

Section 10

Advice to others in the future: The benefit of hindsight

Section 10: Advice to others in the future

Anything participants wish they had known earlier

In the structured interview, participants were asked if there was anything they wish they had known earlier. The most common things that participants had wished they'd known earlier were to be assertive, an advocate, informed, and to ask questions (50.00%), and that they had understood the cause and risk factors of the condition (16.67%). Other themes included to be open to complementary approaches (8.33%), to look after emotional wellbeing (8.33%), that there was more community awareness of their condition (8.33%), and that they had understood the extent of the transmission risk they posed to others (8.33%).

Aspect of care or treatment they would change

In the structured interview, participants were asked if there was any aspect of their care or treatment they would change. The most common theme was that they would not change any aspect of their care or treatment (41.67%). Others would have stopped or changed treatment sooner (8.33%), would have liked to have had access to a specialist in their condition sooner (8.33%), they would have liked to have access to care closer to home (8.33%), they would have liked to have access to doctors that speak their language (8.33%), and they would have liked to have had more monitoring of their condition and earlier access to treatment (8.33%).

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Participant wishes they had known to be assertive, an advocate, informed, and ask questions

Maybe on how to control it and asked whether it could lead to other kinds of hepatitis. Probably I should have known earlier, yeah.

Participant 001_2023AUHDV

Participant wishes they had understood the cause and risk factors of the condition

Yeah, why I I just wish you know, there was a way. I was informed about this earlier, you know... I had no clue about this and I would have known what to do in order to prevent this from occurring in the first place. I think that would have been great if I had known, you know, stop doing this or that. I think I would have prevented, as some people would say, you know, if I could look into the future, then this situation wouldn't be occurring at all. So that's just what I wish to talk.

Participant 006_2023AUHDV

Participant wishes they had known to look after emotional wellbeing

The emotional impact being diagnosed at a very formative age, I think that there could have been a bit more intervention about the emotional impact. That I carried on my own for so long.

Participant 004_2023AUHDV

Participant wishes that there was more community awareness of their condition

I think just in general with I think they're up to about hepatitis E or F or something nowadays. There needs to be some education around the fact that there isn't just hepatitis has a disease...it's a range of conditions that basically have the one symptom.

Participant 007_2023AUHDV

Participant wishes they had understood the extent of the transmission risk they posed to others

Like specifically about physical contact and the the do's and don'ts there, because I was very much left in the dark...I would have, I would have liked, I would have liked to have known a bit more about that and had that explained.

Participant 011_2023AUHDV

Table 10.1: Anything participants wish they had known earlier

THEME	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant wishes they had known to be assertive, an advocate, informed, and ask questions	6	50.00	2	33.33	4	66.67	5	62.50	1	25.00	3	50.00	3	50.00	0	0.00	6	54.55	0	0.00	6	54.55
Participant wishes they had understood the cause and risk factors of the condition	2	16.67	1	16.67	1	16.67	2	25.00	0	0.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Participant wishes they had known to be open to complementary approaches	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant wishes they had known to look after emotional wellbeing	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant wishes that there was more community awareness of their condition	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	0	0.00	1	16.67	1	100.00	0	0.00	1	100.00	0	0.00
Participant wishes they had understood the extent of the transmission risk they posed to others	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant had no particular comment and were satisfied with experience	2	16.67	1	16.67	1	16.67	0	0.00	2	50.00	1	16.67	1	16.67	1	100.00	1	9.09	1	100.00	1	9.09
No particular comment/No response	2	16.67	2	33.33	0	0.00	1	12.50	1	25.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18

