

Section 10

Advice to others in the future: The benefit of hindsight

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Anything participants wish they had known earlier

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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 themes were that they would have liked to have had access to a specialist in their condition sooner (25.00%), and would have liked health care professionals to have had more knowledge and awareness of their condition (20.00%). Other themes included would have stopped or changed treatment sooner (10.00%), would have liked to have had a better understanding of their condition (10.00%), would not change any aspect of their care or treatment, with no reason given (5.00%), would have liked more time and personalised attention with healthcare professionals (5.00%), would have switched health professionals (5.00%), would like to change a lot or all of their treatment, without giving specific details (5.00%), would have changed a single negative experience (5.00%), and wanting treatment closer to where they live (5.00%).

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

Yes, I wish that I had have known that the treatments had been developed. But nobody ever tells you anything because most people, most GPs, don't even know what the disease is. So. You go to the doctors or to the hospital. I mean, I can tell you I've been to the hospital on dozens of occasions throughout my life, and not one until until, like three years ago, not one of the doctors, surgeons or otherwise ever told me that there was actually commitment for the disease. It wasn't until this nurse told me about the HS clinic. And that nurse was from community health.
Participant 005_2023AUHIS

That's, that's a big question. Yeah, I wish that. Look, I I just think I I just wish I'd been given clearer information about what treatment options were. And you know and knowledge about what what supports were out there.
Participant 007_2023AUHIS

I wish I had a known that more about the disease process before making a decision to subject my son to surgery. When? Yeah, because he his wounds kept breaking down and then because it was in the groin like he has like a 22 11 centimetre scars that overlap each other in the groin and yeah they would. And also the scar tissue that is formed now, he's got flares and constant nodules underneath the scar and I. Yeah. If I had of known more about the disease process, I'm wondering, well, I don't know more. I'm just wondering the what if if he hadn't have done the surgery and we had to put him onto the Humira six weeks, six months earlier, would he, would he have these hard nodules underneath the scar? I don't know. So yes, I would would want to know about the disease process a bit more before making those types of decisions.
Participant 009_2023AUHIS

Participant wishes they had gotten a diagnosis sooner

I guess I wish I knew what it was sooner, yeah. Because, you know, being seven years old and having to deal with it on my own was not a fun time.
Participant 014_2023AUHIS

I wish I got this diagnosed earlier.
Participant 004_2023AUHIS

I just wish I'd been diagnosed earlier. I honestly think if I had been diagnosed with this when I had my first flare and then put on. The medication and the creams and had the area removed, I don't think that it would have progressed and I don't think I would have it anywhere else. I don't think I'll be sitting here talking to you today. I think because it took 15 years to diagnose and it was well rooted in my system and in my skin by that point that now it's a drama and nobody knows what they're doing and they're leaving bits and bobs when they cut it out and not getting it all and. It's just would have been a lot easier when it was just a little pee and yeah, if we'd all just known. But yeah, apparently there's no way to know until it gets this bad because it looks like a cyst. So I'm not blaming health professionals, but it'd be cool if there was a blood test or something. That you know, could just identify straight up and instead of going oh, that's a sebaceous cyst or an ingrown hair go we're going to test in case it's HS because not not wait till going Oh no, it mustn't be those things then and we've tried to treat it now it's HS. It's like no, try and find out if it's HS first, eliminate that and then go off on your sebaceous cyst journey. And because it's, it's, it's. Yeah, that's where this is. It's just the lack of care and just being on my own with it for nearly 20 years hasn't, you know, been good. It would have been good to know what was going on back then.
Participant 006_2023AUHIS

Participant wishes they had known to pace themselves or know triggers and limitations

I think I've mentioned this before, but definitely like food eliminations because I didn't know when I was younger when I first had this disease, that certain things can make it worse. I also smoked when I was, you know, 16, 17, which is. Quite young, but I smoked cigarettes and I didn't realize that that was something that can aggravate the disease more, which I now do not smoke and I've seen improvement, slight improvement in the disease. So I guess just a bit more

information about how to help or keep the disease calm.

Participant 010_2023AUHIS

PARTICIPANT: Yeah. Had it done a lot earlier, yeah.

INTERVIEWER: And that would have changed the way that you made decisions.

PARTICIPANT: I I feel like, yeah, I feel like it would have helped me knowing a lot earlier as to, you know, what the causes are, how I can prevent them. And being at

a younger age where I was probably a little bit more in control of my life and then control of my body. I mean, it's still something I can do. But, you know, I've got kids and family and money restrictions now, so yeah, yeah.

INTERVIEWER: And you waited 14 years.

PARTICIPANT: Yeah, that's right.

