

Section 8 Quality of life

Section 8: Experience of quality of life

Quality of life

- In the questionnaire, participants were asked to indicate which symptoms they had experienced and then rate their quality of life while experiencing those symptoms. The most common symptom experienced by nearly all participants (n=93, 93.00%) was raw, sensitive, swollen skin from scratching followed by thickened, cracked, dry scaly skin (n=89, 89.00%), itching which is uncomfortable but reasonably controlled (n=88, 88.00%), small, raised bumps, which may leak fluid and crust (n=87, 87.00%) and red to brownish-grey patches (n=82, 82.00%).
- Across all symptoms experienced, the average number of symptoms that participants experienced increased with severity of AD. The average number of symptoms experienced by the total cohort was 6.52, for mild AD it was 4, for moderate AD it was 6.12 for severe AD it was 7 and for very severe AD it was 7.36 symptoms per participant.
- As a follow-up question, participants were asked to rate their quality of life while experiencing symptoms on a scale of 1 to 7 where 1 is life was very distressing and 7 is life was good. All symptom mean scores were within the 'life was very distressing' to 'life was a little distressing' range. The symptom that scored the poorest quality of life was sores that may become infected by bacteria or viruses (1.91), followed by itching which is severe and not controlled (2.00), regular sleep disturbance (2.35), and raw, sensitive, swollen skin from scratching (2.62). The symptoms that scored the highest in relation to quality of life were itching, which is uncomfortable but reasonably controlled (3.53) and red to brownish-grey patches (3.04).
- In the structured interview, participants were asked how their condition affect their quality of life. The most common theme noted by close to half of all participants (n=43, 43.00%) was that AD caused a significant impact in relation to self-esteem and confidence. Participants also spoke about this leading to social isolation. This was followed by an impact on relationships with family and friends (n=31, 32.00%). There were 28 participants (28.00%) that noted that there was a significant impact in relation to not being able to work and 24 participants (24.00%) that described not being able to do everyday activities. Other themes that emerged included participants feeling as though quality of life was good now, but not when they were younger (n=24, 24.00%) and the impact of itchiness on quality of sleep (n=22, 22.00%).
- There were three sub-group variations. Participants with mild AD reported the impact on self-esteem and confidence less frequently than the general cohort (9.09% compared to 43.00%). They also did not describe the impact on relationships at all (0.00% compared to 32.00% in the general cohort) and this sub-group described the impact on being able to work less frequently (9.09% compared to 28.00% in the general cohort).
- The theme of impact on sleep was further explored with a prompted question that asked whether AD affected their sleep and the implications of this. There were 41 participants (41.00%) that described AD having an impact on sleep and this primarily referred to itchiness. The next most common theme (n=28, 28.00%) was restlessness and agitation throughout the night to manage their AD. There were 19 participants (19.00%) that described heat affecting their AD and therefore their sleep and 14 participants (14.00%) described not being able to function properly following poor sleep.

Regular activities to maintain health

- Participants were asked what they considered to be some of the things that they needed to do regularly to maintain their health? There were 87 participants (87.00%) that described a daily routine of applying creams (moisturisers, QV cream, steroid cream), this was followed by needing to avoid some types of food (dairy, gluten etc.) or change their diet (n=24, 24.00%), needing to preventing skin from drying (n=17, 17.00%), needing to avoid getting too hot/cold to control eczema (n=16, 16.00%), and taking medicine as part of daily routine (n=15, 15.00%).
- There were a number of sub-group variations. Participants with mild AD reported having a daily routine of moisturizers less frequently than the general cohort (63.64% compared to 87.00% in the general cohort). Participant with moderate AD reported needing to avoid certain foods less frequently than the general cohort (11.54% compared to 24.00% in the general cohort) while participants with severe AD reported this more frequently (36.59% compared to 24.00% in the general cohort).

- As a follow-up question, participants were asked what their usual routine was for showering and getting ready in the morning. In answering this question, some participants spoke about the time required, which was anywhere between 20 minutes to over one hour, while other participants spoke about the routine that they needed to adhere to in order to get ready each day. Another key theme described by 10 participants (10.00%) was that AD had a significant impact on relationships in relation to self-esteem and confidence/being embarrassed.

Impact on relationships

- Participants were asked whether their condition has had an impact on personal relationships with family and friends. There was a reasonably even response with 53 participants (53.00%) describing no impact, or limited impact while they were managing flares, and 47 participants (47.00%) stating that there was a significant impact. Where there was an impact, the most common challenge described (n=16, 16.00%) was a significant impact on relationships with their family member, specifically intimacy with their partner. The next most common theme was a significant impact on quality of life in relation to becoming isolated/not being able to go out and be social (n=12, 12.00%).
- There were two sub-group variations. Participants with mild AD reporting having no impact on their relationships less frequently than the general cohort (81.81% compared to 53.00% in the general cohort). They also described having a significant impact on relationships less frequently (18.18% compared to the general cohort).
- As a follow-up question, participants were asked whether they felt their condition had resulted in any additional burden on their family. Half of all participants (n=50, 50.00%) described not needing any additional assistance. These participants spoke about being independent and being able to manage their condition themselves. There were 16 participants (16.00%) that described AD being a burden on their family and this was primarily in relation to needing additional assistance or the additional financial burden to their family. Another theme that emerged was that participants felt as though AD was not a burden now, but that it was when they were younger (n=12, 12.00%). There were also an additional 10 participants that specifically spoke about needing and appreciating the assistance and care that was provided to them by their mother (10.00%).
- There were a number of sub-group variations. Participants with moderate AD reported not needing any additional assistance more frequently than the general cohort (65.38% compared to 50.00% in the general cohort). Participants with mild AD reported not needing assistance now, but needing assistance in earlier life, more frequently than the general cohort (36.36% compared to 12.00%).

Anxiety and 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, with a higher score denoting increased anxiety. Overall the entire cohort had a median total score of 28.00, which is a score in the second lowest quintile indicating a small amount of fear.
- Those with very severe disease had a greater fear of progression compared with those with mild, moderate or severe disease.
- Those with comorbid depression and anxiety had a greater fear of progression compared to those without.

Experience of quality of life: symptoms experienced

In the questionnaire, participants were asked to indicate which symptoms they had experienced and then rate their quality of life while experiencing those symptoms. The most common symptom experienced by nearly all participants (n=93, 93.00%) was raw, sensitive, swollen skin from scratching followed by thickened, cracked, dry scaly skin (n=89, 89.00%), itching which is uncomfortable but reasonably controlled (n=88, 88.00%), small, raised bumps, which may leak fluid and crust (n=87, 87.00%) and red to brownish-grey patches (n=82, 82.00%).

Across all symptoms experienced, the average number of symptoms that participants experienced increased with severity of AD. The average number of symptoms experienced by the total cohort was 6.52, for mild AD it was 4, for moderate AD it was 6.12 for severe AD it was 7 and for very severe AD it was 7.36 symptoms per participant.

Table 8.1: Quality of life

Symptoms experienced	Total Participants		Mild Atopic Dermatitis		Moderate Atopic Dermatitis		Severe Atopic Dermatitis		Very Severe Atopic Dermatitis	
	n=100	%	n=11	%	n=26	%	n=41	%	n=22	%
Raw, sensitive, swollen skin from scratching	93	93.00	8	72.72%	25	96.15	38	92.68	22	100
Thickened, cracked, dry, scaly skin	89	89.00	6	54.54	23	88.46	39	95.12	21	95.45
Itching, which is uncomfortable but reasonably controlled	88	88.00	10	90.90	24	92.31	37	90.24	17	77.27
Small, raised bumps, which may leak fluid and crust over	87	87.00	6	54.54	23	88.46	37	90.24	21	95.45
Red to brownish-grey patches	82	82.00	7	63.63	23	88.46	33	80.49	19	86.36
Regular sleep disturbance	75	75.00	3	27.27	16	61.54	35	85.37	21	95.45
Itching, which is severe and not controlled	73	73.00	3	27.27	11	42.31	38	92.68	21	95.45
Sores (lesions) that may become infected by bacteria or viruses.	65	65.00	1	9.09	14	53.85	30	73.17	20	90.90

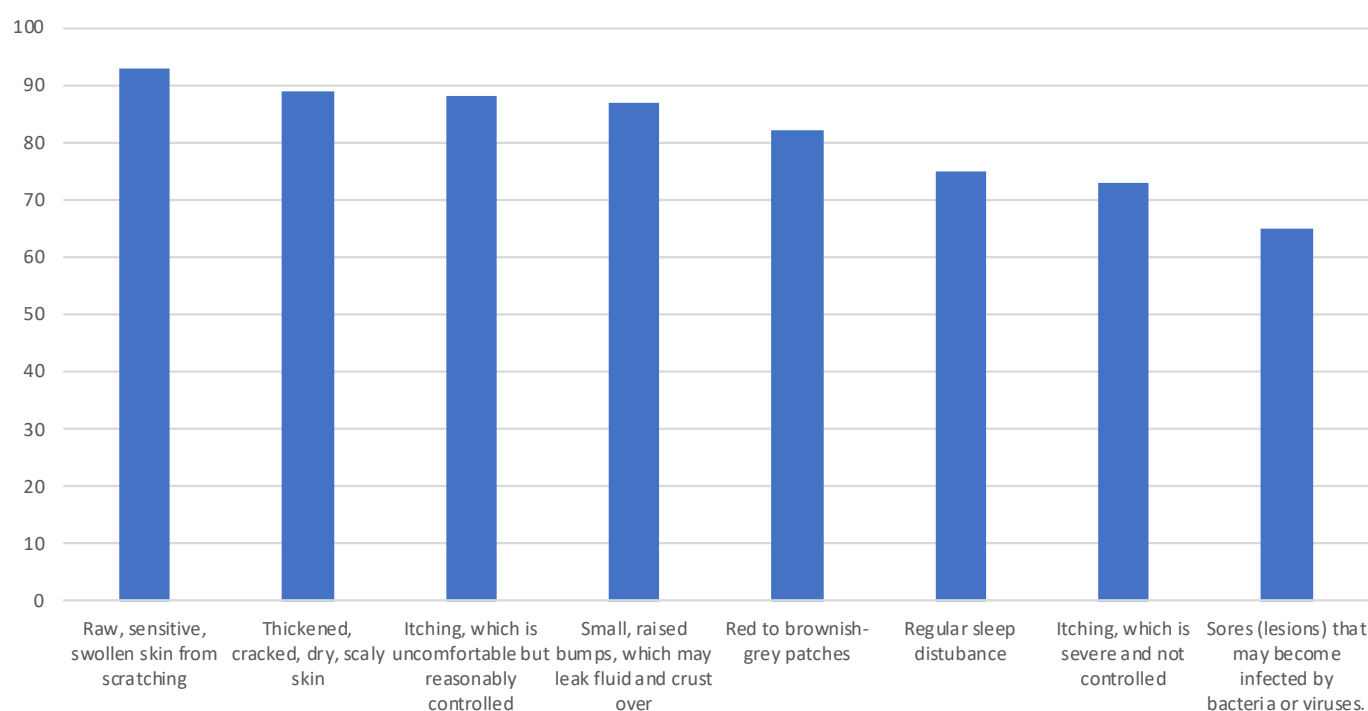


Figure 8.1: Quality of life (% of all participants)

Table 8.2: Number of symptoms per participant (Mean)

Symptoms experienced	Total Participants		Mild Atopic Dermatitis		Moderate Atopic Dermatitis		Severe Atopic Dermatitis		Very Severe Atopic Dermatitis	
	n=100	Mean	n=11	Mean	n=26	Mean	n=41	Mean	n=22	Mean
Total no. of symptoms experienced per participant	652	6.52	44	4.00	159	6.12	287	7.00	162	7.36