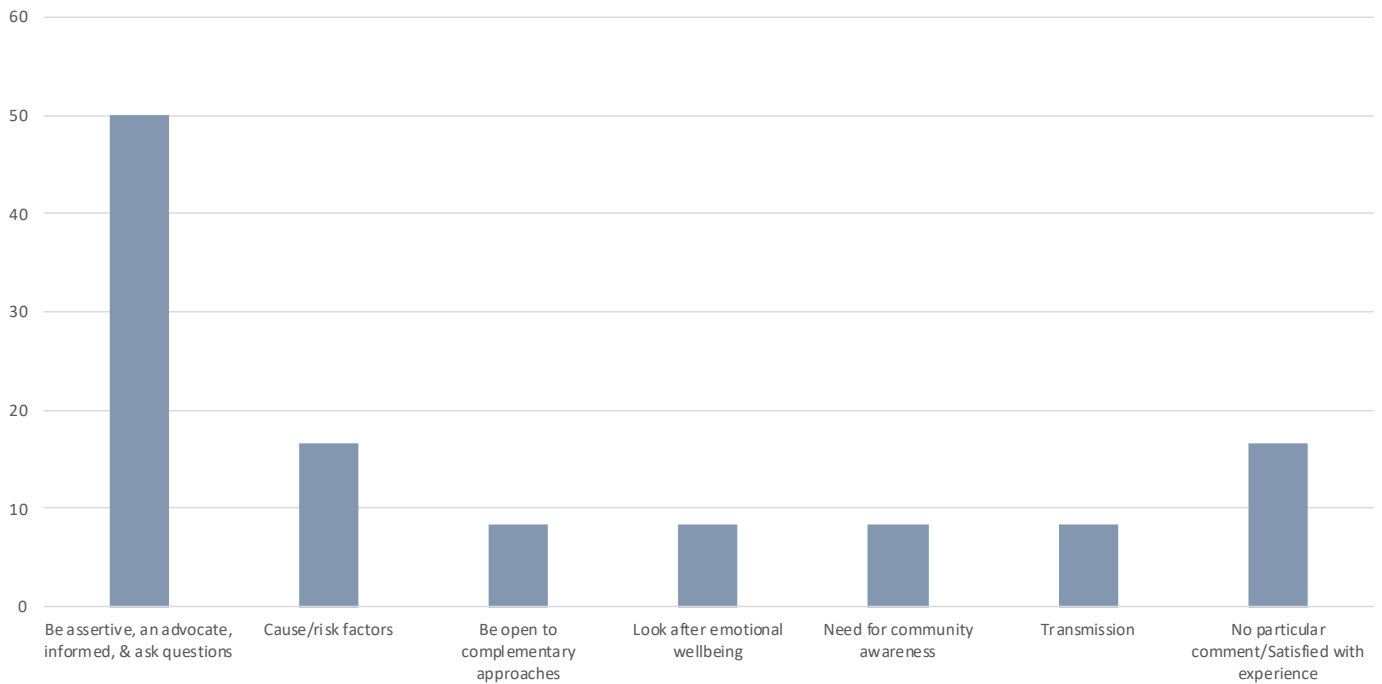


Figure 10.1: Anything participants wish they had known earlier

Table 10.2: Anything participants wish they had known earlier – subgroup variations

Anything participants wish they had known earlier	Reported less frequently	Reported more frequently
Participant wishes they had known to be assertive, an advocate, informed, and ask questions	Female Aged 45 and older	Male Aged 18 to 44

Aspect of care or treatment they would change

In the structured interview, participants were asked if there was any aspect of their care or treatment they would change. The most common theme was that they would not change any aspect of their care or treatment (41.67%). Others would have stopped or changed treatment sooner (8.33%), would have liked to have had access to a specialist in their condition sooner (8.33%), they would have liked to have access to care closer to home (8.33%), they would have liked to have access to doctors that speak their language (8.33%), and they would have liked to have had more monitoring of their condition and earlier access to treatment (8.33%).

Participant would not change any aspect of their care or treatment, with no reason given

*No, no, no. Not that moment of nothing.
Participant 001_2023AUHDV*

Participant would have liked to have access to a specialist in their condition, sooner

*The only thing possibly would be to have started treatment earlier, but that was purely a case of the circumstances at the time.
Participant 007_2023AUHDV*

Participant would have liked to have access to care closer to home

*PARTICIPANT: Not really. I tried to find someone who can speak that language. Yes. Yeah, but I I can't.
INTERVIEWER: OK. Yeah. OK. Yeah, those.
PARTICIPANT: We have some available, I think more near the city or...Um, yeah, but it just took time to travel.
Participant 003_2023AUHDV*

Participant would have liked to have had more monitoring of their condition and earlier access to treatment

*Yeah, definitely. Related to the question we just talked about, yeah, I would have liked more monitoring between the diagnosis and getting onto the treatment... I think it really was sort of an accident that I even got asked about it...I would have liked much more monitoring of my condition, specifically around my liver health, because I could have gone on to those treatments a bit earlier and maybe it would have been easier to treat.
Participant 011_2023AUHDV*

Participant would not change any aspect of their care or treatment and were satisfied with care and treatment received

