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Atopic Dermatitis Australian Study

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Summary of results

Section 1: Introduction and methodology

- Atopic dermatitis (AD) is an inflammatory skin condition associated with other atopic manifestations such as asthma, rhinitis and food allergy.
- It presents in varying degrees of severity from a mild disease treated with over-the-counter products to severe disease requiring treatment with systemic immunosuppressive agents.
- Common symptoms of AD include itchiness, red to brownish-grey patches on the skin, small, raised bumps, which may leak fluid and crust over when scratched, and/or thickened, cracked, dry, scaly skin.
- Onset of AD occurs most commonly in infants and children, however it can occur at any age with clinical features varying with age of onset.
- Patient Experience, Expectations and Knowledge (PEEK) is a research program developed by the International Centre for Community-Driven Research (CCDR). The aim of PEEK is to conduct patient experience studies across several disease areas using a protocol that will allow for comparisons over time (both quantitative and qualitative components). PEEK studies give us a clear picture and historical record of what it is like to be a patient at a given point in time, and by asking patients about their expectations, PEEK studies give us a way forward to support patients and their families with treatments, information and care.
- In this PEEK study, 100 people diagnosed with AD throughout Australia participated in the study that included a structured interview and quantitative questionnaire. This study in AD is therefore the largest mixed methodology study worldwide conducted in last five years and the only study that focuses on an Australian population. In addition, PEEK is a comprehensive study covering all aspects of disease experience from symptoms, diagnosis, treatment, healthcare communication, information provision, care and support, quality of life, and future treatment and care expectations.

Section 2: Demographics and study population characteristics

- One hundred participants from Australia were included in the study.
- Participants reported a current Patient Oriented Eczema Measure (POEM) score to determine severity of disease. 11 were mild (11.00%), 26 Moderate (26.00%), 41 severe (41.00%) and 22 very severe (22.00%).
- Participants came from NSW (45.00%), Queensland (17.00%), Victoria (13.00%), Western Australia (11.00%), South Australia (5.00%), Australian Capital Territory (4.00%), Tasmania (4.00%) and the Northern Territory (1.00%); from major cities (59.00%) and regional/rural (41.00%).
- Eighty-eight females (88.00%) and 12 males (12.00%) were included in this study.
- Subgroup analysis were included throughout the study. The subgroups were disease severity - mild (11.00%), moderate (26.00%), severe (41.00%) and very severe (22.00%); those with comorbid anxiety and depression (39.00%) and those without (61.00%); by location- Major city (59.00%) or Regional/Remote (41.00%); and by education status - those with a university degree (58.00%) and those with high school or trade (42.00%).
- The baseline health SF36 scores for the entire cohort were very good for physical functioning and role limitations due to physical health; the scores for role limitations due to emotional problems, emotional well-being, social functioning and pain were good; and the scores for energy/fatigue, general health and health change were moderate.
- Participants with very severe disease scored worse than all other groups for the physical functioning, role limitations due to physical health, emotional well-being, social functioning, pain, and general health SF36 scales, and had worse scores than those with moderate or severe disease for energy/fatigue. There were no differences between disease severity groups for role limitations due to emotional problems or for health change scores.
- Participants with comorbid depression and anxiety scored worse on the physical functioning, role limitations due to emotional problems, emotional well-being, social functioning, pain and general health SF36 scales compared to those that did not have comorbid depression and anxiety. There were no differences between these groups for energy/fatigue, role limitations due to physical health, and health change scores.
- Participants that had a university degree had better outcomes compared to those with high school or trade

for the social functioning, pain and general health SF36 scales.

- No differences in SF36 subscales were observed for those that lived in major cities compared to those that live in regional/rural areas.

Section 3: Experience of symptoms and diagnosis

Symptoms at diagnosis

- The most common symptoms leading to diagnosis were rash-like symptoms (n=38, 38.00%) followed by thickened, cracked, dry, scaly skin (n=23, 23.00%) and allergies that led to the diagnosis of AD (n=17, 17.00%). There were also 25 participants (25.00%) that were unable to describe specifically what led to their diagnosis as they were a child or infant at the time.
- There were a number of sub-group variations. Participants that were high school or trade education reported having allergies that led to diagnosis more frequently than the general cohort (28.57% compared to 17.00% in the general cohort). Participants with mild AD reported having red to brownish-grey patches that led to diagnosis more frequently than the general cohort (54.55% compared to 15.00% in the general cohort) while participants with moderate AD reported this symptom less frequently (3.85% compared with 15.00% in the general cohort).
- There were various combinations of diagnostic tests conducted with the most common tests recalled being skin examination only (n=41, 41.00%) followed by skin examination, blood test, patch test and review of medical history (n=24, 24.00%).
- There was one sub-group variation. Participants with mild AD reported having a skin examination only, more frequently than the general cohort (90.91% compared to 41.00% in the general cohort) and they did not report having other tests such as blood tests, patch tests or review of medical history.
- 64 participants (64.00%) noted that they had no support at diagnosis, (n=21; 21.00%) reported having some support, but not enough and (n=15, 15.00) reported having enough support.
- There were a number of sub-group variations. Participants with mild AD reported having no support more frequently than the general cohort (81.82% compared to 64.00% in the general cohort). Participants with moderate AD reported having enough support less frequently than the general cohort (3.85% compared to 15.00% in the general cohort).

Genetic/biomarker tests

- Participants were asked whether they had ever had a discussion about genetic tests or tests to see if there were biomarkers that might be relevant to their condition or treatment. The majority of participants (n=96; 96.00%) had not had a discussion while four participants (4.00%) stated they had had a discussion about this kind of test of which, two brought the topic up with their doctor.
- Participants were also asked about their interest in this type of test if it was available. The majority of participants (n=89, 89.00%) were interested in having it if it were available, three participants (3.00%) indicated that they paid for this test themselves while eight participants (8.00%) indicated that they were not interested in this type of test.

Knowledge of condition and prognosis

- In relation to how much participants knew about their condition at diagnosis, the main theme was that participants, or their parents, knew nothing or very little about their condition (n=45, 45.00%). 18 participants (18.00%) described having some knowledge about AD and this was primarily due to having another family member who also had the condition. There were also 19 participants (19.00%) that commented that they have lived their whole life with AD and it is therefore the only way of life that they knew.
- There was one sub-group variation in relation to participants that have very severe AD who reported knowing about AD through other family members, more frequently than the general cohort (31.82% compared to 18.00% in the general cohort).
- Participants were asked whether anyone talked to them about prognosis. Over half of the participants (n=54, 54.00%) described that they understood that AD was a lifelong condition and did not expect it to get better. 22 participants (22.00%) that noted that they did not have a clear prognosis and these participants also spoke about the uncertainty of their situation.
- There were two sub-group variations. Participants with mild AD reported their prognosis as being something

they will have for their lifetime less frequently than the general cohort (27.27% compared to 54.00% in the general cohort). Participants with very severe AD reported having their AD under control less frequently than the general cohort (4.55% compared to 18.00% in the general cohort).

Section 4: Experience of health professional communication

Conversations about treatments

- Participants were asked to describe the conversations they have had about their AD in relation to treatment options. The main theme noted by 72 participants (72.00%) within this section was that participants felt that they were not really provided with options and that the majority of discussions focused on steroid cream.
- There was one sub-group variation. Participants with very severe AD described feeling as though there were no or limited treatment options more frequently than the general cohort (90.91% compared to 72.00% in the general cohort).

Decision-making

- Participants were asked who was involved in decisions made about treatment and care. Participants clinician and 5 The most common theme was that decision-making was primarily between the patient and their clinician (n=52, 52.00%). There were 37 participants (37.00%) that described also including their family in decisions while 32 participants (32.00%) spoke about decision-making as ultimately something they do on their own.
- There was one sub-group variation. Participants with mild AD reported decision-making as an individual thing more frequently than the general cohort (63.63% compared to 32.00% in the general cohort).
- Participants were asked about the things that they take into consideration when making decisions about treatment. The most common theme was that participants considered how much time the treatment would take to administer and this was noted by 34 (34.00%) of participants. There were 31 participants (31.00%) that described considering the severity of side effects, 30 participants (30.00%) spoke about understanding the evidence behind the treatment option, cost was another consideration that was noted by 27 participants (27.00%) and there also 19 participants (19.00%) that spoke about considering the long-term effect of treatment and how it will impact their overall health.
- There were three sub-group variations. Participants with mild AD reported considering the severity of side effects less frequently than the general cohort (18.18% compared to 31.00% in the general cohort) They also reported considering the treatment effectiveness/evidence base less frequently than the general cohort (18.00% compared to 30.00% in the general cohort). Participants that had a high school or trade education also reported considering the treatment effectiveness/evidence base more frequently than the general cohort (42.86 compared to 30.00% in the general cohort).
- Participants were asked whether they felt the way they made decisions had changed over time since they were diagnosed. The most common theme was that participants had changed the way they made decisions (n=31, 31.00%) and 24 participants described taking more of an active role or interest in their condition in adulthood.
- There was one sub-group variation. Participants with mild AD reported changes in the way they make decisions and becoming more informed, less frequently than the general cohort (18.18% compared to 31.00% in the general cohort).

Section 5: Experience of treatment and service provision

Treatments experienced

- The most common treatments reported by nearly all participants were corticosteroid creams (n=94, 94.00%). This was followed by non-prescription creams that control itching (n=61, 61.00%), antihistamines (n=61, 61.00%) and wet dressings (n=47, 47.00%). Antibiotics and calamine lotion were both reported by 40 participants (40.00%).
- Participants were asked to rate their quality of life on a scale of 1 to 7, while using each specific treatment (with 1 being 'Life was very distressing and 7 being 'Life was great'). Mean quality of life scores ranges from 2.40 to 3.62, that is, all quality of life scores were with the 'life was distressing' to 'Life was a little distressing' range. The treatments that scored the least impact on quality of life were non-prescription creams that control itching and inflammation (average score 3.62), antihistamines (average score 3.33), creams to repair cracked skin (average score 3.31), stress reduction treatments (average score 3.21) and corticosteroid creams (average score 3.03). The treatments that had the greatest impact on quality of life were antibiotics (average score 2.40), diluted bleach baths (average score 2.42) and relaxation or behaviour modification (average score 2.42).
- Participants were asked to rate how effective the participant felt the treatment was on a scale of 1 to 5 (with 1 being ineffective and 5 being very effective). All treatments scored between a range of 1.53 to 3.86, that is ineffective to moderately effective. The most effective treatments were oral or injectable corticosteroids (average score 3.86), corticosteroid creams (average score 3.42), and wet dressings (average score 3.13). The least effective treatments were calamine lotion (average score 1.53), stress reduction techniques (average score 2.21) and diluted bleach baths (average score 2.29).
- In relation to side effects that participants felt they could cope with, the main theme was that there were no significant side effects of treatment noted, but the eczema itself needed to be managed (n=47, 47.00%). There were 13 participants (13.00%) that described being able to cope with all side effects, 12 participants (12.00%) that described being able to cope with dryness and/or scarring and/or bruising, 10 participants (10.00%) that described being able to cope with dryness and/or scarring and/or bruising, and 10 participants (10.00%) that described being able to cope with the thinning of skin. There were a further 11 participants (11.00%) that did not describe any side effects that they could cope with, rather they only described side effects that were difficult.
- In relation to sub-group variations, participants with mild AD reported no significant side effects more frequently than the general cohort (63.64% compared to 47.00% in the general cohort) while participants with very severe AD reported this less frequently (31.82% compared to 47.00% in the general cohort). There were also no participants with mild AD that reported only having difficult side effects.
- For the participants that did speak about difficult side effects, there was a broad range of difficult side effects noted by participants including coping with the impact on mental health, skin dryness, cracking, bruising and thinning, and the long-term impact of treatment, however no themes were coded more than ten times. The most common theme overall was difficulty coping with the impact on mental health (n=7, 7.00%).
- While we acknowledge that there were few significant themes identified in relation to difficult side effects, it is important to note that there were six participants (6.00%) that also noted the difficulties in managing long term side effects of treatment as this is also aligned with the psychological stress associated with AD.

Adherence to medication

- The main theme noted by 23 participants (23.00%) was that they would stick to a treatment for as long as it was working for them. In relation to a specific time frame in which participants would adhere to a treatment, the main time frame was about a month (n=19, 19.00%) followed by a week or less (n=16, 16.00%) and two to three months (n=16, 16.00%).
- There was one sub-group variation where participants with mild AD reported sticking to a treatment for as long as it worked more frequently than the general cohort (36.36% compared to 20.00% in the general cohort).

- Participants were asked what needed to change for them to feel as though a treatment was working. The key theme noted by over half of the cohort was needing to have a reduction in itchiness (n=53, 53.00%). Participants describes this as a key symptom that causes discomfort and the importance of ameliorating this. The next most common theme was that the AD needed to disappear in general (n=33, 33.00%) and there were three additional, common themes including needing to see a reduction in rash, redness or inflammation (n=26, 26.00%), needing to feel more comfortable in general (n=19, 19.00%) and a reduction on skin dryness, flakiness or skin cracking (n=18, 18.00%).
- There was one sub-group variation where there were no participants that had mild AD who reported needing the AD to disappear in general (compared to 33.00% in the general cohort).

Complementary therapies

- The main theme was that participants considered using various creams and gentle soaps as complementary therapies (n=36, 36.00%). This was followed by dietary changes that were also considered to be complementary therapies. There were 27 participants (27.00%) that described accessing naturopaths or homeopaths and 24 participants (24.00%) that described accessing Chinese medicine and acupuncture.
- There were a number of sub-group variations. Participants with mild AD reported using creams and gentle soaps more frequently than the general cohort (81.82% compared to 36.00% in the general cohort), while participants with moderate AD reported this less frequently (19.23% compared to 36.00% in the general cohort). In relation to dietary changes, participants with mild AD reported this less frequently (9.09% compared to 35.00% in the general cohort) and participants with severe AD reported this more frequently (51.22% compared to 36.00% in the general cohort). With the exception of using creams and gentle washes, participants with mild AD reported overall less use of complementary treatments over all themes.

Service provision and affordability

- The majority of patients had private healthcare insurance (n=75, 75%), and half of the participants were treated mostly as a public patient (n=50, 50%). Of those that were treated for atopic dermatitis in hospital, most were treated in a public hospital (n=39, 6.94%)
- Approximately half of the participants have never missed medical appointments due to cost (n=52, 52.00%), and have never been unable to afford prescription medications (n=49, 49.50%), however, approximately half of the participants have missed appointments or been unable to pay for medications at some point. The majority of participants have never had trouble paying for basic needs due to their diagnosis with atopic dermatitis (n=62, 62.00%).

Section 6: Information and communication

Access to information

- The majority of participants (n=75, 75.00%) described the internet as their main source of information. There was a large gap between this main theme and the next most common theme of accessing information through their treating clinician which was noted by 25 participants (25.00%).
- There were a number of sub-group variations. Participants with very severe AD described accessing information through their treating clinician less frequently than the general cohort (9.09% compared to 25.00% in the general cohort), while those with moderate AD accessed information this way more frequently (42.31% compared to 25.00% in the general cohort). There were also no participants with very severe AD that did not seek information about their condition, compared to 12.00% in the general cohort.

Information that was helpful

- 21 participants (21.00%) felt that was that no information or little information was particularly helpful. This primarily referred to participants feeling as though there were no concrete answers or that information did not offer anything beyond what they already knew. There were 14 participants that described information about diet as being a useful topic and 14 participants (14.00%) that described information about other people's experience as helpful. There were 13 participants (13.00%) that described the internet being a

useful source of information. Some of the specific topics that participants described as being useful, in addition to diet, were information about treatments (n=10, 10.00%) and information about allergies and triggers (n=9, 9.00%).

- In relation to sub-group variations, participants with mild AD described dietary information as being helpful more frequently than participants in the general cohort (36.36% compared to 14.00% in the general cohort) and however overall, this group reported the various types of information as being useful, less frequently than the general cohort.

Information that was not helpful

- The main theme in this section was that there was not information that was not helpful (n=28, 28.00%). There were 15 participants (15.00%) that described being confident in deciding whether or not information was credible in relation to determining if it was useful. The next most common theme was that information based on the experience of others was not helpful (n=13, 13.00%). Information provided by general practitioners or specialists was described as not being helpful by 11 participants (11.00%). The final theme in this section was in relation to a lack of new information (n=10, 10.00%).
- There were two sub-group variations. Participants with mild AD reported no information as being unhelpful more frequently than the general cohort (54.55% compared to 28.00% in the general cohort) and also reported receiving conflicting information more frequently than the general cohort (18.18% compared to 4.00% in the general cohort).

Timing of information

- The two most common themes were being most receptive to information when AD becomes worse (during flares) (n=22, 22.00%) and the same number of people had no particular time in which they could absorb information better. The next most common theme was that participants were most receptive to information when they were well and not too busy (n=17, 17.00%). Participants described that the time during flares and when life is busy, is too distracting to take in information.
- Participants with mild AD reported having a preference for information during flares, more frequently than the general cohort (45.45% compared to 22.00% in the general cohort). This sub-group also reported having no preference in relation to timing of information less frequently (9.09% compared to 22.00% in the general cohort) and receiving information at times when they are not too busy, less frequently (9.09% compared to 22.00% in the general cohort). Participants with moderate AD reported a preference for receiving information at times when they are not too busy, more frequently (30.77% compared to 17.00% in the general population and participants with very severe AD reported this less frequently (4.55% compared to 17.00% in the general population).

Health professional communication

- The main theme described by close to half of all participants (n=48, 48.00%) was that they felt their AD was dismissed by health professionals in general. The next most common theme was that communication was overall positive (n=32, 32.00%). There were also 15 participants that spoke about health professionals not understanding AD and therefore, not always providing accurate information.
- In relation to sub-group variations, participants with mild AD and moderate AD reported overall positive communication (holistic) more frequently than the general cohort (45.45% and 46.15% compared to 32.00% in the general cohort) while participants with severe and very severe AD reported this less frequently (26.83% and 16.16% compared to 32.00% in the general cohort).

Respect shown to patients

- The majority of participants (n=51, 51.00%) reported that they had been treated with respect. There were 35 participants (35.00%) that reported that they were treated with respect however, they also felt that they were often dismissed and/or that their AD was not being taken seriously
- In relation to sub-group variations, participants with mild AD reported being treated respectfully more frequently (72.73%) while participants with very severe AD reported this less frequently (31.82%) than the general cohort (51.00%). Participants with mild AD reported not being heard or feeling like there was a lack

of knowledge about AD, less frequently (18.18%) while participants with very severe AD reported this more frequently (45.45%) than the general cohort (35.00%). Participants with very severe AD also reported not being treated respectfully more frequently than the general cohort (22.73% compared to 11.00% in the general cohort).

Knowledge and confidence

The Partners in Health questionnaire (PIH) measures an individual's knowledge and confidence for managing their own health. The Partners in Health comprises a global score, 4 sub scales; knowledge, treatment, symptoms and coping. A higher score denotes a better outcome.

- Overall, the participants scored in the top quintile for, adherence to treatment, and management of symptoms, indicating very good outcomes; the overall median score for knowledge, and mean score for coping and total score were all in the second highest quintile indicating outcomes.
- Participants with very severe disease scored lower compared to all other groups in the PIH coping and PIH total score.
- There were no differences observed in PIH subscales by comorbid depression and anxiety, location and education status.

Information given by healthcare professionals and searched for independently.

- Information about treatment options (77.00%), disease management (41.00%) and dietary information (27.00%) were most frequently given to participants by healthcare professionals, and information about clinical trials (3.00%) and psychological support (2.86%) were given least often.
- Information about treatment options (74.00%), disease cause (58.00%), and disease management (57.00%) were most often searched for independently by participants, and clinical trials (14.00%) and how to interpret test results (16.00%) were least searched for.

Most trusted information sources

- Across all participants, information from the not for profit or charitable organisations was most trusted followed by participants' hospital or clinic, then government, and then pharmaceutical companies. This order of trusted information source was the same for all of the subgroups (disease severity, comorbid depression and anxiety, location and education) with the exception of those with moderate disease. Those with moderate disease most trusted information from government.

Section 7: Experience of care and support

Coordination of care

- Overall the entire cohort had a mean communication score of 38.06, total score of 64.06, a median score of 5.00 for care co-ordination and 6.00 for care received; these scores fall in the middle of the scale. The median score for navigation was 26.00, this falls in the second highest quintiles indicating good navigation.
- The care coordination navigation scores and total scores were better for those with moderate disease compared to those with either severe or very severe; and the care coordination communication scores were better for those with moderate disease compared to those with very severe disease.
- There was a significant difference between those that live in metropolitan areas compared with those that live in regional/rural areas for care coordination. Those that live in regional/rural areas had a higher score.
- There were no significant differences in care coordination between the comorbid depression and anxiety subgroups or the education status subgroups.

Care and support

- Participants were asked what care and support they had received throughout their experience. The majority of participants described care and support coming from family and friends (n=76; 76.00%), and this was the most common theme followed by care and support accessed from the hospital or clinical setting (n=27;

27.00%). There were also 16 (16.00%) participants that described feeling as though they did not need additional support, however, participants that had severe AD were stated this less frequently (9.09% compared to 16.00% in the general cohort). This was also stated less frequently by participants that had a high school/trade education (7.14 compared to 16.00% in the general cohort).

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.

Section 9: Expectations of future treatment, care and support, information and communication

Expectations of future treatment

- When asked about their expectations of future treatment, there were a number of themes that emerged. The most common single them (n=27, 27.00%) was that there should be a more holistic approach to treatment and this included access to different treatment options. There were two similar themes in relation

to the expectation or hope that treatments would make the eczema go away (n=19, 19.00%) and that treatments would offer a cure (n=18, 18.00%). In relation to treatments that would make eczema go away, there was an underlying acknowledgement that eczema would always be part of the person's life. This differentiated the theme from treatments that would offer a cure where the hope or expectation was there, however the participants realised it was potentially unrealistic.

- There were 15 participants (15.00%) that described the expectation or hope that treatments would be affordable or less costly. The final theme noted by 15 participants (15.00%) was in relation to the severity of side effects. Participants described the expectation that treatments would be safe and not be detrimental to their long-term health.
- Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it. The most important aspects reported were severe and uncontrolled itching and raw sensitive swollen skin from scratching, the least important sleep disturbance and sores that may become infected.
- Participants were asked to rank what is important for them overall when they make decisions about treatment and care. The most important aspects were safety of treatment/weighing up risks and benefits, severity of side effects and impact on quality of life. The least important were cost, ability to stick to treatment and including family in decision-making.
- Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care. The two most important values were quality of life and access for all patients to all treatments and services, the least important was economic value to government.

Expectation of future information provision

- Participants were asked what they would like to see in the future in relation to information provision. The most frequent theme was that participants would like information to be more available and easy to access (n=39, 39.00%). This theme included being able to know where to find information, which is not always obvious. There were 19 participants (19.00%) that were not able to provide recommendations on future information. Within these comments there was a sense of apathy that, because there were no cures or they did not think there were any advancements in treatments, there was little point in offering more information. Some of the specific topics that participants identified for future information provision were in relation to the causes of AD (n=10, 10.00%) and also how to identify and manage flares (n=10, 10.00%).

Expectation of future healthcare professional communication

- In relation to what participants would like to see improved in relation to the way that health professionals communicate with patients, the most frequent theme was the expectation that health professionals communicate with more compassion, empathy and to take their condition seriously (n=28, 28.00%). There were 20 participants (20.00%) that described the need for more accurate information and for health professionals to have more expertise in the field. An additional theme identified was that participants expect health professionals to listen to the patient, as they know their body best (n=14, 14.00%). This was followed by the expectation to have a care plan or structured follow-up (n=12, 12.00%) and finally, the expectation that health professionals should offer information about all treatments, medical and complementary (n=10, 10.00%).

Expectation of future care and support

- Participants were asked whether there was anything they would like to see in relation to the way the care and support they receive. There were two main themes identified including recommendations to develop opportunities to understand their condition, whether it is in relation to allergies, triggers or how to manage their condition (n=18, 18.00%). The second main theme was the recommendation for specialist services, either a clinic or telephone support line that is accessible to people diagnosed with AD (n=13, 13.00%).