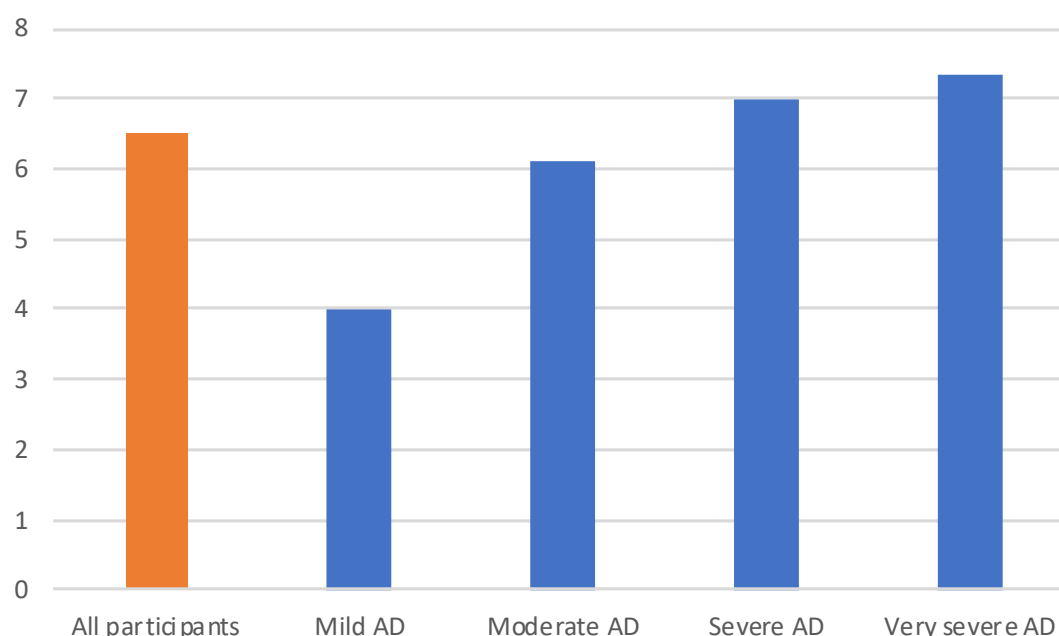


Figure 8.2: Number of symptoms per participant (Mean)

Quality of life while experiencing symptoms

As a follow-up question, participants were asked to rate their quality of life while experiencing symptoms on a scale of 1 to 7 where 1 is life was very distressing and 7 is life was good. All symptom mean scores were within the 'life was very distressing' to 'life was a little distressing' range. The symptom that scored the poorest quality of life was sores that may become

infected by bacteria or viruses (1.91), followed by itching which is severe and not controlled (2.00), regular sleep disturbance (2.35), and raw, sensitive, swollen skin from scratching (2.62). The symptoms that scored the highest in relation to quality of life were itching, which is uncomfortable but reasonably controlled (3.53) and red to brownish-grey patches (3.04).

Table 8.3: Quality of life while experiencing symptoms

Symptoms at diagnosis		Range	Mean QoL score	Life was very distressing (Score = 1)		Life was distressing (Score = 2)		Life was a little distressing (Score = 3)		Life was average (Score = 4)		Life was good (Score = 5)		Life was very good (Score = 6)		Life was great (Score = 7)	
	n=	Range	Mean	n=	%	n=	%	n=	%	n=	%	n=	%	n=	%	n=	%
Sores (lesions) that may become infected by bacteria or viruses.	65	1 (min) – 5 (max)	1.91	25	38.46	26	40.00	11	16.92	1	1.54	2	3.08	0	0.00	0	0.00
Itching, which is severe and not controlled	73	1 (min) – 6 (max)	2.00	29	39.73	23	31.51	16	21.92	3	4.11	1	1.37	1	1.37	0	0.00
Regular sleep disturbance	75	1 (min) – 6 (max)	2.35	22	29.33	23	30.67	17	22.67	9	12.00	3	4.00	1	1.33	0	0.00
Raw, sensitive, swollen skin from scratching	93	1 (min) – 7 (max)	2.46	28	30.11	23	24.73	24	25.81	11	11.83	4	4.30	2	2.15	1	1.08
Small, raised bumps, which may leak fluid and crust over	87	1 (min) – 6 (max)	2.62	17	19.54	27	31.03	22	25.29	15	17.24	5	5.75	1	1.15	0	0.00
Thickened, cracked, dry, scaly skin	89	1 (min) – 7 (max)	2.79	16	17.98	23	25.84	25	28.09	16	17.98	8	8.99	0	0.00	1	1.12
Red to brownish-grey patches	82	1 (min) – 6 (max)	3.04	10	12.20	22	26.83	21	25.61	16	19.51	10	12.20	3	3.66	0	0.00
Itching, which is uncomfortable but reasonably controlled	88	1 (min) – 6 (max)	3.53	6	6.82	6	6.82	30	34.09	30	34.09	13	14.77	3	3.41	0	0.00

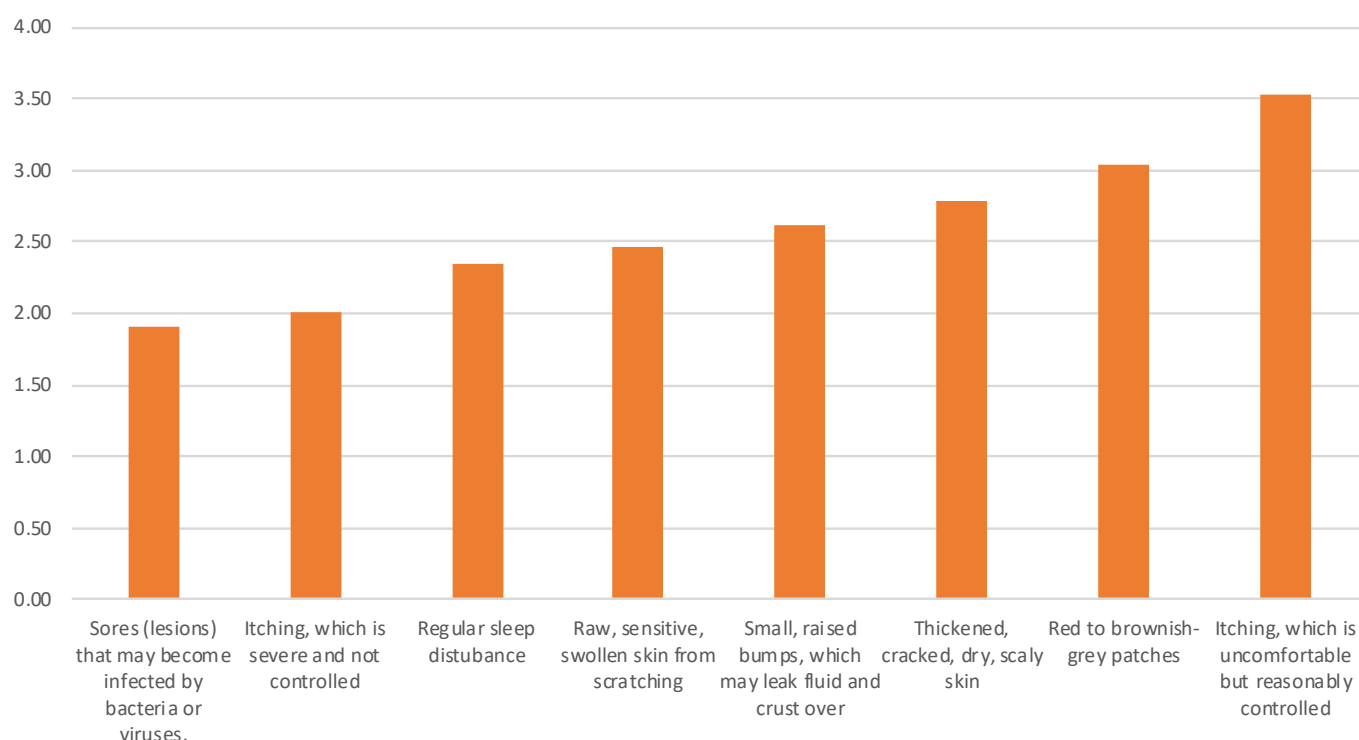


Figure 8.3: Quality of life while experiencing symptoms

Quality of life

In the structured interview, participants were asked how their condition affect their quality of life. The most common theme noted by close to half of all participants (n=43, 43.00%) was that AD caused a significant impact in relation to self-esteem and confidence. Participants also spoke about this leading to social isolation. This was followed by an impact on

relationships with family and friends (n=31, 32.00%). This theme included participants feeling as though they were not able to do all of the activities that they would like to with their family and also challenges in relation to being intimate with their partner. There were 28 participants (28.00%) that noted that there was a significant impact in relation to not being able to work and 24 participants (24.00%) that described not being able to do everyday activities. Other themes that

emerged included participants feeling as though quality of life was good now, but not when they were younger (n=24, 24.00%) and the impact of itchiness on quality of sleep (n=22, 22.00%). There were three sub-group variations. Participants with mild AD reported the impact on self-esteem and confidence less frequently than the general cohort (9.09% compared to 43.00%). They also did not describe the impact on relationships at all (0.00% compared to 32.00% in the general cohort) and this sub-group described the impact on being able to work less frequently (9.09% compared to 28.00% in the general cohort).

There were two sub-group variations. Participants with mild AD reported itch affecting their sleep less frequently than the general cohort (27.27% compared to 41.00% in the general cohort). They also reported having no impact on sleep more frequently than the general cohort (27.27% compared to 12.00% in the general cohort).

Table 8.4: Impact on quality of life

	Total Participants (n=100)		Mild Atopic Dermatitis (n=11)		Moderate Atopic Dermatitis (n=26)		Severe Atopic Dermatitis (n=41)		Very Severe Atopic Dermatitis (n=22)	
Participant describes a significant impact on quality of life in relation to self esteem and confidence and isolation (feeling embarrassed)	43	43.00	1	9.09	14	53.85	19	46.34	9	40.91
Participant describes a significant impact on quality of life in relation to relationships with their family (children, Intimacy with partner)	32	32.00	0	0.00	7	26.92	15	36.59	10	45.45
Participant describes a significant impact on quality of life in relation to work (not being able to work or not being able to do a specific work activity)	28	28.00	1	9.09	7	26.92	15	36.59	5	22.73
Participant describes impact of eczema during a flare as significant impact on quality of life, not being able to do everything they need to do	24	24.00	2	18.18	11	42.31	7	17.07	4	18.18
Participant describes the significant impact of being itchy including its impact on sleep	22	22.00	3	27.27	3	11.54	9	21.95	7	31.82
Participant describes eczema as having minimal impact on the quality of life of themselves and family members	14	14.00	4	36.36	8	30.77	2	4.88	0	0.00
Participant describes minimal impact on quality of life now however eczema severely impacted their quality of life as a child	11	11.00	3	27.27	6	23.08	2	4.88	0	0.00

	Total Participants (n=100)		Mild Atopic Dermatitis (n=11)		Moderate Atopic Dermatitis (n=26)		Severe Atopic Dermatitis (n=41)		Very Severe Atopic Dermatitis (n=22)	
Participant describes a significant impact on quality of life in relation to self esteem and confidence and isolation (feeling embarrassed)	43	43.00	1	9.09	14	53.85	19	46.34	9	40.91
Participant describes a significant impact on quality of life in relation to relationships with their family (children, Intimacy with partner)	32	32.00	0	0.00	7	26.92	15	36.59	10	45.45
Participant describes a significant impact on quality of life in relation to work (not being able to work or not being able to do a specific work activity)	28	28.00	1	9.09	7	26.92	15	36.59	5	22.73
Participant describes impact of eczema during a flare as significant impact on quality of life, not being able to do everything they need to do	24	24.00	2	18.18	11	42.31	7	17.07	4	18.18
Participant describes the significant impact of being itchy including its impact on sleep	22	22.00	3	27.27	3	11.54	9	21.95	7	31.82
Participant describes eczema as having minimal impact on the quality of life of themselves and family members	14	14.00	4	36.36	8	30.77	2	4.88	0	0.00
Participant describes minimal impact on quality of life now however eczema severely impacted their quality of life as a child	11	11.00	3	27.27	6	23.08	2	4.88	0	0.00

