

## Section 8

### Quality of life

## **Section 8: Quality of life**

### **Impact on quality of life**

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Most commonly, the descriptions suggested that there was an overall negative impact on quality of life (75.00%), and overall a minimal impact on quality of life (5.00%).

The most common themes in relation to a negative impact on quality of life were emotional strain (including family/change in relationship dynamics) (35.00%), and reduced capacity for physical activity/needing to slow down (25.00%). Other themes included intimacy challenges (20.00%), reduced social interaction (20.00%), financial strain (10.00%), managing side effects and symptoms (10.00%), and the impact on self image (10.00%).

The most common theme in relation to a positive impact on quality of life was that it brings people together/highlights supportive relationships (10.00%).

### **Impact on mental health**

In the structured interview, participants were asked if there had been an impact on their mental health. Most commonly, the descriptions suggested that overall, there was at least some impact on mental health (80.00%), overall, there was no impact on mental health (5.00%), and other or mixed experience (5.00 %).

### **Regular activities to maintain mental health**

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common response was mindfulness and/or meditation (40.00%), no activities to maintain mental health (20.00%), and the importance of family and friends in maintaining their mental health (15.00 %). Other themes included consulting a mental health professional (10.00%), allowing time to cry, then gets on with it (10.00%), keeping busy (10.00%), coping strategies such as remaining social, lifestyle changes and hobbies (5.00%), the importance of physical exercise (5.00%), and keeping informed about their condition (5.00%).

### **Regular activities to maintain health**

In the structured interview, participants were asked what were some of the things they needed to do everyday to maintain their health? The most common activities for general health were complying with treatment/management (45.00%), and hygiene routine (45.00%). Other themes included avoiding flare triggers (25.00%), understanding their limitations (20.00%), being organised and planning ahead (10.00%), using complementary therapies (10.00%), maintaining a healthy diet (10.00%), mindfulness and/or meditation (10.00%), doing physical exercise/physically active (10%), self care e.g. more rest, accepting help, pacing (10.00%), covering up lesions (10.00%), being aware of their body and limitations (5.00%), and maintaining a normal routine (5%).

### **Experience of vulnerability**

In the structured interview, participants were asked if there had been times that they felt vulnerable. The most common responses were that they felt vulnerable experiencing side effects from treatment or symptoms from condition (25.00%), when having sensitive discussion (diagnosis, treatment decision) (20.00%), and because of interactions with the medical team (20.00 %). Other themes included during/after treatments (15.00%), during diagnostic procedure (10.00%), thinking about disease course/incurable condition (10.00%), and did not feel vulnerable (5.00%).

### **Methods to manage vulnerability**

In the structured interview, participants described ways that they managed feelings of vulnerability. The most common ways to manage vulnerability were getting support from family and friends (15.00%), and using self-help methods (resilience, acceptance, staying positive) (10.00%). Other themes included support from mental health professionals (5.00%), being informed and knowing what to expect (5.00%), and sticking to their treatment regimen (5.00%).

## **Impact on relationships**

Most commonly, the descriptions suggested that overall, there was a negative impact on relationships (50.00%), and overall, there no impact on relationships (15.00%). Other themes included overall, there was a positive impact on relationships (10.00%), and overall, there was an impact on relationships that was both positive and negative (5.00%).

The most common themes in relation to having a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships (20.00%), from feeling dismissed or not believed by others(10.00%), and due to intimacy challenges (10.00 %). Other themes included from managing symptoms (5.00%), and from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition (5.00%).

The most common theme in relation to a positive impact on relationships were brings people together/highlights supportive relationships (10.00%).

## **Burden on family**

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Most commonly, the descriptions suggested that overall, there was a burden on their family (60.00%), overall, there was not a burden on their family (15.00%), and having no particular comment (25.00 %).

The main reasons that participant described their condition being a burden were the extra financial assistance needed (10.00%), the mental/emotional strain placed on their family (10.00%), and that the burden on family was temporary or only during treatment (10.00 %). Other themes included the extra assistance needed getting to appointments (5.00%), intimacy problems (5.00%),managing symptoms (5.00%), and eding to take time off work (5.00%).

The main reason that participant described their condition not =being a burden were because they were independent and did not need any help (15.00%), and that they were not a burden because no one knows about their diagnosis (5.00%).

## **Cost considerations**

In the structured interview, participants were asked about any significant costs associated with having their condition. The most common descriptions were that overall, there was at least some cost burden (75.00%), and overall, there was no cost burden (15.00%).

Where participants described a cost burden associated with their condition, it was most commonly in relation to the cost of treatments (including repeat scripts) (65.00%), the cost specialist appointments (50.00%), and needing to take time off work (25.00 %). Other themes included needing a special diet or lifestyle adaptation (15.00%), a family member needing to take time off work (10.00%),the cost of parking and travel to attend appointments (including accommodation) (5.00%), and diagnostic tests and scans (5.00%).

Where participants described no cost burden associated with their condition, it was most commonly in relation to them prioritizing going to work over attending appointments (5.00%), being able to afford all costs(5.00%), and they had no treatment or management (5.00 %).

## Impact on quality of life

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Most commonly, the descriptions suggested that there was an overall negative impact on quality of life (75.00%), and overall a minimal impact on quality of life (5.00%).

The most common themes in relation to a negative impact on quality of life were emotional strain (including family/change in relationship dynamics) (35.00%), and reduced capacity for physical activity/need to slow down (25.00%). Other themes included intimacy challenges (20.00%), reduced social interaction (20.00%), financial strain (10.00%), managing side effects and symptoms (10.00%), and the impact on self image (10.00%).

The most common theme in relation to a positive impact on quality of life was that it brings people together/highlights supportive relationships (10.00%).

**Participant describes a negative impact on quality of life due to the emotional strain (including family/change in relationship dynamics)**

*Yeah, it's affected my quality of life, I guess, and my kids.*

*Participant 003\_2023AUHIS*

*Yes, it has. Particularly when you're constantly having abscesses galore and you're looking like a zombie bandaged from head to toe with dressings and you don't feel. Beautiful or pretty people making comments about wounds and what not. You're in pain and discomfort, not so much with family, and you think no one's going to fall in love with you. You're not going to have a family or that sort of thing. And even friends don't. No one understands what you're going for, even if you do try and explain it to them.*

*Participant 013\_2023AUHIS*

*It's ruined my life and it's ruined my family's life too, because they I can't support my family.*

*Participant 004\_2023AUHIS*

**Participant describes a negative impact on quality of life due to reduced capacity for physical activity/need to slow down**

*It has probably affected the quality of my life somewhat. I probably struggle to be active because I am tired quite a lot. It can struggle, you know it*

*depending on where where I'm at at the time. If I'm flaring I can struggle to do things around the home. So it has had an impact on, on day-to-day living, has impacted relationships, yes and no. You know, my husband has been involved in my my diagnosis from the beginning and has a fair understanding of how it impacts me. So it hasn't been easy on him. So it has impacted the relationship to some degree, but at the same time he's been involved in it and he has an understanding of what I'm going through and what it's like for me, so.*

*Participant 001\_2023AUHIS*

*I don't mental and emotional pretty well fine. But where it that has become like there's times when I you know be as active as I was because I'm in significant pain and or they're best thing everywhere and disgusting. And you don't want to be and then and you're petite, when that hits, you're fatigued and they're draining and they're feral. You don't want to actually be going out and doing this and doing that. So I think there's those lost opportunities that you have to be mindful that they do have that.*

*Participant 002\_2023AUHIS*

**Participant describes a negative impact on quality of life due to intimacy challenges**

*I don't live with my family, so, like, my mum's gone. Yeah, my dad wouldn't bother. Nothing to do with him, but I have a partner and yeah, since. Like, this is going to be crazy, but like, we haven't slept together in over a year, probably 2 years, and we're still together and we're not seeing anyone else. And that is because he understands that like when you do stuff or get hot or sweaty down there, it flares up and then I'm screwed up for days, so. Like, we just need to wait till I can get this surgery and then and then like, maybe I want to have kids. But, you know, hormones and stuff just flare this shit right up. So I'd prefer to have it gone before I'm pregnant or something, you know?*

*Participant 006\_2023AUHIS*

*Yeah, it has a lot. You know, it's quite a physical presenting disease, but it's almost falls into the invisible disease category that people don't understand because you can't exactly be like, oh hey look. And trying to explain that why a little red dot that you know it's not even risen a meal out of your skin is on fire. It's really hard for people to understand. And that's just, that's just humans. You know when you say an Abscess, people just are disgusted by it. They don't hear the rest, but just my ability to do*

things. And yeah, intimate relationships, like I don't. It affects a lot.

Participant 018\_2023AUHIS

**Participant describes a negative impact on quality of life due to reduced social interaction**

Look, while symptoms were present, yeah, absolutely not. I suppose because I've seen what it could be or how bad it could be. Not to that extent. But yeah, definitely very uncomfortable. It's very painful and it sort of, yeah, it certainly had a minimizing impact. On on what you did and then how well you felt to go and to go and do usual things. And I suppose in terms of family, yeah, as a single parent, that then also meant if I didn't feel up to it, that my daughter wouldn't go places because I wasn't in a position to be able to take her and support that.

Participant 007\_2023AUHIS

I would say yes, definitely. It's affected my quality of life, you know, I feel different to everyone else. I feel ashamed. When I go out going to the beach and doing fun activities like I can't really enjoy because I have to cover up this area of my body. I can't be as active as I'd like to be because when I run it's it's hodging on the

area that I have the disease and it's very painful in terms of relationships with my family, I think. It's not so much the disease that caused it, but I think there's a bit of animosity between my mother and I because she didn't do anything about it when I was young. So I don't know, I kind of take it out on her for not giving me care when I was younger and it was more treatable and in intimate relationships. As well, just because the disease is in a very intimate area. So I can't enjoy, I guess, yeah, being intimate with my partner because I'm very ashamed of the disease. Even with, you know, past boyfriends and stuff, you know, they would tell me to keep my shirt on because they didn't want to see it, things like that. So yeah, I would say a lot.

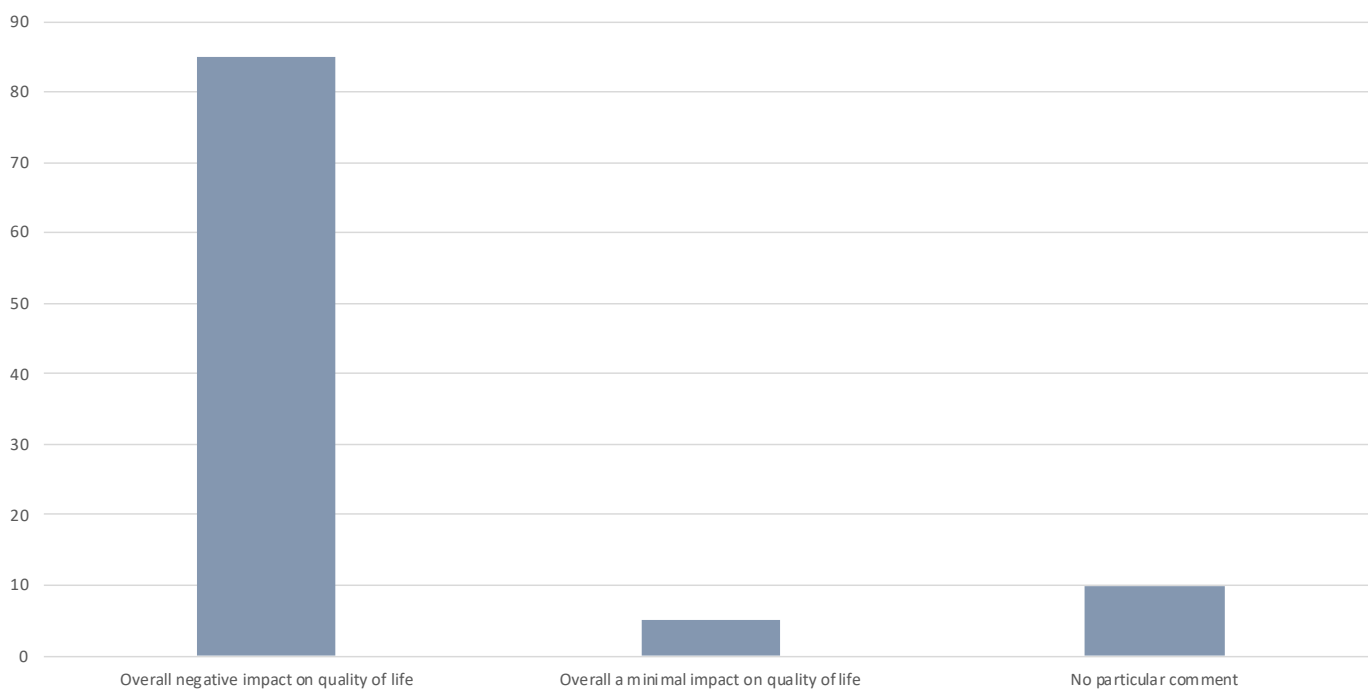
Participant 010\_2023AUHIS

**Experience described suggests that there was overall a minimal impact on quality of life**

Compared to my other conditions, I wouldn't say it's impacted with all that much. Participant 019\_2023AUHIS