Messages

- Participants were asked what their message to people who make decisions about their condition would be. There was one main theme noted by over half of the cohort (n=56, 56.00%) where participants had the message that their condition should be taken seriously and that there is a need for compassion and to actively listen to patients. This included that their condition can be debilitating and that it is life-long. There were 34 participants that whose message was to treat the condition holistically, including emotional

support, having a care plan and being told about treatment options. An additional 15 participants (15.00%) had the message that there needs to be more funding, not only for research but to develop health professionals to have more understanding and knowledge of the condition. The final theme was a message to consider the cost of treatments and financial burden patients often face (n=11, 11.00%).

Section 10: Advice to other patients and families

Summary

- Participants were asked what advice they would give to other people who are newly diagnosed with AD and their families. There were two key themes including to find what works best for you and this was noted by 26 participants (26.00%). The next most common theme was in a similar vein where participants spoke about various individual products that had worked for them, demonstrating the individual nature of the condition (n=24, 24.00%). Other themes included to pay attention to your diet, as many people found this to be helpful (n=18, 18.00%), do as much of your own research as possible (n=11, 11.00%) and to use gentle body washes and moisturizers - be diligent with moisturizing (n=11, 11.00%).

Table i: Sub-group variations

	Mild AD	Moderate AD	Severe AD	Very severe AD	Depression/ Anxiety	Regional/ Rural	Metropolitan	University educated	High school/ Trade educated
Baseline health				Poorer scores for physical functioning, role limitations due to physical health, emotional well-being, social functioning, pain, and general health SF36 scales, and fatigue	Poorer scores for physical functioning, role limitations due to emotional problems, emotional well-being, social functioning, pain and general health			Better scores for social functioning, pain and general health	
Symptoms that led to diagnosis	Red to brownish-grey patches	Red to brownish-grey patches							Allergies that led to diagnosis
Diagnostic tests	Skin examination only								
Support at diagnosis	No support at diagnosis	Enough support at diagnosis							
Knowledge of disease at diagnosis				Knew about AD through other family members					
Description of prognosis	AD is something they will have for their lifetime			AD is under control					
Discussions about treatments				No or limited treatment options					
Decisions about treatment	An individual process								

Summary

	Mild AD	Moderate AD	Severe AD	Very severe AD	Depression/ Anxiety	Regional/ Rural	Metropolitan	University educated	High school/ Trade educated
Considerations when making decisions about treatment	Severity of side effects Treatment effectiveness								Treatment effectiveness
Changes in approach to decision making	More informed over time								
Side effects	No significant side effects No difficult side effects			No significant side effects					
Adherence to medication	As long as it works AD needs to disappear								
Complementary therapies	Creams and gentle soaps Use of comp. therapies in general	Creams and gentle soaps	Dietary changes						
Access to information		Through their treating clinician		Through their treating clinician Did not seek information at all					
Helpful information	Information about diet								
Unhelpful information	No information is unhelpful Conflicting information								
Timing of information	During flares No preference When busy/not distracted	When busy/not distracted		When busy/not distracted					

Summary

	Mild AD	Moderate AD	Severe AD	Very severe AD	Depression/ Anxiety	Regional/ Rural	Metropolitan	University educated	High school/ Trade educated
Trusted information			Information from government						
Partners in Health				Lower coping and total score		Higher care coordination score			
Health professional communication	Positive and holistic	Positive and holistic	Positive and holistic	Positive and holistic					
Care coordination		Better navigation and communication						Received better care	
Respect	Treated respectfully Not being heard			Treated respectfully Not being heard	Not treated respectfully				
Care and support				No additional support needed					No additional support needed
Average no. symptoms experienced	4	6.12	7	7.36					
Quality of life	Impact on self- esteem Impact on relationships Impact on being able to work Itch affecting sleep No impact on sleep								
Everyday activities to maintain health	Daily routine of moisturizers	Avoid certain foods		Avoid certain foods					
Impact on relationships	No burden on relationships Significant burden on relationships								

Summary

	Mild AD	Moderate AD	Severe AD	Very severe AD	Depression/ Anxiety	Regional/ Rural	Metropolitan	University educated	High school/ Trade educated
Burden on family	No assistance now, but would have in earlier years	No additional assistance needed							
Fear of Progression				Greater fear of progression	Greater fear of progression				

Key

Less frequently

More frequently

Section 1 Introduction and methods

Section 1: Introduction and methodology

Summary

- Atopic dermatitis (AD) is an inflammatory skin condition associated with other atopic manifestations such as asthma, rhinitis and food allergy.
- It presents in varying degrees of severity from a mild disease treated with over-the-counter products to severe disease requiring treatment with systemic immunosuppressive agents.
- Common symptoms of AD include itchiness, red to brownish-grey patches on the skin, small, raised bumps, which may leak fluid and crust over when scratched, and/or thickened, cracked, dry, scaly skin.
- Onset of AD occurs most commonly in infants and children, however it can occur at any age with clinical features varying with age of onset.
- Patient Experience, Expectations and Knowledge (PEEK) is a research program developed by the International Centre for Community-Driven Research (CCDR). The aim of PEEK is to conduct patient experience studies across several disease areas using a protocol that will allow for comparisons over time (both quantitative and qualitative components). PEEK studies give us a clear picture and historical record of what it is like to be a patient at a given point in time, and by asking patients about their expectations, PEEK studies give us a way forward to support patients and their families with treatments, information and care.
- In this PEEK study, 100 people diagnosed with AD throughout Australia participated in the study that included a structured interview and quantitative questionnaire. This study in AD is therefore the largest mixed methodology study worldwide conducted in last five years and the only study that focuses on an Australian population. In addition, PEEK is a comprehensive study covering all aspects of disease experience from symptoms, diagnosis, treatment, healthcare communication, information provision, care and support, quality of life, and future treatment and care expectations.

Introduction

Atopic dermatitis (AD) is an inflammatory skin condition associated with other atopic manifestations such as asthma, rhinitis and food allergy.¹⁻³ It presents in varying degrees of severity from a mild disease treated with over-the-counter products to severe disease requiring treatment with systemic immunosuppressive agents.⁴ AD can be classified into either intrinsic or extrinsic AD with the classification of disease depending on co-existence with allergic features.⁵ Common symptoms of AD include itchiness, red to brownish-grey patches on the skin, small, raised bumps, which may leak fluid and crust over when scratched, and/or thickened, cracked, dry, scaly skin.⁶ Onset of AD occurs most commonly in infants and children, however it can occur at any age with clinical features varying with age of onset.⁷

Genetic predisposition and environmental factors are known to be related to the development of AD. The biological mechanisms that lead to AD are characterised by epidermal barrier defects and T-helper type 2 mediated inflammation.⁸ Barrier defects associated with AD result in what is known as the 'atopic march' which can lead to food allergy, allergic rhinitis and asthma.⁹ This march is thought to occur due to epicutaneous sensitization by allergens followed by migration of sensitized immune cells to respiratory epithelia.¹⁰ The mutation of the filaggrin gene, which encodes a protein that is important in maintaining epidermal barrier protection, and is a risk factor for AD.¹¹ This mutation has been observed to increase susceptibility to asthma and allergic rhinitis in people who also have AD.¹¹ Abnormalities in other epidermal barrier proteins include loricrin and involucrin.¹²

AD has been linked to multiple non-atopic comorbidities such as learning disorders in children (ADHD), speech disorders, anxiety and depression headaches, anaemia and epilepsy.⁴ AD is also associated with injury such as fractures and is likely from low bone mineral density attributable to oral corticosteroid and cutaneous inflammation that leads directly to bone loss.^{13,14}

The prevalence of atopic dermatitis in Australia is poorly reported, the most recent publication from the ABS that reports data on eczema was the 2004-5 National Health Survey, and this publication does not report specifically on atopic dermatitis but a more general term of dermatitis and eczema.¹⁵ The prevalence of dermatitis and eczema in Australia in the 2004-5 Australian National Health Survey is

estimated at 221, 200, approximately 1.1% of the population.¹⁵ The age group most affected are those aged 0-14, with a prevalence of 99,400, approximately 2.5 % of children aged 0 to 14. Other studies of atopic dermatitis in Australia report the estimate the prevalence rates in children in Australia and New Zealand at 10.7%,¹⁶ in Australian pre-schoolers at 30.8%,¹⁷ and adults in central Victoria at 6.9%.¹⁸

Patient Experience, Expectations and Knowledge (PEEK)

Patient Experience, Expectations and Knowledge (PEEK) is a research program developed by the International Centre for Community-Driven Research (CCDR). The aim of PEEK is to conduct patient experience studies across several disease areas using a protocol that will allow for comparisons over time (both quantitative and qualitative components). PEEK studies give us a clear picture and historical record of what it is like to be a patient at a given point in time, and by asking patients about their expectations, PEEK studies give us a way forward to support patients and their families with treatments, information and care.

The research protocol used in PEEK studies is independently driven by CCDR. PEEK studies include a quantitative and qualitative component. The quantitative component is based on a series of validated tools. The qualitative component is the result of two years of protocol testing by CCDR to develop a structured interview that solicits patient experience data and provides patients with the opportunity to provide advice on what they would like to see in relation to future treatment, information and care. The structured interview has also been designed so that the outcomes of PEEK studies can inform policy, research, care, information, supportive care services and advocacy efforts.

Methodology

Participants

To be eligible for the study, participants needed to have been diagnosed with AD, have experienced the healthcare system in Australia, be 18 years of age or older, be able to speak English, and be able to give consent to participate in the study. Recruitment commenced on 7 October 2017 and the study closed for recruitment on 5 December 2017. Participants were recruited via email and social media through CCDR and the Eczema Association of Australasia and Allergy and Anaphylaxis Australia.

Ethics

Ethics approval for this study was granted (as a low or negligible risk research study) by the Centre for Community-Driven Research Ethics Committee (Reference CS_Q4_03).

Data collection

Data for the online questionnaire was collected using Zoho Survey (Zoho Corporation Pvt. Ltd. Pleasanton, California, USA, www.zoho.com/survey). Participants completed the survey between October 2017 and January 2018.

There were seven researchers who conducted telephone interviews and used standardised prompts throughout the interview. The interviews were recorded and transcribed verbatim. Identifying names and locations were not included in the transcript. All transcripts were checked against the original recording for quality assurance.

Interview data was collected from October 2017 and January 2018.

Online questionnaire (quantitative)

The online questionnaire consisted of the 36-Item Short Form Health Survey (SF36) (RAND Health)¹, a modified Cancer Care Coordination Questionnaire for Patients (CCCQ) (Young et al 2011²), the Short Fear of

Progression Questionnaire (FOP12) (Hinz et al³), and the Partners in Health version 2 (PIH) (Petrov 2010)⁴. In addition investigator derived questions about demographics, diagnosis, treatment received and future treatment decisions making were included.

Structured Interview (qualitative)

Interviews were conducted via telephone by a registered nurse, allied health professional or researcher with a background in psychology, who were trained in qualitative research. The first set of interview questions guided the patient through their whole experience from when symptoms were noticed up to the present day.

The next set of questions allowed patients to reflect on what they would like to see in the future in relation to treatment and care, and asked them what their messages to decision-makers would be about the care and treatment patients with their condition receive. The interview also asks patients about the advice they would give to others recently diagnosed with their condition or disease. All interviews were recorded and transcribed verbatim.

Questionnaire analysis

Statistical analysis was conducted using R included in the packages “car”, “dplyr” and “ggplot2” (R 3.4.3 GUI 1.70 El Capitan build (7463)). The aim of the statistical analysis of the SF36, CCCQ, FOP12, and PIH responses was to identify variations by respondent type (by disease severity, location and by education), and by co-morbidity or symptom type (co-morbid depression and anxiety). Global scales and sub scales were calculated according to reported instructions.^(1,3,4) For comparisons by disease severity, a one-way analysis of variance (ANOVA) analysis was conducted. A Tukey HSD test was used post-hoc to identify the source of any differences identified in the one-way ANOVA test. Where the assumptions for the one-way ANOVA were not met, a Kuskal-Wallis rank sum test on care was conducted with post hoc pairwise comparisons using Wilcoxon rank sum test. When the assumption of

³ Hinz et al. Fear of progression in patients 6 months after cancer rehabilitation-a validation study of the fear of progression questionnaire FoPQ-12. Support Care Cancer. 2015 Jun;23(6):1579-87. doi: 10.1007/s00520-014-2516-5. Epub 2014 Nov 21.

⁴ Petkov J, Harvey P, Battersby M. The internal consistency and construct validity of the partners in health scale: validation of a patient rated chronic condition self-management measure. Qual Life Res. 2010 Sep;19(7):1079-85. doi: 10.1007/s11136-010-9661-1. Epub 2010 May 1.

¹ 36-Item Short Form Survey (SF-36) Scoring instructions https://www.rand.org/health/surveys_tools/mos/36-item-short-form/scoring.html

² Young et al. Measuring cancer care coordination: development and validation of a questionnaire for patients. BMC Cancer. 2011; 11: 298. Published online 2011 Jul 15. doi: 10.1186/1471-2407-11-298

equal variances were not met, a Welch one-way test was used with post-hoc pairwise t-tests with no assumption of equal variances.

For all other comparisons, a two-sample t-test was used when assumptions for normality and variance were met, or when assumptions were not met, a Wilcoxon rank sum test with continuity correction was used.

Questions where participants were asked to rank preferences were analysed using weighted averages. Weights were applied in reverse, the most preferred option was given the largest weight equal to the number of options, the least preferred option was given the lowest weight of 1.

Structured interviews analysis

A content analysis was conducted using conventional analysis to identify major themes from structured interviews. Text from the interviews were read line-by-line by the lead researcher and then imported into NVivo 8 (QSR International). Each question within the interview was individually analysed. Initial categories and definitions were identified and registered in NVivo. The minimum coded unit was a sentence however there were also paragraphs and phrases that were coded as a unit.

A second researcher verified the codes and definitions, and the text was coded until full agreement was reached using the process of consensual validation. In general, a theme needed to occur more than ten times to be discussed within the results.

Data analysis and final reporting was completed on 16 February 2018.

Position of this study

A search was conducted in Pubmed to identify AD quality of life or patient experience studies of adults that had been conducted in the past five years in any developed country (Table 1.1).

Thirty-four studies were identified that collected patient self reported data. One study employed mixed methodology that included quantitative data on 110 participants about exercise participation and satisfaction, of this cohort, 11 participants had in depth interviews¹⁹. The remaining 33 studies including patient reported quantitative data. Fifteen clinical trials were identified of between 15 and 1379

patients (Table 1.1). Three of these studies collected anxiety, Health Related Quality of Life (HRQoL) and symptoms²⁰⁻²³, one collected HRQoL, patient experience and symptoms²⁴, two HRQoL and symptoms^{25,26}, one anxiety and symptoms²⁷, one HRQoL and patient experience²⁸, three collected symptoms²⁹⁻³¹, two with HRQoL^{32,33}, and one with anxiety³⁴.

Three studies focused on HRQoL, two collecting only HRQoL^{2,35}, and one including HRQoL, patient navigation and patient experience³⁶. Two studies focused on burden of disease with one collecting comorbidities and healthcare utilization³⁷, and another collecting symptoms⁶. Two studies explored heliotherapy collecting HRQoL and symptoms^{38,39}. Two studies extracted data from national health surveys, one collected anxiety, HRQoL and productivity data⁴⁰, another collected anxiety^{41,42}. The remaining studies include a work productivity study collecting HRQoL, productivity and symptoms⁴³, two studies that collected anxiety and symptoms, one focused on adherence to treatment⁴⁴ and one on symptoms⁴⁵. A willingness to pay study collected anxiety and cost data⁴⁶, a patient education study collected anxiety and symptoms data⁴⁷, three studies collected symptoms data, one focused on lifestyle³, one on care models⁴⁸ and another on disease markers⁴⁹.

In this PEEK study, 100 people diagnosed with AD throughout Australia participated in the study that included a structured interview and quantitative questionnaire. This study in AD is therefore the largest mixed methodology study conducted in the last five years, and the only study focused on an Australian population. In addition, PEEK is a comprehensive study covering all aspects of disease experience from symptoms, diagnosis, treatment, healthcare communication, information provision, care and support, quality of life, and future treatment and care expectations.

Table 1.1: Comparative studies

Author, Year, Country	Number AD participants	Study Focus	Anxiety	Quality of Life	Care coordination	Patient navigation	Patient experience	Cost	Expectations/priorities for future	Comorbidities	Productivity	Healthcare utilisation	Symptoms	Lifestyle modification	Qualitative
Lonne-Rahm et al ¹⁹ , 2014, Sweden	110	Lifestyle												X	n=11 in depth interview
Simpson et al ²¹ , 2016, International	1379	Clinical Trial	X	X									X		
Blauvelt et al ²³ , 2017, International	440	Clinical trial	X	X									X		
Simpson et al ^{20,22} , 2016, International	380	Clinical Trial	X	X									X		
Ständer et al ²⁴ , 2016, Germany	70	Clinical Trial		x			x						x		
Åckerström et al ²⁶ , 2015, Sweden	172	Clinical Trial		X									X		
Caillaud et al ²⁵ , 2014, South Korea	22	Clinical trial		X									X		
Lopes et al ²⁷ , 2015, Portugal	78	Clinical Trial	X										X		
Brandt et al, 2014, ²⁸ USA	57	Clinical trial		X			X								
Hoffman and Kircik ⁵⁰ , 2017, USA	120	Clinical Trial		X											
Lynde and Andriessen ²⁹ , 2014, Canada	118	Clinical Trial											X		
Jesenak et al ³⁰ , 2016, Slovakia	105	Clinical Trial											X		
Kircik ³¹ , 2014, USA	20	Clinical Trial											X		
Matsumoto et al ³² , 2014, Japan	44	Clinical Trial		X											
Onumah et al ³³ , 2013, USA	20	Clinical trial		X											
Wyrzykowska et al ³⁴ , 2015, Denmark	15	Clinical Trial	X												
Holm et al ³⁵ , 2016, Denmark	191	HRQoL		X											
Torrelo et al ³⁶ , 2013, Spain	141	HRQoL		X		X	X								
Heede et al ² , 2017, Denmark	102	HRQoL		X											
Eckert et al ³⁷ , 2018, USA	306	Burden of AD								X		X			
Vakharia et al ⁶ , 2017, USA	305	Burden of AD		X									X		
Karppinen et al ³⁸ , 2017, Finland	53	Heliotherapy		X									X		
Karppinen et al ³⁹ , 2015, Finland	13	Heliotherapy		X									X		
Lee et al ⁴¹ , 2018, Kwak et al ⁴² , 2017, South Korea	677	National health survey	X												
Eckert et al ⁵¹ , 2017, USA	349	National health survey	X	X							X				
Yano et al ⁴³ , 2013, Japan	112	Work productivity		X							X		X		
Ortiz de Frutos et al ⁴⁴ , 2014, Spain	125	Adherence to treatment	X									X			
Wei et al ⁴⁵ , 2017, USA	678	Symptoms	X									X			
Beikert et al ⁴⁶ , 2014, Germany	384	Willingness to pay	X					X							
Heratizadeh et al ⁴⁷ , 2017, Germany	315	Patient education	X										X		
Langenbruch et al ⁵² , 2014, Germany															
Steinke et al ⁵³ , 2014, Germany	1678	Therapeutic benefit		X											
Nosrati et al ³ , 2017, USA	169	Lifestyle											X		
Armstrong et al ⁴⁸ , 2015, USA	156	Care model											X		
Mizawa et al ⁴⁹ , 2013, Japan	30	Disease marker											X		

Abbreviations

AD	Atopic Dermatitis
CCDR	Centre for Community-Driven Research
DF	Degrees of Freedom. The number of values in the final calculation of a statistic that are free to vary.
IQR	Interquartile range. A measure of statistical dispersion, being equal to the difference between 75th and 25th percentiles, or between upper and lower quartiles.
F	F-statistic. An F statistic is a value you get when you run an ANOVA test or a regression analysis to find out if the means between two populations are significantly different.
FOP	Fear of Progression. Tool to measure anxiety related to progression.
HRQoL	Health Related Quality of Life
MS	Mean of Squares. Estimates of variance across groups
SD Standard Deviation.	A quantity expressing by how much the members of a group differ from the mean value for the group.
SF 36	Short Form Health Survey 36
SS or χ^2	Sum of the Squares. The sum of squares is used as a mathematical way to find the function which best fits (varies least) from the data.
t	t-Statistic. Size of the difference relative to the variation in your sample data.
PEEK	Patient Experience, Expectations and Knowledge
PIH	Partners in Health
P	Probability value. A small <i>p</i> -value (typically ≤ 0.05) indicates strong. A large <i>p</i> -value (> 0.05) indicates weak evidence.
QoL	Quality of Life
W	Kendall's W statistic (sometimes called the Coefficient of Concordance) is a non parametric statistic. It's used to assess agreement between different raters, and ranges from 0 to 1.

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Section 2 Demographics

Section 2: Demographics and study population characteristics

- One hundred participants from Australia were included in the study.
- Participants reported a current Patient Oriented Eczema Measure (POEM) score to determine severity of disease. 11 were mild (11.00%), 26 Moderate (26.00%), 41 severe (41.00%) and 22 very severe (22.00%).
- Participants came from NSW (45.00%), Queensland (17.00%), Victoria (13.00%), Western Australia (11.00%), South Australia (5.00%), Australian Capital Territory (4.00%), Tasmania (4.00%) and the Northern Territory (1.00%); from major cities (59.00%) and regional/rural (41.00%).
- Eighty-eight females (88.00%) and 12 males (12.00%) were included in this study.
- Subgroup analysis were included throughout the study. The subgroups were disease severity - mild (11.00%), moderate (26.00%), severe (41.00%) and very severe (22.00%); those with comorbid anxiety and depression (39.00%) and those without (61.00%); by location- Major city (59.00%) or Regional/Remote (41.00%); and by education status - those with a university degree (58.00%) and those with high school or trade (42.00%).
- The baseline health SF36 scores for the entire cohort were very good for physical functioning and role limitations due to physical health; the scores for role limitations due to emotional problems, emotional well-being, social functioning and pain were good; and the scores for energy/fatigue, general health and health change were moderate.
- Participants with very severe disease scored worse than all other groups for the physical functioning, role limitations due to physical health, emotional well-being, social functioning, pain, and general health SF36 scales, and had worse scores than those with moderate or severe disease for energy/fatigue. There were no differences between disease severity groups for role limitations due to emotional problems or for health change scores.
- Participants with comorbid depression and anxiety scored worse on the physical functioning, role limitations due to emotional problems, emotional well-being, social functioning, pain and general health SF36 scales compared to those that did not have comorbid depression and anxiety. There were no differences between these groups for energy/fatigue, role limitations due to physical health, and health change scores.
- Participants that had a university degree had better outcomes compared to those with high school or trade for the social functioning, pain and general health SF36 scales.
- No differences in SF36 subscales were observed for those that lived in major cities compared to those that live in regional/rural areas.

Demographics

One hundred participants from Australia were recruited into the study, including 88 females (88.00%) and 12 males (12.00%). The majority of participants were from NSW (n=45, 45.00%), Queensland (n=17, n=17.00%), and Victoria (n=13, 13.00%), and most live in major cities (n=59, 59.00%). Participants reported a current Patient Oriented Eczema Measure (POEM) score to determine severity of disease. Within this study 11 participants had mild

AD (11.00%), 26 Moderate AD (26.00%), 41 severe AD (41.00%) and 22 very severe AD (22.00%). Subgroup analysis were included throughout the study. The subgroups were by location, major city (59.00%) or regional or remote (41.00%); those with comorbid anxiety and depression (39.00%) and those without (61.00%); those with a university degree (58.00%) and those with high school or trade (42.00%); and by disease severity measured by POEM score. Demographics of participants are available in Table 2.1.