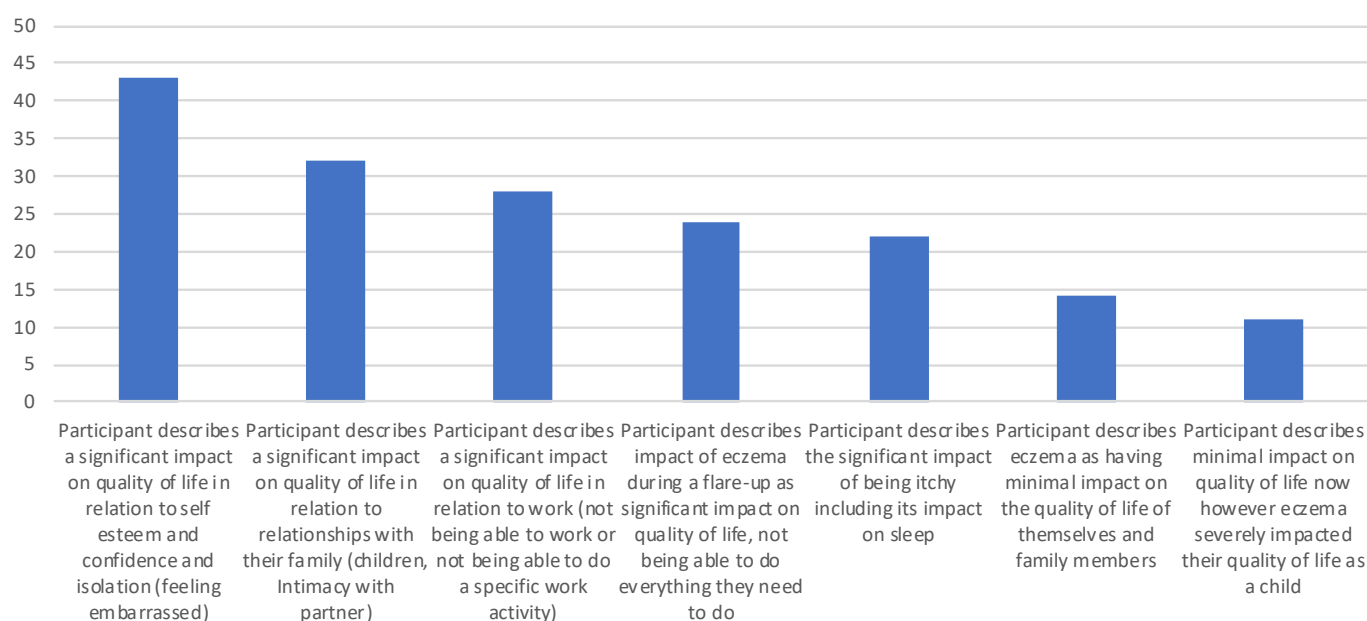


Figure 8.4: Impact on quality of life

Participant describes a significant impact on quality of life in relation to self-esteem and confidence and isolation (feeling embarrassed)

*Yeah, I think it's probably contributed to some of my feelings of anxiety and to some degree to social withdrawal or certain limitations on those sort of things. It certainly got me off being involved in sport and that sort of thing, and so some of the sort of the social situations in life have probably been restricted by the eczema. So, I think some of it's probably personal problems as well, but it did, at school, it kind of made me fairly reserved, and I was probably a reserved type of character anyway, butwe they tend to impact on each other. One is just a symptom of the other, or what. But certainly it caused me to lose sleep, but I've had situation where that's become quite problematic. And it just leads to a lack of confidence in whatever I'm trying to tackle in life, and it undermines self-esteem, I feel, a bit, and those sort of things are of great concern. **Participant 62***

It was really embarrassing to go to Mums groups because I have to say to everyone, "I'm sorry, I'm not contagious, it's okay. It's just eczema." It looks awful. It was quite confronting so people haven't seen that before to look at and so it was embarrassing to just have to tell everyone, "Sorry, no it's eczema." Even going to the supermarket and handing over your part of your money or something like that, I found I was hiding my hands a lot just because I looked so awful. Then it could-- It stressed me out too because I've got open sores on my hand and I'm trying not to get them infected. Because I didn't want to wait patiently but I

*also didn't want to-- I just open my hands up. gladly for infection. It was quite stressful and awful. I'm really happy that my hands are covered. It's made a really big difference. It's worrisome from an infection point of view. It's also quite embarrassing, on a social point of view, because you look awful. It does, it hurts. **Participant 63***

*It cripples me, I can't even take my daughter to school, she gets picked up, she's like five, yet I can't take her to school because some days I can't feel my legs it's very embarrassing and when I got to go out I have to use a taxi. I can't often get the bus, I have to go upstairs or something. I tend to walk, well really quickly to get it done because I'm very embarrassed, of my appearance. People look like when they see you if you're out at a restaurant or shopping, or whatever and they see, your hands and sores all over the arms, people tend to shy away or judge. I actually wanted to make a t-shirt up that said, "It's DESCRIPTIVE WORD eczema," You know what I mean? They don't know how bad it affected me, really badly. Emotionally, physically and mentally, all three, it's a crippling thing. Even if I just have a little bit on the hands but mine's worse off from face my hands, there's sores all over my hands, bad and very, very embarrassing. Lately, I was thinking why don't you go to that beautiful hands, but you don't feel it. The weight gains in the Cortisone. It's so very upsetting, even talk about. **Participant 89***

Participant describes a significant impact on quality of life in relation to relationships with their family

*It definitely takes its toll when it's bad and it's something that I'm already ... Especially my Mum, she still feels, like if my skin's itchy, it probably almost brings, like, flashbacks for her of how bad I used to be as a child. So, I know it has affected her. And, even my brother as well and my husband. You know, they have almost ... You know they're very concerned. And it sort of has taken a toll in that way, where it's this thing that almost makes life stop for a little period of time. Because, if I'm really bad I don't want to do anything. I just want to wrap myself up in bed and not be around anybody or speak to anybody. Especially if it breaks out on my face and I have really bad rashes. You know you don't want to go outside, you don't want to see anybody. **Participant 18***

*It does it impact it a lot actually. I feel like I'm kind of not there for my kids at certain times because it will hurt my skin. I've been in tears while I was trying to breastfeed my children before because my skin was aching that much. Because their skin was touching mine. I feel like I have to pull back from a lot of people because they feel like they can't touch me. I can't do a lot of normal things. Like, just to go for a swim and places without having to lather yourself up with barrier creams first. Just so, actually, your skin doesn't hurt. I've got fair skin and I need sunscreen. And trying to find sunscreen that doesn't interact your eczema, it's really difficult. **Participant 51***

Well let's just say we are a family that doesn't have eczema, we are a family that is eczema. Our entire daily routine is based around my health and it breaks my heart that some days my kids can't hug me and I have to say to them you can keep this hug, I can't today sorry. I'm sorry, I'm getting emotional. Having to constantly feel like a burden on my husband because he is my carer. I need him to do so much for me both as just a co-parent but also with creams and, obviously I can't see my own back to see where I need creams and things and he has to do all sorts of things for me when I'm just too sore or too sick to do anything. And our ability to go anywhere or do anything is also highly affected. At times, I've had to say no to my children, you're just gonna have to sit in front of the TV again or here's some more colouring in and they're begging to go to the park but I can't leave the house because I'm just in too much discomfort. I can't see because my eyes are so swollen. Yeah. It's everyday so that's why I now feel bad because yes I can have a hug with my child today, I'm not frightened of they're here tickling my face or of them climbing on me and splitting my skin

because it's so raw. So, a five year old saying 'can I hug you today mummy?'. And being allergic to my own lounge... To put a sheet over my lounge to sit on it because the chemicals they put in the fabric to clean it or to waterproof it, I react to something inside.

Participant 90

Participant describes impact of eczema during a flare-up as significant impact on quality of life, not being able to do everything they need to do

*I guess, so then when you have is when it affects your quality of life. And I guess it depends on how severe the outbreak is as to how much it affects them. If you're wanting to get a coat hanger and stuff it down the back of your shirt and scratch the beezers out of your back, and what you've got is that itch, and wanting to scratch and itch her and nothings gonna take the itch away. I have to say, that probably then, quite significantly impacts on the quality of life. But, yeah, mostly around flare ups and how bad. Like, I can get minor flare up. You might have more discomfort for a day or two, and then it's gone. I do feel sorry for those people who've got more extreme eczema, who have it all the time because that must be most unbearable to live with, I have to say. Because, to me, when it's bad on my back, it means you don't feel comfortable laying down or you're lying there wanting to itch and scratch. So, sometimes it does make getting off to sleep a bit more difficult when you just want to scratch. **Participant 8***

*I wouldn't say it plays a big part when it's on the down times but when it's flared up it can be quite hard to do a lot of things, because it is my hands. Even just holding the steering wheel, when I'm driving, can be quite painful and then when it cracks and everything. That's probably two or three days that it's quite hard to deal with. It doesn't really have an impact on my family they just ignore me when I complain. **Participant 29***

*With the eczema being on my feet. If I have a flare-up, I can barely walk some days. I have not worn a pair of shorts, probably, all my adult life. I can't take my kids to the beach because I can't walk on the sand. Even running with the kids because it will break open. It would stretch my skin and all the eczema will break open. **Participant 84***

Participant describes minimal impact on quality of life now however eczema severely impacted their quality of life as a child

It has very much affected my quality of life in my younger years growing up. Now I'm older, it's not so bad, I can manage it. But, I've married to my husband

for 27 years and he doesn't know what it's like to be with someone with normal skin, so. He's just used to flaking feet and I think having a very understanding partner is so important. But, I don't really know any different, because I've had it my whole life, so. But that definitely affects quality of life, I mean people stare at you. When it's really bad, you get stared at. Because it's not acne or anything like that, people feel the need to talk to you about it all the time, and that was really hard growing up. Yeah. Or "What's on your face," or those kind of comments. **Participant 28**

As a child, yes for sure, because they've always got to get all of these treatment done and they're very mindful of where we go, because of the skin flare ups and because like in summertime you don't want to wear dresses and stuff like that. It just impacts on how you feel about your body and yourself. Yeah. And then when you're out and about, people judge you for it. Like you don't have the chance to be carefree about what you wear because that will make me really conscious about it. But the time when it's summer or spring I'm so conscious. I'll wear leggings and will have long sleeves on, because it got to that point when it's really red. I remember one time I went out with a dude and the guy's like, "What's wrong with your legs?" I was like, "Oh". I had covered it up with make up and that really wasn't a good idea with stockings. So yeah, I'm just a bit conscious about it, with the effects it has. **Participant 21**

In my younger years I suffered quite a bit to the extent that my skin used to bleed badly. We used to change

the sheets very often. I never wear white shirts because I bleed that kind of stuff. I'm lucky that now I don't bleed like I used to but there is still a little bit here and there it's hard to tell sometimes. **Participant 52**

Participant describes the significant impact of being itchy including its impact on sleep

When it's bad, I suffer from it quite a lot. More at night, in the heat so when it's hot, so when I was sleeping in the like flannelette and warmer, like the heat affects it. So probably at night I'm affected more. It affects my sleep. It affects my husband, cause I'm up like scratching, and irritated. **Participant 27**

It is with sleep, because you're scratching at night. The ointment that you have to wear ... the cortisone ointment that I use stains the sheets, and it stains the clothes, and I find that annoying. The constant itch certainly impacts on your day to day functioning. I don't know how that impacts my family at all. **Participant 44**

I just got to a stage where it's just so much easier to stay home. And because I was taking medication, I'd go to bed and then I'd think I haven't done paperwork. I'm so far behind in this. I'm so far behind in that. That would start making me itch because I would start getting stressed. Basically, they have no medication to take myself so that I could actually sleep. I would be waking up. One night I woke up at 2:30 and I itched for an hour. I just sat there and I cried and I cried. I itched and I itched. I got to the point that then I just got cold towels because my skin was weeping. **Participant 86**

The theme of impact on sleep was further explored with a prompted question that asked whether AD affected their sleep and the implications of this. There were 41 participants (41.00%) that described AD having an impact on sleep and this primarily referred to itchiness:

*It definitely does if it's quite bad, but that's fairly rare occurrence. It definitely does if I'm having a flare-up and night time can be when the itching is the worst, and that can definitely mean a bad night sleep. That can mean you feel crappy the next day basically. Tired and sore if you've been scratching yourself to bits the night before. **Participant 22***

*Yes it does, actually. Lately, I've had a bit of a flare up on my neck and I'll just wake up in the middle of the night and I'm just scratching and I don't even know. It's going to wake me up, because it is so itchy. Yes, that's been several times in the past few weeks, few months, that I've woken myself up and I can't get back to sleep and that does affect your day at work, the next day. **Participant 38***

*It was pretty awful. I have always been a really good sleeper. During a flare up it was awful. I'd wake up and I usually didn't have trouble getting to sleep but staying asleep was an issue. I'd wake up multiple times scratching. Often there'd be little bits of blood on the bed or whatever in the morning and that I've been unaware of so obviously. My partner said that there are times that he'd have to wake me up and tell me to stop scratching because I'd be scratching in my sleep. **Participant 72***

The next most common theme (n=28, 28.00%) was restlessness and agitation throughout the night to manage their AD:

*It certainly can do. For example, last night I was woken up by heat, and itchiness and being uncomfortable probably about six or seven times last night, so that means today I'm feeling washed out and tired. **Participant 33***

It really does because, I mentioned earlier, my husband will hear me scratching at night and he will sometimes have to stop me by waking me up and just say, "Look, stop. You're scratching yourself to death. You've got to stop this." And again, I'll fall back to sleep and I'll start itching again because I don't realise I'm doing it and, I've worn gloves to bed before to try and stop my being able to break the skin and that often causes, the next day I'm obviously tired and he's tired as well and again

*it causes that stress, that crankiness as well. **Participant 66***

*Yes, it does....you might get four hours sleep once daylight comes. You can't go to sleep at night, because your cortisol are all shot. They go through the roof, and you sweat. If you sweat, the evaporating sweat makes you itch more. You're up and down in bed, and what have you all night. You might sleep once daylight comes because you're exhausted by then. **Participant 82***

There were 19 participants (19.00%) that described heat affecting their AD and therefore their sleep and 14 participants (14.00%) described not being able to function properly following poor sleep:

Participant describes their sleep being affected due to the heat

*Oh my sleep. At the moment it's alright. But if it's a really, really hot day, like today is a hot day in [METROPOLITAN CITY]. I have like no sleep. But I think currently it's okay, because I always have the fan or the air con on. And I'll just have shower prior to, because then I'm more cool. Yeah. **Participant 21***

*If I'm having a flare up I might be going through a period of having a lot of difficulty where I'll wake through the night and I'll be really hot and can't sleep and just... but I would just scratch in my sleep generally, while I was asleep, and probably annoy the hell out of my partner. But he sleeps really well. So, for him to say to me, "I hate hearing you scratch." And also, it's horrible because I drop a lot of skin and stuff if I'm going through different phases, and I'm self conscious, like in the car, or some black, you can't wear dark clothing or stuff like that. **Participant 53***

*Yep. It does affect my sleep because if my hands get too hot, I scratch and all that sort of stuff. **Participant 2***

Participant describes not being able to function after not sleeping

*I must say, it probably affects more interrupted sleep. You've got that itch and you just can't get it calmed down. I probably wasn't getting much sleep, and I guess, yeah, you are affected the next day if you haven't slept. As well as, not as much as you normally would. Yeah, so it does affect sleep. **Participant 8***

Sometimes I'll often wake myself up scratching my hands or I might wake up to find that yes, I've been scratching one of them. Scratch a bit too hard and one of the blisters is now bleeding. Usually, I try to ignore it

and go back to sleep but sometimes it can be hard because all you want to do is scratch. Then next day I am usually not the brightest person because I require a lot of sleep. **Participant 29**

Yes, definitely 100%. Unfortunately for me and both someone I would potentially be sleeping next to is that I scratch in my sleep, and that's definitely ... something probably that I have been less observant about in the past two years. I don't actually notice if I'm scratching anymore, but I have someone that tells me that, "Yeah,

hey you scratch all night in your sleep." That in itself is disturbing for me. I wish I could lie next to someone and not have that conversation. I still find myself functioning quite well, but as I said to you earlier I am here today being able to have this conversation because I'm off work, because last night I was up until 6:00 AM just dealing with my eczema and trying to work out what that was, that I wasn't able to attend work today. Yeah, it's definitely ... it's tolling. It's Definitely tolling. **Participant 54**

Table 8.5: Impact on sleep

	Total Participants (n=100)		Mild Atopic Dermatitis (n=11)		Moderate Atopic Dermatitis (n=26)		Severe Atopic Dermatitis (n=41)		Very Severe Atopic Dermatitis (n=22)	
Participant describes how itch impacts sleep (scratching)	41	41.00	3	27.27	9	34.62	20	48.78	9	40.91
Participant describes restlessness and agitation during the night (being up through the night to attend to AD)	28	28.00	3	27.27	9	34.62	11	26.83	5	22.73
Participant describes their sleep being affected due to heat	19	19.00	2	18.18	5	19.23	7	17.07	5	22.73
Participant describes not being able to function after not sleeping	14	14.00	2	18.18	3	11.54	5	12.20	4	18.18
Participant describes no impact on sleep	12	12.00	3	27.27	4	15.38	4	9.76	1	4.55
Participant describes how flares particularly impact sleep	11	11.00	1	9.09	4	15.38	6	14.63	0	0.00
Participant describes needing a sedative or sleeping pill to get to sleep	9	9.00	0	0.00	2	7.69	3	7.32	4	18.18
Participant describes impact of no sleep on partner/spouse	8	8.00	1	9.09	1	3.85	5	12.20	1	4.55

	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
Participant describes how itch impacts sleep (scratching)	17	43.59	17	41.46	24	40.68	24	41.38	17	40.48
Participant describes restlessness and agitation during the night (being up through the night to attend to AD)	9	23.08	10	24.39	18	30.51	16	27.59	12	28.57
Participant describes their sleep being affected due to heat	8	20.51	9	21.95	10	16.95	11	18.97	8	19.05
Participant describes not being able to function after not sleeping	8	20.51	4	9.76	10	16.95	9	15.52	5	11.90
Participant describes no impact on sleep	5	12.82	5	12.20	7	11.86	10	17.24	2	4.76
Participant describes how flares particularly impact sleep	4	10.26	6	14.63	5	8.47	6	10.34	5	11.90
Participant describes needing a sedative or sleeping pill to get to sleep	4	10.26	2	4.88	7	11.86	5	8.62	4	9.52
Participant describes impact of no sleep on partner/spouse	2	5.13	2	4.88	6	10.17	4	6.90	4	9.52

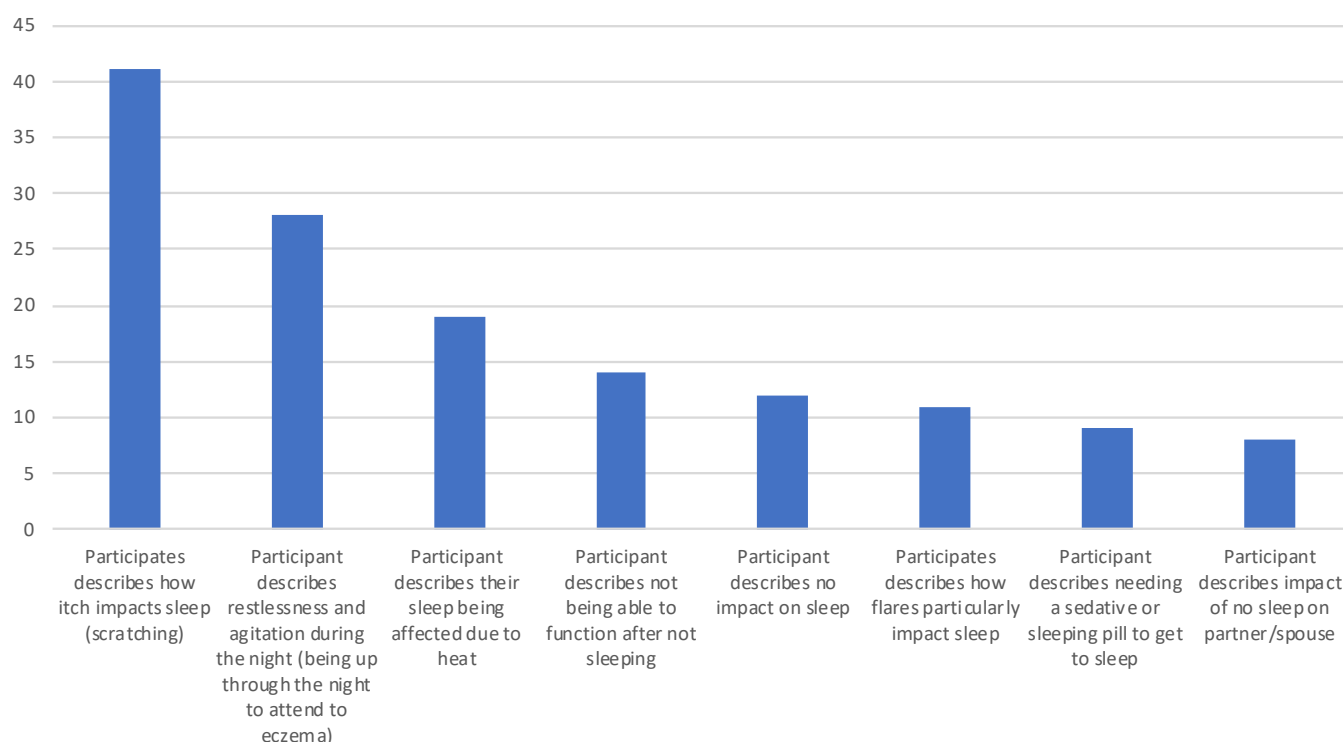


Figure 8.5: Impact on sleep

Everyday activities to manage health

Participants were asked what they considered to be some of the things that they needed to do regularly to maintain their health? There were 87 participants (87.00%) that described a daily routine of applying creams (moisturisers, QV cream, steroid cream), this was followed by needing to avoid some types of food (dairy, gluten etc.) or change their diet (n=24, 24.00%), needing to preventing skin from drying (n=17, 17.00%), needing to avoid getting too hot/cold to control eczema (n=16, 16.00%), and taking medicine as part of daily routine (n=15, 15.00%).

There were a number of sub-group variations. Participants with mild AD reported having a daily routine of moisturizers less frequently than the general cohort (63.64% compared to 87.00% in the general cohort). Participant with moderate AD reported needing to avoid certain foods less frequently than the general cohort (11.54% compared to 24.00% in the general cohort) while participants with severe AD reported this more frequently (36.59% compared to 24.00% in the general cohort).