I might have more access to clinical trials in the future, so I would still choose to be monitored by the hospital. I think one of the good things is even though I'm

monitored twice a year, one point of time in the year, it should be telehealth and the rest because they want me to go in for a fibro scan at the day and everything else. So yeah I guess more to monitor the progression part and knowing about other kinds of hepatitis. Participant 004_2023AUHDV

Table 10.3: Aspect of care or treatment they would change

Aspect of care or treatment they would change	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant would not change any aspect of their care or treatment, with no reason given	5	41.67	3	50.00	2	33.33	4	50.00	1	25.00	3	50.00	2	33.33	0	0.00	5	45.45	0	0.00	5	45.45
Participant would have stopped or changed treatment sooner	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant would have liked to have access to a specialist in their condition, sooner	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	0	0.00	1	16.67	1	100.00	0	0.00	1	100.00	0	0.00
Participant would have liked to have access to care closer to home	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant would have liked to have access to doctors that speak their language	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant would have liked to have had more monitoring of their condition and earlier access to treatment	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant would not change any aspect of their care or treatment and were satisfied with care and treatment received	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant is not sure if they would change anything	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Other\No response	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09

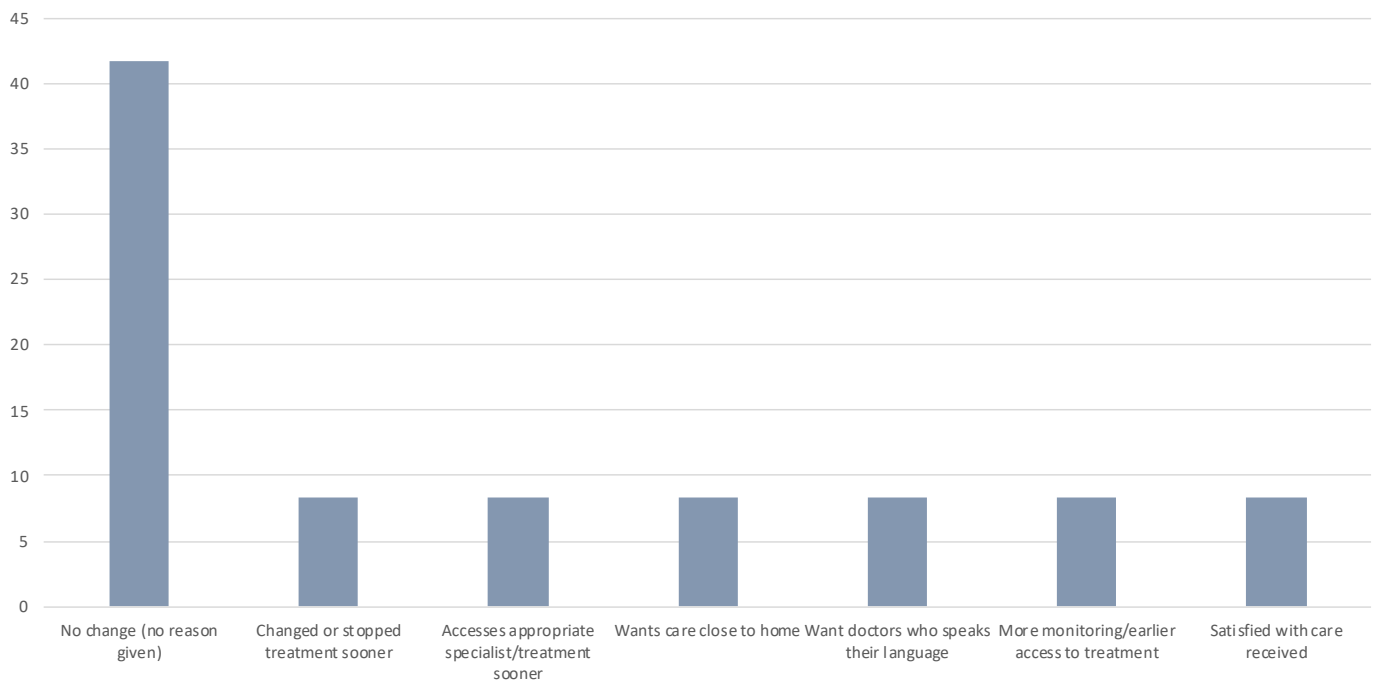


Figure 10.2: Aspect of care or treatment they would change

Table 10.4: Anything participants wish they had known earlier – subgroup variations

Aspect of care or treatment they would change	Reported less frequently	Reported more frequently
Participant would not change any aspect of their care or treatment, with no reason given	Aged 45 and older	-