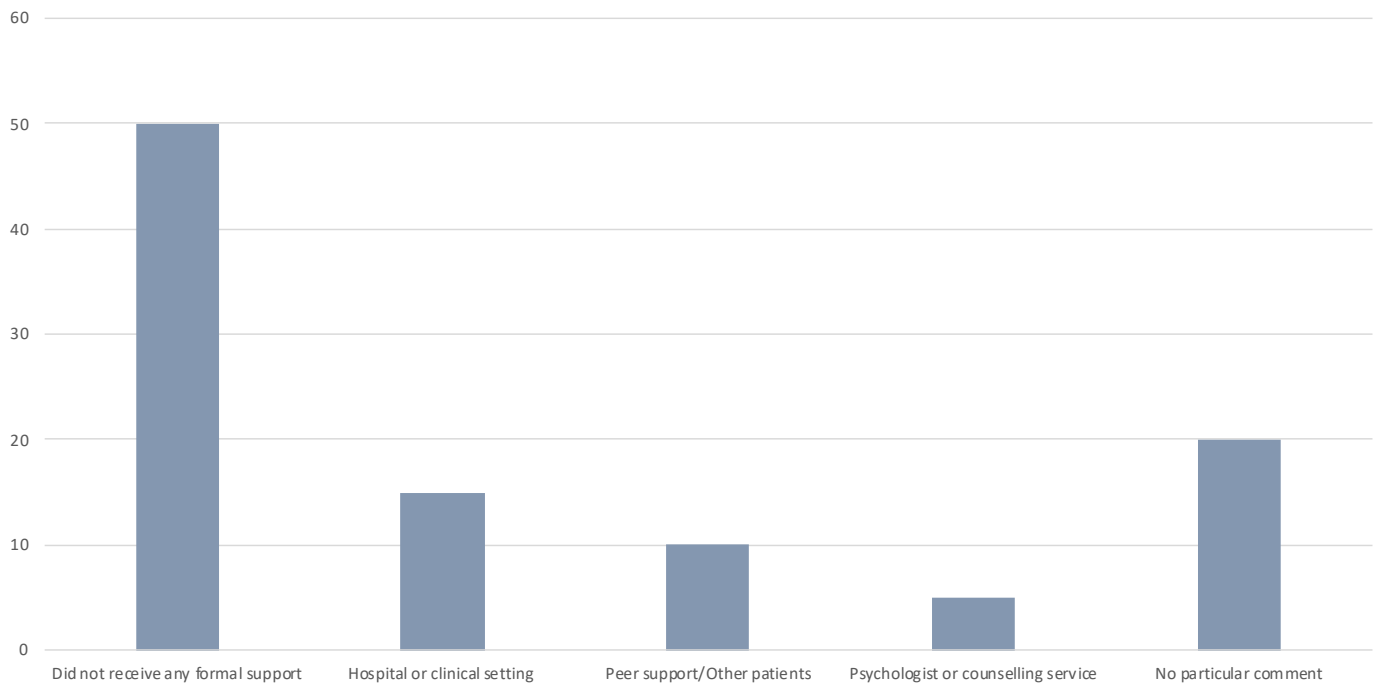


Figure 7.36: Experience of care and support