Table 8.6: Everyday activities to manage health

	Total Participants (n=100)		Mild Atopic Dermatitis (n=11)		Moderate Atopic Dermatitis (n=26)		Severe Atopic Dermatitis (n=41)		Very Severe Atopic Dermatitis (n=22)	
Participant describes a daily routine of applying creams (moisturisers, QV cream, steroid cream)	87	87.00	7	63.64	24	92.31	37	90.24	19	86.36
Participant describes needing to avoid some types of food (dairy, gluten etc.) or change their diet	24	24.00	2	18.18	3	11.54	15	36.59	4	18.18
Participant describes needing to avoid getting too hot/cold to control eczema	16	16.00	1	9.09	7	26.92	4	9.76	4	18.18
Participant describes taking medicine as part of daily routine	15	15.00	0	0.00	2	7.69	8	19.51	5	22.73
Participant describes particular types of soaps and washing detergents to avoid flare up (fragrance free soaps, washing detergents)	13	13.00	4	36.36	2	7.69	6	14.63	1	4.55
Participant describes needing to take antihistamines	11	11.00	0	0.00	4	15.38	5	12.20	2	9.09
Participant describes having to avoid particular types of clothes	8	8.00	1	9.09	2	7.69	4	9.76	1	4.55
Participant describes needing to keep things clean (avoid dust and dirt)	8	8.00	2	18.18	2	7.69	3	7.32	1	4.55
Participant describes using wet wraps/bandages/dressing	6	6.00	0	0.00	3	11.54	1	2.44	2	9.09
Participant describes having to change bed sheets or clothes regularly because of grease from creams or blood	5	5.00	0	0.00	2	7.69	1	2.44	2	9.09
Participant describes needing to wear gloves/arm socks	5	5.00	1	9.09	2	7.69	1	2.44	1	4.55
Participant describes needing to reduce stress and keep calm	5	5.00	0	0.00	0	0.00	3	7.32	2	9.09
Participant describes needing to avoid some social interaction and remain isolated at times	4	4.00	0	0.00	1	3.85	0	0.00	3	13.64

	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/ Trade educated (n=42)	
Participant describes a daily routine of applying creams (moisturisers, QV cream, steroid cream)	37	94.87	36	87.80	51	86.44	52	89.66	35	83.33
Participant describes needing to avoid some types of food (dairy, gluten etc.) or change their diet	9	23.08	13	31.71	11	18.64	15	25.86	9	21.43
Participant describes needing to avoid getting too hot/cold to control eczema	5	12.82	8	19.51	8	13.56	10	17.24	6	14.29
Participant describes taking medicine as part of daily routine	2	5.13	5	12.20	10	16.95	8	13.79	7	16.67
Participant describes particular types of soaps and washing detergents to avoid flare up (fragrance free soaps, washing detergents)	3	7.69	6	14.63	7	11.86	8	13.79	5	11.90
Participant describes needing to take antihistamines	2	5.13	5	12.20	6	10.17	9	15.52	2	4.76
Participant describes having to avoid particular types of clothes	1	2.56	3	7.32	5	8.47	7	12.07	1	2.38
Participant describes needing to keep things clean (avoid dust and dirt)	3	7.69	5	12.20	3	5.08	6	10.34	2	4.76
Participant describes using wet wraps/bandages/dressing	2	5.13	4	9.76	2	3.39	3	5.17	3	7.14
Participant describes having to change bed sheets or clothes regularly because of grease from creams or blood	4	10.26	2	4.88	3	5.08	3	5.17	2	4.76
Participant describes needing to wear gloves/arm socks	0	0.00	4	9.76	1	1.69	3	5.17	2	4.76
Participant describes needing to reduce stress and keep calm	2	5.13	2	4.88	3	5.08	4	6.90	1	2.38
Participant describes needing to avoid some social interaction and remain isolated at times	4	10.26	3	7.32	1	1.69	1	1.72	3	7.14

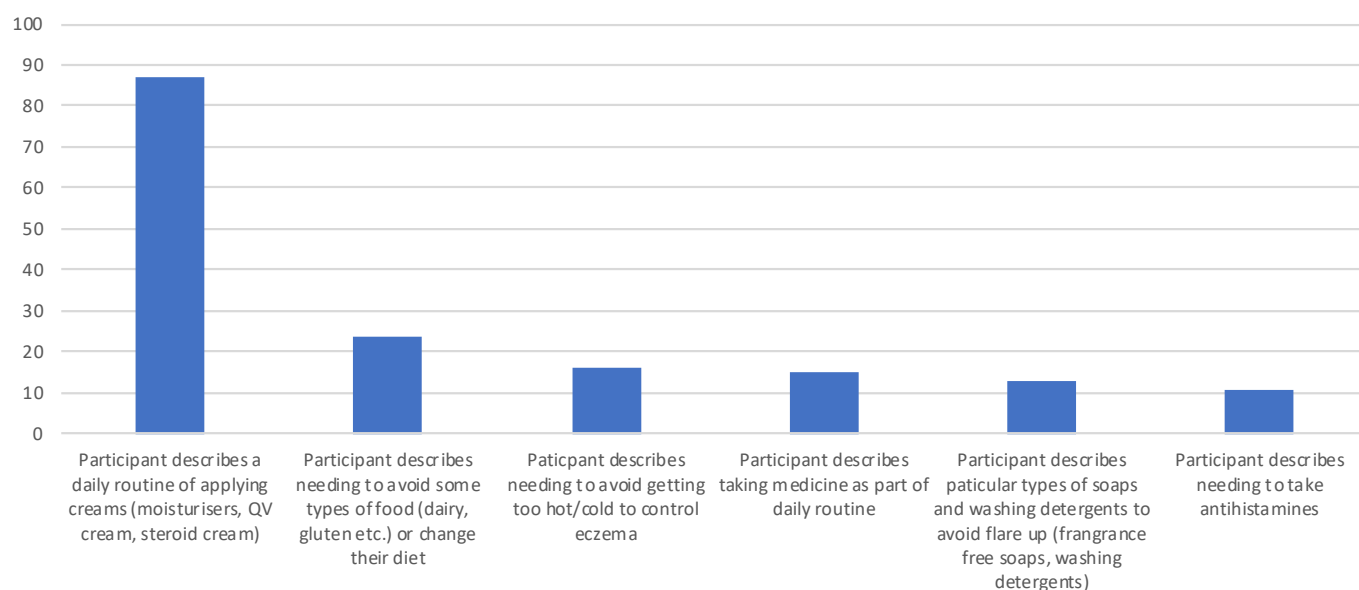


Figure 8.6: Everyday activities to manage health (% of all participants)

As a follow-up question, participants were asked what their usual routine was for showering and getting ready in the morning. In answering this question, some participants spoke about the time required, which was anywhere between 20 minutes to over one hour, while other participants spoke about the routine that they needed to adhere to in order to get ready each day. Exemplar descriptions of these routines is provided below presented from participants with mild, moderate, severe and very severe AD:

*It's every day is moisturizing with QV cream all over twice a day, using the QV body wash kind of thing, not using any scented stuff. Also, keeping an eye on my diet and the foods that I'm eating, avoiding those foods that I'm allergic to or it'll cause issues. Keeping the house clean and regular cleaning that because I'm allergic to dust and that affects and causes eczema too. That's something I can't do because I'm allergic to dust and my husband has to do that. The clothes that I wear. I can't wear woollen and flannel, so I have to make sure I've got the right clothing or light layers that I can take off when I get too hot so I don't get the flare-up. Same with your bedding as well. God, I didn't even realize all these things that I'm doing [laughs]. That I just take for granted but yes actually all of it. Just like I said, making sure that I keep cool so it doesn't flare-up. Just the environment because it's all connected with allergies, Hay Fever signs all that. Pollen, I take antihistamines for four months of the year, daily. (morning routine) Like I said, it has become part of my routine. To get ready like that it's like half an hour. **Participant 6***

*Having short showers, moisturizing all the time, putting steroid cream on when I need to, using any dressing cotton and then tie stuff that brace easily, like polyesters. I have to make sure that I've got right type of-- washing the bathroom, washing the kitchen stuff making sure it's not anything that I can't put my hands in. I'm a nurse, so at work I don't use Latex. I make sure that my skin integrity is good. Make sure I'm moisturized regularly for that and cover any open eczema areas. **Participant 13***

*Yes. Forever. No, really, it does take a while. The shower, I try to limit to a maximum of 10 minutes. Then the moisturizing is what takes up the most, because I have to look everywhere and see where I need to put the steroid cream first and then moisturize everywhere. It can take anything between 30 minutes or up to get ready. That's not even applying makeup or doing my hair. That's just taking a shower, moisturizing. **Participant 15***

*Probably an hour to two hours. Especially if it was not cleared up, I would often do...not Cortisone, but the barrier cream and wrap it in Glad Wrap as well, like a cold wrap. You'd have to wipe it off the bed and all of that stuff and not get too hot, because that would get really bad, really in the winter, it was awful for me. **Participant 16***

I'd have to start getting ready, even to prep myself before getting ready, like an hour beforehand. So, in the shower I'd try to get all of that dead skin off in the shower, re-moisturize, let the skin settle down. Because

sometimes, even after I put the moisturiser on it, it can flair up a bit again. Almost just like sitting there waiting for your skin not to flair up before you put clothes on. Because, a couple times, when I was fine I put clothes on then my skin would get irritated. Then I'd have to have another shower. So, then you sort of go through that whole process again. So, it was a bit of back and forth. It's not that long, it would be two years ago, when I was working more. I'm lucky enough I'm only working three days a week. But, before when I was working four to five days, that process was quite intense. Then through the day, I would have to take the moisturiser and do, like a lunchtime, a scrub off with my skin. Then reapply the moisturiser. Then settle it down before I go back to work for the afternoon. So, sort of a morning noon and night sort of procedure. And, I think it's about, just trying to get yourself ready. You know making sure you have your clothes ready, your food. So doing all the other things that everybody else does, but just allowing more time. Allocating more time to do that process. **Participant 18**

I have a regime whereby taking medications both orally and regime for using topical treatments. That's one thing. That's a bit of time in the day. I have to be very conscious of not getting too hot, not getting too cold. [laugh] It does seem to be very subject to extremes of, well, not necessarily extremes but changes in temperature and humidity and that sort of thing. I'm always thinking of what am I going to experience in the next half hour? Whatever it is, if I'm going out, those issues. Everyone has to do that, of course. I think it's compounded a little by the eczema. **Participant 20**

Yeah, well I think that's one of the frustrations that I have, one of my complaints with, how long I have to take in the bathroom, so ...All the sort of chairs and so forth But I've got a routine I use daily both in the morning and at night with moisturising and ointments and whatever might be needed at the time. So, that adds ten minutes or so to the time spent in the bathroom in the morning. And there's another routine before bedtime. I'll be putting moisturiser on my hands and whatever, through the day, fairly constantly, and like I said, my hands have become a problem in the last nine months. So I'm rubbing cream all over them, all day, every day, but other than that there it's just extra time spent on the skin care for ...And I've got to just make sure that I don't create flare-ups. Well luckily I've got a partner who understands and has her own issues in a similar area, so we can sort it out. And that doesn't entirely remove the frustration I suppose at waiting for someone to get out of the damned bathroom. Because it's her routine, and all that, so I think there are, you

know, ongoing things in there, which really you just deal with as you can. **Participant 62**

I need to make sure that we put filters on all the showers and baths and most of the taps around here, but not all of them. I have to-- One of our bathrooms, the taps in that bathroom don't have a filter on it. I have to just try and avoid that bathroom. If I do use that bathroom, I have to walk through the house to find the tap that do have the filters. After that, I have to wear rubber gloves if I'm watering the garden because I react to the garden water out there. I live in the desert and I really like gardening. It's just I have to do it otherwise I react to the water. I have to water the garden otherwise it'll die. Yes, I put rubber gloves on to do that. If I have to hand wash any pots or pans, there's no way I can just chuck my hands in the water. I have to wear gloves for that, as well. At the moment, I'm using that Diprosone cream that I got prescribed twice a day, just to get everything settled down. I can't forget to use that at the moment. Then, I moisturize them not as much as I used to because my skin healed over better now that I'm holding moisture in better. I still moisturize, maybe, four times a day on my hands. I definitely make sure that that's part of my routine, as well. There's a few different things that I have to adjust. They don't sound like much but if you don't do them, then you end up going backwards. I have to make sure I do. (morning routine) Not too much longer than usual. The shower's pretty much the same now that we've got the filters on there. That's okay. I just pat a bit of cream on. Then, usually wait for that to soak in and then, wait for my hands to dry out from that then I tack on a moisturizer. I don't know. Because I've done it for so often for so long now, it's just part of my routine. I don't think it takes me too much longer than if I didn't do it. Maybe an extra minute out of my day. If my daughter's around with the cream or if I've got in and used it in one bathroom and not the other. I've put it somewhere else. [chuckles] Sometimes, I do spend a bit of time searching for it, thinking, "Where did I put that again?" Sometimes, I put it in my handbag or the nappy bag, somewhere like that. It does take me a little bit to go off and find wherever I've put it. Yes, usually, I know where it is and it's not too much longer out of my day. **Participant 63**