Participant 011_2023AUHIS

Table 10.1: Anything participants wish they had known earlier

Wish they had known earlier	All participants	
	n=20	%
Participant wishes they had known to be assertive, an advocate, informed, and ask questions	9	45.00
Participant wishes they had gotten a diagnosis sooner	5	25.00
Participant wishes they had known to pace themselves or know triggers and limitations	4	20.00
Participant had no particular comment and were satisfied with experience	2	10.00
Participant wishes they had understood the costs of treatment and management	1	5.00
No particular comment/No response	1	5.00

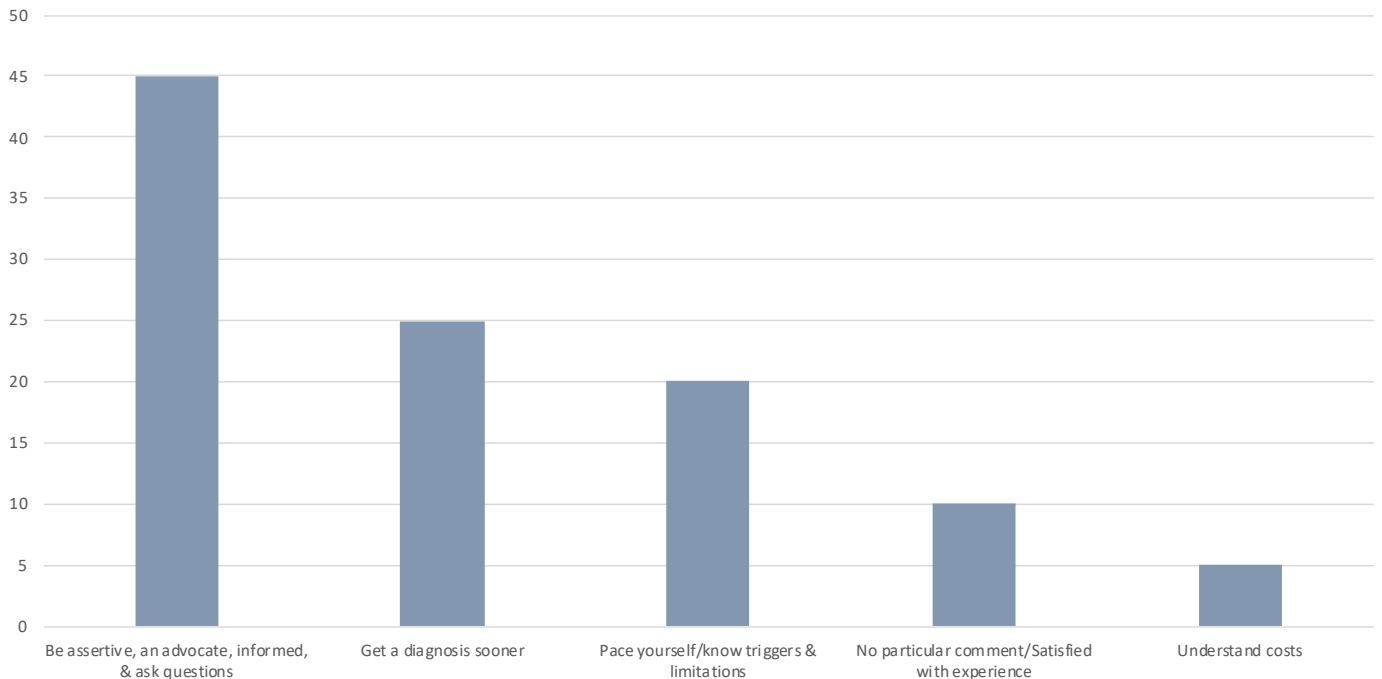


Figure 10.1: Anything participants wish they had known earlier

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 themes were that they would have liked to have had access to a specialist in their condition sooner (25.00%), and would have liked health care professionals to have had more knowledge and awareness of their condition (20.00%). Other themes included would have stopped or changed treatment sooner (10.00%), would have liked to have had a better understanding of their condition (10.00%), would not change any aspect of their care or treatment, with no reason given (5.00%), would have liked more time and personalised attention with

healthcare professionals (5.00%), would have switched health professionals (5.00%), would like to change a lot or all of their treatment, without giving specific details (5.00%), would have changed a single negative experience (5.00%), and wanting treatment closer to where they live (5.00%).

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

I suppose, yeah. Again, just at that very first stage and seeking support. But you know, if I don't know what they're doing. That's OK. But then make a referral to someone who might, yeah, rather than minimizing the patient, yeah.

Participant 007_2023AUHIS

The only thing I would change is pushing to receive treatment a lot sooner, before it progressed to the stage that I'm at. But you know, when I was younger, I didn't have a choice. It was up to my parents to kind of. Look after me and and seek better help, but if I could go back I'd probably push harder to my parents to get me to seek.

Participant 010_2023AUHIS

No, I think just having, yeah, having access to being able to receive more accessible care and treatment and yeah, money wise and things like that. But otherwise, yeah, I think I also like as a personal level instead of leaving it to the point where I'm in excruciating pain and just dealing with it going, getting that support sooner and that helps sooner.

Participant 011_2023AUHIS

Participant would have liked health care professionals to have had more knowledge and awareness of their condition

So yeah, surgery plus imaging, ultrasound. MRI or whole body scans to uncover the damage under the skin, because we can talk about it, we can say what's happening and until you have a picture which demonstrates what your skin is doing to you. There's always kind of these doctors who get down on you and think nothing. This is a serious disease and I'm glad you CDDR is taking it seriously.