**Table 8.1: Impact on quality of life**

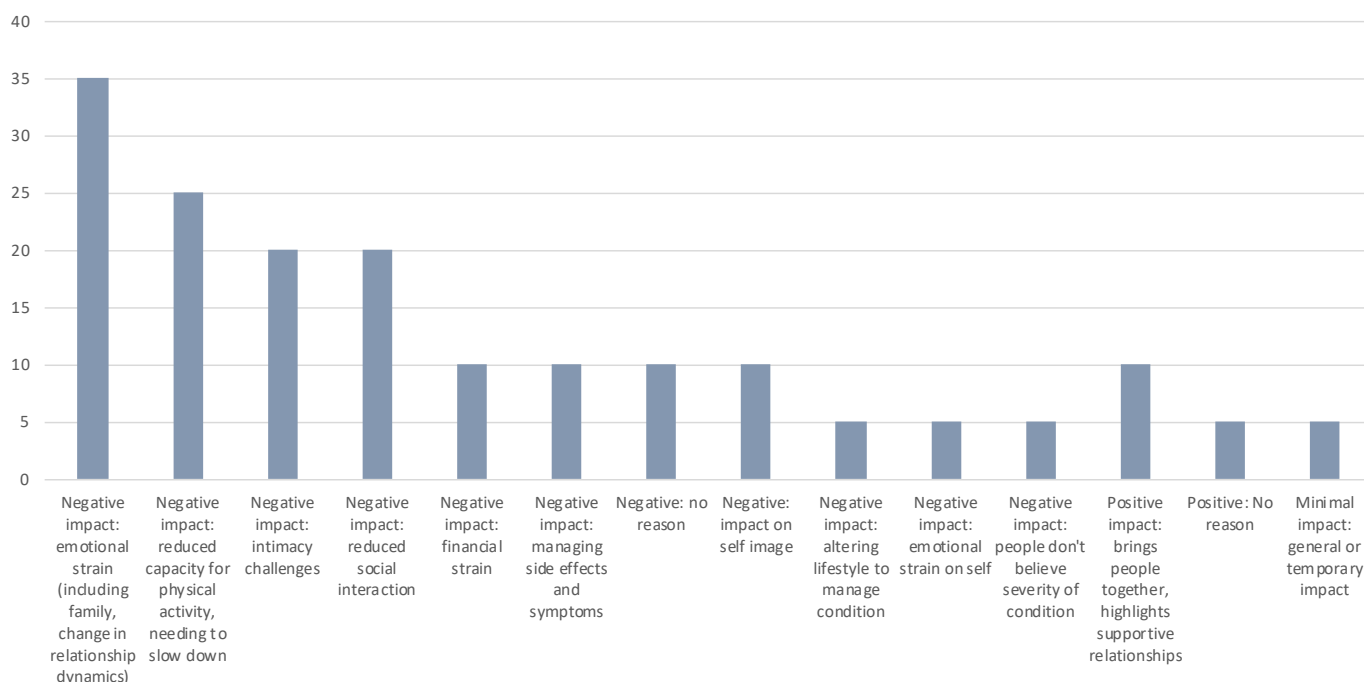
Impact on quality of life	All participants	
	n=20	%
Experience described suggests that there was an overall negative impact on quality of life	13	75.00
Experience described suggests that there was overall a minimal impact on quality of life	1	5.00
No particular comment	2	10.00



**Figure 8.1: Impact on quality of life**

**Table 8.2: Impact on quality of life (Reasons)**

Impact on quality of life (reasons)	All participants	
	n=20	%
Participant describes a negative impact on quality of life due to the emotional strain (including family/change in relationship dynamics)	7	35.00
Participant describes a negative impact on quality of life due to reduced capacity for physical activity/needing to slow down	5	25.00
Participant describes a negative impact on quality of life due to intimacy challenges	4	20.00
Participant describes a negative impact on quality of life due to reduced social interaction	4	20.00
Participant describes a negative impact on quality of life due to financial strain	2	10.00
Participant describes a negative impact on quality of life due to managing side effects and symptoms	2	10.00
Participant describes a negative impact on quality of life without giving a reason	2	10.00
Participant describes a negative impact on quality of life due to the impact on self image	2	10.00
Participant describes a negative impact on quality of life due to altering lifestyle to manage condition (including being immunocompromised)	1	5.00
Participant describes a negative impact on quality of life due to the emotional strain on self	1	5.00
Participant describes a negative impact on quality of life because people don't believe the severity of condition	1	5.00
Participant describes a positive impact on quality of life because it brings people together/highlights supportive relationships	2	10.00
Participant describes a positive impact on quality of life without giving a reason	1	5.00
Participant describes a minimal impact on quality of life that has a general or temporary impact	1	5.00



**Figure 8.2: Impact on quality of life (Reasons)**

### Impact on mental health

In the structured interview, participants were asked if there had been an impact on their mental health. Most commonly, the descriptions suggested that overall, there was at least some impact on mental health (80.00%), overall, there was no impact on mental health (5.00%), and other or mixed experience (5.00 %).

**Experience described suggests that overall, there was at least some impact on mental health**

*It can affect my mental and emotional health and that can vary from day-to-day. I can have, you know, at the moment I have a flare and that can get me down because it's just kind of like you suddenly you're feeling well and then bang, you know, it's almost like there's no lit up. Like you, you you just go for a day*

*and you think you're doing really well and then suddenly you've got, you know, one flare pops up and. Your arms uncomfortable or whatever. So yeah, look, it can, but I think in that for me, I've had to put things in place to help me with my mental health. So that's for me that's talking about my condition. It's practicing mindfulness and mental health and wellbeing type of activities that keep me, keep me focused on the positive rather than allowing, you know, the focus to become the HS. Participant 001\_2023AUHIS*

*Sorry, I'm crying, but yeah, it affects my mental health a lot. I would say. You know, I have ever an episode at least twice a month where I break down. About having the disease, because I just think, why me? Like why do I have this? And it's just it's ugly and I compare*

*myself to other people all the time who, you know, don't have it. I like there's not much I can do for myself in terms of having disease because it's so hard to pull myself out of this. Like mental thought that it's ugly and it's something I should be ashamed of and it's just kind of, I need to let myself cry about it and then I move on because it's not going anywhere. So I just have to, you know, get over it. I'd say my partner is definitely someone who helps a lot with my mental health. He'll just remind me that, like, I'm still a great person with or without the disease.*

**Participant 010\_2023AUHIS**

*Yeah, 100% it does it affect because it affects yourself esteem. It makes you stress about. The pain you're experiencing, or even just knowing that it's coming is sometimes worse. Stressing about money, taking time off of work, it's a lot of sometimes I think the mental and emotional roller coaster puts you through*

*sometimes worse than the physical, so that I know it's a lot worse for other people. Thankfully, I'm probably classed more as mild, especially these days. It's not as rampant as what it was, but yeah.*

**Participant 018\_2023AUHIS**

*Yeah, it definitely has an impact. It sort of makes you feel like. You're a bit less lovable. I don't know. There's just a lot going on, I guess. And yeah, I see a psychologist.*

**Participant 019\_2023AUHIS**

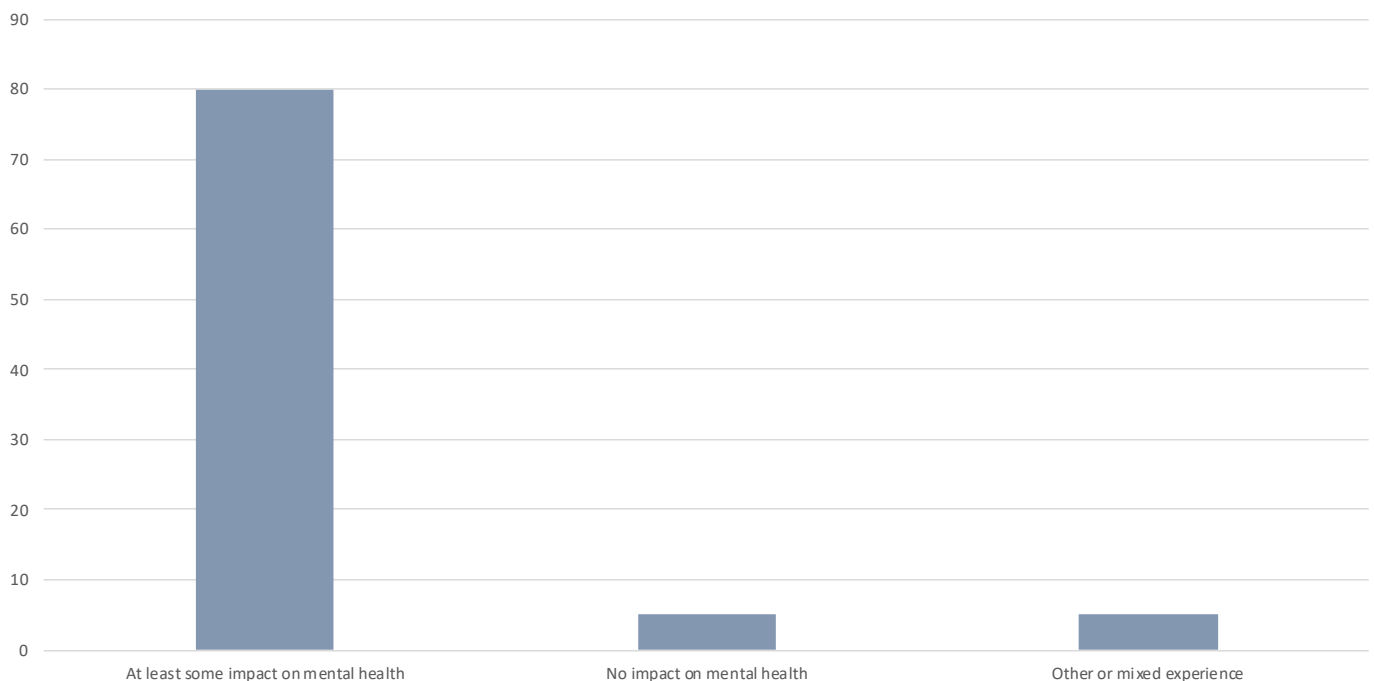
**Experience described suggests that overall, there was no impact on mental health**

*It would. It would affect me if I let it, like if I just dwelled. Yeah, on it. But to be honest, I'm more concerned about my leg and my mother.*

**Participant 006\_2023AUHIS**

**Table 8.3: Impact on mental health**

Impact on mental health	All participants	
	n=20	%
Experience described suggests that overall, there was at least some impact on mental health	16	80.00
Experience described suggests that overall, there was no impact on mental health	1	5.00
Other or mixed experience	1	5.00
No particular comment	2	10.00



**Figure 8.3: Impact on mental health**

### Regular activities to maintain mental health

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common response was mindfulness and/or meditation (40.00%), no activities

to maintain mental health (20.00%), and the importance of family and friends in maintaining their mental health (15.00 %). Other themes included consulting a mental health professional (10.00%),

allowing time to cry, then gets on with it (10.00%), keeping busy (10.00%), coping strategies such as remaining social, lifestyle changes and hobbies (5.00%), the importance of physical exercise (5.00%), and keeping informed about their condition (5.00%).