Well, I need to just be really careful with the products that I'm using, with trying to get enough sleep, with making sure that my skin is moisturized, making sure I keep away from anything that I know might affect my skin and to then do thorough things like baths and whatever if my skin is worse than usual. For the many times I get up in the morning, [laughs] I start with eye drops and a couple of glasses of water to try and then I

keep the fluid up. It's more the continual things throughout the day, it adds extra time in the morning when you're getting ready, but during the day, I have to take time to have - I wet my hands and I let them air-dry. Sometimes, I wet them again when they dry to try and just get moisture in the skin, then put the cream on top of it when they're moist-ish. Before this, probably more because there's such a long time in bed when something like moisture that might not be getting onto your skin. Usually it's a bath- (before bed) Then of course, when you're slightly damp then you've got to grease up and then when all the grease is absorbed, I grease up again with half the amount that I greased up the first time. Then, you're pretty greasy so you have to stand around for quite some time not touching anything which everything is greasy [laughs] like your bed. Everything is too greasy. You've got to just let all the absorption happen before you touch anything or not getting to be or anything like that. **Participant 70**

I need to shower regularly like a couple of times a day. I often take an antidepressant which has a sleeping effect. I take deep trend which helps me sleep better at night but it often means that on those days that I can't have a sleep. I asked my husband actually about quality of life. He's had to get up with the kids every single day in the last two and a half years because I get my best sleep between about 4 am and 8 am. I can't get up at six with him if I'm only going to sleep at four. It affects the whole family. Back to your question, what was the question again? (prompt repeated) Yes, I take the sleeping pill, make sure that I shower. Make sure that I've got the right cream to put on my skin after the shower. I've tried to stay cool a lot. I drink a lot of water or wear cool clothes, go to cool places. I also have to manage my stress very well. (length of shower) Probably about twenty minutes. It's not that the shower takes that long but I'm afraid to get out because of the pain that happens when I get outside. **Participant 80**

I get out of the shower. I would probably sit there for about 45 minutes. Moisturizing, letting it soak in, and putting more on or doing different parts at a time. I do it on my arms, then let that soak in and do it again. Once that's done, put on my back, where I can reach

and then eventually put it on my legs. For me, I'll get out of the shower and put an episode of something on Netflix and just sit there the whole time and do my moisturizer. (When you get ready in the morning, takes you 45 minutes to shower and apply the cream and dress) I have showers in the evenings because if I have them in the morning, I'm going to have to do that routine and I don't have time. I'm not a morning person. Plus, cream, if you've got them on during the day, for me, they get all sweaty and they come off anyways and I'll feel embarrassed if I've got it on. But at night, I'll put it on, I'll let it soak in. In the morning, I'll wake up and put it under my arms and around my-- put it in my neck if it was a little bit dry, so I'll put it there if I have to. **Participant 83**

All right well starting from the morning so ... I mean this is probably most people do it anyway but I have to wash my hair every day, because I have eczema on my scalp, so if I go two days without washing it the eczema gets really, really itchy and also because the eczema is on my head, it's shed, so I look like I've got dandruff, so I have to every morning pick all the skin out of my hair, which takes a long time and then wash it. I've got all the special shampoos and special skin treatments that are expensive again and so you do that, cover yourself in cream and everything ... And then I guess the diet, so I spend a lot of time juicing and making healthy smoothies and everything and I compare that to my partner who just puts cereal in a bowl and milk in a bowl and he's done, so his job is 20 seconds long, mine is about 10 minutes long. **Participant 91**

If it's really bad, I probably even the morning what I used to do which no one ever told me to do but I was like, the itching would be so bad that I would go and hold an ice block from the freezer just on my hand. It'd actually just sit there before I even got ready, I'd just sit there holding some ice on it to get the itching, just to get the inflammation and itching to go down. I would actually have a period in the morning where I would just have to try and get everything under control. If you're having a shower, it becomes really hard. Then, you get in the shower then it all just aggravates it. **Participant 99**

Table 8.7: Showering/morning routine

	Total Participants (n=100)		Mild Atopic Dermatitis (n=11)		Moderate Atopic Dermatitis (n=26)		Severe Atopic Dermatitis (n=41)		Very Severe Atopic Dermatitis (n=22)	
Participant describes integrating their AD needs into their regular routine	10	10.00	1	9.09	1	3.85	6	14.63	2	9.09
Participant describes needing to wait extra time after showering and moisturising to be able to get dressed	9	9.00	0	0.00	2	7.69	5	12.20	2	9.09
Participant describes taking longer than usual to shower/get ready (time not specified)	9	9.00	0	0.00	2	7.69	6	14.63	1	4.55
Minimal impact on showering and moisturising	8	8.00	2	18.18	1	3.85	4	9.76	1	4.55
Participant describes no impact on showering/getting dressed	6	6.00	0	0.00	4	15.38	2	4.88	0	0.00
Participant describes needing shower multiple times in a day	5	5.00	0	0.00	2	7.69	1	2.44	2	9.09
Participant describes taking upto 20 minutes to shower and get dressed	18	18.00	7	63.64	5	19.23	5	12.20	1	4.55
Participant describes taking about 30 minutes to shower and get dressed	15	15.00	1	9.09	10	38.46	4	9.76	0	0.00
Participant describes taking about 40 minutes to shower and get dressed	2	2.00	0	0.00	0	0.00	1	2.44	1	4.55
Participant describes taking about 60 minutes or more to shower and get dressed	5	5.00	0	0.00	1	3.85	1	2.44	3	13.64

	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/ Trade educated (n=42)	
Participant describes integrating their AD needs into their regular routine	5	12.82	6	14.63	4	6.78	4	6.90	6	14.29
Participant describes needing to wait extra time after showering and moisturising to be able to get dressed	6	15.38	4	9.76	5	8.47	5	8.62	4	9.52
Participant describes taking longer than usual to shower/get ready (time not specified)	3	7.69	4	9.76	5	8.47	5	8.62	4	9.52
Minimal impact on showering and moisturising	4	10.26	3	7.32	5	8.47	6	10.34	2	4.76
Participant describes no impact on showering/getting dressed	1	2.56	3	7.32	3	5.08	3	5.17	3	7.14
Participant describes needing shower multiple times in a day	2	5.13	2	4.88	3	5.08	4	6.90	1	2.38
Participant describes taking upto 20 minutes to shower and get dressed	3	7.69	6	14.63	12	20.34	12	20.69	6	14.29
Participant describes taking about 30 minutes to shower and get dressed	7	17.95	5	12.20	10	16.95	12	20.69	3	7.14
Participant describes taking about 40 minutes to shower and get dressed	0	0.00	1	2.44	1	1.69	0	0.00	2	4.76
Participant describes taking about 60 minutes or more to shower and get dressed	2	5.13	3	7.32	2	3.39	3	5.17	2	4.76

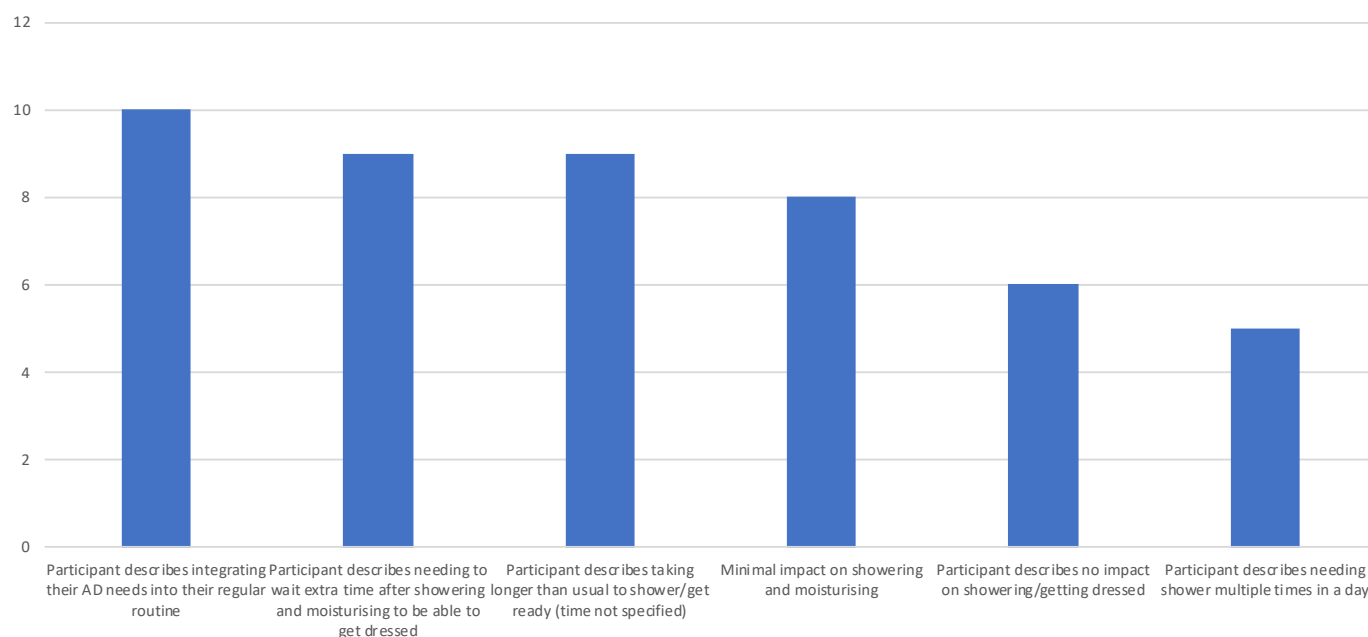


Figure 8.7: Showering/morning routine

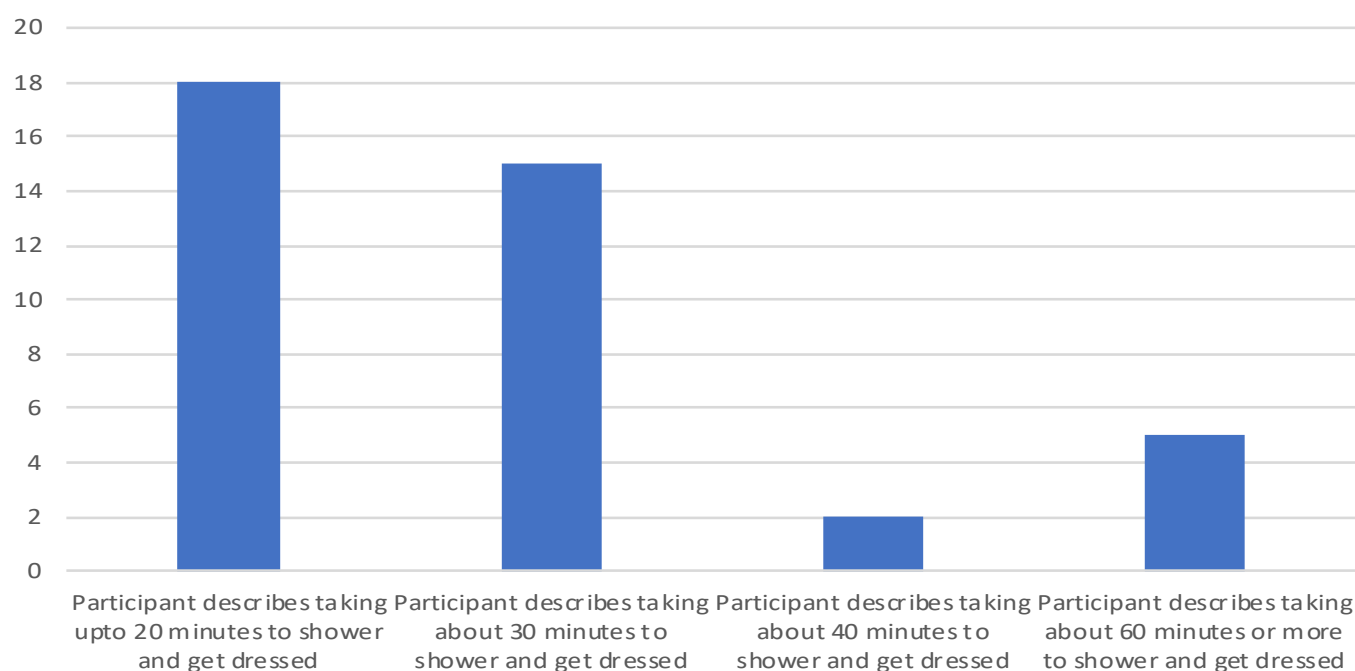


Figure 8.8: Showering/morning routine (Time)