Table 2.1: Demographics

Characteristic	n=	Percentage of Participants
Gender (n=100)		
Female	88	88.00
Male	12	12.00
Type of atopic dermatitis, measured by POEM (n=100)		
Mild	11	11.00
Moderate	26	26.00
Severe	41	41.00
Very severe	22	22.00
Location (n=100)		
Major city	59	59.00
Inner Regional	28	28.00
Outer Regional	10	10.00
Very remote	3	3.00
Index of Relative Socio-economic Advantage and Disadvantage (Decile) * 1= most disadvantaged, 10= most advantaged) (n=100)		
1	7	7.00
2	8	8.00
3	4	4.00
4	11	11.00
5	12	12.00
6	11	11.00
7	10	10.00
8	7	7.00
9	15	15.00
10	15	15.00

Section 2

Characteristic	n=	Percentage of Participants
State (n=100)		
NSW	45	45.00
QLD	17	17.00
VIC	13	13.00
WA	11	11.00
SA	5	5.00
ACT	4	4.00
TAS	4	4.00
NT	1	1.00
Associate, Bachelor or Graduate Degree (n=100)		
Yes	58	58.00
No	42	42.00
Comorbid Depression and Anxiety (n=100)		
Yes	39	39.00
No	61	61.00
Age group (n=100)		
18-24	15	15.00
25-34	24	24.00
35-44	31	31.00
45-54	15	15.00
55-64	9	9.00
65-74	6	6.00
Country of birth (n=100)		
Australia	75	75.00
New Zealand	6	6.00
United Kingdom	5	5.00
United States of America	4	4.00
Brazil	2	2.00
South Africa	2	2.00
Chile	1	1.00
Germany	1	1.00
India	1	1.00
Philippines	1	1.00
Singapore	1	1.00
Vietnam	1	1.00

Section 2

Characteristic	n=	Percentage of Participants
What race or ethnicity (n=100)		
Caucasian/White	80	80.00
Asian	9	9.00
Australian	5	5.00
Arab	1	1.00
Caucasian/Asian	1	1.00
European	1	1.00
Hispanic/Latino	1	1.00
Latino/Caucasian	1	1.00
Other	1	1.00
What is the highest level of education completed (n=100)		
Less than high school degree	2	2.00
High school degree or equivalent	19	19.00
Some college but no degree	15	15.00
Trade	6	6.00
Associate degree	3	3.00
Bachelor degree	34	34.00
Graduate degree	21	21.00
Accessed "My Health Record" (n=100)		
Yes	16	16.00
No	45	45.00
Not sure	8	8.00
I don't know what "My Health Record" is	31	31.00
Usefulness of "My Health Record" in managing condition (n=16)		
Good	1	6.25
Acceptable	4	25.00
Poor	5	31.25
Very poor	6	37.50

Characteristic	n=	Percentage of Participants
Employment status (Can choose more than one option) (n=100)		
Employed, working part time	36	36.00
Employed, working full time	34	34.00
Full/part time study	10	10.00
Not employed, looking for work	10	10.00
Currently receiving Centrelink support	9	9.00
Retired	8	8.00
Full/part time carer	7	7.00
Disabled, not able to work	3	3.00
Current relationship status (n=100)		
Married	51	51.00
Single, never married	17	17.00
Not married, but co-habiting with a significant other	12	12.00
Not married, but in a relationship with a significant other	7	7.00
Divorced	6	6.00
In a domestic partnership or civil union	4	4.00
Separated	3	3.00
Full time or part time carer status (n=100)		
Children	35	35.00
Parents	1	1.00
Siblings	1	1.00
Spouse/partner	1	1.00
Not a carer	62	62.00
Number of dependent children under 18 (n=100)		
0	62	62.00
1	9	9.00
2	16	16.00
3	9	9.00
4 or more	4	4.00

Section 2

Characteristic	n=	Percentage of Participants
Religion (Can choose more than one option) (n=66)		
No Religion	36	54.55
Catholicism	13	19.70
Christianity	11	16.67
Judaism	4	6.06
Buddhism	3	4.55
Anglican	1	1.52
Presbyterian	1	1.52
Protestantism	1	1.52
Interested in national politics (n=66)		
Extremely interested	3	4.55
Very interested	10	15.15
Moderately interested	25	37.88
Slightly interested	15	22.73
Not at all interested	13	19.70
Political leanings (n=65)		
Extremely left	3	4.62
Moderately left	13	20.00
Slightly left	9	13.85
Neither/neutral	30	46.15
Slightly right	5	7.69
Moderately right	4	6.15
Extremely right	1	1.54

Baseline health

The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual. The SF36 comprises nine sub scales: physical functioning, role limitations due to physical health, role limitations due to emotional problems, energy and fatigue, emotional well-being, social function, pain, general health, and health change from one year ago. A higher score denotes a better health/function.

Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 2.2, where the scale has a normal distribution mean and sd are used as a central measure, otherwise the median and IQR are used. The overall scores for the cohort were in the highest quintile for physical functioning (Median=95.00, IQR=20.00), and role limitations due to physical functioning (Median = 100, IQR = 75.00) indicating very good scores for the

cohort. The scores for role limitations due to emotional problems (Median=66.67, IQR=100.00), emotional well-being (Median=68.00, IQR=28.00), social functioning (Median=62.50, SD = 37.50) and pain (Median=67.50, IQR = 45.00) were in the second highest quintile indicating good scores. The energy/fatigue (Mean=42.00, SD=19.17), general health (Median= 60.00, IQR=40.00) and health change (Median=50.00, IQR=50.00) scales had scores in the middle quintile indicating moderate scores.

Comparisons of SF36 have been made based on disease severity (Figures 2.1 to 2.9, Tables 2.3 to 2.7), comorbid depression/anxiety status (Figures 2.10 to 2.18, Tables 2.8 to 2.9), location (Figures 2.19 to 2.27, Tables 2.10 to 2.11), and education level (Figures 2.28 to 2.36, Tables 2.12 to 2.13).

Table 2.2: SF36 scores for entire cohort

Scale	Median	IQR	Possible range
Physical functioning	95.00	20.00	0-100
Role limitations due to physical health	100.00	75.00	0-100
Role limitations due to emotional problems	66.67	100.00	0-100
Energy/fatigue*	42.00	19.17	0-100
Emotional well-being	68.00	28.00	0-100
Social functioning	62.50	37.50	0-100
Pain	67.50	45.00	0-100
General health	60.00	40.00	0-100
Health change	50.00	50.00	0-100

*Mean and SD used, Energy/Fatigue had a normal distribution

Comparisons of SF36 sub scales by disease severity

Comparisons of SF36 sub scales were made between participants by disease severity; mild, moderate, severe and very severe. Boxplots of each SF36 scale by disease severity are displayed in Figures 2.1-2.9, and summary statistics are listed in Tables 2.3. A one-way ANOVA test was used with the assumptions for response variable residuals were normally distributed and variances of populations were equal. When the ANOVA test indicated a significant result, post hoc comparisons were made using the Tukey HSD test (Tables 2.4 – 2.5). When the assumptions for a one-way ANOVA were not met, a Kruskal-Wallis test was used, and when a significant result was indicated, it

was followed by post hoc Wilcoxon rank sum tests between groups (Tables 2.6 – 2.7).

A one way ANOVA test indicated a significant difference in the SF36 energy/fatigue scale between groups [$F(3,96) = 4.54$, $p = 0.0051$] (Table 2.4). Post hoc comparisons using the Tukey HSD test indicated that the mean score for those with very severe disease was significantly lower than those with moderate or severe disease (Table 2.5). A one way ANOVA test indicated a significant differences between groups for the social functioning [$F(3,96) = 10.56$, $p < 0.0001$], pain and [$F(3,96) = 18.60$, $p < 0.0001$] and general health [$F(3,96) = 11.20$, $p < 0.0001$] scales (Table 2.4). Post hoc comparisons using the Tukey HSD test indicated that the mean

score for those with very severe disease was significantly lower than any other group for the social functioning, pain and general health scales (Table 2.5).

A Kruskal-Wallis test indicated a significant difference between severity for the physical function [$\chi^2(3) = 10.84$, $p=0.0126$], role limitations due to physical health [$\chi^2(3) = 10.06$, $p=0.0181$] and emotional well-being scales [$\chi^2(3) = 11.06$, $p=0.0114$] (Table 2.8).

Post hoc pairwise comparisons using Wilcoxon rank sum test indicated that the median scores were significantly lower for the very severe group compared to all other groups for the physical function, role limitations due to physical health and emotional well-being scales (Table 2.9). There were no significant differences between the groups for role limitations due to emotional problems or for health change (Table 2.8).

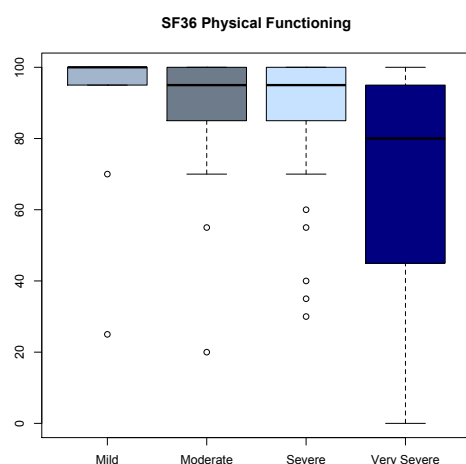


Figure 2.1: Boxplot of SF36 physical functioning by disease severity

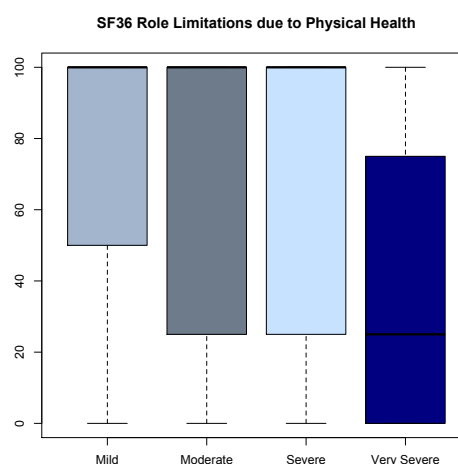


Figure 2.2: Boxplot of SF36 role limitations due to physical health by disease severity

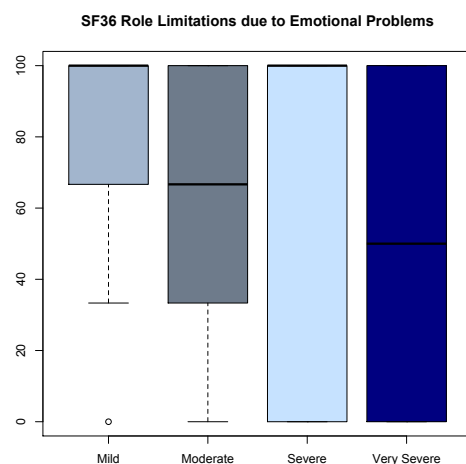


Figure 2.3: Boxplot of SF36 role limitations due to emotional problems by disease severity

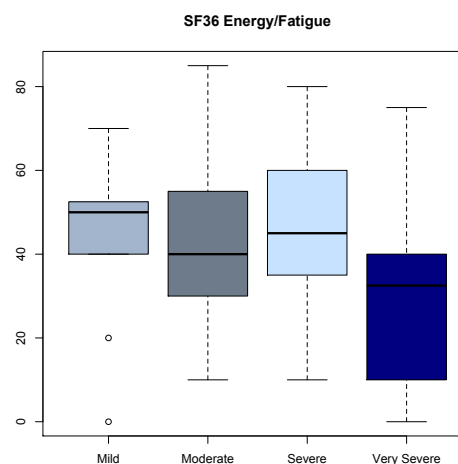


Figure 2.4: Boxplot of SF36 energy/fatigue by disease severity

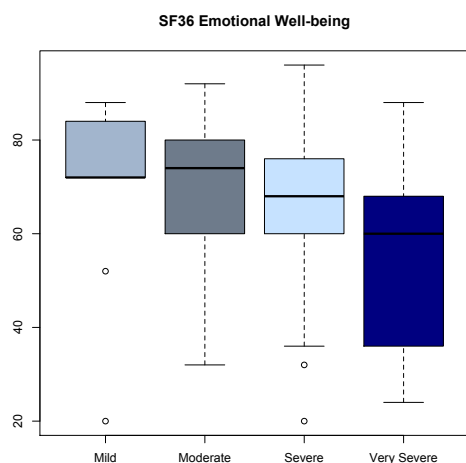


Figure 2.5: Boxplot of SF36 emotional well-being by disease severity

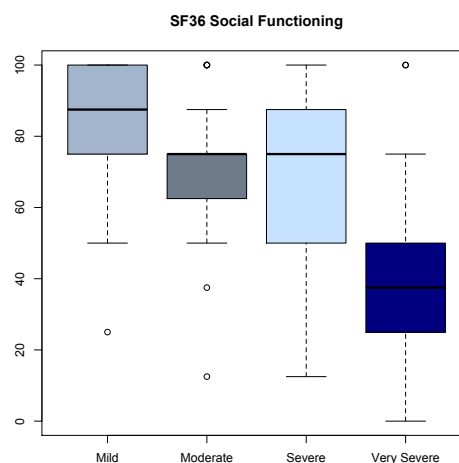


Figure2.6: Boxplot of SF36 social functioning by disease severity

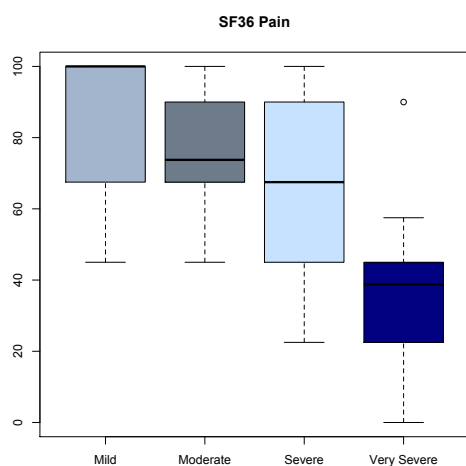


Figure 2.7: Boxplot of SF36 pain by disease severity

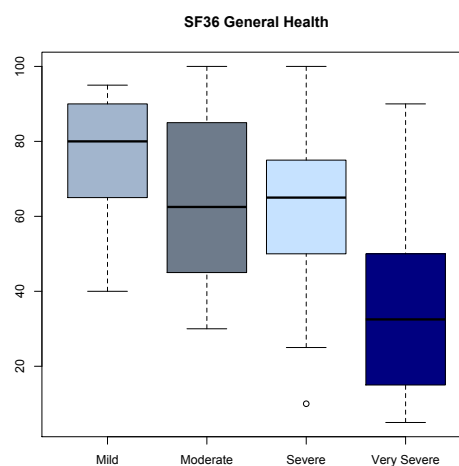


Figure2.8: Boxplot of SF36 general health by disease severity

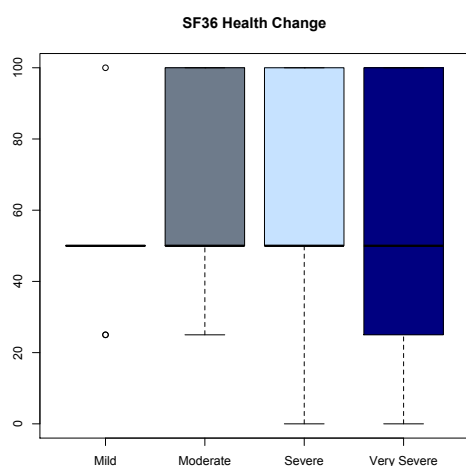


Figure 2.9: Boxplot of SF36 health change by disease severity

Table 2.3: Summary statistics by disease severity

SF36 subscale	Group	Count	Mean	Sd	Median	IQR
Physical function	Mild	11	89.10	23.00	100.00	5.00
	Moderate	26	89.00	18.00	95.00	12.80
	Severe	41	86.80	18.40	95.00	15.00
	Very severe	22	68.90	30.50	80.00	47.50
Role limitations due to physical health	Mild	11	75.00	38.70	100.00	50.00
	Moderate	26	68.30	41.00	100.00	68.00
	Severe	41	71.30	40.90	100.00	75.00
	Very severe	22	39.80	40.60	25.00	75.00
Role limitations due to emotional problems	Mild	11	78.8	37.30	100.00	33.30
	Moderate	26	60.30	40.00	66.70	66.70
	Severe	41	65.90	43.10	100.00	100.00
	Very severe	22	48.50	43.30	50.00	100.00
Energy/Fatigue	Mild	11	44.10	19.30	50.00	12.50
	Moderate	26	44.00	18.80	40.00	22.50
	Severe	41	46.80	15.40	45.00	25.00
	Very severe	22	29.50	21.60	32.50	30.00
Emotional well-being	Mild	11	71.30	19.90	72.00	12.00
	Moderate	26	69.40	15.90	74.00	18.00
	Severe	41	67.20	17.70	68.00	16.00
	Very severe	22	54.20	19.90	60.00	31.00
Social Functioning	Mild	11	81.80	24.60	87.50	25.00
	Moderate	26	70.20	19.70	75.00	12.50
	Severe	41	71.00	23.10	75.00	37.50
	Very severe	22	40.90	28.90	37.50	25.00
Pain	Mild	11	84.30	20.80	100.00	32.50
	Moderate	26	75.00	16.60	73.80	20.00
	Severe	41	67.00	23.30	67.50	45.00
	Very severe	22	36.10	22.20	38.80	22.50
General health	Mild	11	75.00	17.50	80.00	25.00
	Moderate	26	63.70	22.10	62.50	37.50
	Severe	41	62.80	21.00	65.00	25.00
	Very severe	22	35.70	24.50	32.50	33.80
Health change	Mild	11	50.00	19.4	50.00	0.00
	Moderate	26	64.40	27.5	50.00	50.00
	Severe	41	61.00	30.6	50.00	50.00
	Very severe	22	53.4	33.0	50.00	62.50

Table 2.4: One-way ANOVA table for SF36 scales by disease severity

SF36 subscale		Sum of squares	Df	Mean square	F	P
Energy/Fatigue	Between Groups	4525	3	1508	4.54	0.0051*
	Within Groups	31875	96	332		
	Total	36400	99			
Social Functioning	Between Groups	18060	3	6020	10.56	P <0.0001*
	Within Groups	54707	96	570		
	Total	72767	99			
Pain	Between Groups	25122	3	8374	18.60	P <0.0001*
	Within Groups	43217	96	450		
	Total	68339	99			
General health	Between Groups	15899	3	5300	11.20	P <0.0001*
	Within Groups	45445	96	473		
	Total	61344	99			

Table 2.5: Post hoc Tuckey HSD test for SF36 scales by disease severity

SF36 subscale	Comparison	Mean difference	Lower	Upper	P adjusted
Energy/Fatigue	Moderate -Mild	-0.05	-17.19	17.08	1.0000
	Severe-Mild	2.74	-13.44	18.92	0.9709
	Very severe – Mild	-14.55	-32.14	3.05	0.1415
	Severe-Moderate	2.79	-9.15	14.73	0.9284
	Very Severe-Moderate	-14.49	-28.29	-0.69	0.0357*
	Very Severe-Severe	-17.28	-29.87	-4.69	0.0029*
Social Functioning	Moderate -Mild	-11.63	-34.08	10.82	0.5312
	Severe-Mild	-10.78	-31.98	10.41	0.5462
	Very severe – Mild	-40.91	-63.96	-17.86	<0.0001*
	Severe-Moderate	0.84	-14.80	16.49	0.9990
	Very Severe-Moderate	-29.28	-47.36	-11.20	0.0003*
	Very Severe-Severe	-30.13	-46.62	-13.63	<0.0001*
Pain	Moderate -Mild	-9.32	-29.27	10.635	0.6151
	Severe-Mild	-17.37	-36.20	1.47	0.0819
	Very severe – Mild	-48.18	-68.67	-27.70	<0.0001*
	Severe-Moderate	-8.05	-21.96	5.86	0.4337
	Very Severe-Moderate	-38.86	-54.93	-22.79	<0.0001*
	Very Severe-Severe	-30.81	-45.48	-16.15	<0.0001*
General health	Moderate -Mild	-11.35	-31.81	9.12	0.4718
	Severe-Mild	-12.20	-31.51	7.12	0.3555
	Very severe – Mild	-39.32	-60.33	-18.31	<0.0001*
	Severe-Moderate	-0.85	-15.11	13.41	0.9986
	Very Severe-Moderate	-27.97	-44.45	-11.49	0.0001*
	Very Severe-Severe	-27.12	-42.16	-12.09	<0.0001*

* Statistically significant at p<0.05

Table 2.6: Summary statistics and Kruskal-Wallis rank sum test for SF36 scales by disease severity

SF36 subscale	χ^2	Df	P
Physical functioning	10.84	3	0.0126*
Role limitations due to physical health	10.06	3	0.0181*
Role limitations due to emotional problems	5.20	3	0.1573
Emotional well-being	11.06	3	0.0114*
Health change	2.76	3	0.4294

* Statistically significant at $p < 0.05$

Table 2.7: Post hoc pairwise comparisons using Wilcoxon rank sum test, p-values

SF36 subscale	Group	Mild	Moderate	Severe
Physical functioning	Moderate	0.535		
	Severe	0.297	0.535	
	Very severe	0.036*	0.036*	0.036*
Role limitations due to physical health	Moderate	0.714		
	Severe	0.876	0.714	
	Very severe	0.052*	0.052*	0.027*
Emotional well-being	Moderate	0.505		
	Severe	0.420	0.522	
	Very severe	0.030*	0.025*	0.025*

* Statistically significant at $p < 0.05$

Comparisons of SF36 sub scales by comorbid depression and anxiety status

Comparisons of SF36 subscales were made between those that have comorbid depression and anxiety and those that do not. Boxplots of each SF36 scale by comorbid depression and anxiety status are displayed in Figures 2.10-2.18, and summary statistics are listed in Tables 2.8 and 2.9.

A two-sample t-test was used when assumptions for normality and variance were met (Table 2.8), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.9).

A two sample t-test indicated no significant differences between the two groups for the SF36 energy/fatigue scale (Table 2.8). Wilcoxon rank sum tests with continuity corrections revealed a significant difference between those that have both depression and anxiety and those that do not for the SF36 Physical functioning [$W=1465.00$, $P=0.0460$], role limitations due to emotional problems [$W=1679.50$, $p=0.0002$], emotional well-being [$W=1808.00$, $p<0.0001$], social functioning [$W=1750.00$, $p<0.0001$], pain [$W=1530.00$, $p=0.0155$], and general health [$W=1470.00$, $p<0.0473$] (Table 2.9). In each of these scales, those with both depression and anxiety scored worse than those that did not have both depression and anxiety (Table 2.9).