**Participant describes mindfulness and/or meditation to maintain their mental health**

*My mindset definitely helps my mental health, but I'm also medicated for mental health and anxiety. Participant 005\_2023AUHIS*

*Yeah, I. I I find walking. I haven't done a lot of that lately. Walking helps mental and emotional health. Emotional health. I'm not sure exactly how to answer that because I'm self aware enough to know that I've tucked my emotions away for the most part, without seeking sympathy, I lead a sad life. I I read, watch TV, read. Stuff about HS was engaged in the whatever. It's an online community of people involved with HS advocacy and research. But I'm gradually withdrawing from that, feeling like I've done enough and there's too much politics and you don't know who's in the zoo and farmers everywhere. So pulling away from all that, I find meditation for me is easy, and that helps. It's not really an obvious meditation, but I can. I can lie down and put everything out of my head and just. Exists to be that kind of meditation, you know, no worries, no, no bad thoughts. I find that easy to do. I do it frequently there. There's there's no one thing that I do that fixes. Problems. Participant 008\_2023AUHIS*

**Participant describes no activities to maintain mental health to maintain their mental health**

*I mean, it is right now. It's certainly, yeah, we're having a flare up. It could be quite frustrating, painful and upsetting, but I don't. I don't seek out any. Participant 011\_2023AUHIS*

*I don't really have any strategies because until I'm not in pain it's very difficult for me to look after my mental health because the more pain I'm in, the worse my mental state gets and the more over stimulated I get, which is you can't really come back from that very often. Participant 012\_2023AUHIS*

**Participant describes the importance of family and friends in maintaining their mental health to maintain their mental health**

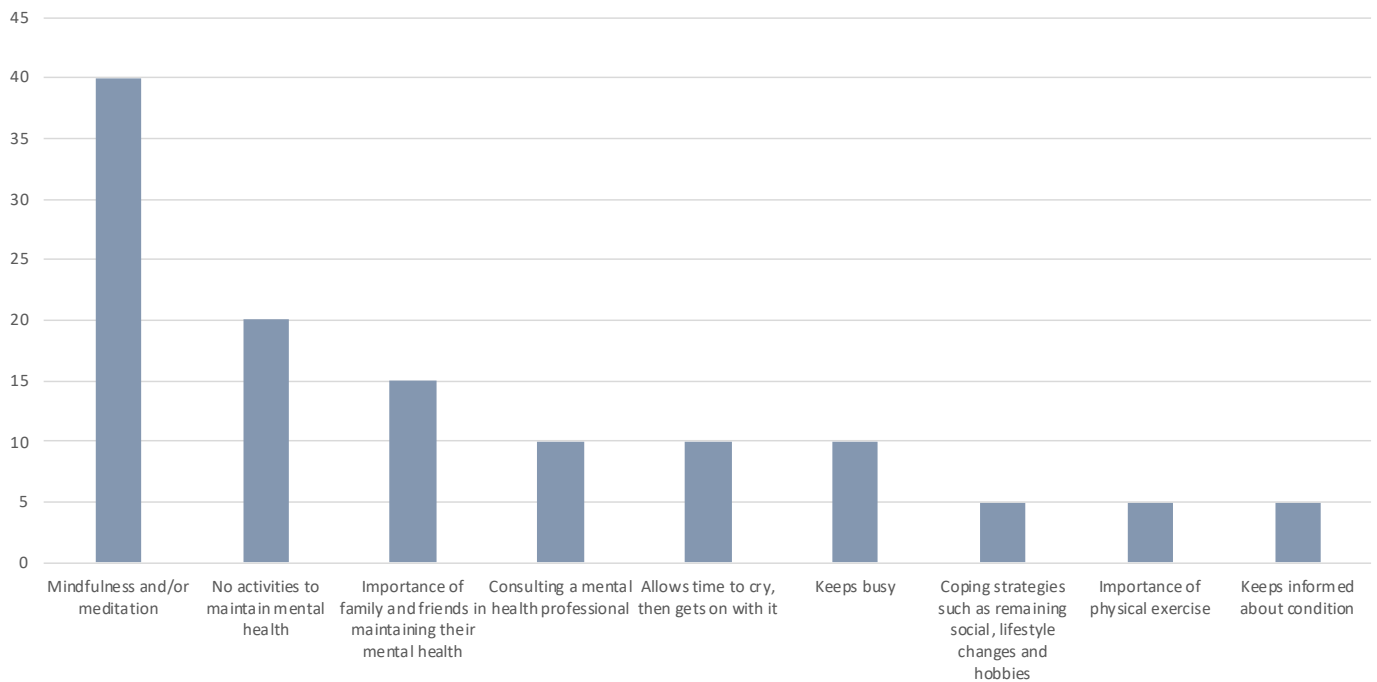
*So I would say I would say yes around the time it, it probably did to maybe a mild, mild to moderate sort of severity level I through the work I do anyway and really a very strong advocate for the self care and you know catching myself with any negative self talk and and those sorts of things. I I spoke to family and close friends and was really I suppose to open and and honest and expressing where I was at so that I sort of had a sounding board and a place to and a place to share that. So I think those things were really. Important I didn't go and seek a psychologist because, like, I know them all really well around here and they're all colleagues and I supervise a lot of them. And yeah, in a small country town, that just didn't feel like an option. Participant 007\_2023AUHIS*

*Educating myself, making sure I have hobbies and whatnot. Getting on with life, not letting HS rule me so much, and having a supportive, understanding partner. Participant 013\_2023AUHIS*

**Table 8.4: Regular activities to maintain mental health**

Regular activities to maintain mental health	All participants	
	n=20	%
Participant describes mindfulness and/or meditation to maintain their mental health	8	40.00
Participant describes no activities to maintain mental health to maintain their mental health	4	20.00
Participant describes the importance of family and friends in maintaining their mental health to maintain their mental health	3	15.00
Participant describes consulting a mental health professional to maintain their mental health	2	10.00
Participant describes allowing time to cry, then gets on with it, to maintain their mental health	2	10.00
Participant describes keeping busy to maintain their mental health	2	10.00
Participant describes coping strategies such as remaining social, lifestyle changes and hobbies to maintain their mental health	1	5.00
Participant describes the importance of physical exercise to maintain their mental health	1	5.00
Participant describes keeping informed about their condition to maintain their mental health	1	5.00





**Figure 8.4: Regular activities to maintain mental health**

### Regular activities to maintain health

In the structured interview, participants were asked what were some of the things they needed to do everyday to maintain their health? The most common activities for general health were complying with treatment/management (45.00%), and hygiene routine (45.00%). Other themes included avoiding flare triggers (25.00%), understanding their limitations (20.00%), being organised and planning ahead (10.00%), using complementary therapies (10.00%), maintaining a healthy diet (10.00%), mindfulness and/or meditation (10.00%), doing physical exercise/physically active (10%), self care e.g. more rest, accepting help, pacing (10.00%), covering up lesions (10.00%), being aware of their body and limitations (5.00%), and maintaining a normal routine (5%).

#### Participant describes the importance of complying with treatment/management in maintaining their general health

*That would be bleach baths, yeah. Using my topical creams. Using the Hydrochlorid bandaids or pimple patches, yeah. Not wearing underwear? Yeah. Not being overly not eating or drinking one particular thing overly if that makes sense. Like just don't gorge yourself on anything. Like I'll have whatever, but I mean don't have chocolate three days in a row and eat the whole block 3 days in a row. You know, like you're going to have toxins trying to get out of you and. Regardless of whether or not it's a flare, it's you know you're gonna get pimples or whatnot, so probably just have some bananas or I know something*

*better than that. So I try to be mindful of what I'm eating and not have too much oil.*

*Participant 006\_2023AUHIS*

*Good hygiene, as in making sure the affected areas are well cleaned and protected. I take vitamins to help counteract. I take medication when it's prescribed. Just looking after myself and getting on with life.*

*Participant 013\_2023AUHIS*

#### Participant describes the importance of their hygiene routine in maintaining their general health

*Well, basically I mean on that one there's not a I mean I'm help him with his when he's got flares like you know, I do all these the preparation of his his patches and with he also uses just a a general body wash thing to keep the the microbes down. The chlorhexadine. So yeah keep him supplied with with all of those things and on his back to to make sure cause he's 16 on his back to make sure that he's having the the right hy hygiene stuff but as we you know as we all know hygiene doesn't even really play a part in in this so yes just making sure that he's. He's well he's pre prepared and that he's getting that emotional support so that he can keep keep moving forward and we're all about normalizing his life at the moment when you know if he's he's getting back into some some sport but not at a a a competitive level and if he can do it he can do it. If he can't well he's just got to accept that. So we're we're trying to modify expectations, etc.*

*Participant 009\_2023AUHIS*

*I have to make sure I'll have to clean myself. I have to wear appropriate clothing specifically in relation to whether or not I'm wearing pads or. Or bandaids to cover lesions that are weeping. I have to make sure that I have those supplies with me at any given time. I have to be sure that I am within reach of pain medication. If we were to just go away, I would take my and don't, regardless of whether I had a flare or anything. I I am limited in my mobility, so I have to be mindful of the activities I need to do to get me from A to B or, you know, from one activity to another, whether it's, you know, working or being home. What my mobility situation is at any given time and whether I can sustain it, So I had a massive flare last week. Thursday would have been a fun day to talk to you and I couldn't shower for three days, so there was no, I was working from home. That's, you know, at any given time it it's it's just being able to cater to you, the current situation. Is that kind of what you were?*

*Participant 015\_2023AUHIS*

**Participant describes the importance of avoiding flare triggers in maintaining their general health**

*My one rule is that I threw away all my bras that had under wire in them because that shit makes everything worse and I stopped wearing those like a year ago. So much better. So delete those from the earth and make sure like wearing appropriate clothing because some clothing will just trigger a flare like. Don't do it. It's bad choice. I put something on and I'm like, no regret. Take it off sitting on comfortable things. If I sit on the chair, I will instantly know if it's going to give me a flare from the pressure it puts on me. So I have to make those choices. It's like every day things, there's just things everywhere that you have to avoid.*

*Participant 014\_2023AUHIS*

**Table 8.5: Regular activities to maintain health**

*Managing treatments I guess is the biggest one and and try my best to prevent further flare. Yeah, at the moment I don't feel like there's a lot I can do to prevent that, so it probably isn't having a massive impact, but I'm sure once I start the injections that will do.*

*Participant 019\_2023AUHIS*

**Participant describes the importance of understanding their limitations in maintaining their general health**

*Try not to overheat is the big one. I don't even drink alcohol anymore because I noticed, you know, a day. If I drank on a Saturday by Tuesday, it's just really limited. A lot of social stuff just because I know just not to do it and then it it won't happen. So no real exercise, no fun stuff.*