Impact on relationships

Participants were asked whether their condition has had an impact on personal relationships with family and friends. There was a reasonably even response with 53 participants (53.00%) describing no impact, or limited impact while they were managing flares, and 47 participants (47.00%) stating that there was a significant impact. Where there was an impact, the most common challenge described (n=16, 16.00%) was

a significant impact on relationships with their family member, specifically intimacy with their partner:

Definitely, yes. The last time I had a boyfriend, he was really offended that I needed to wear something at night. That's probably been a constant thing through my life. It's like, "Okay, we'll we've finished being intimate there, I need to put my pyjamas on." If I don't, then I won't sleep well because I'm itching and sticky. It's not a good look if you're with some hot guy and

you're wearing white cotton gloves, and you've smothered your skin with the greasy oil. **Participant 1**

Yes. When my partner said, "You got to do something about this." Because I go, "Don't touch me." And the after, they've got to understand sometimes why you can't do something. But that could be because your skin is sore. So, yes, definitely does affect most of my relationships. **Participant 51**

He'd say no, I'd say yes (laughs). Certainly, in the last couple of months, with the severity of the flair ups, there's been no, shall we say, bedroom intimacy because it just can't happen. It's just, anything that's slightly too much heat and I just go instantly into a flair up. So, it has affected that part of our relationship, yes. **Participant 65**

The next most common theme was a significant impact on quality of life in relation to becoming isolated/not being able to go out and be social (n=12, 12.00%):

I think so. I think I would tend not to want to organise social interactions in those times. So I've become a bit more of a hermit. **Participant 53**

I think it has. I'm, as a result of it, I can be quite moody. So, obviously for them, then I'm, you know, I just wanna shut away. And, and especially if I've, you know, got events to go to, and my skin's bad, I get a bit depressed; not clinically - ... depressed, but I get upset, and - ... I well, yeah, so it has definitely affected - ... relationships, especially when I was a bit younger. But, yeah and, and at work, as well. **Participant 60**

I've got one good friend who for the five months I was in bed, she came around. She did my shopping-anything I needed. Well the ex, he didn't understand anything. As I said it was more last year and we left when he left, he split four years ago. I avoid now when the kids come home, when he drops them. But tonight I don't go out there. I'll come back in and I'll be itchy. I've lost a lot of friends because it's partly due to the mental health. It's because you plan something to catch up for coffee and I've had a bad night itching, to the point where it's like not, I need to put too much cream on and frequently and I need to stay in my pyjamas. Or mentally, I'm not traveling well. And then after a while, I just give up. **Participant 86**

My wife, she loves going out to the party and things like that, and I'm still the person that's hiding in the corner all the time. It does affect you socially. I turned out to be a bit of a hermit because of it. **Participant 96**

Table 8.8: Impact on personal relationships

Impact on personal relationships	Total Participants (n=100)		Mild Atopic Dermatitis (n=11)		Moderate Atopic Dermatitis (n=26)		Severe Atopic Dermatitis (n=41)		Very Severe Atopic Dermatitis (n=22)	
Participant describes generally having no impact on their relationships - only mildly when they are irritated with itching and/or flares	53	53.00	9	81.82	17	65.38	22	53.66	5	22.73
Participant describes a significant impact on their relationships	47	47.00	2	18.18	9	34.62	19	46.34	17	77.27

Impact on personal relationships	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
Participant describes generally having no impact on their relationships - only mildly when they are irritated with itching and/or flares	21	53.85	25	60.98	28	47.46	31	53.45	22	52.38
Participant describes a significant impact on their relationships	18	46.15	16	39.02	31	52.54	27	46.55	20	47.62

Another key theme described by 10 participants (10.00%) was that AD had a significant impact on relationships in relation to self-esteem and confidence/being embarrassed:

Yes, you don't feel very attractive, when you're having an outbreak, that's for sure. Actually, I remember when I was a teenager, I had it really bad, in the creases of your arms and I actually had an employer ask me if I was a drug addict, like a junkie because I had scabs. It was so embarrassing, I was absolutely mortified.
Participant 23

Maybe just things with being out here is making new friends affected a little bit. That was probably just more me being really embarrassed having to say to these people I don't know very well and I'm trying to make friends in a town that I don't know anyone. "It's just eczema. I'm not contagious or anything like that." People have been really nice and accepting about it.

They haven't made me feel like I'm awful or anything like that. I think it's more me feeling quite embarrassed, I have to say that too.
Participant 63

Yes, like I say, you feel like a mangy, dirty person, because you're shedding skin everywhere. You just leave a trail, you can walk around behind me with a dust pan and broom picking up skin. Like I said, you must grow extra, because you lose everyday, I'd say, over a half a cup of skin a day you get out of the bathroom. It's coming off all the time, so you must grow extra, and otherwise you'll be down to bone.
Participant 82

There were two sub-group variations within this section. Participants with mild AD reporting having no impact on their relationships less frequently than the general cohort (81.81% compared to 53.00% in the general cohort). They also described having a significant impact on relationships less frequently (18.18% compared to the general cohort).

Table 8.9: Impact on personal relationships (Specific challenges)

	Total Participants (n=100)		Mild Atopic Dermatitis (n=11)		Moderate Atopic Dermatitis (n=26)		Severe Atopic Dermatitis (n=41)		Very Severe Atopic Dermatitis (n=22)	
Participant describes a significant impact on relationships in relation to relationships with their family (Intimacy with partner)	16	16.00	0	0.00	4	15.38	6	14.63	6	27.27
Participant describes a significant impact on relationships in relation to becoming isolated/not being able to go out and be social	12	12.00	0	0.00	1	3.85	6	14.63	5	22.73
Participant describes a significant impact on relationships in relation to self esteem and confidence/being embarrassed	10	10.00	0	0.00	3	11.54	4	9.76	3	13.64
Participant describes a significant impact on relationships in relation to relationships with their family (Relationship with parents, siblings, children)	6	6.00	0	0.00	1	3.85	3	7.32	2	9.09
Participant describes a significant impact on relationships in relation to everything (very severe impact)	6	6.00	0	0.00	0	0.00	2	4.88	4	18.18
participant describes being stressed/angry/depressed	6	6.00	0	0.00	2	7.69	4	9.76	0	0.00

	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
Participant describes a significant impact on relationships in relation to relationships with their family (Intimacy with partner)	7	17.95	7	17.07	9	15.25	7	12.07	9	21.43
Participant describes a significant impact on relationships in relation to becoming isolated/not being able to go out and be social	4	10.26	3	7.32	9	15.25	6	10.34	6	14.29
Participant describes a significant impact on relationships in relation to self esteem and confidence/being embarrassed	3	7.69	5	12.20	5	8.47	9	15.52	1	2.38
Participant describes a significant impact on relationships in relation to relationships with their family (Relationship with parents, siblings, children)	2	5.13	1	2.44	5	8.47	3	5.17	3	7.14
Participant describes a significant impact on relationships in relation to everything (very severe impact)	3	7.69	3	7.32	3	5.08	1	1.72	5	11.90
participant describes being stressed/angry/depressed	2	5.13	0	0.00	6	10.17	4	6.90	2	4.76

As a follow-up question, participants were asked whether they felt their condition had resulted in any additional burden on their family. Half of all participants (n=50, 50.00%) described not needing any additional assistance. These participants spoke about being independent and being able to manage their condition themselves:

No, no burden at all. It's just one of these things. I count myself lucky that it was eczema and not something else. It could be a lot worse. Participant 7

No, because they don't need to do anything. I'm self-caring. Actually they do, they need to be [laughs] ... Yeah, actually they do. They need to be patient, because so often we're just about to go out, and I look in the mirror and my skin has started to have a flaking

effect, you know, on your face? And, "Whoa, hang on, I've just gotta deal with this before we go out." So I guess they've just gotta be patient, and we deal with me shedding a layer of skin. **Participant 32**

No. Not really. They're all up to help out if I need application of cream on my back or something. Usually a volunteer process here. [laughs] They're all very good. **Participant 64**

There were 16 participants (16.00%) that described AD being a burden on their family and this was primarily in relation to needing additional assistance or the additional financial burden to their family:

Yes. Definitely. It's extra care, because you have to look after yourself. Like I said, my kids have it too. What I'm doing for myself times that by three, because it's me and my two boys who have it. Then there's a cost associated with that care. The moisturizers aren't cheap. The steroid creams aren't cheap. It is a burden. Oh, I personally feel like having eczema is a burden on my family just ... yeah, definitely. The amount of money my parents have invested in trying to give me the best possible opportunity at life. Yeah it's definitely a financial burden, but I know that again as I said I wouldn't be the person I am today without it, it's nice to look at it that way, but yeah it's definitely financially it costs them a lot of money to try to work out how to give me the best opportunities, and also every time Mum buys me clothes it's, "Will this be okay for your eczema, will it suit your eczema?" So everything that's happened is trying to accommodate for it. **Participant 54**

Yes, yes it is. Yeah. So as a family we all have to be aware of my eczema. It comes into play with whatever we are choosing and the things that we do, where we go, the climate that we're in and again, whether I feel well enough to even leave this house sometimes. So, yeah, it's a burden for everybody. They have to keep it in the back of their minds. And, if I run out of my cream, that's another source of stress because I have to go to the doctor, find time to do that during the working week, I've got to get a script, go to a chemist and get it filled so, it can be very interruptive as well in our normal routine. **Participant 66**

I actually do put in our budget when I do our banking. I calculate our trips to the chemist separately. Only because a couple of years they said, that if you spend a certain amount over the PBS scripts you get, you can claim some of it back. I know they removed it last year. Yes. I think when I did my tax last financial year they said, "They removed that." I was like, "That's unfortunate." But I still do it just in case it's changed. It does add up throughout the year the cost of going, the scripts and the creams and the special shampoos and special wash. Yes. **Participant 15**

Another theme that emerged was that participants felt as though AD was not a burden now, but that it was when they were younger (n=12, 12.00%). There were also an additional 10 participants that specifically spoke about needing and appreciating the assistance and care that was provided to them by their mother (10.00%).

Participant describes not needing assistance now, but in earlier life, they would have answered this differently.

It is one of those things, definitely I think probably more so as a child when you do rely on your parents, it was constant for my Mum and dad to bandage me. You know, we used to even do stuff like where we'd bathe in oatmeal baths. Or we'd bathe in tea. And, we'd bathe in all sorts of stuff. And, my dad would take us to the ocean, which was like an hour and a half away, he would drive to the sea, just to get me in the saltwater to stop the infection. You know, I just think it was a constant thing. It was a part of our lives. **Participant 18**

I think it was when I was young. Now, I don't think it would be because I'm independent now, other than yeah, if I need a little bit of help with the cream. But I wouldn't say it's a burden now, but definitely when I was younger, it would have been on them. **Participant 34**

Not to my family, but growing up it was ... Yeah, there's a lot of the teenage issues of self esteem, and those sorts of things, that I think was quite difficult for my parents to deal with. I was an only child. So that, for me, was a big focus, and not having any siblings to sort of distract from what was going on in my life. I can remember being quite ... Self absorbed is not really the right term, but just sort of being fixated on not looking right. If you had asked me then I would have said that it's the fact I looked ugly, was the biggest problem with

my eczema, as opposed to the pain or the discomfort that it caused. **Participant 37**

Participant describes needing assistance specifically from their mother

Definitely. My poor mother. Yes, I think ever since I was diagnosed when I was two years old, it has been an extra burden on Mum and dad, because I used to wake up screaming in the middle of the night. Wake them in the middle of the night to come and clean me up or if I was screaming, because I was scratching so much or things like that. Not only was it an emotional burden, but financially, they've had to pay for all of the treatment up until I was 18. Since then, I've been paying for them both. Yes, Mum and dad definitely took a hit and I think as a child growing up, I was definitely the most difficult one in the family. **Participant 38**

A little bit but not so much anymore. Only in the sense of, especially in winter when I'm taking up to twice as

long to take a bath with the oils or stuff like that. Or when I was younger and mum was running around trying to change the sheets constantly or vacuum up. **Participant 73**

I was pretty much bedbound for two months. I could not get out of bed. I was in so much pain and I was in so much discomfort with the burning sensation, itchiness that I needed care from my mother so it was, I did feel like it was a bit of a burden on her during that time but since then I've been able to manage on my own. **Participant 67**

There were a number of sub-group variations. Participants with moderate AD reported not needing any additional assistance more frequently than the general cohort (65.38% compared to 50.00% in the general cohort). Participants with mild AD reported not needing assistance now, but needing assistance in earlier life, more frequently than the general cohort (36.36% compared to 12.00%).