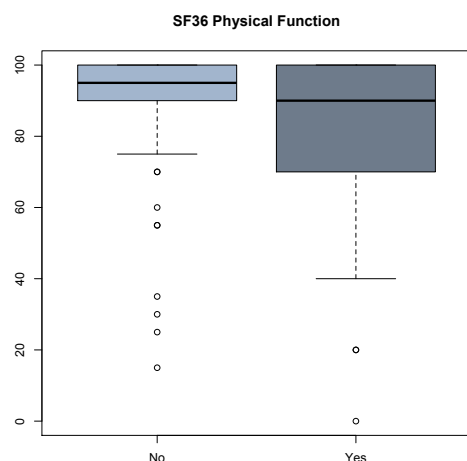


Figure 2.10: Boxplot of SF36 physical functioning by depression and anxiety status

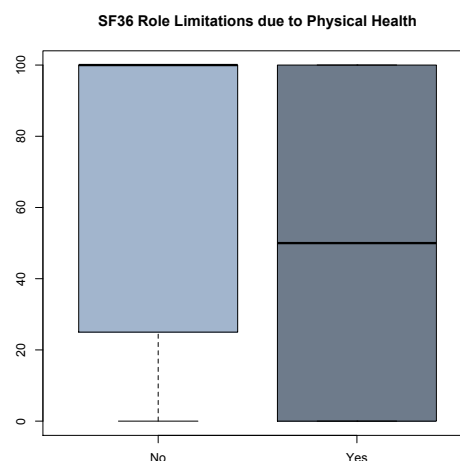


Figure 2.11: Boxplot of SF36 role limitations due to physical health by depression and anxiety status



Figure 2.12: Boxplot of SF36 role limitations due to emotional problems by depression and anxiety status

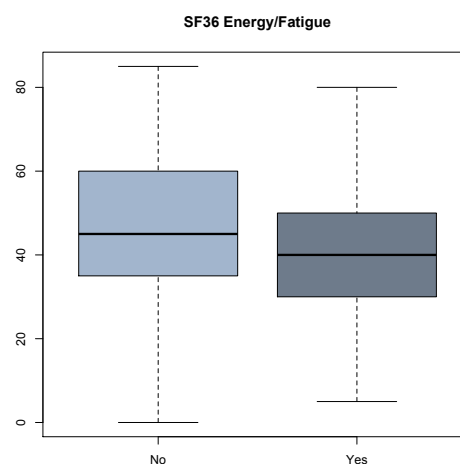


Figure 2.13: Boxplot of SF36 energy/fatigue by depression and anxiety status

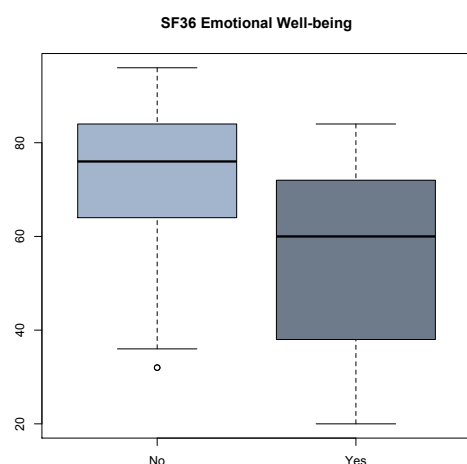


Figure 2.14: Boxplot of SF36 emotional well-being by depression and anxiety status

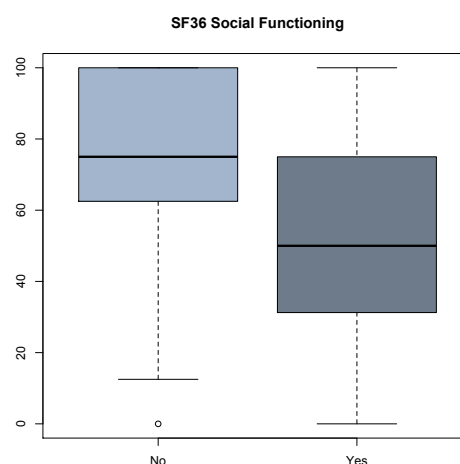


Figure 2.15: Boxplot of SF36 social functioning by depression and anxiety status

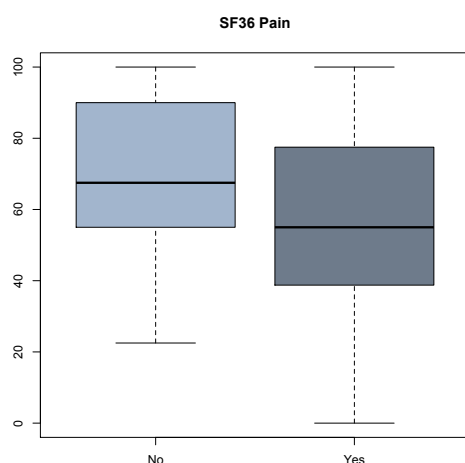


Figure 2.16: Boxplot of SF36 pain by depression and anxiety status

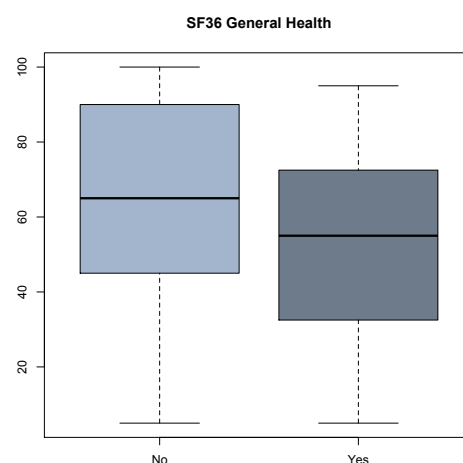


Figure 2.17: Boxplot of SF36 general health by depression and anxiety status

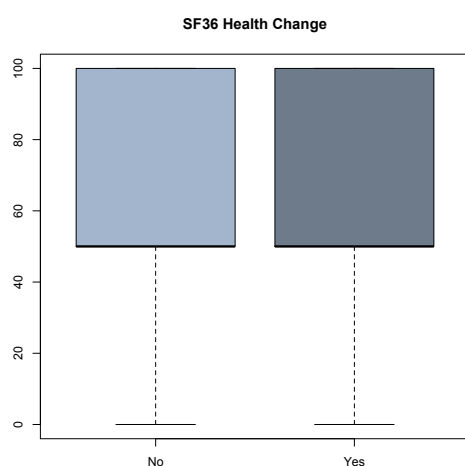


Figure 2.18: Boxplot of SF36 health change by depression and anxiety status

Table 2.8 Summary statistics and two sample t-test SF36 subscales by depression and anxiety status

SF36 subscale	Depression and Anxiety	Count	Mean	SD	t	df	P
Energy/Fatigue	No	61	43.70	18.80	1.10	60	0.2729
	Yes	39	39.40	19.60			

Table 2.9: Summary statistics Wilcoxon rank sum test with continuity correction SF36 subscales by depression and anxiety status

SF36 subscale	Depression and Anxiety	Count	Median	IQR	W	P
Physical functioning	No	61	95.00	10.00	1465.00	0.0460*
	Yes	39	90.00	30.00		
Role limitations due to physical health	No	61	100.00	75.00	1414.00	0.0855
	Yes	39	50.00	100.00		
Role limitations due to emotional problems	No	61	100.00	33.30	1679.5	0.0002*
	Yes	39	33.30	83.30		
Emotional well-being	No	61	76.00	20.00	1808.00	<0.0001*
	Yes	39	60.00	34.00		
Social functioning	No	61	75.00	37.50	1750.00	<0.0001*
	Yes	39	50.00	43.80		
Pain	No	61	67.50	35.00	1530.00	0.0155*
	Yes	39	55.00	38.80		
General Health	No	61	65.00	45.00	1470.00	0.0473*
	Yes	39	55.00	40.00		
Health change	No	61	50.00	50.00	1180.00	0.9450
	Yes	39	50.00	50.00		

* Statistically significant at $p < 0.05$

Comparisons of SF36 sub scales by location

Comparisons of SF36 sub scales were made between participants that live in major cities compared to those that live in regional or rural areas. Boxplots of each SF36 scale by location are displayed in Figures 2.19-2.27, and summary statistics are listed in Tables 2.10 and 2.11. A two-sample t-test was used when assumptions for normality and variance were met

(Table 2.10), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.11). No statistically significant differences were observed between these two groups for any SF36 sub scale (Tables 2.10 and 2.11).

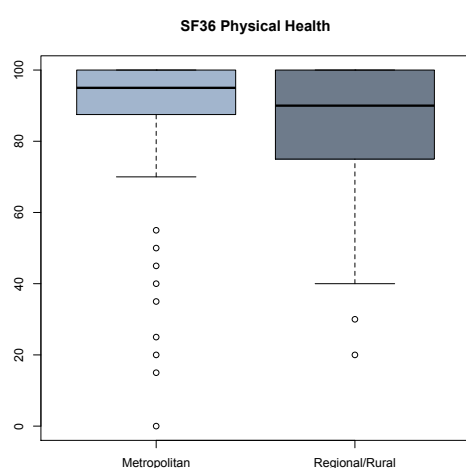


Figure 2.19: Boxplot of SF36 physical functioning by location



Figure 2.20: Boxplot of SF36 role limitations due to physical health by location



Figure 2.21: Boxplot of SF36 role limitations due to emotional problems by location

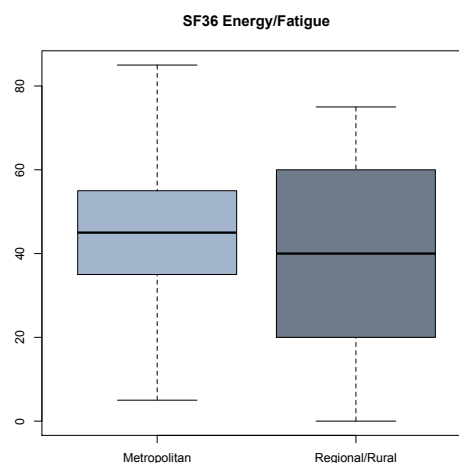


Figure 2.22: Boxplot of SF36 energy/fatigue by location

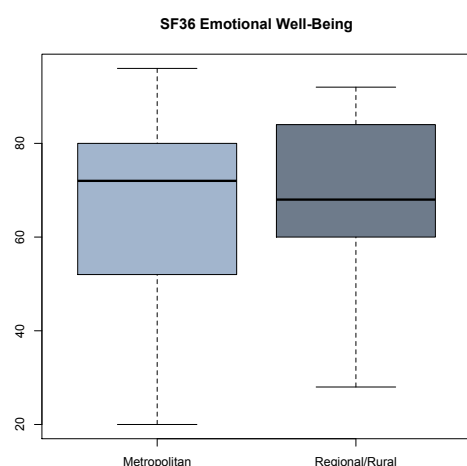
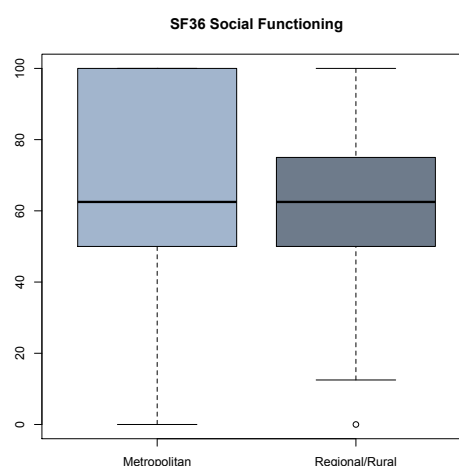


Figure 2.23: Boxplot of SF36 emotional well-being by location



2.24: Boxplot of SF36 social functioning by location

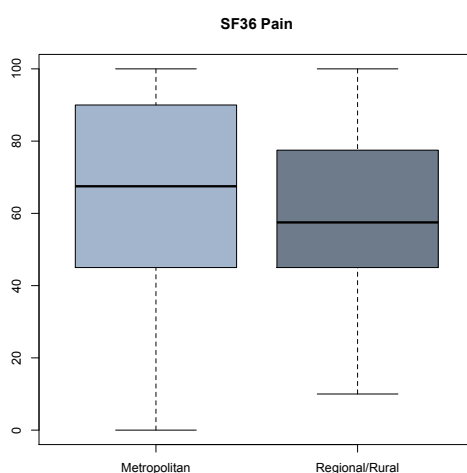
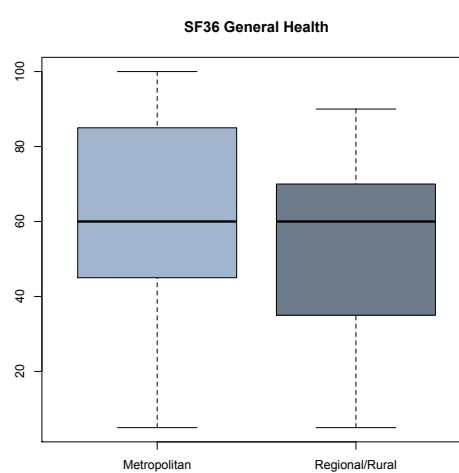


Figure 2.25: Boxplot of SF36 pain by location



2.26: Boxplot of SF36 general health by location

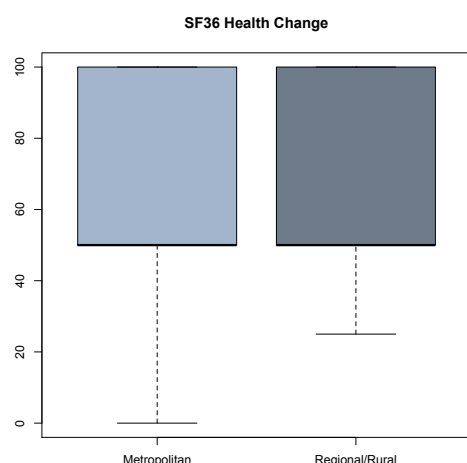


Figure 2.27: Boxplot of SF36 health change by location

Table 2.10: Summary statistics and two sample t-test SF36 subscales by location

SF36 subscale	Location	Count	Mean	SD	T	df	p
Energy/Fatigue	Major City	59	45.10	17.20	1.96	98	0.0532
	Regional/Remote	41	37.60	21.20			

Table 2.11: Summary statistics Wilcoxon rank sum test with continuity correction SF36 subscales by location

SF36 subscale	Depression and Anxiety	Count	Median	IQR	W	P
Physical functioning	Major City	59	95.00	12.50	1422.00	0.1271
	Regional/Remote	41	90.00	25.00		
Role limitations due to physical health	Major City	59	100.00	75.00	227.50	0.8940
	Regional/Remote	41	100.00	75.00		
Role limitations due to emotional problems	Major City	59	66.70	100.00	1102.00	0.4220
	Regional/Remote	41	100.00	66.70		
Emotional well-being	Major City	59	72.00	28.00	1228.00	0.8993
	Regional/Remote	41	68.00	24.00		
Social functioning	Major City	59	62.50	50.00	1357.50	0.2949
	Regional/Remote	41	62.50	25.00		
Pain	Major City	59	67.50	45.00	1414.00	0.1498
	Regional/Remote	41	57.50	32.50		
General Health	Major City	59	60.00	40.00	1432.00	0.1188
	Regional/Remote	41	60.00	35.00		
Health change	Major City	59	50.00	50.00	1221.50	0.9303
	Regional/Remote	41	50.00	50.00		

* Statistically significant at $p < 0.05$

Comparisons of SF36 sub scales by education

Comparisons of SF36 subscales were made by education status, comparing the highest level of education obtained, either university or high school/trade. Boxplots of each SF36 scale by education status are displayed in Figures 2.28-2.36, and summary statistics are listed in Tables 2.12 and 2.13. A two-sample t-test was used when

assumptions for normality and variance were met (Table 2.12), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.13).

Wilcoxon rank sum tests with continuity corrections revealed a significant difference between those with a university degree compared to those with high school or trade for the SF36 social functioning [$W=917.50$,

$p=0.0338$]; pain [$W=852.00$, $p=0.0101$]; and the general health score [$W=918.00$, $p=0.0360$] (Table 2.13).

In each of these scales, those with a university degree scored better than those with high school or trade

(Table 2.13). No other significant differences were observed (Tables 2.12 and 2.13).

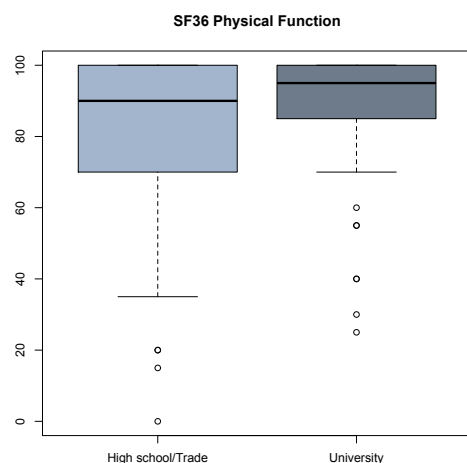


Figure 2.28: Boxplot of SF36 physical functioning by education



Figure 2.29: Boxplot of SF36 role limitations due to physical health by education

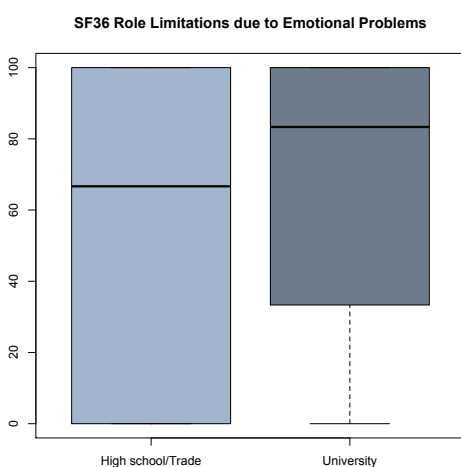


Figure 2.30: Boxplot of SF36 role limitations due to emotional problems by education

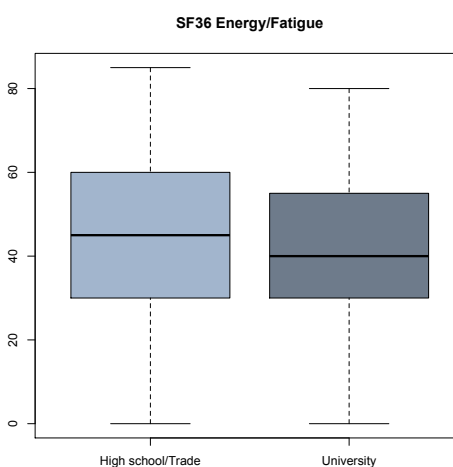


Figure 2.31: Boxplot of SF36 energy/fatigue by education

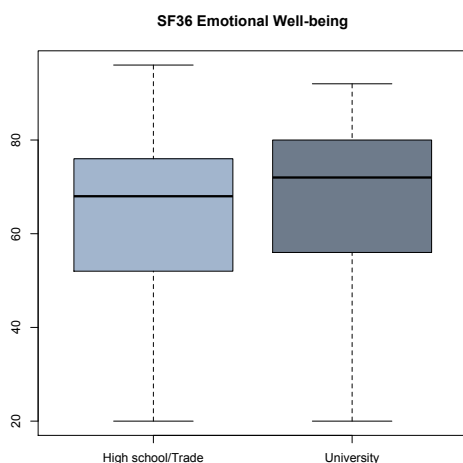
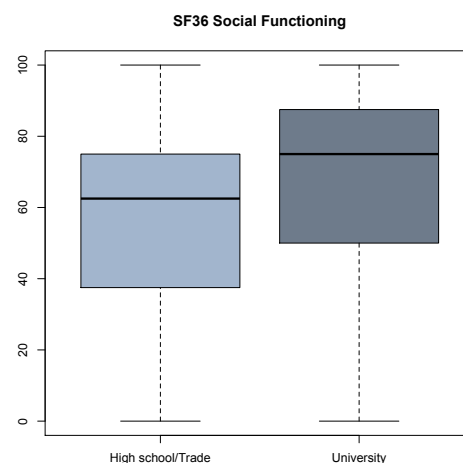


Figure 2.32: Boxplot of SF36 emotional well-being by education



2.33: Boxplot of SF36 social functioning by education

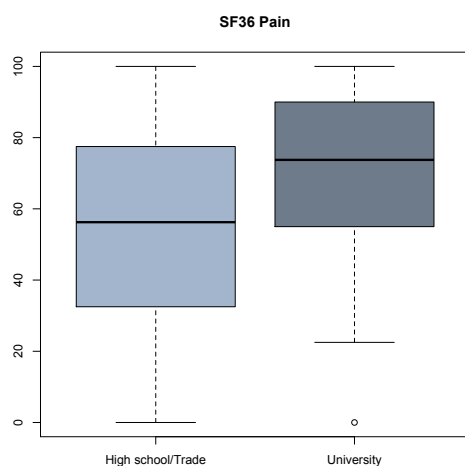
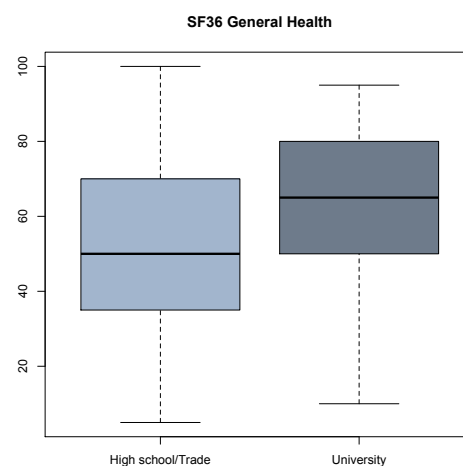


Figure 2.34: Boxplot of SF36 pain by education



2.35: Boxplot of SF36 general health by education

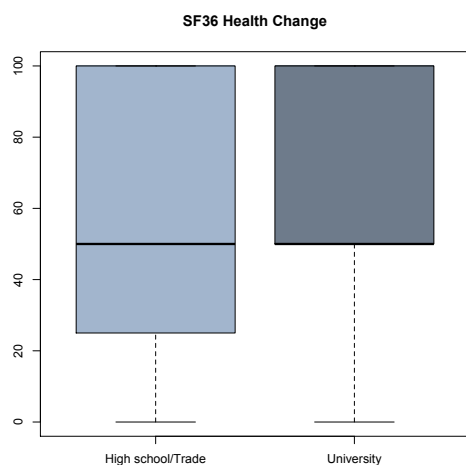


Figure 2.36: Boxplot of SF36 health change by education

Table 2.12: Summary statistics and two sample t-test SF36 subscales by education

SF36 subscale	Location	Count	Mean	SD	t	df	p
Energy/Fatigue	High school/Trade	42	42.00	20.70	0.01	98	0.9916
	University degree	58	42.00	18.20			

Table 2.13: Summary statistics Wilcoxon rank sum test with continuity correction SF36 subscales by location

SF36 subscale	Depression and Anxiety	Count	Median	IQR	W	P
Physical functioning	High school/Trade	42	90.00	28.80	958.00	0.0628
	University degree	58	95.00	13.80		
Role limitations due to physical health	High school/Trade	42	75.00	93.80	1060.50	0.2336
	University degree	58	100.00	75.00		
Role limitations due to emotional problems	High school/Trade	42	66.70	100.00	1125.00	0.4891
	University degree	58	83.30	66.70		
Emotional well-being	High school/Trade	42	68.00	24.00	1056.50	0.2593
	University degree	58	72.00	23.00		
Social functioning	High school/Trade	42	62.50	37.50	917.50	0.0338*
	University degree	58	75.00	34.40		
Pain	High school/Trade	42	56.20	42.50	852.00	0.0101*
	University degree	58	73.80	34.40		
General Health	High school/Trade	42	50.00	35.00	918.00	0.0360*
	University degree	58	65.00	30.00		
Health change	High school/Trade	42	50.00	62.50	1040.50	0.1799
	University degree	58	50.00	50.00		

* Statistically significant at $p < 0.05$

Section 2 Demographics

Section 2: Demographics and study population characteristics

- One hundred participants from Australia were included in the study.
- Participants reported a current Patient Oriented Eczema Measure (POEM) score to determine severity of disease. 11 were mild (11.00%), 26 Moderate (26.00%), 41 severe (41.00%) and 22 very severe (22.00%).
- Participants came from NSW (45.00%), Queensland (17.00%), Victoria (13.00%), Western Australia (11.00%), South Australia (5.00%), Australian Capital Territory (4.00%), Tasmania (4.00%) and the Northern Territory (1.00%); from major cities (59.00%) and regional/rural (41.00%).
- Eighty-eight females (88.00%) and 12 males (12.00%) were included in this study.
- Subgroup analysis were included throughout the study. The subgroups were disease severity - mild (11.00%), moderate (26.00%), severe (41.00%) and very severe (22.00%); those with comorbid anxiety and depression (39.00%) and those without (61.00%); by location- Major city (59.00%) or Regional/Remote (41.00%); and by education status - those with a university degree (58.00%) and those with high school or trade (42.00%).
- The baseline health SF36 scores for the entire cohort were very good for physical functioning and role limitations due to physical health; the scores for role limitations due to emotional problems, emotional well-being, social functioning and pain were good; and the scores for energy/fatigue, general health and health change were moderate.
- Participants with very severe disease scored worse than all other groups for the physical functioning, role limitations due to physical health, emotional well-being, social functioning, pain, and general health SF36 scales, and had worse scores than those with moderate or severe disease for energy/fatigue. There were no differences between disease severity groups for role limitations due to emotional problems or for health change scores.
- Participants with comorbid depression and anxiety scored worse on the physical functioning, role limitations due to emotional problems, emotional well-being, social functioning, pain and general health SF36 scales compared to those that did not have comorbid depression and anxiety. There were no differences between these groups for energy/fatigue, role limitations due to physical health, and health change scores.
- Participants that had a university degree had better outcomes compared to those with high school or trade for the social functioning, pain and general health SF36 scales.
- No differences in SF36 subscales were observed for those that lived in major cities compared to those that live in regional/rural areas.

Demographics

One hundred participants from Australia were recruited into the study, including 88 females (88.00%) and 12 males (12.00%). The majority of participants were from NSW (n=45, 45.00%), Queensland (n=17, n=17.00%), and Victoria (n=13, 13.00%), and most live in major cities (n=59, 59.00%). Participants reported a current Patient Oriented Eczema Measure (POEM) score to determine severity of disease. Within this study 11 participants had mild

AD (11.00%), 26 Moderate AD (26.00%), 41 severe AD (41.00%) and 22 very severe AD (22.00%). Subgroup analysis were included throughout the study. The subgroups were by location, major city (59.00%) or regional or remote (41.00%); those with comorbid anxiety and depression (39.00%) and those without (61.00%); those with a university degree (58.00%) and those with high school or trade (42.00%); and by disease severity measured by POEM score. Demographics of participants are available in Table 2.1.