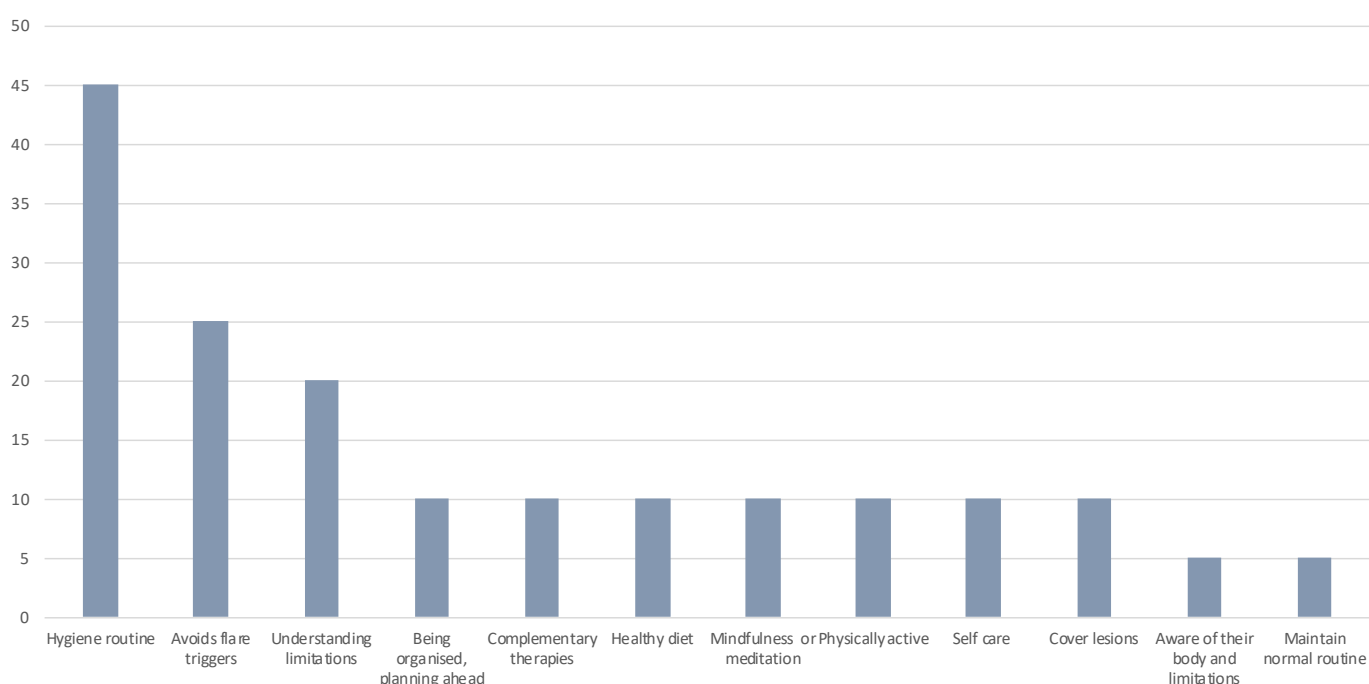
*Participant 018\_2023AUHIS*

**Participant describes the importance of being organised and planning ahead in maintaining their general health**

*So if I've got a break out. I need to make sure that I've got bandaging to be able to wear. I need to have. Funnily enough, I haven't had any really strong pain relief for a very long for over a year now, and I'm quite happy about that. I need to be able to maybe cancel things in short notice if if that's the case, you know. I need, I feel like I need certainly access to an endless supply of Chlorhexidine and I have the biggest Band-Aid and bandage collection in the world. So yeah, yeah, so I guess, I guess. Physically, to be able to, you know, wear undergarments, I need to be able to, you know, have enough padding to protect, you know, and I guess also obviously I need access to my medication and I need access, yeah.*

*Participant 017\_2023AUHIS*

Regular activities to maintain general health	All participants	
	n=20	%
Participant describes the importance of complying with treatment/management in maintaining their general health	9	45.00
Participant describes the importance of their hygiene routine in maintaining their general health	9	45.00
Participant describes the importance of avoiding flare triggers in maintaining their general health	5	25.00
Participant describes the importance of understanding their limitations in maintaining their general health	4	20.00
Participant describes the importance of being organised and planning ahead in maintaining their general health	2	10.00
Participant describes the importance of using complementary therapies in maintaining their general health	2	10.00
Participant describes the importance of maintaining a healthy diet in maintaining their general health	2	10.00
Participant describes the importance of mindfulness and/or meditation in maintaining their general health	2	10.00
Participant describes the importance of doing physical exercise/physically active in maintaining their general health	2	10.00
Participant describes the importance of self care e.g. more rest, accepting help, pacing in maintaining their general health	2	10.00
Participant describes the importance of covering up lesions in maintaining their general health	2	10.00
Participant describes the importance of being aware of their body and limitations in maintaining their general health	1	5.00
Participant describes the importance of maintaining a normal routine in maintaining their general health	1	5.00



**Figure 8.5: Regular activities to maintain health**

## Experience of vulnerability

In the structured interview, participants were asked if there had been times that they felt vulnerable. The most common responses were that they felt vulnerable experiencing side effects from treatment or symptoms from condition (25.00%), when having sensitive discussion (diagnosis, treatment decision) (20.00%), and because of interactions with the medical team (20.00 %). Other themes included during/after treatments (15.00%), during diagnostic procedure (10.00%), thinking about disease course/incurable condition (10.00%), and did not feel vulnerable (5.00%).

### Experiencing side effects from treatment or symptoms from condition

*Yeah, so I the vulnerability that I have, the disease come in my social and intimate life. So as I said, I have the disease. In my breast area, which is very intimate area, so I find it hard to be intimate with my partner. Sometimes if I'm having a flare up, I don't want to get undressed. I don't want him to see me even though I know he doesn't care and he still loves me. But it's still hard for me to feel beautiful and wanted when I'm dealing with this. As well as just going out and going to the beach. Like I can't wear a bikini because then the disease is just kind of on display. And I, you know, there was a time where I said, you know, like through it, like I'm going to wear a bikini. And then, you know, I saw people looking at it and asking questions like*

*what's on your chest? And yeah, it just sucks because I don't want. People to point it out or look at it or anything like that and it just makes me feel embarrassed.*

*Participant 010\_2023AUHIS*

*Yes, there has. Particularly when the condition was just getting out of control and you turn to a specialist for help and their answer is there's nothing I can do. And these are that, that they don't offer alternative suggestions. For instance, hang on, I'm going to call, I was having. A chronic Abscess that just would not heal. And the surgeon I saw just said there's nothing he can do anymore. And I but he didn't offer alternative solutions like go and see this person or what not. And that I still vividly remember being very vulnerable and alone in the world, thinking no one can help.*

*Participant 013\_2023AUHIS*

#### **Vulnerable when having sensitive discussion (diagnosis,treatment decision)**

*When I was told that I had to. That I really only had Humira as my only option. I did feel very vulnerable then, yeah.*

*Participant 017\_2023AUHIS*

*Anytime I kinda have to ask for help because I have to start from the beginning. And yeah, I've really gotta you wait for the no and the the here's the antibiotics and the just the standard stuff that you know isn't gonna do anything, but you have to do it so they can tick off their list that they've tried that.*

*Participant 018\_2023AUHIS*

#### **Vulnerable because of interactions with the medical team**

*The most vulnerable was that time I described being naked and being told that I need to keep smoking and lose weight and take Humira and then I'll be fine. I'm not sure they realise that. I left it on the opposite side of the city and it took me. An hour and a half on public transport to get there. 30 minute walk. That's a lot of effort just for doctors and nurses to point their finger*

*at you while you're naked and tell you you're the problem, NAME. That's why I've not seen a dermatologist since.*

*Participant 008\_2023AUHIS*

*Really. They treated me like I was infectious in hospital, so no one knew the their treatment of my pain level. They made me feel like I was just a heroin addict who who's come in to get some end down. So I cried so hard and then you know I followed that up with. That visit, and it was just, it was a joke. I'd never felt more, I'd never felt more unseen. Talked at like I was not a person of any circumstance. I wasn't even poorly dressed, I'd have to say if you thought I was anything other than a professional at that point. And the way he spoke to me in the presence of others, the nurse at the end of it, because he was just taking so long showing off in front of his registrar, this nurse came in and literally looked at me and said, you've taken enough of his time. And I remember laughing so hard because I was literally sitting there just being poked and prodded that no one was talking to me. You know, you regurgitated the lose weight, quit smoking. But wash yourself. And I remember just going. You have no idea what I do. And I could be just, you know, do you want my skin to be red before you'd be satisfied that the amount of bleach I'm scrubbing into myself daily and all the while still feeling extremely dirty? It's really horrific. I've quit smoking for years and never saw a difference. I was not even overweight at that time. Like, there's no rhyme or reason at that point that I could say these are contributing factors.*

*Participant 015\_2023AUHIS*

#### **Vulnerable during/after treatments**

*PARTICIPANT: Probably, probably actually the most vulnerable would have felt after my first surgery when I had expected it to be like a two day recovery.*

*INTERVIEWER: Yeah, but do you think you needed to like, address or overcome that vulnerability?*

*PARTICIPANT: Probably just information.*

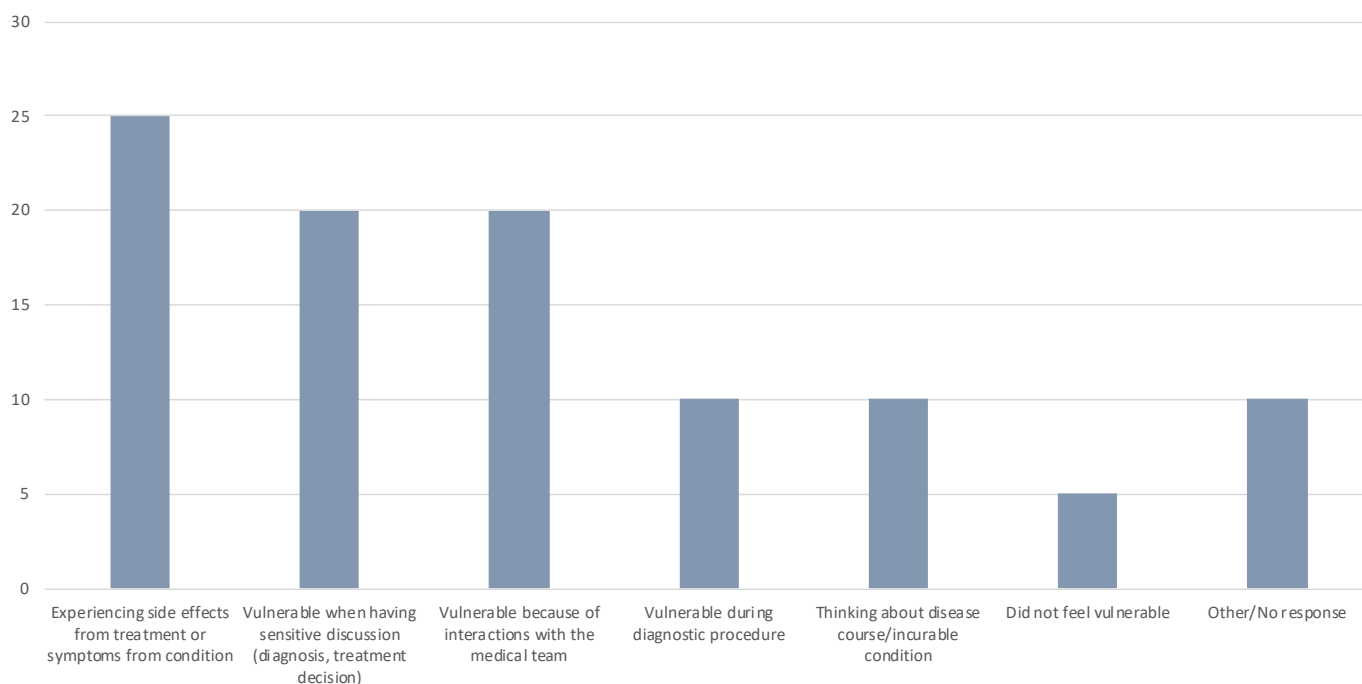
*INTERVIEWER: Yeah, more knowing.*

*PARTICIPANT: Knowing what to expect, yeah.*

*Participant 007\_2023AUHIS*

**Table 8.6: Experience of vulnerability**

Experience of vulnerability	All participants	
	n=20	%
Participant describes feeling vulnerable experiencing side effects from treatment or symptoms from condition	5	25.00
Participant describes feeling vulnerable when having sensitive discussion (diagnosis, treatment decision)	4	20.00
Participant describes feeling vulnerable because of interactions with the medical team	4	20.00
Participant describes feeling vulnerable during/after treatments	3	15.00
Participant describes feeling vulnerable during diagnostic procedure	2	10.00
Participant describes feeling vulnerable thinking about disease course/incurable condition	2	10.00
Participant describes that they did not feel vulnerable	1	5.00
No particular comment	2	10.00



**Figure 8.6: Experience of vulnerability**

## Methods to manage vulnerability

In the structured interview, participants described ways that they managed feelings of vulnerability. The most common ways to manage vulnerability were getting support from family and friends (15.00%), and using self-help methods (resilience, acceptance, staying positive) (10.00%). Other themes included support from mental health professionals (5.00%), being informed and knowing what to expect (5.00%), and sticking to their treatment regimen (5.00%).