Table 8.10: Burden on family

	Total Participants (n=100)		Mild Atopic Dermatitis (n=11)		Moderate Atopic Dermatitis (n=26)		Severe Atopic Dermatitis (n=41)		Very Severe Atopic Dermatitis (n=22)	
Participant describes not needing any additional assistance	50	50.00	6	54.55	17	65.38	19	46.34	8	36.36
Participant describes condition being a burden on their family (assistance and financial burden)	16	16.00	1	9.09	4	15.38	6	14.63	5	22.73
Participant describes not needing assistance now, but in earlier life, they would have answered this differently.	12	12.00	4	36.36	3	11.54	4	9.76	1	4.55
Participant describes needing assistance from their family in general	10	10.00	0	0.00	2	7.69	4	9.76	4	18.18
Participant describes needing assistance specifically from their mother	10	10.00	1	9.09	0	0.00	7	17.07	2	9.09
Participant describes AD being a financial burden on them and / or their family	8	8.00	0	0.00	3	11.54	3	7.32	2	9.09

	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/ Trade educated (n=42)	
Participant describes not needing any additional assistance	22	56.41	20	48.78	30	50.85	30	51.72	20	47.62
Participant describes condition being a burden on their family (assistance and financial burden)	5	12.82	5	12.20	11	18.64	9	15.52	7	16.67
Participant describes not needing assistance now, but in earlier life, they would have answered this differently.	1	2.56	4	9.76	8	13.56	8	13.79	4	9.52
Participant describes needing assistance from their family in general	5	12.82	5	12.20	5	8.47	5	8.62	5	11.90
Participant describes needing assistance specifically from their mother	4	10.26	4	9.76	6	10.17	6	10.34	4	9.52
Participant describes AD being a financial burden on them and / or their family	3	7.69	2	4.88	6	10.17	4	6.90	4	9.52

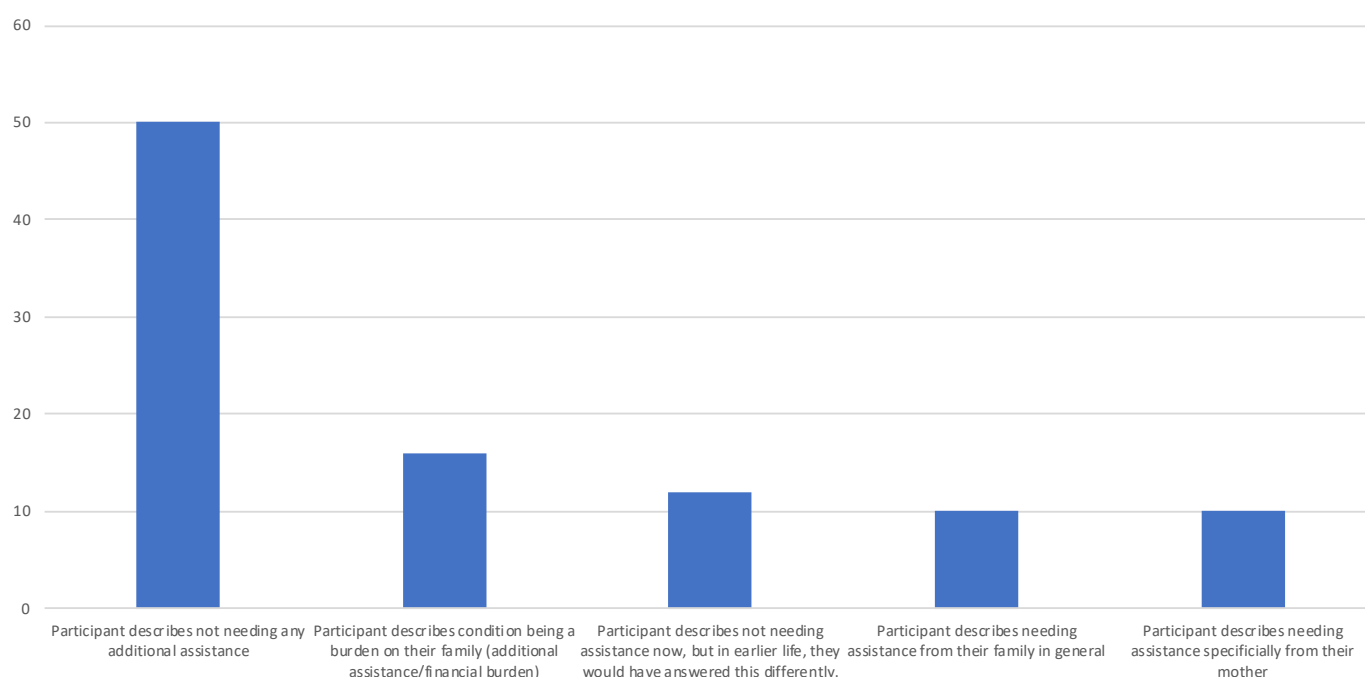


Figure 8.9: Burden on family (% of all participants)

Experience of anxiety related to disease 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, with a higher score denoting increased anxiety. Summary statistics for the entire cohort are displayed alongside the possible range of the scale in Table 8.11. Overall the entire cohort had a median total score of 28.00, which is a score in the second lowest quintile indicating a small amount of fear.

Boxplots of FOPTS by disease severity, comorbid depression and anxiety, location, and education status are displayed in Figures 8.10 to 8.13.

Comparisons of FOPTS were made by disease severity, comorbid depression and anxiety, location, and education status. A one-way ANOVA test with post hoc Tukey HSD tests were used to compare disease severity (Tables 8.11 to 8.13). For all other comparisons, a two-sample t-test was used when assumptions for

normality and variance were met (Table 8.15), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 8.16).

A one way ANOVA test indicated a significant difference in the fear of progression total score between groups [$F(3,96) = 25479$, $p < 0.0001$] (Table 8.15). Post hoc comparisons using the Tukey HSD test indicated that the mean score for those with very severe disease was significantly higher than any other group, and that the mean score for those with severe disease had a higher score than those with mild or moderate disease (Table 8.12 and 8.13).

A two sample t-test indicated that those that had comorbid depression and anxiety had a higher fear of progression compared to those that did not [$t(98) = -2.68$, $p = 0.0087$] (Table 8.15). There were no significant differences by location or education status (Table 8.16).

Table 811: Fear of Progression Total Score

Scale	Median	IQR	Possible range
Total score	28.00	16.25	12-60

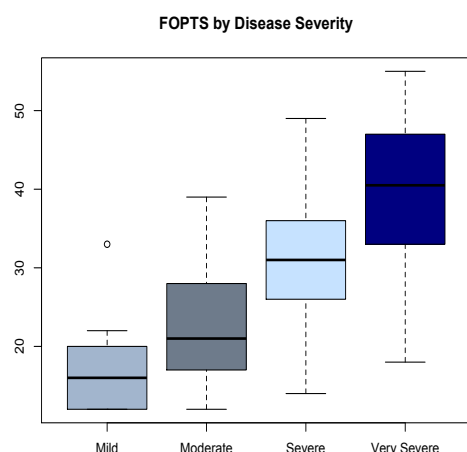


Figure 8.10: Boxplot of FOPTS by disease severity

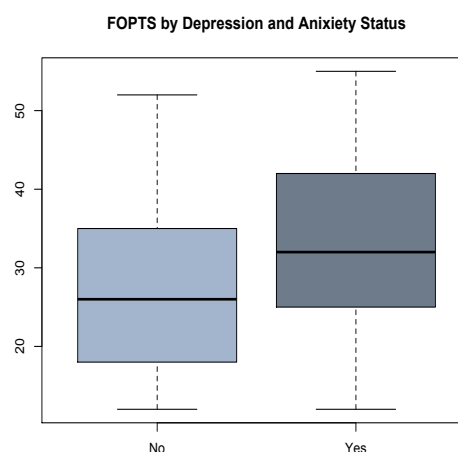


Figure 8.11: Boxplot of of FOPTS by depression and anxiety status

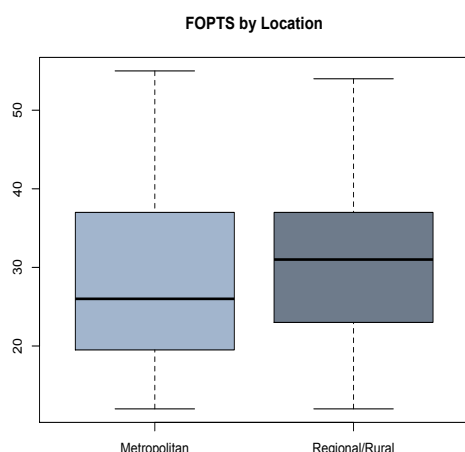


Figure 8.12: Boxplot of FOPTS by location

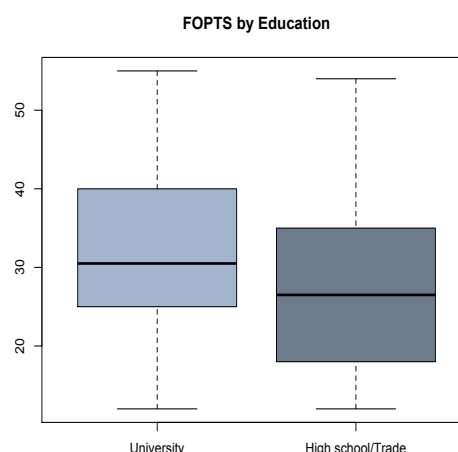


Figure 8.13: Boxplot of FOPTS by education

Table 8.12: Summary statistics for FOPTS by disease severity

FOPTS: Disease severity	Group	Count	Mean	Sd
Disease severity	Mild	11	17.50	6.36
	Moderate	26	22.70	7.30
	Severe	41	31.40	8.38
	Very severe	22	39.80	10.40

Table 8.13: ANOVA table for FOPTS by disease severity

FOPTS: Disease severity		Sum of squares	Df	Mean square	F	P
Disease Severity	Between Groups	5276	3	1758.7	24.79	<0.0001*
	Within Groups	6811	96	70.9		
	Total	12087	99			

Table 8.14: Post hoc Tuckey HSD test FOPTS by disease severity

FOPTS: Disease severity	Comparison	Mean difference	Lower	Upper	P adjusted
Disease Severity	Moderate -Mild	5.28	-2.64	13.20	0.3081
	Severe-Mild	13.94	6.46	21.41	<0.0001*
	Very severe – Mild	22.36	14.23	30.50	<0.0001*
	Severe-Moderate	8.66	3.14	14.18	0.0005*
	Very Severe-Moderate	17.09	10.71	23.47	<0.0001*
	Very Severe-Severe	8.42	2.61	14.25	0.0015*

* Statistically significant at $p < 0.05$

Table 8.15: Summary statistics and two sample t-test FOPTS

FOPTS	Group	Count	Mean	SD	t	df	p
Depression and anxiety	No	61			-2.68	98	0.0087*
	Yes	39					

* Statistically significant at $p < 0.005$

Table 8.16: Summary statistics Wilcoxon rank sum test with continuity correction of FOPTS

FOPTS	Group	Count	Median	IQR	W	P
Location	Metropolitan	59	26.00	17.50	1051	0.2678
	Regional/Rural	41	31.00	14.00		
Education	High school/Trade	42	30.50	14.80	1454	0.0998
	University	58	26.50	16.50		