Table 2.1: Demographics

Characteristic	n=	Percentage of Participants
Gender (n=100)		
Female	88	88.00
Male	12	12.00
Type of atopic dermatitis, measured by POEM (n=100)		
Mild	11	11.00
Moderate	26	26.00
Severe	41	41.00
Very severe	22	22.00
Location (n=100)		
Major city	59	59.00
Inner Regional	28	28.00
Outer Regional	10	10.00
Very remote	3	3.00
Index of Relative Socio-economic Advantage and Disadvantage (Decile) * 1= most disadvantaged, 10= most advantaged) (n=100)		
1	7	7.00
2	8	8.00
3	4	4.00
4	11	11.00
5	12	12.00
6	11	11.00
7	10	10.00
8	7	7.00
9	15	15.00
10	15	15.00

Section 2

Characteristic	n=	Percentage of Participants
State (n=100)		
NSW	45	45.00
QLD	17	17.00
VIC	13	13.00
WA	11	11.00
SA	5	5.00
ACT	4	4.00
TAS	4	4.00
NT	1	1.00
Associate, Bachelor or Graduate Degree (n=100)		
Yes	58	58.00
No	42	42.00
Comorbid Depression and Anxiety (n=100)		
Yes	39	39.00
No	61	61.00
Age group (n=100)		
18-24	15	15.00
25-34	24	24.00
35-44	31	31.00
45-54	15	15.00
55-64	9	9.00
65-74	6	6.00
Country of birth (n=100)		
Australia	75	75.00
New Zealand	6	6.00
United Kingdom	5	5.00
United States of America	4	4.00
Brazil	2	2.00
South Africa	2	2.00
Chile	1	1.00
Germany	1	1.00
India	1	1.00
Phillipines	1	1.00
Singapore	1	1.00
Vietnam	1	1.00

Section 2

Characteristic	n=	Percentage of Participants
What race or ethnicity (n=100)		
Caucasian/White	80	80.00
Asian	9	9.00
Australian	5	5.00
Arab	1	1.00
Caucasian/Asian	1	1.00
European	1	1.00
Hispanic/Latino	1	1.00
Latino/Caucasian	1	1.00
Other	1	1.00
What is the highest level of education completed (n=100)		
Less than high school degree	2	2.00
High school degree or equivalent	19	19.00
Some college but no degree	15	15.00
Trade	6	6.00
Associate degree	3	3.00
Bachelor degree	34	34.00
Graduate degree	21	21.00
Accessed "My Health Record" (n=100)		
Yes	16	16.00
No	45	45.00
Not sure	8	8.00
I don't know what "My Health Record" is	31	31.00
Usefulness of "My Health Record" in managing condition (n=16)		
Good	1	6.25
Acceptable	4	25.00
Poor	5	31.25
Very poor	6	37.50

Section 2

Characteristic	n=	Percentage of Participants
Employment status (Can choose more than one option) (n=100)		
Employed, working part time	36	36.00
Employed, working full time	34	34.00
Full/part time study	10	10.00
Not employed, looking for work	10	10.00
Currently receiving Centrelink support	9	9.00
Retired	8	8.00
Full/part time carer	7	7.00
Disabled, not able to work	3	3.00
Current relationship status (n=100)		
Married	51	51.00
Single, never married	17	17.00
Not married, but co-habiting with a significant other	12	12.00
Not married, but in a relationship with a significant other	7	7.00
Divorced	6	6.00
In a domestic partnership or civil union	4	4.00
Separated	3	3.00
Full time or part time carer status (n=100)		
Children	35	35.00
Parents	1	1.00
Siblings	1	1.00
Spouse/partner	1	1.00
Not a carer	62	62.00
Number of dependent children under 18 (n=100)		
0	62	62.00
1	9	9.00
2	16	16.00
3	9	9.00
4 or more	4	4.00

Section 2

Characteristic	n=	Percentage of Participants
Religion (Can choose more than one option) (n=66)		
No Religion	36	54.55
Catholicism	13	19.70
Christianity	11	16.67
Judaism	4	6.06
Buddhism	3	4.55
Anglican	1	1.52
Presbyterian	1	1.52
Protestantism	1	1.52
Interested in national politics (n=66)		
Extremely interested	3	4.55
Very interested	10	15.15
Moderately interested	25	37.88
Slightly interested	15	22.73
Not at all interested	13	19.70
Political leanings (n=65)		
Extremely left	3	4.62
Moderately left	13	20.00
Slightly left	9	13.85
Neither/neutral	30	46.15
Slightly right	5	7.69
Moderately right	4	6.15
Extremely right	1	1.54

Baseline health

The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual. The SF36 comprises nine sub scales: physical functioning, role limitations due to physical health, role limitations due to emotional problems, energy and fatigue, emotional well-being, social function, pain, general health, and health change from one year ago. A higher score denotes a better health/function.

Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 2.2, where the scale has a normal distribution mean and sd are used as a central measure, otherwise the median and IQR are used. The overall scores for the cohort were in the highest quintile for physical functioning (Median=95.00, IQR=20.00), and role limitations due to physical functioning (Median = 100, IQR = 75.00) indicating very good scores for the

cohort. The scores for role limitations due to emotional problems (Median=66.67, IQR=100.00), emotional well-being (Median=68.00, IQR=28.00), social functioning (Median=62.50, SD = 37.50) and pain (Median=67.50, IQR = 45.00) were in the second highest quintile indicating good scores. The energy/fatigue (Mean=42.00, SD=19.17), general health (Median= 60.00, IQR=40.00) and health change (Median=50.00, IQR=50.00) scales had scores in the middle quintile indicating moderate scores.

Comparisons of SF36 have been made based on disease severity (Figures 2.1 to 2.9, Tables 2.3 to 2.7), comorbid depression/anxiety status (Figures 2.10 to 2.18, Tables 2.8 to 2.9), location (Figures 2.19 to 2.27, Tables 2.10 to 2.11), and education level (Figures 2.28 to 2.36, Tables 2.12 to 2.13).

Table 2.2: SF36 scores for entire cohort

Scale	Median	IQR	Possible range
Physical functioning	95.00	20.00	0-100
Role limitations due to physical health	100.00	75.00	0-100
Role limitations due to emotional problems	66.67	100.00	0-100
Energy/fatigue*	42.00	19.17	0-100
Emotional well-being	68.00	28.00	0-100
Social functioning	62.50	37.50	0-100
Pain	67.50	45.00	0-100
General health	60.00	40.00	0-100
Health change	50.00	50.00	0-100

*Mean and SD used, Energy/Fatigue had a normal distribution

Comparisons of SF36 sub scales by disease severity

Comparisons of SF36 sub scales were made between participants by disease severity; mild, moderate, severe and very severe. Boxplots of each SF36 scale by disease severity are displayed in Figures 2.1-2.9, and summary statistics are listed in Tables 2.3. A one-way ANOVA test was used with the assumptions for response variable residuals were normally distributed and variances of populations were equal. When the ANOVA test indicated a significant result, post hoc comparisons were made using the Tukey HSD test (Tables 2.4 – 2.5). When the assumptions for a one-way ANOVA were not met, a Kruskal-Wallis test was used, and when a significant result was indicated, it

was followed by post hoc Wilcoxon rank sum tests between groups (Tables 2.6 – 2.7).

A one way ANOVA test indicated a significant difference in the SF36 energy/fatigue scale between groups [$F(3,96) = 4.54$, $p = 0.0051$] (Table 2.4). Post hoc comparisons using the Tukey HSD test indicated that the mean score for those with very severe disease was significantly lower than those with moderate or severe disease (Table 2.5). A one way ANOVA test indicated a significant differences between groups for the social functioning [$F(3,96) = 10.56$, $p < 0.0001$], pain and [$F(3,96) = 18.60$, $p < 0.0001$] and general health [$F(3,96) = 11.20$, $p < 0.0001$] scales (Table 2.4). Post hoc comparisons using the Tukey HSD test indicated that the mean

score for those with very severe disease was significantly lower than any other group for the social functioning, pain and general health scales (Table 2.5).

A Kruskal-Wallis test indicated a significant difference between severity for the physical function [$\chi^2(3) = 10.84$, $p=0.0126$], role limitations due to physical health [$\chi^2(3) = 10.06$, $p=0.0181$] and emotional well-being scales [$\chi^2(3) = 11.06$, $p=0.0114$] (Table 2.8).

Post hoc pairwise comparisons using Wilcoxon rank sum test indicated that the median scores were significantly lower for the very severe group compared to all other groups for the physical function, role limitations due to physical health and emotional well-being scales (Table 2.9). There were no significant differences between the groups for role limitations due to emotional problems or for health change (Table 2.8).

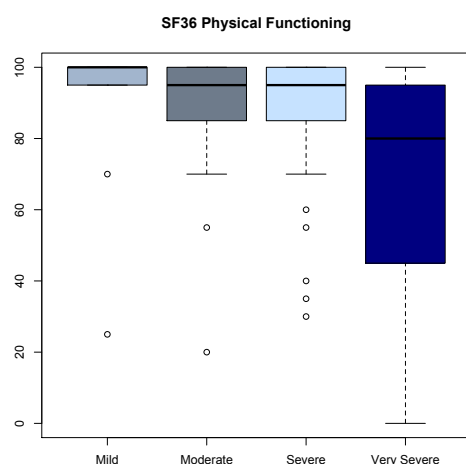


Figure 2.1: Boxplot of SF36 physical functioning by disease severity

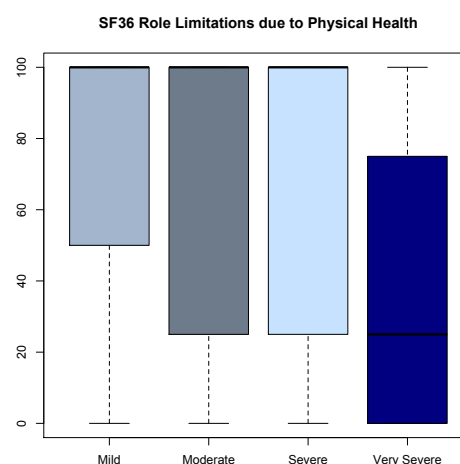


Figure 2.2: Boxplot of SF36 role limitations due to physical health by disease severity

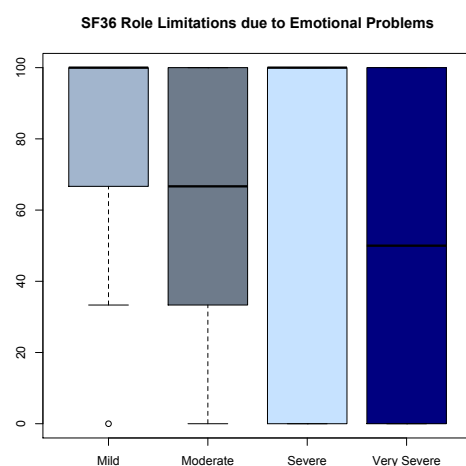


Figure 2.3: Boxplot of SF36 role limitations due to emotional problems by disease severity

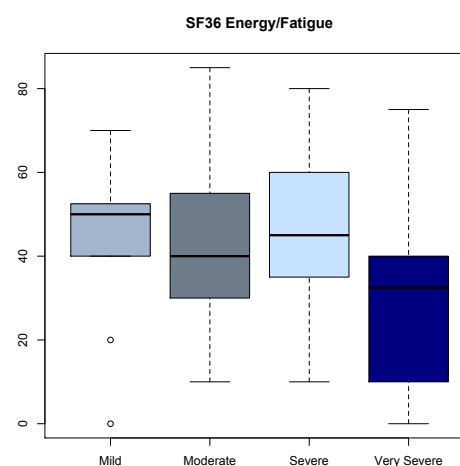


Figure 2.4: Boxplot of SF36 energy/fatigue by disease severity

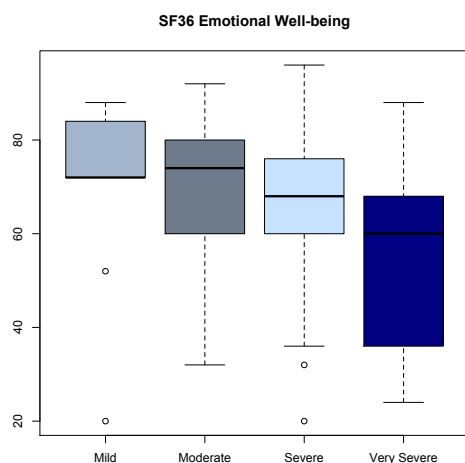


Figure 2.5: Boxplot of SF36 emotional well-being by disease severity

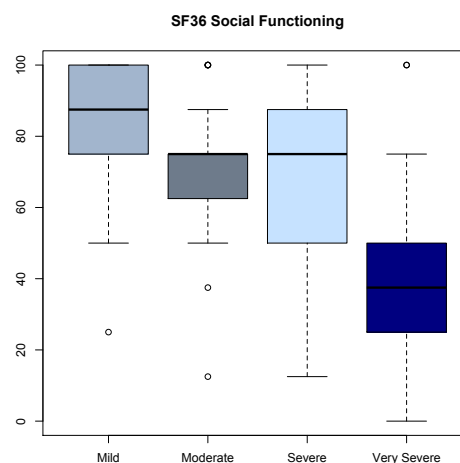


Figure2.6: Boxplot of SF36 social functioning by disease severity

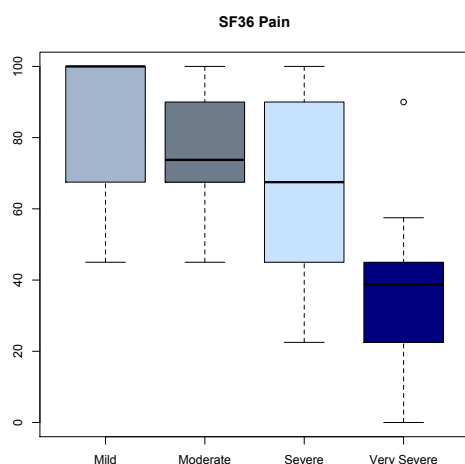


Figure 2.7: Boxplot of SF36 pain by disease severity

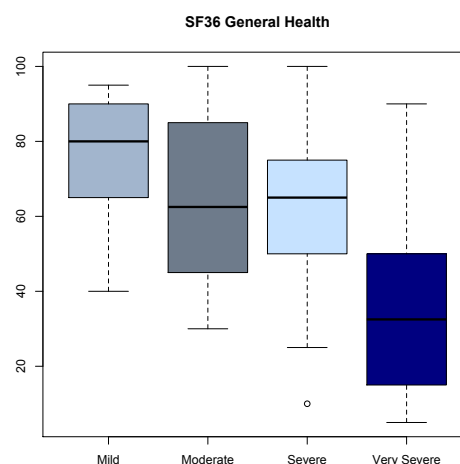


Figure2.8: Boxplot of SF36 general health by disease severity

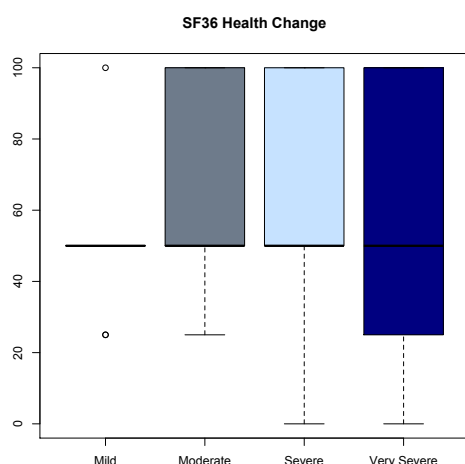


Figure 2.9: Boxplot of SF36 health change by disease severity

Table 2.3: Summary statistics by disease severity

SF36 subscale	Group	Count	Mean	Sd	Median	IQR
Physical function	Mild	11	89.10	23.00	100.00	5.00
	Moderate	26	89.00	18.00	95.00	12.80
	Severe	41	86.80	18.40	95.00	15.00
	Very severe	22	68.90	30.50	80.00	47.50
Role limitations due to physical health	Mild	11	75.00	38.70	100.00	50.00
	Moderate	26	68.30	41.00	100.00	68.00
	Severe	41	71.30	40.90	100.00	75.00
	Very severe	22	39.80	40.60	25.00	75.00
Role limitations due to emotional problems	Mild	11	78.8	37.30	100.00	33.30
	Moderate	26	60.30	40.00	66.70	66.70
	Severe	41	65.90	43.10	100.00	100.00
	Very severe	22	48.50	43.30	50.00	100.00
Energy/Fatigue	Mild	11	44.10	19.30	50.00	12.50
	Moderate	26	44.00	18.80	40.00	22.50
	Severe	41	46.80	15.40	45.00	25.00
	Very severe	22	29.50	21.60	32.50	30.00
Emotional well-being	Mild	11	71.30	19.90	72.00	12.00
	Moderate	26	69.40	15.90	74.00	18.00
	Severe	41	67.20	17.70	68.00	16.00
	Very severe	22	54.20	19.90	60.00	31.00
Social Functioning	Mild	11	81.80	24.60	87.50	25.00
	Moderate	26	70.20	19.70	75.00	12.50
	Severe	41	71.00	23.10	75.00	37.50
	Very severe	22	40.90	28.90	37.50	25.00
Pain	Mild	11	84.30	20.80	100.00	32.50
	Moderate	26	75.00	16.60	73.80	20.00
	Severe	41	67.00	23.30	67.50	45.00
	Very severe	22	36.10	22.20	38.80	22.50
General health	Mild	11	75.00	17.50	80.00	25.00
	Moderate	26	63.70	22.10	62.50	37.50
	Severe	41	62.80	21.00	65.00	25.00
	Very severe	22	35.70	24.50	32.50	33.80
Health change	Mild	11	50.00	19.4	50.00	0.00
	Moderate	26	64.40	27.5	50.00	50.00
	Severe	41	61.00	30.6	50.00	50.00
	Very severe	22	53.4	33.0	50.00	62.50

Table 2.4: One-way ANOVA table for SF36 scales by disease severity

SF36 subscale		Sum of squares	Df	Mean square	F	P
Energy/Fatigue	Between Groups	4525	3	1508	4.54	0.0051*
	Within Groups	31875	96	332		
	Total	36400	99			
Social Functioning	Between Groups	18060	3	6020	10.56	P <0.0001*
	Within Groups	54707	96	570		
	Total	72767	99			
Pain	Between Groups	25122	3	8374	18.60	P <0.0001*
	Within Groups	43217	96	450		
	Total	68339	99			
General health	Between Groups	15899	3	5300	11.20	P <0.0001*
	Within Groups	45445	96	473		
	Total	61344	99			

Table 2.5: Post hoc Tuckey HSD test for SF36 scales by disease severity

SF36 subscale	Comparison	Mean difference	Lower	Upper	P adjusted
Energy/Fatigue	Moderate -Mild	-0.05	-17.19	17.08	1.0000
	Severe-Mild	2.74	-13.44	18.92	0.9709
	Very severe – Mild	-14.55	-32.14	3.05	0.1415
	Severe-Moderate	2.79	-9.15	14.73	0.9284
	Very Severe-Moderate	-14.49	-28.29	-0.69	0.0357*
	Very Severe-Severe	-17.28	-29.87	-4.69	0.0029*
Social Functioning	Moderate -Mild	-11.63	-34.08	10.82	0.5312
	Severe-Mild	-10.78	-31.98	10.41	0.5462
	Very severe – Mild	-40.91	-63.96	-17.86	<0.0001*
	Severe-Moderate	0.84	-14.80	16.49	0.9990
	Very Severe-Moderate	-29.28	-47.36	-11.20	0.0003*
	Very Severe-Severe	-30.13	-46.62	-13.63	<0.0001*
Pain	Moderate -Mild	-9.32	-29.27	10.635	0.6151
	Severe-Mild	-17.37	-36.20	1.47	0.0819
	Very severe – Mild	-48.18	-68.67	-27.70	<0.0001*
	Severe-Moderate	-8.05	-21.96	5.86	0.4337
	Very Severe-Moderate	-38.86	-54.93	-22.79	<0.0001*
	Very Severe-Severe	-30.81	-45.48	-16.15	<0.0001*
General health	Moderate -Mild	-11.35	-31.81	9.12	0.4718
	Severe-Mild	-12.20	-31.51	7.12	0.3555
	Very severe – Mild	-39.32	-60.33	-18.31	<0.0001*
	Severe-Moderate	-0.85	-15.11	13.41	0.9986
	Very Severe-Moderate	-27.97	-44.45	-11.49	0.0001*
	Very Severe-Severe	-27.12	-42.16	-12.09	<0.0001*

* Statistically significant at p<0.05

Table 2.6: Summary statistics and Kruskal-Wallis rank sum test for SF36 scales by disease severity

SF36 subscale	χ^2	Df	P
Physical functioning	10.84	3	0.0126*
Role limitations due to physical health	10.06	3	0.0181*
Role limitations due to emotional problems	5.20	3	0.1573
Emotional well-being	11.06	3	0.0114*
Health change	2.76	3	0.4294

* Statistically significant at $p < 0.05$

Table 2.7: Post hoc pairwise comparisons using Wilcoxon rank sum test, p-values

SF36 subscale	Group	Mild	Moderate	Severe
Physical functioning	Moderate	0.535		
	Severe	0.297	0.535	
	Very severe	0.036*	0.036*	0.036*
Role limitations due to physical health	Moderate	0.714		
	Severe	0.876	0.714	
	Very severe	0.052*	0.052*	0.027*
Emotional well-being	Moderate	0.505		
	Severe	0.420	0.522	
	Very severe	0.030*	0.025*	0.025*

* Statistically significant at $p < 0.05$

Comparisons of SF36 sub scales by comorbid depression and anxiety status

Comparisons of SF36 subscales were made between those that have comorbid depression and anxiety and those that do not. Boxplots of each SF36 scale by comorbid depression and anxiety status are displayed in Figures 2.10-2.18, and summary statistics are listed in Tables 2.8 and 2.9.

A two-sample t-test was used when assumptions for normality and variance were met (Table 2.8), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.9).

A two sample t-test indicated no significant differences between the two groups for the SF36 energy/fatigue scale (Table 2.8). Wilcoxon rank sum tests with continuity corrections revealed a significant difference between those that have both depression and anxiety and those that do not for the SF36 Physical functioning [$W=1465.00$, $P=0.0460$], role limitations due to emotional problems [$W=1679.50$, $p=0.0002$], emotional well-being [$W=1808.00$, $p<0.0001$], social functioning [$W=1750.00$, $p<0.0001$], pain [$W=1530.00$, $p=0.0155$], and general health [$W=1470.00$, $p<0.0473$] (Table 2.9). In each of these scales, those with both depression and anxiety scored worse than those that did not have both depression and anxiety (Table 2.9).