### Support from family and friends to manage the feeling of vulnerability

*PARTICIPANT: I'll just pull back on the people that know about it and support me I have a husband that's very accepting and understanding who comes to my condition, so I'm very lucky.*  
Participant 011\_2023AUHIS

### Self-help (resilience, acceptance, staying positive) to manage the feeling of vulnerability

*PARTICIPANT: I just had to take it day by day, persevere, keep fighting to get and once some he tried a new antibiotic. Fortunately it worked so that the wound could clear up. Otherwise, I was just like abandoned in a dinghy, out at sea, left alone.*  
*INTERVIEWER: Thank you. It was very hard.*  
*PARTICIPANT: Yeah, I think it's just that, OK, they can't help you, but it's just like slamming the door in your face. They didn't. Come up with other options that Oh well, maybe you could go and see this person or try this person. It was just slam bam, out you go.*  
Participant 013\_2023AUHIS

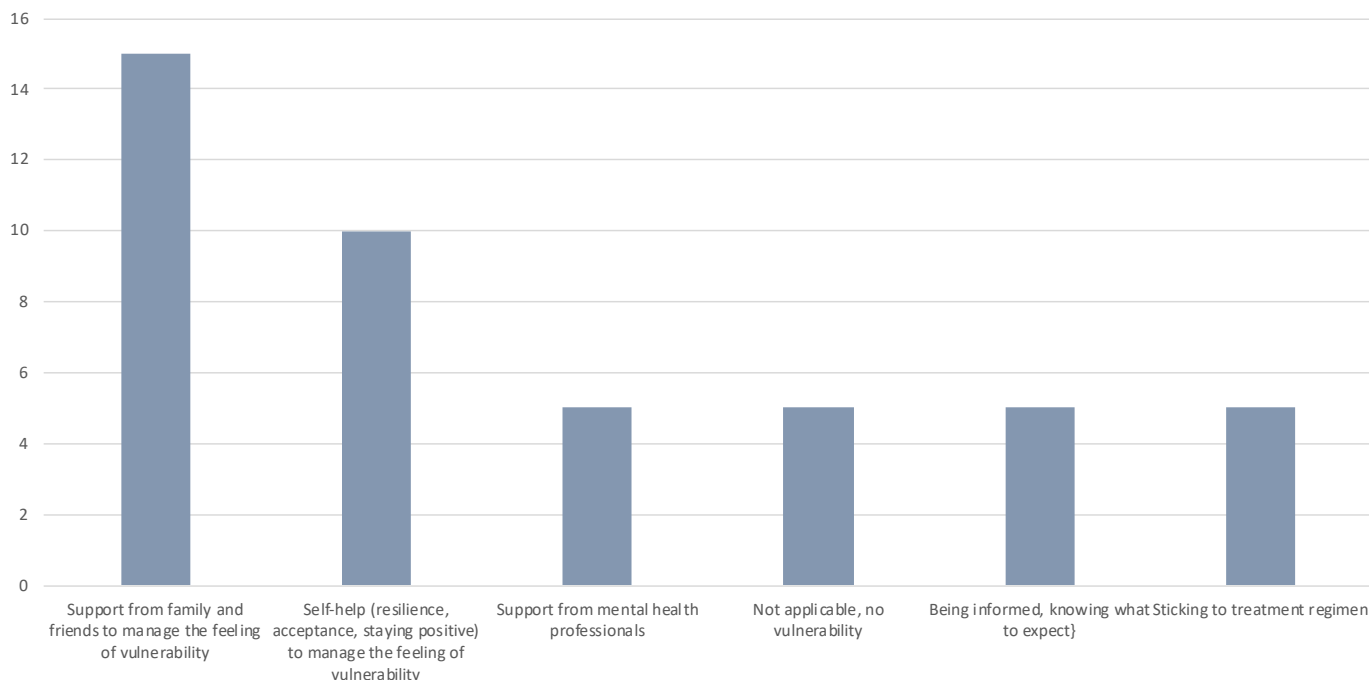
### Being informed, knowing what to expect

*PARTICIPANT: Probably, probably actually the most vulnerable would have felt after my first surgery when I had expected it to be like a two day recovery.*  
*INTERVIEWER: Yeah, but do you think you needed to like, address or overcome that vulnerability?*  
*PARTICIPANT: Probably just information.*  
*INTERVIEWER: Yeah, more knowing.*

**PARTICIPANT: Knowing what to expect, yeah.**  
**Participant 007\_2023AUHIS**

**Table 8.7: Methods to manage vulnerability**

Methods to manage vulnerability	All participants	
	n=20	%
Participant describes getting support from family and friends to manage the feeling of vulnerability	3	15.00
Participant describes using self-help methods (resilience, acceptance, staying positive) to manage the feeling of vulnerability	2	10.00
Participant describes support from mental health professionals to manage the feeling of vulnerability	1	5.00
Participant describes Not applicable, no vulnerability	1	5.00
Participant describes being informed and knowing what to expect to manage the feeling of vulnerability	1	5.00
Participant describes sticking to their treatment regimen to manage the feeling of vulnerability	1	5.00
No particular comment	12	60.00



**Figure 8.7: Methods to manage vulnerability**

**Impact on relationships**

Most commonly, the descriptions suggested that overall, there was a negative impact on relationships (50.00%), and overall, there no impact on relationships (15.00%). Other themes included overall, there was a positive impact on relationships (10.00%), and overall, there was an impact on relationships that was both positive and negative (5.00%).

The most common themes in relation to having a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships (20.00%), from feeling dismissed or not believed by others(10.00%), and due to intimacy challenges (10.00 %). Other themes included from managing symptoms (5.00%), and from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition (5.00%).

The most common theme in relation to a positive impact on relationships were brings people together/highlights supportive relationships (10.00%).

**Overall, there was a negative impact on relationships**

*The only questions that got asked at the one of my face Oh my gosh, I hated going to Christmas. What's on your face? And it's like, Oh my gosh, I don't teach you about your conditions. Yeah. Like, half my family has psoriasis. So, I mean, they think they're worse off and they've got growing skin all the time. But I'm like, and you don't have any sympathy for me.*  
**Participant 003\_2023AUHIS**

*That question, yeah, it's OK. I think I'll move on to the next one. Yep. And do you think having HS has affected your personal relationships with family and friends? Yeah. Maybe up until 2005 I would have said*

*Nah, but I don't think I was. I think I was living in denial. I've been withdrawing from relationships a lot since then and. I don't know for certain if it's HS or personality disorder or whatever, but here I am. Yeah, it has affected sexual relationships in the past and it hasn't, you know, it it varies depending on how you feel on the day and whether your skin is bad. I'm trying to think 2022. It's probably been eight or nine years since I was in a sexual relationship, so. I'm still young, 55, but I just feel like you know, whatever is that HSI don't know. I mean it's it's everything. It's it's my circumstance, my poverty, my withdrawal, my skin disease and. None of it changes day by day. It's all still there when I wake up the next day, so I guess I haven't thought about it that much.*

*Participant 008\_2023AUHIS*

*Well, with the HS, you see like people go to the beach and wear cozies, for instance, or clothing that they like. When you have HS, you got these ugly scars and wounds that are oozing. So you can't necessarily put on your nice bathing suit. You've got to cover up, going out anywhere. You've got to be careful if you've got a wound like, is it? Not going to leak is it covered up? And then you tend to wear clothing that covers up that area, so you can't be your genuine new. You're too busy making sure that things don't leak, that you're dressed appropriately to cover them so you can hide.*

*Participant 013\_2023AUHIS*

*Yeah, I guess I would say it has. Because of making plans and having to cancel because you can't really do the things that you wanted to do. Yeah, I guess it does. And when people don't know why, you'll understand. It makes it difficult because then they just think that you're blowing them off for no reason and it's like, well, no.*

*Participant 014\_2023AUHIS*

**Overall, there no impact on relationships**

*They have to love me because they always will, no matter what. And if they didn't do this because they wouldn't be my friends.*

*Participant 002\_2023AUHIS*

*Probably not. In my case, I have chronic fatigue syndrome, so I've already quite isolated and yeah, sort of focusing on just my main friendship.*

*Participant 019\_2023AUHIS*

**Overall, there was a positive impact on relationships**

*PARTICIPANT: Hasn't affected anything, you know, like with me Dad or whatever, you know, like he knows what's going on. He just thinks that's terrible, you know? But no, like, I have the best friend that I've been best friends with since I was six, and she understands and. If she sees any information or anything, she's like the first to be like, oh, I saw this, you know.*

*INTERVIEWER: That's great.*

*PARTICIPANT: So yeah, no. Like it's, if this was on my back or something and people were seeing it, you know, and my armpit and I had to go look, yeah, you know, like this, you know, then yeah, probably would be a lot, but it's. It's in my like Nether region. I don't get around with that out, so it's not a topic for conversation with most friends. I've got no idea that that is something that I would suffer with.*

*Participant 006\_2023AUHIS*

*I don't know if it's affected it or not. I I couldn't really say. I don't think it's affected it that much. My family's still been really supportive. I. Look, the worst probably do is sometimes my family is tired of me, but that's about it.*

*Participant 012\_2023AUHIS*

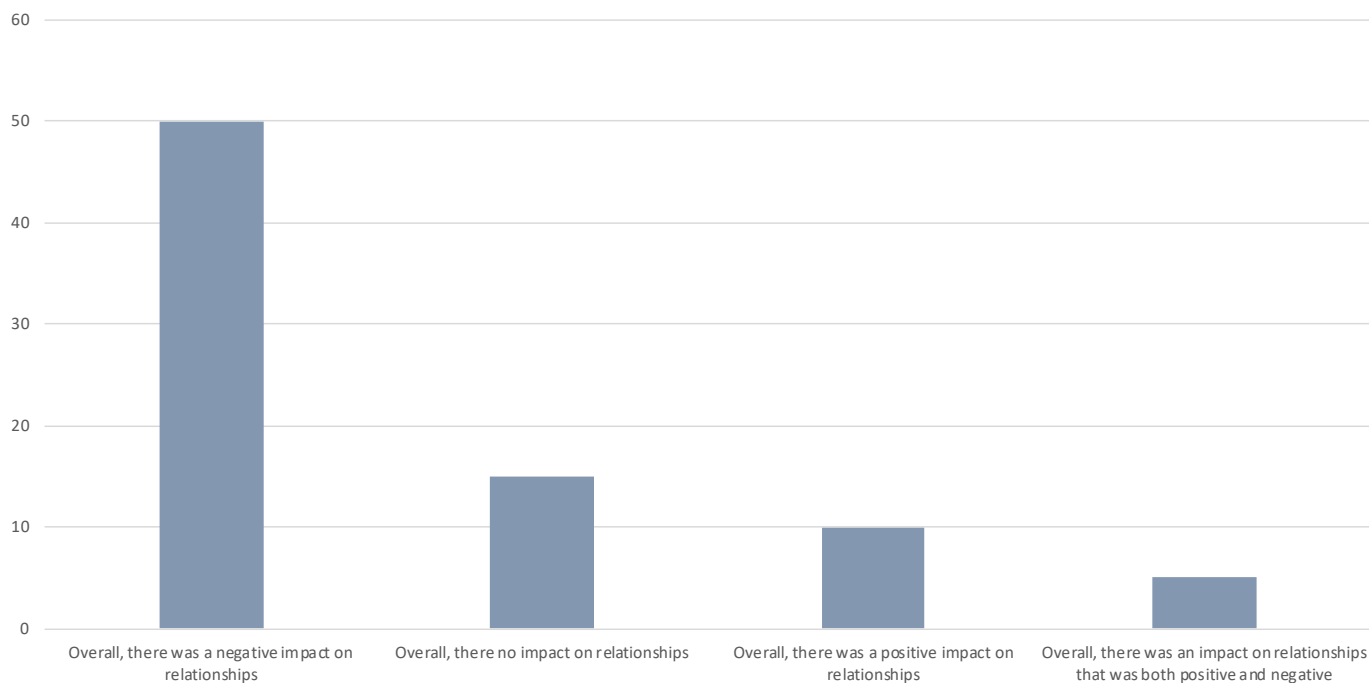
**Overall, there was an impact on relationships that was both positive and negative**

*There are some things like I won't that I won't do so like I won't go to things like water parks and so there's there's some family things that I won't go to. Obviously there are lots of times I have to cancel because as I said pants are not an option and and they kind of required when you leave the house. Very fortunate with regards to. So I've had like I've lost a lot of friendships over the years because you cancel all the time and then they just stop asking you to do things with them. I'm very fortunate in that, you know, both my first husband and my second husband are beautiful men. My first husband is still a beautiful man and and so it didn't affect my physical relationships. But certainly had an impact on my ability to spend time with friends and things like that.*