Participant 008_2023AUHIS

Treatment. There needs to be a lot more research into it. It's not extremely rare and common condition. Now it needs more. More people need to look into it. The care I received, I can tell my 2 current providers the care I received. It could have been a lot better. It left a lot to be desired and that comes down to a lack of information available to medical practice to medical professionals on the condition. I've had to still go to the hospital tomorrow and I've been to the hospital multiple times for this condition and people still ask me, oh what's HS? It just needs more awareness.

Participant 012_2023AUHIS

Well, in the beginning probably not because that that stage it was just antibiotics and where Accutane came out, there wasn't clinical trials. It's only the last, I I believe 10 years that clinical trials have come out and my condition has been quite dormant. So clinical trials are not an option for me, but I think better education and the specialists need to get these. Offer these trials to people.

Participant 013_2023AUHIS

Table 10.2: Aspect of care or treatment they would change

Anything they would change about treatment or care	All participants	
	n=20	%
Participant would have liked to have access to a specialist in their condition, sooner	5	25.00
Participant would have liked health care professionals to have had more knowledge and awareness of their condition	4	20.00
Participant would have stopped or changed treatment sooner	2	10.00
Participant would have liked to have had a better understanding of their condition	2	10.00
Participant would not change any aspect of their care or treatment, with no reason given	1	5.00
Participant would have liked more time and personalised attention with healthcare professionals	1	5.00
Participant would have switched health professionals	1	5.00
Participant would like to change a lot or all of their treatment, without giving specific details	1	5.00
Participant describes a single negative experience that they would have changed	1	5.00
Participant describes wanting treatment closer to where they live	1	5.00
Other/No response	4	20.00

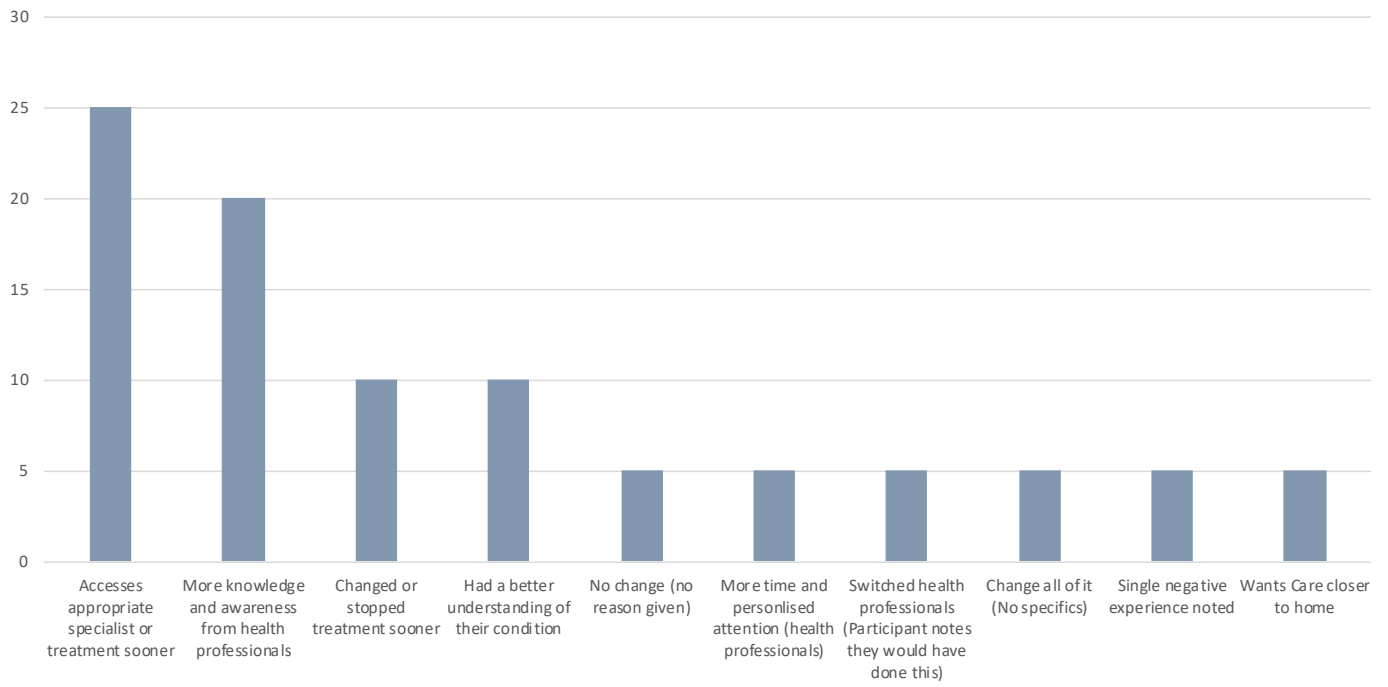


Figure 10.2: Aspect of care or treatment they would change