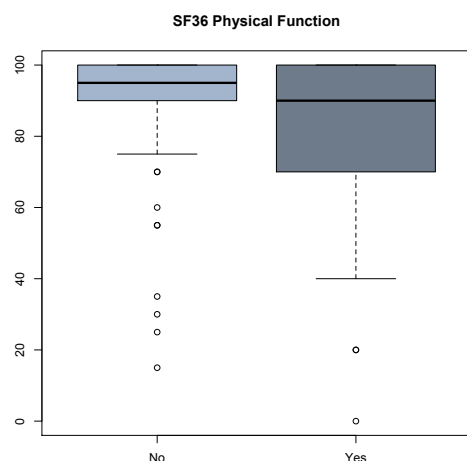


Figure 2.10: Boxplot of SF36 physical functioning by depression and anxiety status

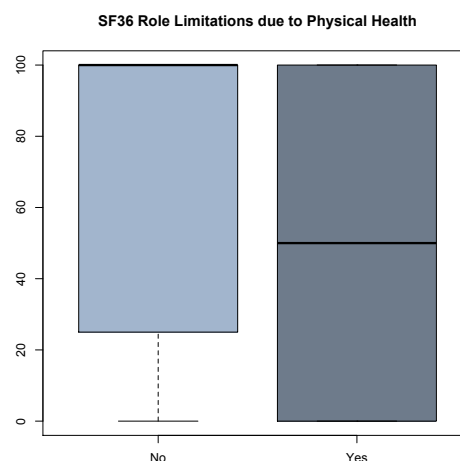


Figure 2.11: Boxplot of SF36 role limitations due to physical health by depression and anxiety status

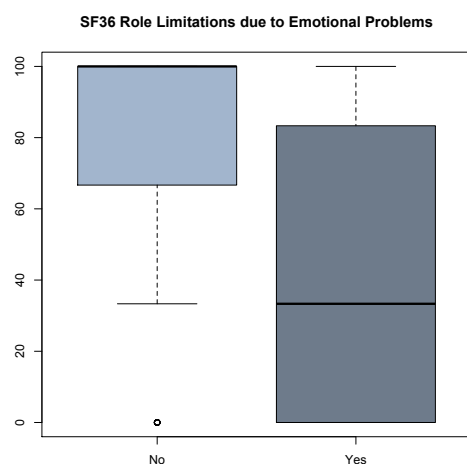


Figure 2.12: Boxplot of SF36 role limitations due to emotional problems by depression and anxiety status

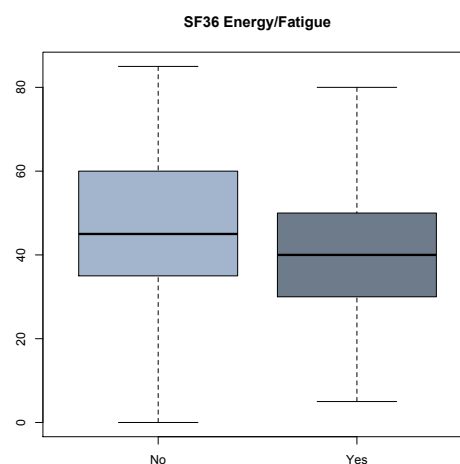


Figure 2.13: Boxplot of SF36 energy/fatigue by depression and anxiety status

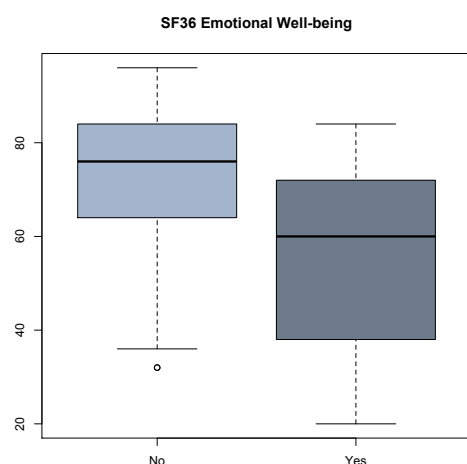


Figure 2.14: Boxplot of SF36 emotional well-being by depression and anxiety status

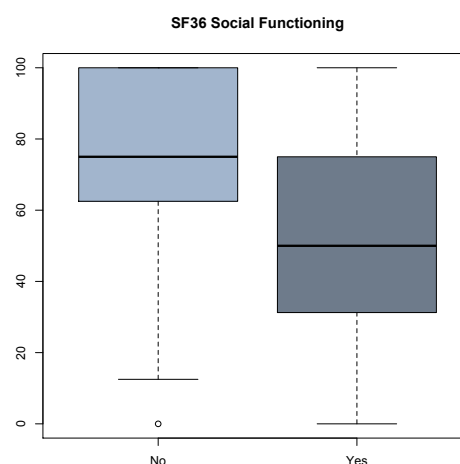


Figure 2.15: Boxplot of SF36 social functioning by depression and anxiety status

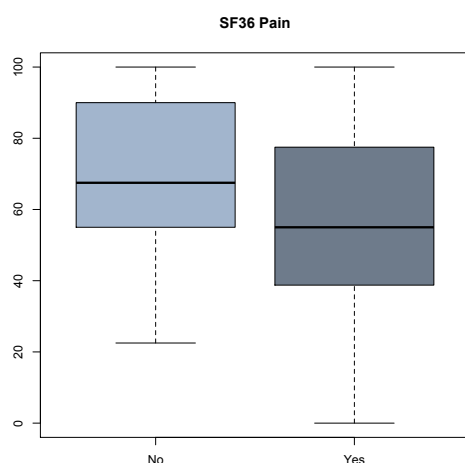


Figure 2.16: Boxplot of SF36 pain by depression and anxiety status

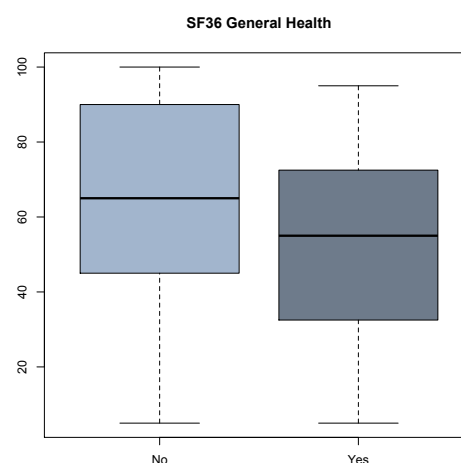


Figure 2.17: Boxplot of SF36 general health by depression and anxiety status

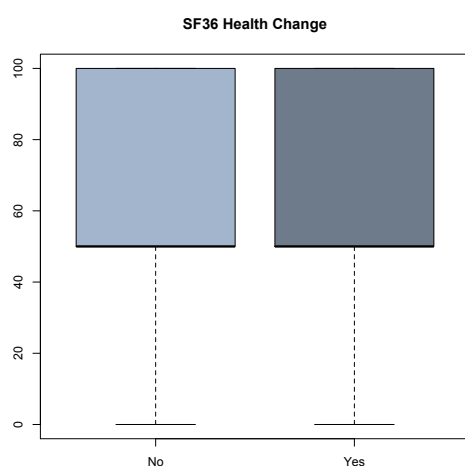


Figure 2.18: Boxplot of SF36 health change by depression and anxiety status

Table 2.8 Summary statistics and two sample t-test SF36 subscales by depression and anxiety status

SF36 subscale	Depression and Anxiety	Count	Mean	SD	t	df	P
Energy/Fatigue	No	61	43.70	18.80	1.10	60	0.2729
	Yes	39	39.40	19.60			

Table 2.9: Summary statistics Wilcoxon rank sum test with continuity correction SF36 subscales by depression and anxiety status

SF36 subscale	Depression and Anxiety	Count	Median	IQR	W	P
Physical functioning	No	61	95.00	10.00	1465.00	0.0460*
	Yes	39	90.00	30.00		
Role limitations due to physical health	No	61	100.00	75.00	1414.00	0.0855
	Yes	39	50.00	100.00		
Role limitations due to emotional problems	No	61	100.00	33.30	1679.5	0.0002*
	Yes	39	33.30	83.30		
Emotional well-being	No	61	76.00	20.00	1808.00	<0.0001*
	Yes	39	60.00	34.00		
Social functioning	No	61	75.00	37.50	1750.00	<0.0001*
	Yes	39	50.00	43.80		
Pain	No	61	67.50	35.00	1530.00	0.0155*
	Yes	39	55.00	38.80		
General Health	No	61	65.00	45.00	1470.00	0.0473*
	Yes	39	55.00	40.00		
Health change	No	61	50.00	50.00	1180.00	0.9450
	Yes	39	50.00	50.00		

* Statistically significant at $p < 0.05$

Comparisons of SF36 sub scales by location

Comparisons of SF36 sub scales were made between participants that live in major cities compared to those that live in regional or rural areas. Boxplots of each SF36 scale by location are displayed in Figures 2.19-2.27, and summary statistics are listed in Tables 2.10 and 2.11. A two-sample t-test was used when assumptions for normality and variance were met

(Table 2.10), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.11). No statistically significant differences were observed between these two groups for any SF36 sub scale (Tables 2.10 and 2.11).

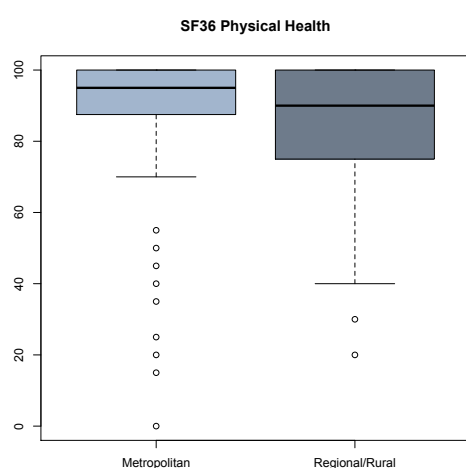


Figure 2.19: Boxplot of SF36 physical functioning by location

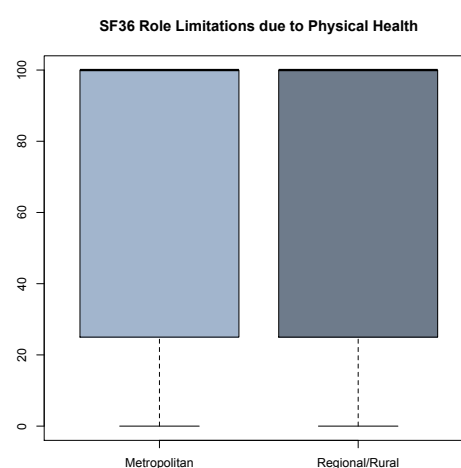


Figure 2.20: Boxplot of SF36 role limitations due to physical health by location



Figure 2.21: Boxplot of SF36 role limitations due to emotional problems by location

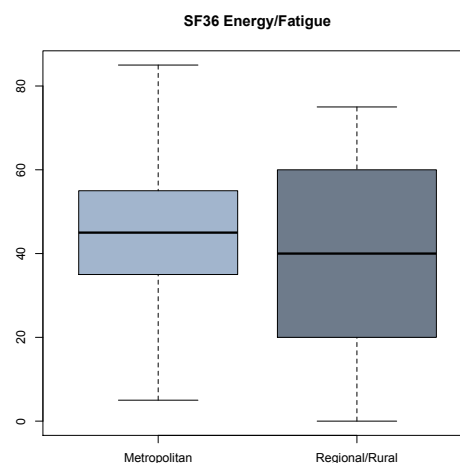


Figure 2.22: Boxplot of SF36 energy/fatigue by location

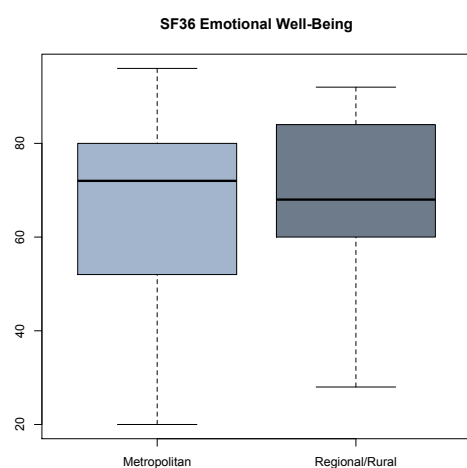
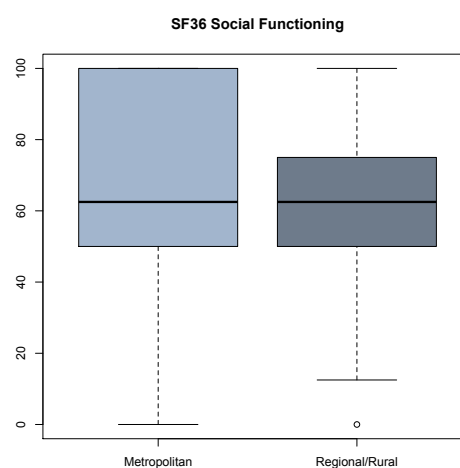


Figure 2.23: Boxplot of SF36 emotional well-being by location



2.24: Boxplot of SF36 social functioning by location

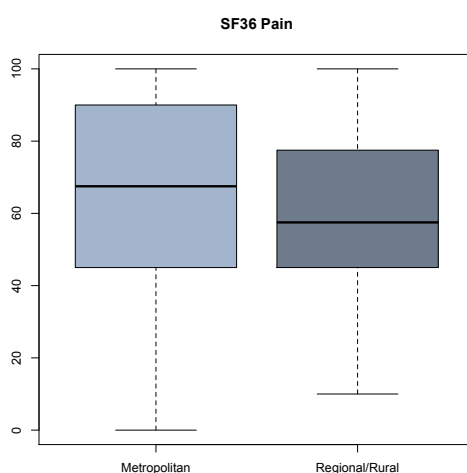
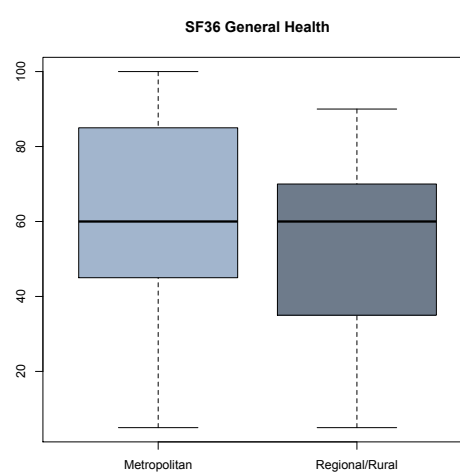


Figure 2.25: Boxplot of SF36 pain by location



2.26: Boxplot of SF36 general health by location

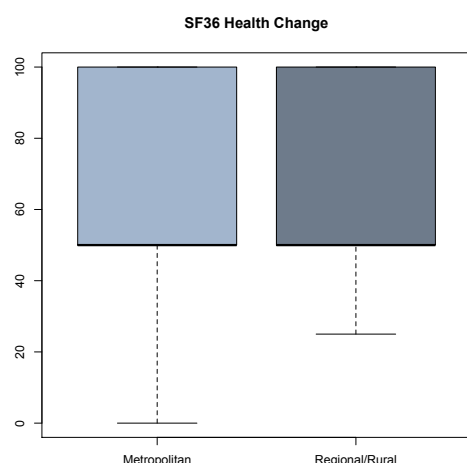


Figure 2.27: Boxplot of SF36 health change by location

Table 2.10: Summary statistics and two sample t-test SF36 subscales by location

SF36 subscale	Location	Count	Mean	SD	T	df	p
Energy/Fatigue	Major City	59	45.10	17.20	1.96	98	0.0532
	Regional/Remote	41	37.60	21.20			

Table 2.11: Summary statistics Wilcoxon rank sum test with continuity correction SF36 subscales by location

SF36 subscale	Depression and Anxiety	Count	Median	IQR	W	P
Physical functioning	Major City	59	95.00	12.50	1422.00	0.1271
	Regional/Remote	41	90.00	25.00		
Role limitations due to physical health	Major City	59	100.00	75.00	227.50	0.8940
	Regional/Remote	41	100.00	75.00		
Role limitations due to emotional problems	Major City	59	66.70	100.00	1102.00	0.4220
	Regional/Remote	41	100.00	66.70		
Emotional well-being	Major City	59	72.00	28.00	1228.00	0.8993
	Regional/Remote	41	68.00	24.00		
Social functioning	Major City	59	62.50	50.00	1357.50	0.2949
	Regional/Remote	41	62.50	25.00		
Pain	Major City	59	67.50	45.00	1414.00	0.1498
	Regional/Remote	41	57.50	32.50		
General Health	Major City	59	60.00	40.00	1432.00	0.1188
	Regional/Remote	41	60.00	35.00		
Health change	Major City	59	50.00	50.00	1221.50	0.9303
	Regional/Remote	41	50.00	50.00		

* Statistically significant at $p < 0.05$

Comparisons of SF36 sub scales by education

Comparisons of SF36 subscales were made by education status, comparing the highest level of education obtained, either university or high school/trade. Boxplots of each SF36 scale by education status are displayed in Figures 2.28-2.36, and summary statistics are listed in Tables 2.12 and 2.13. A two-sample t-test was used when

assumptions for normality and variance were met (Table 2.12), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.13).

Wilcoxon rank sum tests with continuity corrections revealed a significant difference between those with a university degree compared to those with high school or trade for the SF36 social functioning [$W=917.50$,

$p=0.0338$]; pain [$W=852.00$, $p=0.0101$]; and the general health score [$W=918.00$, $p=0.0360$] (Table 2.13).

In each of these scales, those with a university degree scored better than those with high school or trade

(Table 2.13). No other significant differences were observed (Tables 2.12 and 2.13).

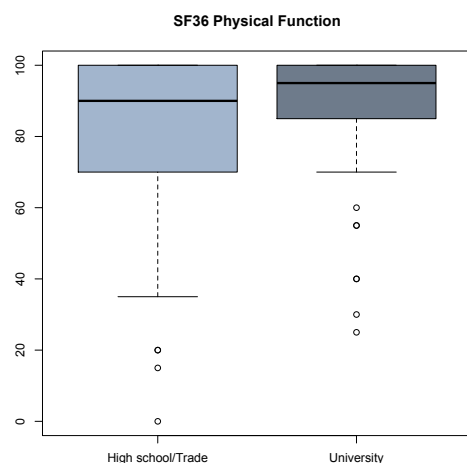


Figure 2.28: Boxplot of SF36 physical functioning by education



Figure 2.29: Boxplot of SF36 role limitations due to physical health by education

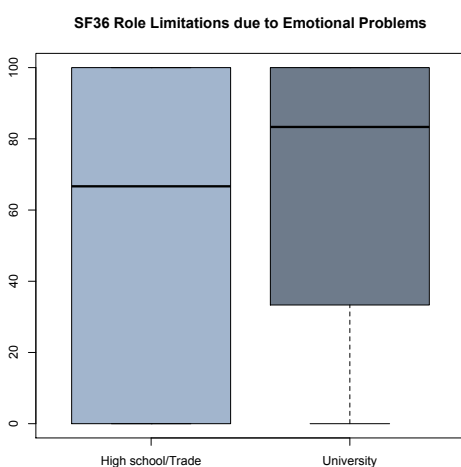


Figure 2.30: Boxplot of SF36 role limitations due to emotional problems by education

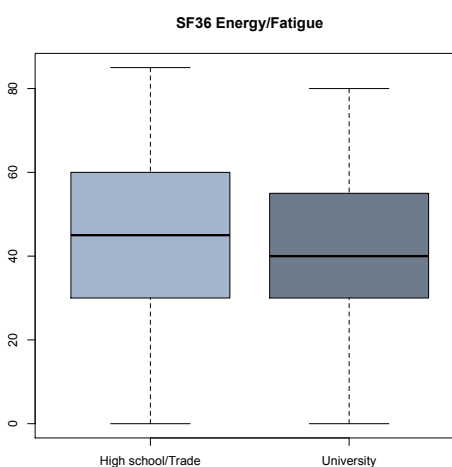
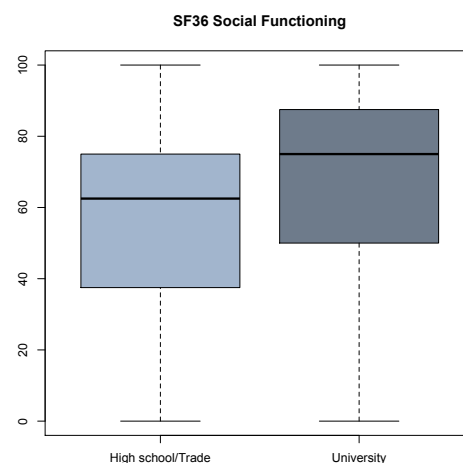


Figure 2.31: Boxplot of SF36 energy/fatigue by education



Figure 2.32: Boxplot of SF36 emotional well-being by education



2.33: Boxplot of SF36 social functioning by education

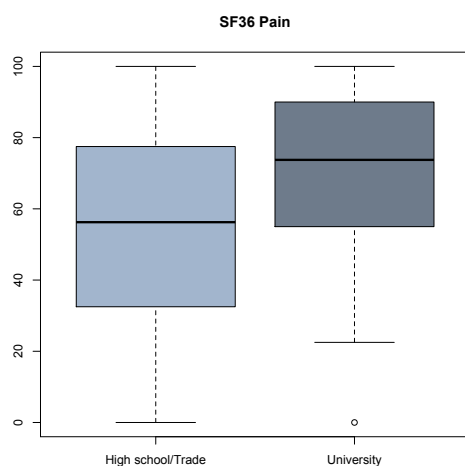
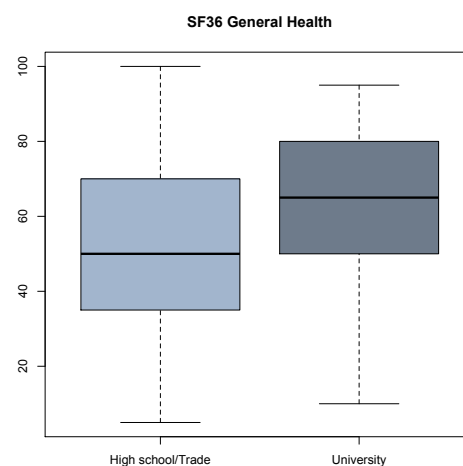


Figure 2.34: Boxplot of SF36 pain by education



2.35: Boxplot of SF36 general health by education

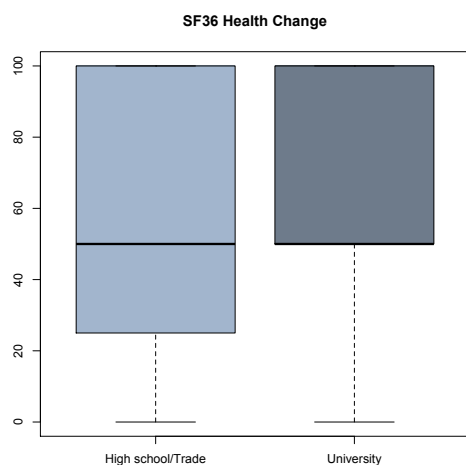


Figure 2.36: Boxplot of SF36 health change by education

Table 2.12: Summary statistics and two sample t-test SF36 subscales by education

SF36 subscale	Location	Count	Mean	SD	t	df	p
Energy/Fatigue	High school/Trade	42	42.00	20.70	0.01	98	0.9916
	University degree	58	42.00	18.20			

Table 2.13: Summary statistics Wilcoxon rank sum test with continuity correction SF36 subscales by location

SF36 subscale	Depression and Anxiety	Count	Median	IQR	W	P
Physical functioning	High school/Trade	42	90.00	28.80	958.00	0.0628
	University degree	58	95.00	13.80		
Role limitations due to physical health	High school/Trade	42	75.00	93.80	1060.50	0.2336
	University degree	58	100.00	75.00		
Role limitations due to emotional problems	High school/Trade	42	66.70	100.00	1125.00	0.4891
	University degree	58	83.30	66.70		
Emotional well-being	High school/Trade	42	68.00	24.00	1056.50	0.2593
	University degree	58	72.00	23.00		
Social functioning	High school/Trade	42	62.50	37.50	917.50	0.0338*
	University degree	58	75.00	34.40		
Pain	High school/Trade	42	56.20	42.50	852.00	0.0101*
	University degree	58	73.80	34.40		
General Health	High school/Trade	42	50.00	35.00	918.00	0.0360*
	University degree	58	65.00	30.00		
Health change	High school/Trade	42	50.00	62.50	1040.50	0.1799
	University degree	58	50.00	50.00		

* Statistically significant at $p < 0.05$

Section 3 Symptoms and diagnosis

Section 3: Experience of symptoms and diagnosis

Symptoms at diagnosis

- The most common symptoms leading to diagnosis were rash-like symptoms (n=38, 38.00%) followed by thickened, cracked, dry, scaly skin (n=23, 23.00%) and allergies that led to the diagnosis of AD (n=17, 17.00%). There were also 25 participants (25.00%) that were unable to describe specifically what led to their diagnosis as they were a child or infant at the time.
- There were a number of sub-group variations. Participants that were high school or trade education reported having allergies that led to diagnosis more frequently than the general cohort (28.57% compared to 17.00% in the general cohort). Participants with mild AD reported having red to brownish-grey patches that led to diagnosis more frequently than the general cohort (54.55% compared to 15.00% in the general cohort) while participants with moderate AD reported this symptom less frequently (3.85% compared with 15.00% in the general cohort).
- There were various combinations of diagnostic tests conducted with the most common tests recalled being skin examination only (n=41, 41.00%) followed by skin examination, blood test, patch test and review of medical history (n=24, 24.00%).
- There was one sub-group variation. Participants with mild AD reported having a skin examination only, more frequently than the general cohort (90.91% compared to 41.00% in the general cohort) and they did not report having other tests such as blood tests, patch tests or review of medical history.
- 64 participants (64.00%) noted that they had no support at diagnosis, (n=21; 21.00%) reported having some support, but not enough and (n=15, 15.00) reported having enough support.
- There were a number of sub-group variations. Participants with mild AD reported having no support more frequently than the general cohort (81.82% compared to 64.00% in the general cohort). Participants with moderate AD reported having enough support less frequently than the general cohort (3.85% compared to 15.00% in the general cohort).