*Participant 005\_2023AUHIS*

**Table 8.8: Impact on relationships**

Impact on relationships	All participants	
	n=20	%
Participant describes that overall, there was a negative impact on relationships	10	50.00
Participant describes that overall, there no impact on relationships	3	15.00
Participant describes that overall, there was a positive impact on relationships	2	10.00
Participant describes that overall, there was an impact on relationships that was both positive and negative	1	5.00
No particular comment	4	20.00

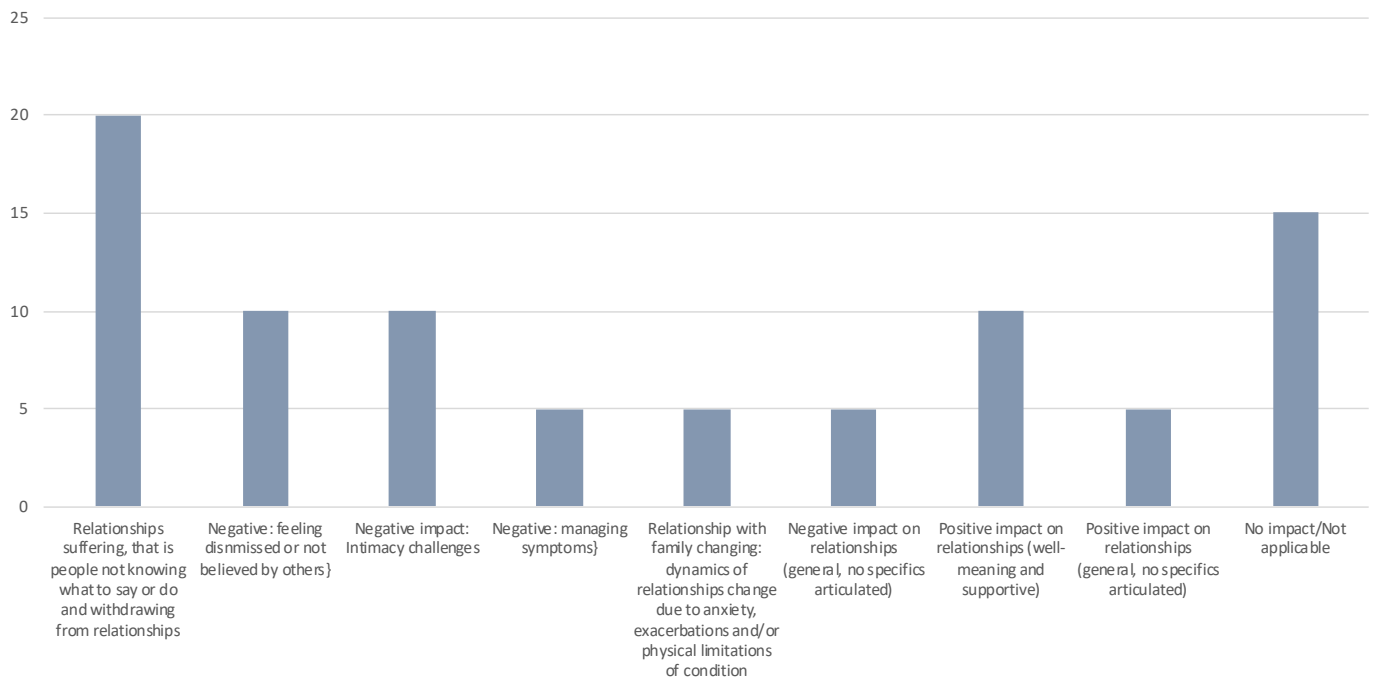


**Figure 8.8: Impact on relationships**

**Table 8.9: Impact on relationships (Reason for impact)**

Impact on relationships (reasons)	All participants	
	n=20	%
Participant describes a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships	4	20.00
Participant describes a negative impact on relationships from feeling dismissed or not believed by others	2	10.00
Participant describes a negative impact on relationships due to intimacy challenges	2	10.00
Participant describes a negative impact on relationships from managing symptoms	1	5.00
Participant describes a negative impact on relationships from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition	1	5.00
Participant describes a negative impact on relationships in general (no specifics articulated)	1	5.00
Participant describes a positive impact on relationships from people being well-meaning and supportive	2	10.00
Participant describes a positive impact on relationships in general (no specifics described)	1	5.00
No impact/Not applicable	3	15.00





**Figure 8.9: Impact on relationships**

### Burden on family

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Most commonly, the descriptions suggested that overall, there was a burden on their family (60.00%), overall, there was not a burden on their family (15.00%), and having no particular comment (25.00 %).

The main reasons that participant described their condition being a burden were the extra financial assistance needed (10.00%), the mental/emotional strain placed on their family (10.00%), and that the burden on family was temporary or only during treatment (10.00 %). Other themes included the extra assistance needed getting to appointments (5.00%), intimacy problems (5.00%), managing symptoms (5.00%), and eding to take time off work (5.00%).

The main reason that participant described their condition not =being a burden were because they were independent and did not need any help (15.00%), and that they were not a burden because no one knows about their diagnosis (5.00%).

#### Participant describes that overall, there was a burden on their family

*I sometimes feel like that, but at at the most part, I mean I I can care for myself, but there. But there are times, there are times when I do feel like that because there might be times when I just you know, I I'm*

*feeling a little bit worse less than normal. So yeah. So for the most part no, but sometimes yes.*

*Participant 001\_2023AUHIS*

*Ohh well you do wonder sometimes when you're asking them to clean up certain parts you can't get to or get your daughter to take images of certain parts of your anatomy she certainly shouldn't be so that she can send you can send them through to the doctor for your Tele health. You know, I'm lucky that she just embraces it and takes it on board, but you know, it is what it is. It's it's our life.*

*Participant 002\_2023AUHIS*

*Them look around the time of the surgeries, yes, I had had friends who lived nearby and my daughter that had to step up and do a lot more for me the rest of the time, not not so much in terms of kind of burden going forward. I know my daughter's quite concerned that she may be impacted by the condition. She's only she's only 11 now so you know she's she's already starting to look at things like you know at school they're being told they've got away deodorant and and she's going off. But is that going to increase the chances of of you know exacerbating that area. So yeah so there's there I suppose there's some burden more so of fear of what might come.*

*Participant 007\_2023AUHIS*

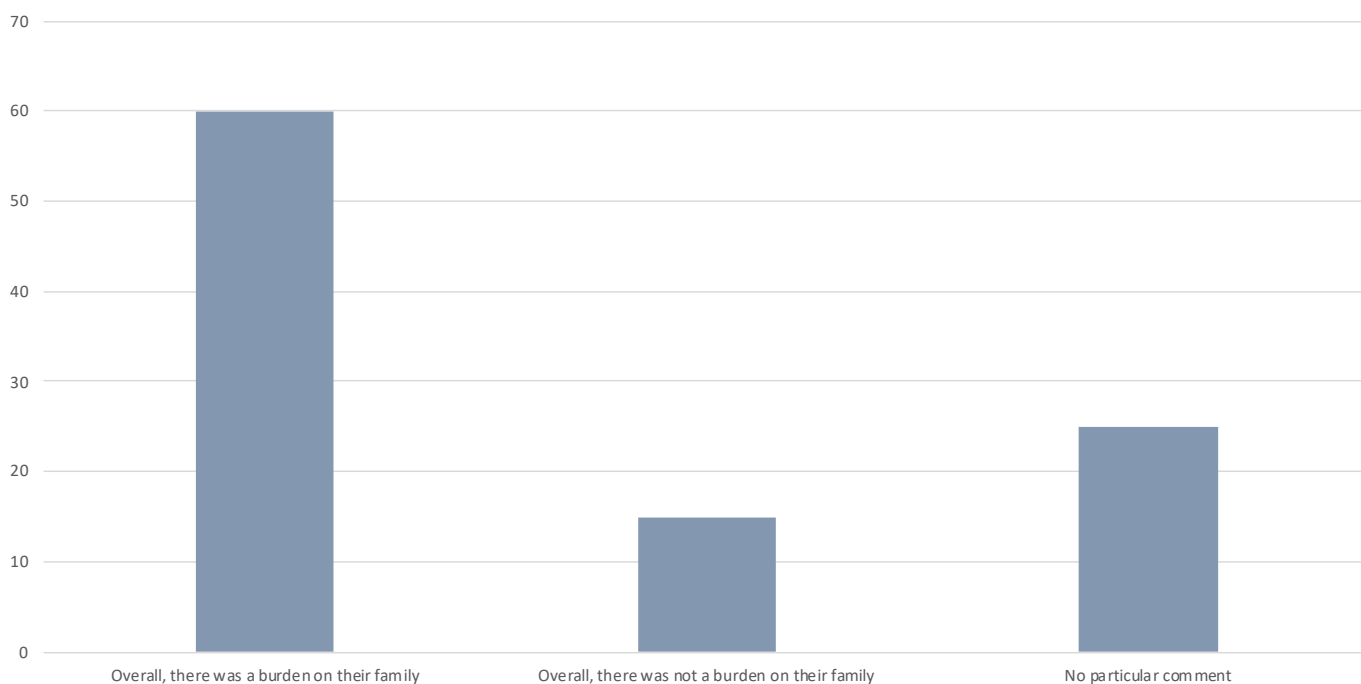
#### Participant describes that overall, there was not a burden on their family

*No, I wouldn't say so. I guess I'm usually the carer, unfortunately. So, yeah.*  
 participant 014\_2023AUHIS

*No, my, my family and none of my friends know I have this. Only my husband. He's the only one.*  
 Participant 017\_2023AUHIS

**Table 8.10: Burden on family**

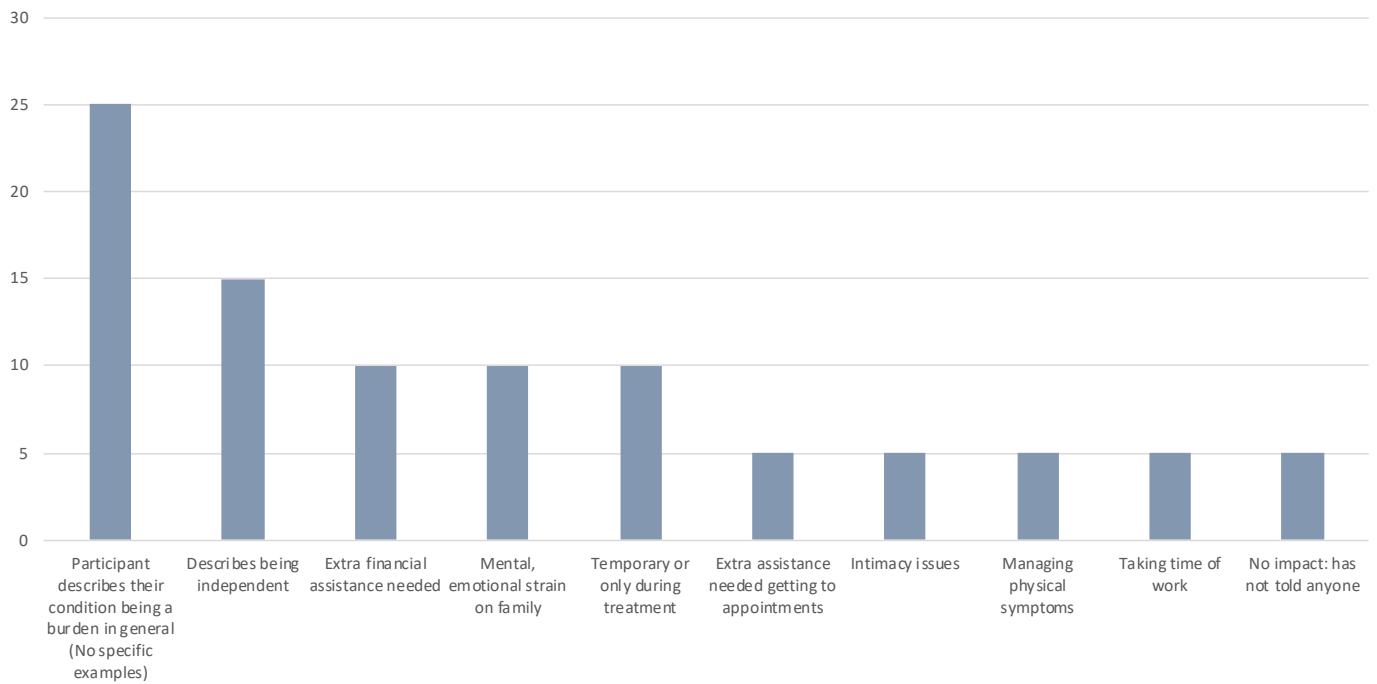
Burden on family	All participants	
	n=20	%
Participant describes that overall, there was a burden on their family	12	60.00
Participant describes that overall, there was not a burden on their family	3	15.00
No particular comment	5	25.00