Genetic/biomarker tests

- Participants were asked whether they had ever had a discussion about genetic tests or tests to see if there were biomarkers that might be relevant to their condition or treatment. The majority of participants (n=96; 96.00%) had not had a discussion while four participants (4.00%) stated they had had a discussion about this kind of test of which, two brought the topic up with their doctor.
- Participants were also asked about their interest in this type of test if it was available. The majority of participants (n=89, 89.00%) were interested in having it if it were available, three participants (3.00%) indicated that they paid for this test themselves while eight participants (8.00%) indicated that they were not interested in this type of test.

Knowledge of condition and prognosis

- In relation to how much participants knew about their condition at diagnosis, the main theme was that participants, or their parents, knew nothing or very little about their condition (n=45, 45.00%). 18 participants (18.00%) described having some knowledge about AD and this was primarily due to having another family member who also had the condition. There were also 19 participants (19.00%) that commented that they have lived their whole life with AD and it is therefore the only way of life that they knew.
- There was one sub-group variation in relation to participants that have very severe AD who reported knowing about AD through other family members, more frequently than the general cohort (31.82% compared to 18.00% in the general cohort).
- Participants were asked whether anyone talked to them about prognosis. Over half of the participants (n=54, 54.00%) described that they understood that AD was a lifelong condition and did not expect it to get better. 22 participants (22.00%) that noted that they did not have a clear prognosis and these participants also spoke about the uncertainty of their situation.
- There were two sub-group variations. Participants with mild AD reported their prognosis as being something they will have for their lifetime less frequently than the general cohort (27.27% compared to 54.00% in the general cohort). Participants with very severe AD reported having their AD under control less frequently than the general cohort (4.55% compared to 18.00% in the general cohort).

Experience of symptoms before diagnosis

Participants were asked to recall the symptoms that they noticed in themselves that led them to pursue further investigation with a clinician. This question was asked both in an online questionnaire and as part of the structured interview. Responses from both sources of information were cross-validated to compile these results. Participants were asked which symptoms led them to being diagnosed with AD. The most common symptoms described by all participants were rash-like symptoms (n=38, 38.00%) followed by thickened, cracked, dry, scaly skin (n=23, 23.00%) and allergies that led to the diagnosis of AD (n=17, 17.00%). There were also 25 participants (25.00%)

that were unable to describe specifically what led to their diagnosis as they were a child or infant at the time.

There were a number of sub-group variations. Participants that were high school or trade education reported having allergies that led to diagnosis more frequently than the general cohort (28.57% compared to 17.00% in the general cohort). Participants with mild AD reported having red to brownish-grey patches that led to diagnosis more frequently than the general cohort (54.55% compared to 15.00% in the general cohort) while participants with moderate AD reported this symptom less frequently (3.85% compared with 15.00% in the general cohort).

Table 3.1: Symptoms leading to diagnosis

Symptoms leading to diagnosis	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)	
Rash-like symptoms (generally blotchy described as AD)	38	38.00	3	27.27	9	34.62	17	41.46	9	40.91
Unable to recall as they were a child	25	25.00	2	18.18	9	34.62	8	19.51	6	27.27
Thickened, cracked, dry, scaly skin	23	23.00	1	9.09	4	15.38	11	26.83	7	31.82
Allergies leading to diagnosis	17	17.00	1	9.09	4	15.38	8	19.51	4	18.18
Red to brownish-grey patches, especially on the hands, feet, ankles, wrists, neck, upper chest, eyelids, inside the bend of the elbows and knees	15	15.00	6	54.55	1	3.85	5	12.20	3	13.64
Itching, which is severe and not controlled	13	13.00	1	9.09	5	19.23	4	9.76	3	13.64
Itching, which is uncomfortable but reasonably controlled	10	10.00	1	9.09	1	3.85	6	14.63	2	9.09
Small, raised bumps, which may leak fluid and crust over when scratched	3	3.00	0	0.00	1	3.85	1	2.44	1	4.55
Sores (lesions) that may become infected by bacteria or viruses	2	2.00	0	0.00	0	0.00	2	4.88	0	0.00

Symptoms leading to diagnosis	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
Rash-like symptoms (generally blotchy described as AD)	14	35.90	17	41.46	21	35.59	21	36.21	17	40.48
Unable to recall as they were a child	13	33.33	12	29.27	13	22.03	16	27.59	9	21.43
Thickened, cracked, dry, scaly skin	13	33.33	10	24.39	13	22.03	13	22.41	10	23.81
Allergies leading to diagnosis	6	15.38	6	14.63	11	18.64	5	8.62	12	28.57
Red to brownish-grey patches, especially on the hands, feet, ankles, wrists, neck, upper chest, eyelids, inside the bend of the elbows and knees	5	12.82	3	7.32	12	20.34	8	13.79	7	16.67
Itching, which is severe and not controlled	7	17.95	3	7.32	10	16.95	5	8.62	8	19.05
Itching, which is uncomfortable but reasonably controlled	2	5.13	3	7.32	7	11.86	4	6.90	6	14.29
Small, raised bumps, which may leak fluid and crust over when scratched	1	2.56	1	2.44	2	3.39	3	5.17	0	0.00
Sores (lesions) that may become infected by bacteria or viruses	1	2.56	1	2.44	1	1.69	2	3.45	0	0.00

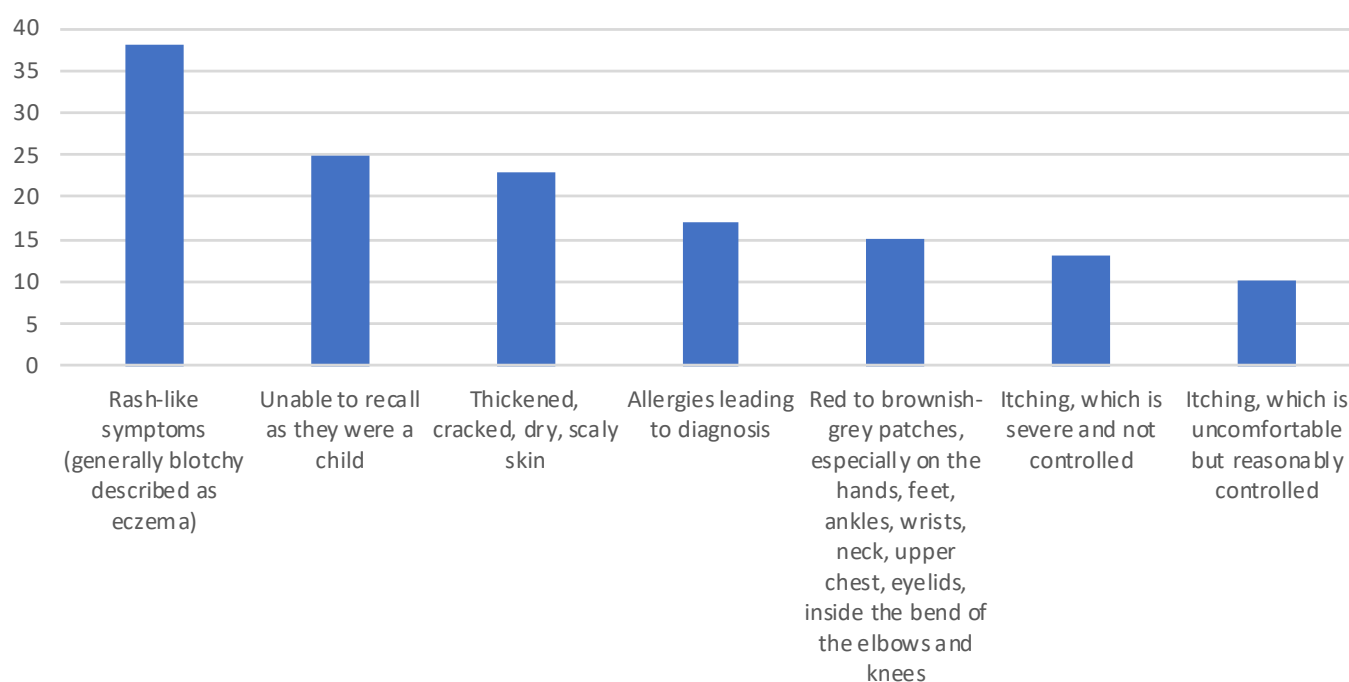


Figure 3.1: Symptoms experienced at diagnosis

As noted, participants were asked to describe the symptoms that led to their diagnosis. Exemplars of these descriptions are provided below:

Rash-like symptoms

There were these rashes in parts of my body and after seeing the doctor with my parents, that was what I was diagnosed with. That's how I knew I had it. **Participant 15**

I was just covered in rashes and so on. I think it was a no brainer for the doctors even in those days...so it was blatantly obvious that I had eczema. **Participant 30**

Yeah of course, so I was seven years old, we'd recently moved to a new house in LOCATION and it was something that we ... Well I personally at that point, looking back on it now, I was seven so I didn't really fathom what it meant, but it was sort of deemed to be insignificant. What happened was I got a little bit of a rash on my foot, and we thought maybe I had an allergic reaction to a tree that we had in our new house, something like that. There were so many things it could have been ... that could have dictated what that was, so my first experience with eczema was quite literally a little tiny rash on my left foot, and I had no idea that it would end up dictating a bit part of my life. **Participant 54**

Atopic Dermatitis 2018 Australian PEEK Study

Thickened, cracked, dry, scaly skin

And then it got worse when I started working in care, which I'm currently working in, in healthcare. So that means I get frequent hand washing, and it was all flaky and scaly and really irritated, so like with moisture gone. I think I went to the doctor's, like ... I'm not sure actually, a while ago actually, because it started to flare up and get really red and raised, so they told me, "Okay, you've got atopic dermatitis" **Participant 21**

Yeah, sure. So, I was apparently born with really dry, strange skin. And by about two years old, I was diagnosed with eczema, so I've always experienced the symptoms of it. So, I can't really reflect on when it first started, because it's always been what I've known. **Participant 34**

Well, it wasn't me who noticed, it was mum. I was a baby still. She... dry skin, scaly. I was always irritated and trying to scratch myself. My skin was red. As I grew older, it was more kind of the white patches because I have dark skin. It was white patches, dry, and scales. Mainly scratching, especially around my eyes and stuff. Yeah, messing and what not. Yeah, that's what she noticed. **Participant 61**

Allergies leading to diagnosis

*I think it chained through because I also have food allergy. It went hand-in-hand with that. It was like when one was diagnosed, the other was picked up as well. **Participant 26***

*When I was 18, I just moved to start Uni. I used to get - because I have a lot of allergies as well, so I would occasionally have reactions from allergies when I've eaten something and I realized that my lips and mouth was very itchy. That was the first time that I realized that something wasn't right and I ended up with eczema all over my face from just starting then. That was probably a month or something until I went for a doctor and then the GP said it was eczema and gave me a prescription for steroid cream and booked me into a dermatologist. I'm not sure, I think by the time that I went to the dermatologist it had gone down from using the creams, but she said it was eczema. **Participant 45***

*We went to a specialist, we were referred to a specialist, he has given us some advice on how to treat Eczema. We went to have his pretest to see whether he has, what allergies he is reacting to, or food allergies. All those things, in other words, have been established as he has got Eczema. **Participant 81***

Itching, which is severe and not controlled

*I was only a few months old. It was so severe that I developed the ability to scratch before a baby should. **Participant 26***

*I was always irritated and trying to scratch myself. My skin was red. As I grew older, it was more kind of the white patches because I have dark skin. It was white patches, dry, and scales. Mainly scratching, especially around my eyes and stuff. Yeah, messing and what not. Yeah, that's what she noticed. **Participant 61***

*My skin just went crazy. It was just flaring up all the time. I couldn't handle it, couldn't maintain it. What doctors said when I was about 15, I think? 15 to 17 and it was just, it wouldn't calm down. Yeah, it was pretty unbearable. **Participant 79***

Diagnostic tests

Participants were asked to recall the types of tests they had to diagnose their AD. There were various combinations of diagnostic tests conducted with the most common tests recalled being skin examination only (n=41, 41.00%) followed by skin examination, blood test, patch test and review of medical history

(n=24, 24/00%). There was one sub-group variation. Participants with mild AD reported having a skin examination only, more frequently than the general cohort (90.91% compared to 41.00% in the general cohort) and they did not report having other tests such as blood tests, patch tests or review of medical history.

Table 3.2: Diagnostic tests

Diagnostic tests	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)	
Skin examination only	41	41.00	10	90.91	12	46.15	12	29.27	7	31.82
Skin examination, blood test, patch test and review of medical history	24	24.00	0	0.00	4	15.38	15	36.59	5	22.73
Unsure	12	12.00	1	9.09	2	7.69	7	17.07	2	9.09
Other combination of Skin examination and/or blood test and/or patch test and/or review of medical history	12	12.00	0	0.00	5	19.23	3	7.32	4	18.18
Skin examination and review of medical history	11	11.00	0	0.00	3	11.54	4	9.76	4	18.18
Diagnostic tests	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
Skin examination only	14	35.90	13	31.71	28	47.46	23	39.66	18	42.86
Skin examination, blood test, patch test and review of medical history	10	25.64	9	21.95	15	25.42	14	24.14	10	23.81
Unsure	4	10.26	8	19.51	4	6.78	7	12.07	5	11.90
Other combination of Skin examination and/or blood test and/or patch test and/or review of medical history	6	15.38	6	14.63	6	10.17	9	15.52	3	7.14
Skin examination and review of medical history	5	12.82	5	12.20	6	10.17	5	8.62	6	14.29

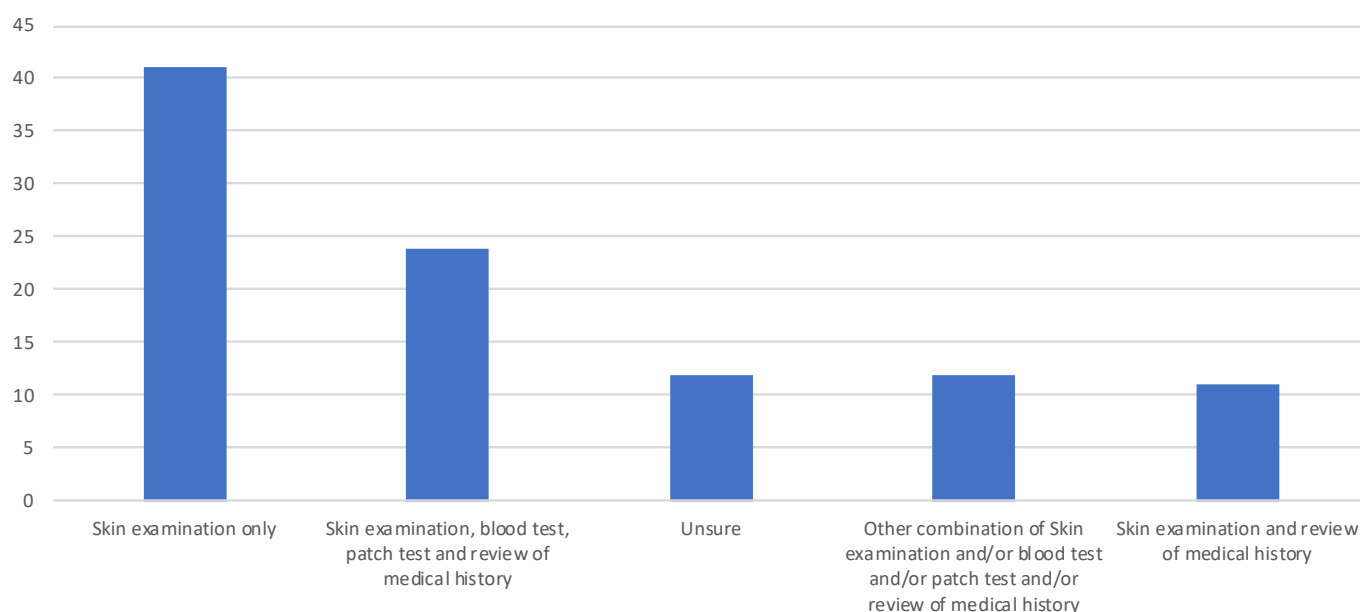


Figure 3.2: Diagnostic tests

Support at diagnosis

In the questionnaire, participants were asked whether they felt supported at the time of diagnosis. There were 64 participants (64.00%) that noted they had no support and this was the most common response followed by having some support, but not enough (n=21; 21.00%) and having enough support (n=15, 15.00%).

There were a number of sub-group variations. Participants with mild AD reported having no support more frequently than the general cohort (81.82% compared to 64.00% in the general cohort). Participants with moderate AD reported having enough support less frequently than the general cohort (3.85% compared to 15.00% in the general cohort).

Table 3.3: Support at diagnosis

Support at diagnosis	Total Participants (n=100)		Mild Atopic Dermatitis (n=11)		Moderate Atopic Dermatitis (n=26)		Severe Atopic Dermatitis (n=42)		Very Severe Atopic Dermatitis (n=22)	
I/we had no support	64	64.00	9	81.82	17	65.38	24	58.54	14	63.64
I/we had some support but it wasn't enough	21	21.00	0	0.00	8	30.77	8	19.51	5	22.73
I/we had enough support	15	15.00	2	18.18	1	3.85	9	21.95	3	13.64
Support at diagnosis	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
I/we had no support	27	69.23	24	58.54	40	67.80	39	67.24	25	59.52
I/we had some support but it wasn't enough	8	20.51	11	26.83	10	16.95	12	20.69	9	21.43
I/we had enough support	4	10.26	6	14.63	9	15.25	7	12.07	8	19.05

Genetic and biomarker tests

Participants were asked whether they had ever had a discussion about genetic tests or tests to see if there were biomarkers that might be relevant to their condition or treatment. The majority of participants (n=96; 96.00%) had not had a discussion while four participants (4.00%) stated they had had a discussion about this kind of test of which, two brought the topic up with their doctor.

Table 3.4: Genetic and biomarker tests

Biomarker/genetic testing (Discussions)	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)	
No one has ever spoken to be about this type of test	96	96.00	11	100.00	25	96.15	40	97.56	20	90.91
My doctor brought up the topic with me for discussion	2	2.00	0	0.00	0	0.00	1	2.44	1	4.55
I brought up the topic with my doctor for discussion	2	2.00	0	0.00	0	0.00	1	2.44	1	4.55
Biomarker/genetic testing (Discussions)	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
No one has ever spoken to be about this type of test	35	89.74	41	100.00	55	93.22	56	96.55	40	95.24
My doctor brought up the topic with me for discussion	2	5.13	0	0.00	2	3.39	1	1.72	1	2.38
I brought up the topic with my doctor for discussion	2	5.13	0	0.00	2	3.39	1	1.72	1	2.38

Participants were also asked about their interest in this type of test if it was available. The majority of participants (n=89, 89.00%) were interested in having it if it were available, three participants (3.00%)

indicated that they paid for this test themselves while eight participants (8.00%) indicated that they were not interested in this type of test.

Table 3.5: Interest in genetic and biomarker tests

Biomarker/genetic testing (Experience)	Total Participants (n=100)		Mild Atopic Dermatitis (n=11)		Moderate Atopic Dermatitis (n=26)		Severe Atopic Dermatitis (n=42)		Very Severe Atopic Dermatitis (n=22)	
I have had this type of test and paid for it myself	3	3.00	0	0.00	0	0.00	1	2.44	2	9.09
I have not had the test but would like to	89	89.00	8	72.73	24	92.31	37	90.24	20	90.91
I have not had this test and am not interested in it	8	8.00	3	27.27	2	7.69	3	7.32	0	0.00
Biomarker/genetic testing (Experience)	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
I have had this type of test and paid for it myself	2	5.13	1	2.44	2	3.39	2	3.45	1	2.38
I have not had the test but would like to	35	89.74	35	85.37	54	91.53	53	91.38	36	85.71
I have not had this test and am not interested in it	2	5.13	5	12.20	3	5.08	3	5.17	5	11.90

Understanding of condition at Diagnosis

Participants were asked how much they knew about their condition at diagnosis. The main theme in this section was that participants, or their parents, knew nothing or very little about their condition (n=45, 45.00%). There were 18 participants (18.00%) that described having some knowledge about AD and this was primarily due to having another family member who also had the condition. There were also 19 participants (19.00%) that commented that they have lived their whole life with AD and it is therefore the only way of life that they know.

There was one sub-group variation in relation to participants that have very severe AD who reported knowing about AD through other family members, more frequently than the general cohort (31.82% compared to 18.00% in the general cohort).

Participant describes themselves or their parents knowing nothing about the condition

I didn't know anything and my Mum wouldn't know anything because she never told me, and I had to figure out things for myself. I wasn't until I was 20 and went to the dermatologist that I got a bit more information, but she said to do things that I had already figured out myself just based on, I needed certain things that Mum washed like certain detergents Mum washed with, were, I knew that I couldn't use fragrant stuff, even from a young age I

figured that out without her. Only silver jewellery. Does that make sense? Participant 13

Not much at all, I just, I wasn't actually told what eczema was really. When I went to the doctor and to many other subsequent doctors, the term eczema's just been thrown around and associated with dermatitis or dry skin but no one's really explained to me how or why that's come about. Participant 67

It wasn't really a lot of questioning I was able to do at that stage and of course my Mum was ... she had no idea about anything and it was never in her family and so she just essentially trusted what the Doctors said and did what they said and yeah that was kind of it. Participant 91

Participant describes their parents having good knowledge about the condition and being able to learn more over time

Yeah, I think I've gained a lot more awareness and understanding as an adult, and probably ... I've been gathering that information since my 20s, but really within the last few years, I've got a better understanding in some ways with some stuff that I didn't realise before. Participant 53

My parents really knew much about it like my Mum, I've asked her a couple of times. She's been an emergency nurse for 30 something years. I said to her, "Even before you had me was there much knowledge

of it?" She always said. The only reason she knows as much about eczema she does because of me.