**Figure 8.10: Burden on family**

**Table 8.11: Burden on family (description)**

Burden on family (reasons)	All participants	
	n=20	%
Participant describes the extra household duties and responsibilities that their family must take on as a burden on their family	5	25.00
Participant describes their condition being a burden in general (No specific examples) as a burden on their family	5	25.00
Participant describes being independent and not a burden on their family	3	15.00
Participant describes the extra financial assistance needed as a burden on their family	2	10.00
Participant describes the mental/emotional strain placed on their family as a burden on their family	2	10.00
Participant describes that the burden on family was temporary or only during treatment	2	10.00
Participant describes the extra assistance needed getting to appointments as a burden on their family	1	5.00
Participant describes the intimacy problems as a burden on their family	1	5.00
Participant describes managing symptoms as a burden on their family	1	5.00
Participant describes needing to take time off work as a burden on their family	1	5.00
Participant describes the that there was no burden on family as they have not told anyone	1	5.00



**Figure 8.11 Burden on family (description)**

### Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. The most common descriptions were that overall, there was at least some cost burden (75.00%), and overall, there was no cost burden (15.00%).

Where participants described a cost burden associated with their condition, it was most commonly in relation to the cost of treatments (including repeat scripts) (65.00%), the cost specialist appointments (50.00%), and needing to take time off work (25.00 %). Other themes included needing a special diet or lifestyle adaptation (15.00%), a family member needing to take time off work (10.00%), the cost of parking and travel to attend appointments (including accommodation) (5.00%), and diagnostic tests and scans (5.00%).

Where participants described no cost burden associated with their condition, it was most commonly in relation to them prioritizing going to work over attending appointments (5.00%), being able to afford all costs (5.00%), and they had no treatment or management (5.00 %).

#### Cost burden in relation to the cost of treatments (including repeat scripts)

*Well, my first appointment with my dermatologist was \$270 and then bandages like for a three pack of the bandages that I get. Is like 11 to \$12.00 which*

*obviously isn't going to last very long. It's expensive and then meds on top of that, yeah.*

*Participant 014\_2023AUHIS*

*PARTICIPANT: Look. Yeah, that's pretty. That's very subjective. I think that question, I think that there's been an overall cost for my son. It's not a financial cost, but it's an educational cost because he has not, you know, you know, in a, you know in the key time of his education he's had, he's taken time off school, his school activities. I think he actually. Got a pretty quick diagnosis. So I don't think that there was that cost there and the cost of the medication well thank God it's on the PBS and he qualified for you know we we qualified for that because he met all the the criteria. I'd like it if it was if we met the criteria to have it like at the the concession card rate because even still at \$30.00 because it and and I like the fact that it's come down. Again. But even at \$30.00 for a month medication, that's a lot for a family. If you, you know to put up it's, you know, it's something he's got to have so it's something he's got to have. But yeah, I if it wasn't covered under the PBS, there's no way we could afford it. Well, we would, you know, I suppose you'd have to make yourself afford it. But it's like, you know, almost. \$1200 a month.*

*INTERVIEWER: That's a non PBS price, right?*

*PARTICIPANT: Non PBS price, yeah.*

*INTERVIEWER: And the PBS price would.*

*PARTICIPANT: Be it's about \$30.00 a month we.*

*INTERVIEWER: Had a concession, yeah.*

*PARTICIPANT: Big difference.*

*INTERVIEWER: Yeah, for sure. Thank goodness for PBS.*

*Participant 009\_2023AUHIS*

### **Cost burden in relation to the cost specialist appointments**

*Well, I mean, I'm on the pension, so medication is generally cheaper, like subsidized for me. But then when the doctors don't want to take my my pension card, it doesn't get subsidized even if I give it to the chemist. And I'm like, well, I'm not paying full price or something when I'm entitled to PBS, like, so that's the only kind of annoying cost I've had to put up with. I just keep going into. I went to a different pharmacy because that was bullcrap, pretty much being told that because I've gone in with that with manuscripts like for my kids, for instance. And they don't provide their pension card because I'm they're on my pension card and they still get PBS. And I'm like, yeah, no, what what? You told me you're trying to get more money out of me, so.*

*Participant 003\_2023AUHIS*

*Yeah, so I did find, I did find the costs were substantial for me on a on a single income the you know this. And as a single parent, there's not a lot of extra. So the yeah. The constant outlay for medications, none of that stuff was like, I don't have a health care card or anything like that. So nothing like that was subsidized and then yeah. Seeing all your specialists, there was always a a significant gap to pay and then I saw as I was lucky that I've been in my job for for a while. So you know over the when I had the surgeries pretty much the six weeks that I needed to take off 3 after surgery I was able to absorb that through my sick leave. I was probably lucky in that sense, but.*

*Participant 007\_2023AUHIS*

*Definitely a cost of even just to see a specialist. You might get a rebate back, but it's still quite expensive to go see the specialist in the first place. Which is the reason why I haven't gone back and in there cost of medication as well. Like it's it's certainly not cheap.*

*Participant 011\_2023AUHIS*

### **Cost burden in relation to needing to take time off work**

*The major cost is because you're treated as a private patient. So every time you go, there's the consultation fee and then the ongoing fee. That was the biggest killer tests. Sometimes they were both billed,*

*sometimes that was out of pocket. Yes, I did have to take off days off work because I couldn't work. Yeah, yeah, every. I think the biggest thing is that all the appointments, it's, it's money, and a lot of it's not covered by Medicare or even your private health insurance. So there's a lot of money being spent upfront.*

*Participant 013\_2023AUHIS*

*Across Yeah, the time off work is really hard. I usually have to try and go back to work as soon as possible after a surgery, which always bites me in the arms, but I'll just deal with it. I was lucky enough to be working at a family wellbeing service that was joined with the medical clinic. So the practice nurse just, you know, she would check my stitches and things like that for me throughout the day just so I could be at work and do my dressing changes there. But yeah, being able to take leave to go to an appointment that I can't afford for the slight chance it might work, it's just not realistic for me.*

*Participant 018\_2023AUHIS*

### **Cost burden in relation to needing to special equipment**

*Yes it's expensive. So I mean look fortunately the the Humira is is affordable but the the bigger cost the bigger cost I I you know impacts things like clothing because that clothing gets ruined and impacts bedding and particularly like when when in the early stages more so just the the cost of dressings and finding the right dressings etcetera. Yeah it was was quite quite costly and quite huge on the condition and even now you know you go buy a dressing that fits in the air and you're paying you know 5 or \$10.00 for one dressing. It's it's yeah. So it it, it, it does have an an impact financially. Participant 001\_2023AUHIS*

*Across I would definitely say there's there's a few. So cost in terms of. Treatment is a big one, so seeing the specialists, I don't have health insurance, so I pay out of pocket to see a specialist, which is roughly \$280 per session with this doctor. My medication costs \$40 a month and you know I have to buy special bras which are very expensive like. Not very expensive, but you know, just constantly having to buy new ones as well that get a bit destroyed because I get puss and blood on them and they get a bit gross and I don't want to wear it so I have to buy new ones. Taking time off work is rare, like I won't normally take time off work for the disease. I just push through and go to work. Just trying to think, even like at home remedies. I'm always buying new creams, powders, things for the*

*bath, antibiotics, stuff like that. I haven't even know how much that would amount to. Over the past 10 years. I've had probably a lot, definitely in the thousands that I've spent on all these different things to try for it.*

*Participant 010\_2023AUHIS*

**Cost burden in needing to special creams, ointments or complementary therapies**

*PARTICIPANT: I currently spend probably say that, like obviously across all of my illnesses, I probably spend close to about \$250 a month on medications and I spend probably twice that on. Dressings which are not covered by the PBS and they're like \$5 each*

*INTERVIEWER: Yes, yes, it adds up in the end, doesn't it? Your cost for the dressings.*

*PARTICIPANT: Dressings is probably my biggest cost*  
*Participant 005\_2023AUHIS*

**Overall, there was no cost burden**

*I don't do time of work. I don't. I forced myself to work all the time like I work full time. I'm even. I even today. I work 300 kilometres from my actual base job and I'm hopped in a car now. And I've just driven back after starting work 7:30 and jumped in the car just before I spoke to you at 6:00 tonight to do a three hour drive and I'll get up tomorrow morning and be at work early tomorrow morning. I have a very slight Dr. hard that I don't not have time off work because of my condition.*

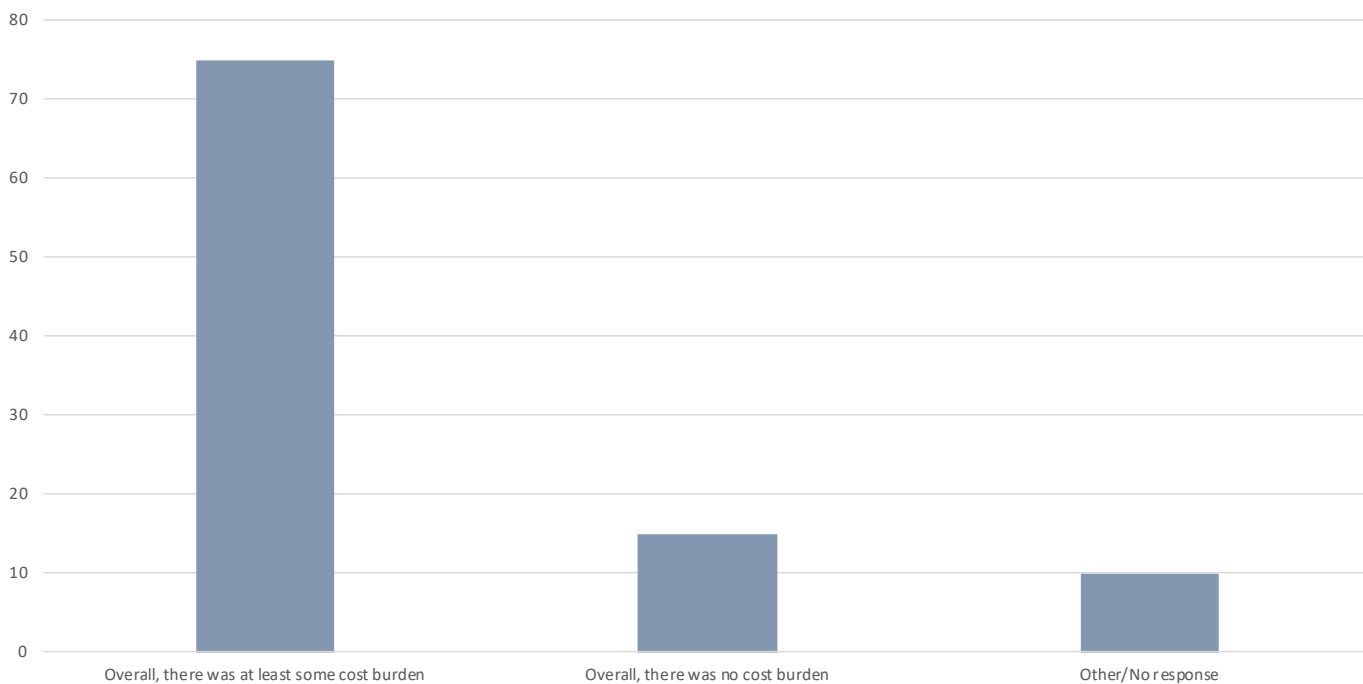
*Participant 018\_2023AUHIS*

*It hasn't been too bad because I haven't had that many treatments. Dermatologist appointments can be quite expensive, but it's it's manageable with me working at the moment. And the Humira injections that I'm about to start are very expensive, but they're on PBS them quite affordably.*

*Participant 019\_2023AUHIS*

**Table 8.12: Cost considerations**

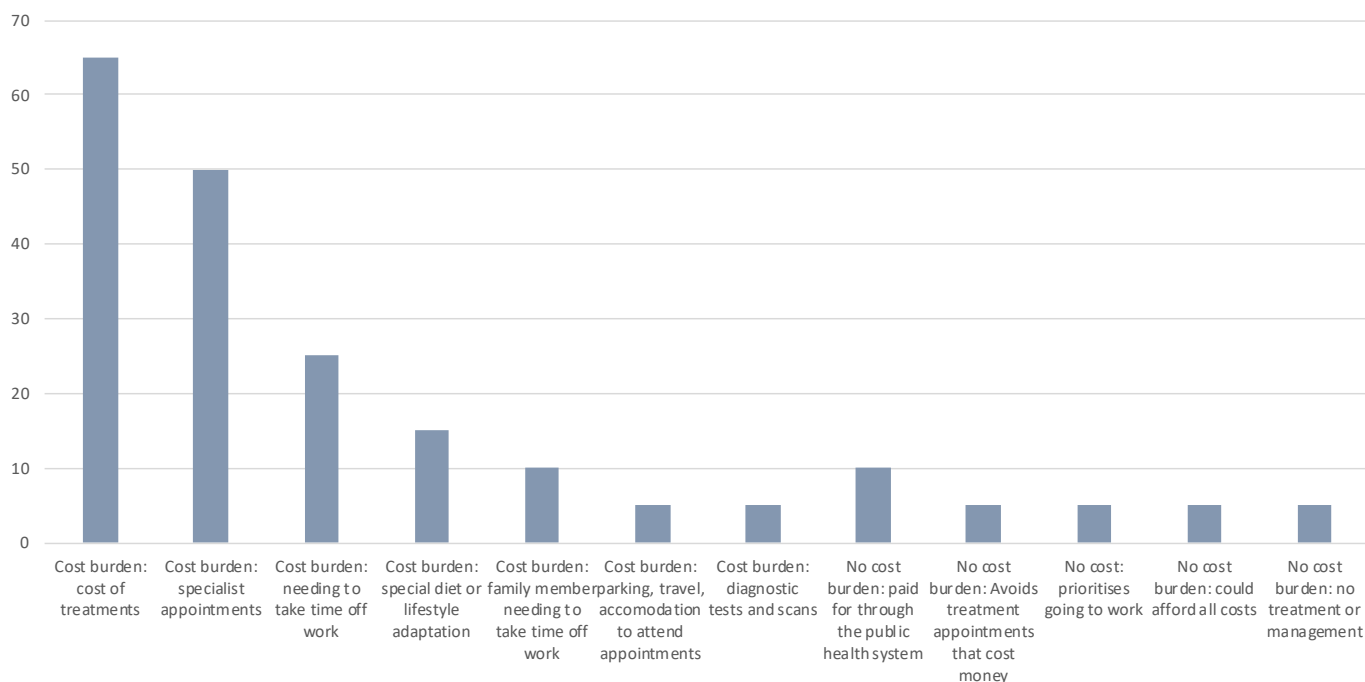
Cost burden	All participants	
	n=20	%
Participant describes that overall, there was at least some cost burden	15	75.00
Participant describes that overall, there was no cost burden	3	15.00
No particular comment	2	10.00



**Figure 8.12: Cost considerations**

**Table 8.13: Cost considerations (Reasons for cost)**

Cost considerations	All participants	
	n=20	%
Cost burden in relation to the cost specialist appointments	10	50.00
Cost burden in relation to needing to take time off work	5	25.00
Cost burden in needing to special creams, ointments or complementary therapies	3	15.00
Cost burden in relation to a family member needing to take time off work	2	10.00
Cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	1	5.00
Cost burden in relation to diagnostic tests and scans	1	5.00
No cost burden and that nearly everything was paid for through the public health system	2	10.00
Avoids treatment appointments that cost money	1	5.00
No cost: prioritises going to work	1	5.00
No cost burden as participant was able to afford all costs	1	5.00
No cost burden as no treatment or management	1	5.00



**Figure 8.13: Cost considerations (Reasons for cost)**

## Experience of anxiety related to disease progression

### Fear of progression

The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their conditions. The Fear of Progression questionnaire comprises a total score, between 12 and 60, with a higher score denoting increased anxiety. Summary statistics for the entire cohort are displayed in Table 8.10. Overall the entire cohort had a mean total score of 36.37 (SD = 9.94), which corresponds to moderate levels of anxiety (Table 8.30)

The overall scores for the cohort were in the second highest quintile for Fear of progression: Total score (mean=44.42, SD=8.69) indicating high levels of anxiety.

The **Fear of Progression** questionnaire measures the level of anxiety people experience in relation to their conditions. On average fear of progression score for participants in this study indicated high levels of anxiety.

**Table 8.14: Fear of progression summary statistics**

Fear of progression (n=20)	Mean	SD	Median	IQR	Possible range	Quintile
Total score*	44.42	8.69	45.00	10.50	12 to 60	4

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

## Experience of anxiety related to disease progression

## Fear of progression individual questions

On average, participants scored in the “Seldom” range for the following questions: “Anxious if not experiencing any side effects think it doesn’t work” (median=2.00, IQR=2.00).

On average, participants scored in the “Sometimes” range for the following questions: “Afraid of pain” (median=3.00, IQR=1.50), “When anxious, has physical symptoms such as a rapid heartbeat, stomach ache or agitation” (median=3.00, IQR=2.50), “Is disturbed that they may have to rely on strangers for activities of daily living” (mean=3.37, SD=1.21), “Afraid of severe medical treatments during the course of illness” (median=3.00, IQR=1.50), “If a treatment and it is working well (limited side effects, no progression of disease), worry what will happen if treatment stopped” (median=3.00, IQR=2.00).

On average, participants scored in the “Often” range for the following questions: “Becomes anxious thinking that disease may progress” (median=4.00, IQR=2.00), “Is nervous prior to doctors appointments or periodic

examinations” (median=4.00, IQR=2.00), “Has concerns about reaching professional and/or personal goals because of illness:” (median=4.00, IQR=2.00), “The possibility of relatives being diagnosed with this disease disturbs participant” (median=4.00, IQR=1.00), “Worried that at some point in time will no longer be able to pursue hobbies because of illness” (median=4.00, IQR=2.00), “Worried that treatment could damage their body” (median=4.00, IQR=2.00), “Worried about what will become of family if something should happen to participant” (median=4.00, IQR=2.00).

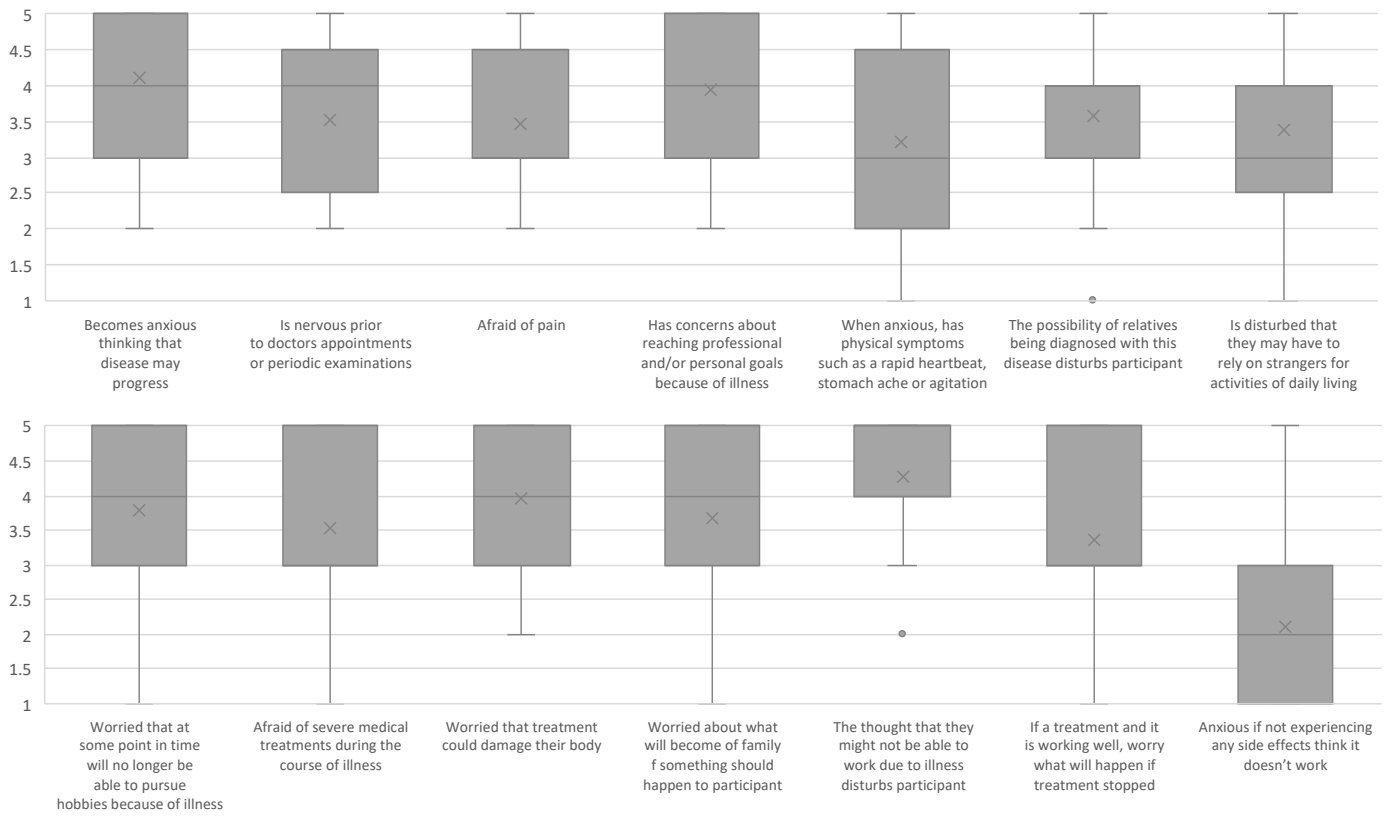
On average, participants scored in the “Very often” range for the following questions: “The thought that they might not be able to work due to illness disturbs participant” (median=5.00, IQR=1.00).

The **Fear of Progression** questionnaire measures the level of anxiety people experience in relation to their conditions. On average fear of progression score for participants in this study indicated high levels of anxiety.

**Table 8.15: Fear of progression individual questions**

Fear of progression (n=20)	Mean	SD	Median	IQR	Average response
Becomes anxious thinking that disease may progress	4.11	0.99	4.00	2.00	Often
Is nervous prior to doctors appointments or periodic examinations	3.53	1.17	4.00	2.00	Often
Afraid of pain	3.47	1.12	3.00	1.50	Sometimes
Has concerns about reaching professional and/or personal goals because of illness:	3.95	1.13	4.00	2.00	Often
When anxious, has physical symptoms such as a rapid heartbeat, stomach ache or agitation	3.21	1.44	3.00	2.50	Sometimes
The possibility of relatives being diagnosed with this disease disturbs participant	3.58	1.07	4.00	1.00	Often
Is disturbed that they may have to rely on strangers for activities of daily living*	3.37	1.21	3.00	1.50	Sometimes
Worried that at some point in time will no longer be able to pursue hobbies because of illness	3.79	1.08	4.00	2.00	Often
Afraid of severe medical treatments during the course of illness	3.53	1.17	3.00	1.50	Sometimes
Worried that treatment could damage their body	3.95	1.08	4.00	2.00	Often
Worried about what will become of family if something should happen to participant	3.68	1.29	4.00	2.00	Often
The thought that they might not be able to work due to illness disturbs participant	4.26	1.05	5.00	1.00	Very often
If a treatment and it is working well (limited side effects, no progression of disease), worry what will happen if treatment stopped	3.37	1.50	3.00	2.00	Sometimes
Anxious if not experiencing any side effects think it doesn't work	2.11	1.37	2.00	2.00	Seldom

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



**Figure 8.14: Fear of progression individual questions**