Participant 83

My Mum sort of managed me more than anything so all I know is that I was extremely uncomfortable, itchy all the time, and my skin was always raw sores. I got bullied quite excessively for having dry skin and redness all the time. It sort of continued through to adulthood quite severely and gotten worse as I've gotten older and I've had various diagnoses of different types of eczema as different symptoms pop up over the years. **Participant 90**

Participant/parents describes knowing little about the condition - only that they itched

At the time, when I was younger, just that it made me really itchy and that I wasn't allowed to itch it. That was about it. I know Mum used a calamine bath and stuff like that. I mean that's what I remember. I remember my hands and sort of- short nails I think I remember the most. I had to have short nails all the time. **Participant 14**

I didn't know a whole lot about it. I knew that I would get really itchy and I would sometimes bleed and it

was a very uncomfortable condition. That's all I really knew, there wasn't the ability to just jump on Google and look up what it was. I think the doctor explained a bit about what might trigger it but it was, it can sometimes be due to allergies and eczema can get worse depending on what time of year it is. If you're very hot that can impact. I think they recommended cold showers, cold baths to try and treat it. But yeah, there wasn't a whole lot of information out there that I remember. Just cream. **Participant 66**

Apparently, I was very unsettled. I would say it affected me quite a lot. I think my family knew about it. I never sort of "It's an itchy skin condition." It never really affected my life too much at that point, apart from the fact I had to wear long sleeves and long pants. I view that I was a bit different but it was never something bad in my head. It was like I just happen to have a good family and good friends and whatnot. That was it. It was just an itchy, I just have an itchy skin basically. **Participant 72**

Not a lot. Just that it was itchy. That just drove me crazy. You know. **Participant 93**

Table 3.6: Knowledge of disease at diagnosis

Knowledge of disease at diagnosis	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/parents describes knowing nothing about the condition	45	45.00	3	27.27	12	46.15	21	51.22	9	40.91
Participant describes that - as an adult - they have lived with all their life (it is all they know)	19	19.00	4	36.36	4	15.38	9	21.95	2	9.09
Participant describes knowing something about the condition from seeing other family members with atopic dermatitis	18	18.00	1	9.09	2	7.69	8	19.51	7	31.82
Participant describes knowing a lot or their parents having good knowledge about the condition	12	12.00	2	18.18	2	7.69	6	14.63	2	9.09
Participant/parents describes knowing little about the condition - only that they itched	9	9.00	1	9.09	4	15.38	4	9.76	0	0.00

Table 3.6 (cont.): Knowledge of disease at diagnosis

Knowledge of disease at diagnosis	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/ Trade educated (n=42)	
Participant/parents describes knowing nothing about the condition	18	46.15	20	48.78	25	42.37	26	44.83	19	45.24
Participant describes that - as an adult - they have lived with all their life (it is all they know)	5	12.82	3	7.32	16	27.12	12	20.69	7	16.67
Participant describes knowing something about the condition from seeing other family members with atopic dermatitis	8	20.51	8	19.51	10	16.95	9	15.52	9	21.43
Participant describes knowing a lot or their parents having good knowledge about the condition	1	2.56	4	9.76	8	13.56	5	8.62	7	16.67
Participant/parents describes knowing little about the condition - only that they itched	4	10.26	4	9.76	5	8.47	5	8.62	4	9.52

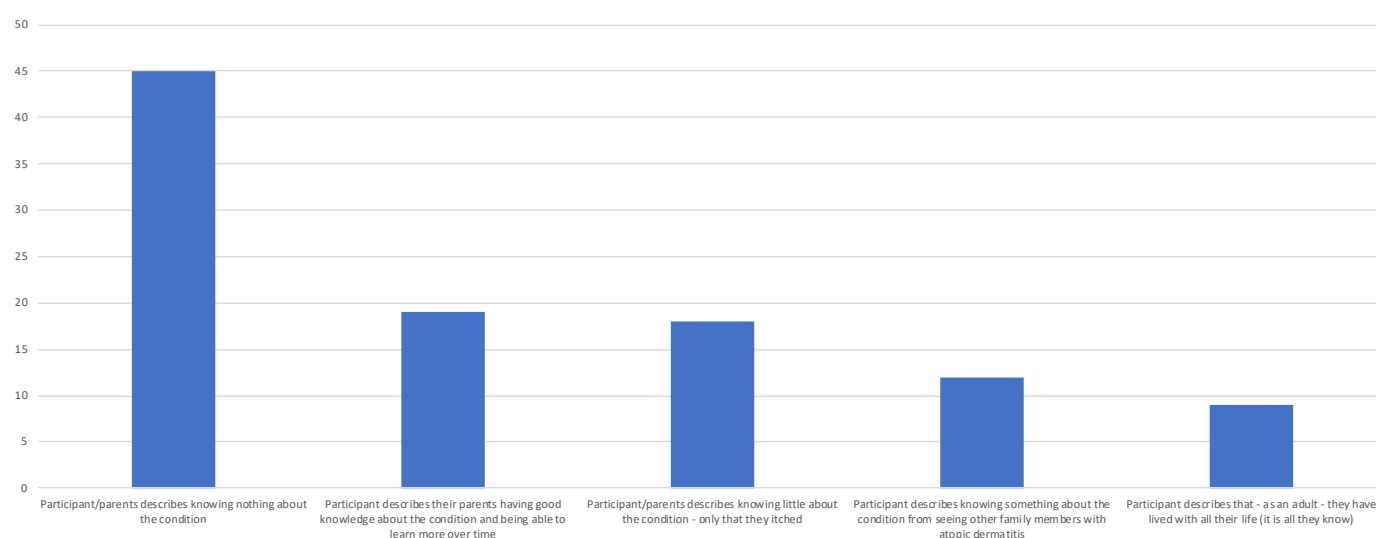


Figure 3.3: Knowledge of disease at diagnosis

Communication and understanding of prognosis

Participants were asked whether anyone talked to them about prognosis. Over half of the participants (n=54, 54.00%) described that they understood that AD was a lifelong condition and did not expect it to get better:

*Given that I've had it for 57 years, I don't think it's going to get any better. No, and supposed to having spoken to both the GP and the dermatologist that I see from time to time, they both say it tends to get worse post menopause, so I'm thinking that it's not going to get any better. **Participant 44***

No. I've been told all along my years, it'll change when you reach puberty, it'll change when you have

*children, it'll change ... Everything. It has changed. It's changed in that it really flares up, rather than that it doesn't flare up. When I was a child, it used to flare up behind my knees, in my arm ... Inside of my elbow, my neck, and my eyelids, there were my flare ups. I used to get them in spots, and as a teenager I got ringworm like eczema. All up my arms, up my legs, on my buttock, my back, sometimes on my tummy ... I used to have this one particular spot on my tummy, always on my neck, and always around my mouth. When as an adult, less on my legs, just more around my arms, my hands, my neck, and my face. My face gets hit. My face and my neck get hit the worst. And now it's the hands, arms, neck and the face. And I used to get, actually, in my hair, on my genital area. There hasn't been a spot that hasn't had it. **Participant 61***

Anyway they told me I was going to grow out of it. "Oh, you'll hit 18 you'll grow out of it, you'll grow out of it." Well, 46 and still haven't grown out of it the days when it's great it's like, "yay". The days it's not I just want some of-- my prescription may tell me it's-- I'm a corticosteroid responsive dermatosis, critical crouch area, yes 20 to 30% of the body surface.

Participant 64

There were 22 participants (22.00%) that noted that they did not have a clear prognosis and these participants also spoke about the uncertainty of their situation:

*Right now, I'm going through an episode. I don't know if it's because of the heat or - I'm pretty stressed. What was the other question? It's been with me throughout my life, but like I said, there was this period in my life where-- there were years where I didn't have any flare ups and I was completely fine. I don't need any steroids or anything like that. I'd say, since I was eight years old I've had it on and off. There's key times in my life where I feel like it flared up, just when I didn't... when I was 18, during uni...Yes. I think probably, another episode I had was in my mid 20s and then when I had kids, is when it reoccurred again. **Participant 15***

*No. They've never said anything like that. They just give me the cream. **Participant 69***

No, that's what I'd like to know. Yeah, I'd like to know, I didn't think I'd ever feel like this. You know, I never

*had a pimple or a blemish. Never had a pimple in my life, and I've never been on so much medicine and stuff now, since I've turned over 50, with that change of life. **Participant 93***

*No doctor has ever, just to be straight, no doctor has ever been helpful, like ever, not that I can remember. They've never said anything. They always just say like, "We don't know why people get eczema." And they give you a lot of cortisone cream which I don't really like continuously using and actually the cortisone cream really seem to have very minor improvement just not much anyway. I just think I've got it for life and that I'm going to have to stay on the pill forever and I hope menopause maybe will make it go away [laughs]. I hope I don't have it forever but I just don't know why. I think it's hormonally related and maybe in menopause that will make it better, but then I think maybe it will make it worse. **Participant 99***

There were two sub-group variations. Participants with mild AD reported their prognosis as being something they will have for their lifetime less frequently than the general cohort (27.27% compared to 54.00% in the general cohort). Participants with very severe AD reported having their AD under control less frequently than the general cohort (4.55% compared to 18.00% in the general cohort).

Table 3.7: Understanding of prognosis

Understanding of prognosis	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 atopic dermatitis as something they will have for their lifetime and not necessarily get any better	54	54.00	3	27.27	16	61.54	22	53.66	13	59.09
Participant describes not having a clear prognosis	22	22.00	2	18.18	4	15.38	12	29.27	4	18.18
Participant describes their atopic dermatitis being under control	18	18.00	6	54.55	6	23.08	5	12.20	1	4.55
Participant describes expecting to be free of eczema in the future	6	6.00	0	0.00	1	3.85	1	2.44	4	18.18
Treatment conversations (Flares)	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
Participant describes atopic dermatitis as something they will have for their lifetime and not necessarily get any better	24	61.54	23	56.10	31	52.54	36	62.07	18	42.86
Participant describes not having a clear prognosis	7	17.95	7	17.07	15	25.42	9	15.52	13	30.95
Participant describes their atopic dermatitis being under control	5	12.82	7	17.07	11	18.64	11	18.97	7	16.67
Participant describes expecting to be free of eczema in the future	3	7.69	4	9.76	3	5.08	3	5.17	3	7.14

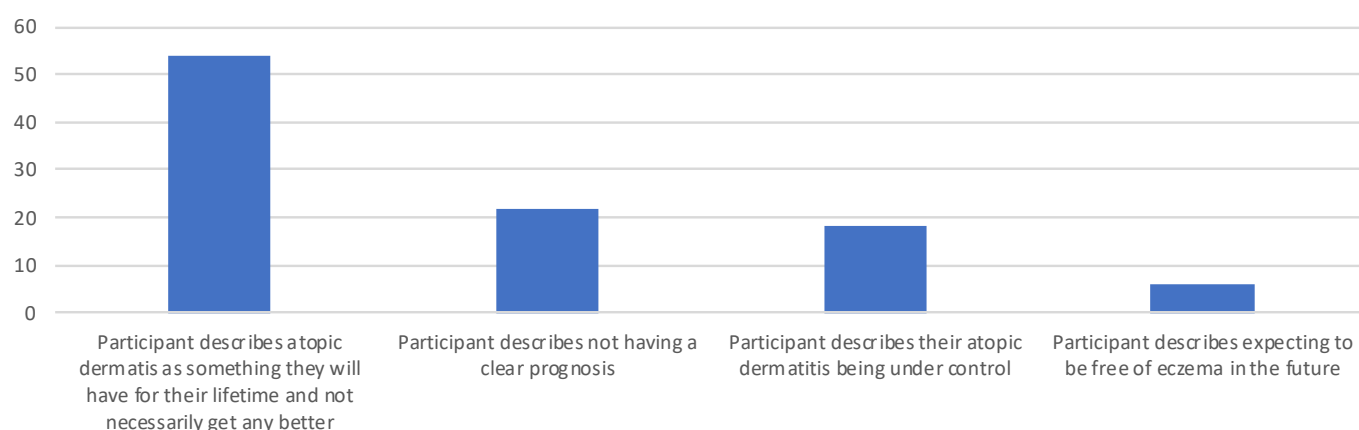


Figure 3.4: Understanding of prognosis

Section 4 Decision-making

Section 4: Experience of health professional communication

Conversations about treatments

- Participants were asked to describe the conversations they have had about their AD in relation to treatment options. The main theme noted by 72 participants (72.00%) within this section was that participants felt that they were not really provided with options and that the majority of discussions focused on steroid cream.
- There was one sub-group variation. Participants with very severe AD described feeling as though there were no or limited treatment options more frequently than the general cohort (90.91% compared to 72.00% in the general cohort).

Decision-making

- Participants were asked who was involved in decisions made about treatment and care. Participants clinician and 5 The most common theme was that decision-making was primarily between the patient and their clinician (n=52, 52.00%). There were 37 participants (37.00%) that described also including their family in decisions while 32 participants (32.00%) spoke about decision-making as ultimately something they do on their own.
- There was one sub-group variation. Participants with mild AD reported decision-making as an individual thing more frequently than the general cohort (63.63% compared to 32.00% in the general cohort).
- Participants were asked about the things that they take into consideration when making decisions about treatment. The most common theme was that participants considered how much time the treatment would take to administer and this was noted by 34 (34.00%) of participants. There were 31 participants (31.00%) that described considering the severity of side effects, 30 participants (30.00%) spoke about understanding the evidence behind the treatment option, cost was another consideration that was noted by 27 participants (27.00%) and there also 19 participants (19.00%) that spoke about considering the long-term effect of treatment and how it will impact their overall health.
- There were three sub-group variations. Participants with mild AD reported considering the severity of side effects less frequently than the general cohort (18.18% compared to 31.00% in the general cohort) They also reported considering the treatment effectiveness/evidence base less frequently than the general cohort (18.00% compared to 30.00% in the general cohort). Participants that had a high school or trade education also reported considering the treatment effectiveness/evidence base more frequently than the general cohort (42.86 compared to 30.00% in the general cohort).
- Participants were asked whether they felt the way they made decisions had changed over time since they were diagnosed. The most common theme was that participants had changed the way they made decisions (n=31, 31.00%) and 24 participants described taking more of an active role or interest in their condition in adulthood.
- There was one sub-group variation. Participants with mild AD reported changes in the way they make decisions and becoming more informed, less frequently than the general cohort (18.18% compared to 31.00% in the general cohort).

Discussions about treatment

Participants were asked to describe the conversations they have had about their AD in relation to treatment options. The main theme noted by 72 participants (72.00%) within this section was that participants felt that they were not really provided with options and that the majority of discussions focused on steroid cream:

I would go to a dermatologist and they would, just give me cortisone creams, and stronger cortisone creams. And, was pretty much told that they manage it. And that there's no other options, really.
Participant 60

There aren't really any discussion. Just cortisone cream, then more cortisone cream.
Participant 69

Um, it's really just the steroid creams and avoid triggers, they don't spend too much time going through options, maybe because there aren't any?
Participant 72

Up until the last few years, the treatment I was aware of was just steroid creams. That was all I had used growing up. When, obviously, it wasn't so bad, I used steroids here and there, and it helped. I don't know what kind of available options there were because of the fact that I didn't really know anything more than steroids at the time. I guess in my childhood it wasn't bad enough to even go with Prednisone or anything. It was literally just the topical steroids. They weren't very strong at that point. I can't remember their names, but it definitely wasn't that strong at that point.
Participant 85

There was one sub-group variation. Participants with very severe AD described feeling as though there were no treatment options more frequently than the general cohort (90.91% compared to 72.00% in the general cohort).

Table 4.1: Discussions about treatment

Conversations about treatment	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 no treatment options as such, primarily one option (Steroid cream in particular)	72	72.00	8	72.73	17	65.38	27	65.85	20	90.91
Participant describes gentle washes/moisturising as part of their management regime	18	18.00	4	36.36	6	23.08	7	17.07	1	4.55
Participant describes being discussions about avoiding triggers	13	13.00	1	9.09	4	15.38	7	17.07	1	4.55
Participant describes being discussions about Alternative/Complementary Therapies	11	11.00	0	0.00	6	23.08	3	7.32	2	9.09
Participant does not recall discussions	11	11.00	1	9.09	3	11.54	6	14.63	1	4.55
Participant describes being discussions about wet dressings	10	10.00	0	0.00	2	7.69	3	7.32	5	22.73
Participant describes being given dietary advice (General, no dairy, no wheat/gluten, no citrus)	7	7.00	3	27.27	3	11.54	1	2.44	0	0.00
Participant describes being discussions about immuno-suppressants	5	5.00	0	0.00	3	11.54	2	4.88	0	0.00

Table 4.1 (cont): Discussions about treatment

Conversations about treatment	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/ Trade educated (n=42)	
Participant describes no treatment options as such, primarily one option (Steroid cream in particular)	28	71.79	35	85.37	37	62.71	44	75.86	28	66.67
Participant describes gentle washes/moisturising as part of their management regime	8	20.51	4	9.76	14	23.73	14	24.14	4	9.52
Participant describes being discussions about avoiding triggers	4	10.26	7	17.07	6	10.17	8	13.79	5	11.90
Participant describes being discussions about Alternative/Complementary Therapies	6	15.38	4	9.76	7	11.86	6	10.34	5	11.90
Participant does not recall discussions	2	5.13	1	2.44	10	16.95	4	6.90	7	16.67
Participant describes being discussions about wet dressings	6	15.38	3	7.32	7	11.86	5	8.62	5	11.90
Participant describes being given dietary advice (General, no dairy, no wheat/gluten, no citrus)	3	7.69	2	4.88	5	8.47	5	8.62	2	4.76
Participant describes being discussions about immuno-suppressants	2	5.13	1	2.44	4	6.78	1	1.72	4	9.52

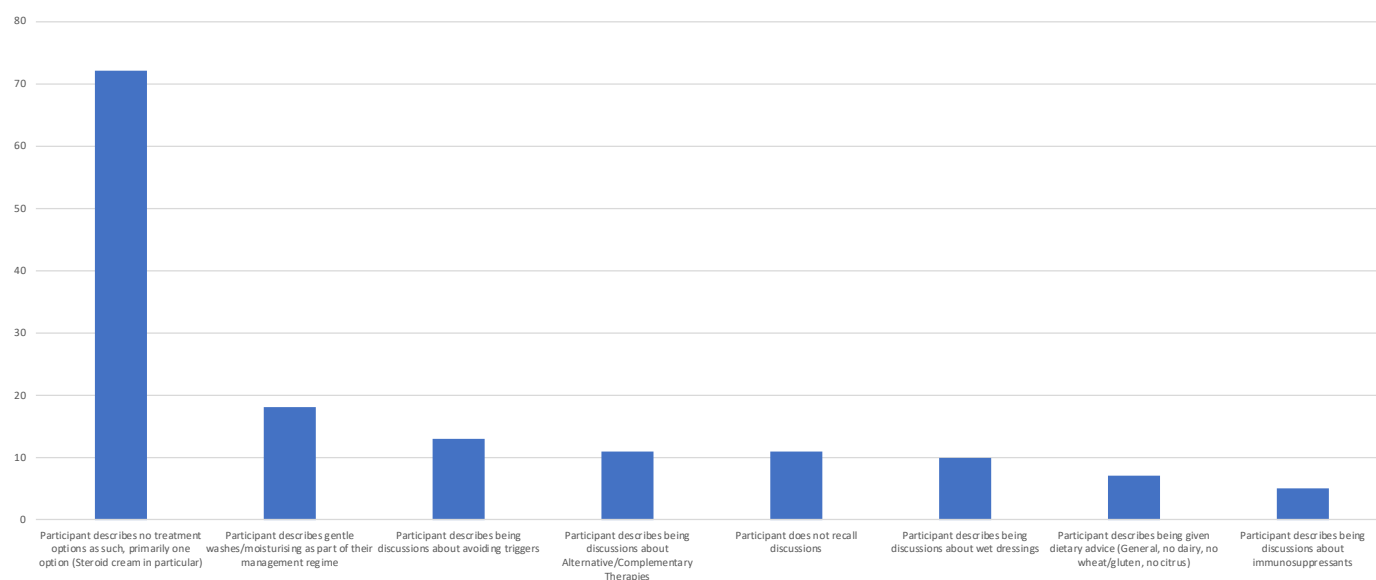


Figure 4.1: Discussions about treatment

Decision-making

Who is involved in decision-making

Participants were asked who was involved in decisions made about treatment and care. The most common theme was that decision-making was primarily between the patient and their clinician (n=52, 52.00%). There were 37 participants (37.00%) that

described also including their family in decisions while 32 participants (32.00%) spoke about decision-making as ultimately something they do on their own.

There was one sub-group variation. Participants with mild AD reported decision-making as an individual thing more frequently than the general cohort (63.63% compared to 32.00% in the general cohort).

Table 4.2: Decision-making process – who patients consult

Decisions about treatment	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	%
Participant describes decision-making primarily with their clinician	52	52.00	6	54.55	15	57.69	21	51.22	10	45.45
Participant describes involving their family in decision-making	37	37.00	5	45.45	9	34.62	15	36.59	8	36.36
Participant describes decision-making as an individual thing (ultimately they make the decision)	32	32.00	1	9.09	7	26.92	19	46.34	5	22.73

Decisions about treatment	Anxiety/Depression		Regional/Rural		Metropolitan		University educated		High school/Trade educated	
	n=39	%	n=41	%	n=59	%	n=58	%	n=42	%
Participant describes decision-making primarily with their clinician	19	48.72	23	56.10	29	49.15	30	51.72	22	52.38
Participant describes involving their family in decision-making	14	35.90	14	34.15	23	38.98	17	29.31	20	47.62
Participant describes decision-making as an individual thing (ultimately they make the decision)	11	28.21	13	31.71	19	32.20	22	37.93	10	23.81

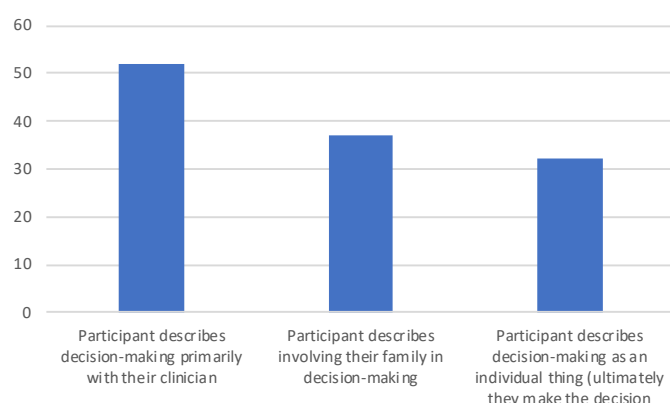


Figure 4.2: Decision-making process – who patients consult

What is considered when making decisions

Participants were asked about the things that they take into consideration when making decisions about treatment. The most common theme was that participants considered how much time the treatment

would take to administer and this was noted by 34 (34.00%) of participants:

Also, the practicality of applying things. One dermatologist would have put me on a regime which would basically, have meant I didn't do anything else 24 hours but treat my skin. Participant 20

*Definitely the practicality of treatment. if it's gonna have a big impact on the way we live our lives. We're an incredibly active family. Which I think also has a lot to do with the eczema, because I'm running here, there, and everywhere after three boys. But if it was something that was going to effect my ability to do that, or effect the types of food that I was eating, or was preparing. Or if I had to make a separate meal for myself, and then another meal for the rest of the family. Sort of things like that. **Participant 37***

*I'd say I take into account the upheaval it's going to cause. How convenient it's going to be for my lifestyle. **Participant 66***

There were 31 participants (31.00%) that described considering the severity of side effects, and this was largely referenced to how potential side effects may impact their quality of life:

Side effects is a big one. I'm quite active, I run my own business. I don't really have time to be sick. That would be the main thing really. What sort of side effects I get from it. **Participant 4**

I'd have to say, for me personally, side effects. Having had some disastrous side effects with a few things, of late. The potential side effects would be a big one for me, and as I seem to have very sensitive skin and be sensitive to lots of things, that's probably one of the things that would really make or break decisions for me. **Participant 8**

I guess maybe overall safety - I'm willing to take-participate in a trial but I'm sure like trials didn't get to a trial's stage needs to be quite safe but it would just be looking at things like...Actually, the doctor talked to last week said he'd been to a conference back in Eastern. He was saying that a recent study was saying that one of the side effects or adverse effects from long-term steroid use of more often overstated in it and it does actually interfere with patient compliance of creams because they're scared to use them for a long time for that reason that he was assuring me that, actually, from this day that they've found there's often more overstated. It ends up being detrimental to patients' treatment outcomes because too afraid to comply with using the cream for too long. Usually, it is stuff like that that I take into consideration. Is it something that's going to be too much with my life? Is there a big side effect or the potential for side effect? Is it more overstated than what's probably a realistic adverse effect or the chance of that happening. **Participant 63**

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Another key consideration for participants was the effectiveness of the treatment. This was noted by 30 participants (30.00%) and included understanding the evidence behind the treatment option:

Effectiveness. That's the only thing I take into consideration. How effective this is. Is this gonna be effective. **Participant 32**

Well, of course, I talk to the clinician about it and try and get the story about the treatment. Then I go home and I do quite a lot of research, but then, because I am a nurse, I will also talk to a couple of my friends who are quite interested in my skin. They're not bored the minute you open your mouth about it. My sister, who is quite intelligent, and loves research. I don't involve my husband, he has no interest at all in my skin. **Participant 70**

Pretty much nothing more than is it going to help. I'm not too fussy as far as I've got assurance that it's going to help. **Participant 85**

Cost was another consideration that was noted by 27 participants (27.00%). This was largely referenced to their current experience where the cost of treatments was often onerous:

For that light therapy thing, I was like, "Is that covered by Medicare?" Yeah that's it. I think it's just a cost thing. **Participant 21**

Cost. Because treatment just seems to get more and more expensive. **Participant 61**

Sometimes the price, the costs of stuff, because some of the ... I was using one cream that was very expensive, Elidel I think it was and then another...something or other that was another different kind of Cortisone that was ... Or a non-steroidal something that I had to get on a private script and that was quite expensive. It worked quite well but I didn't continue because it was so expensive, so the price can sometimes be part of it and convenience I suppose yeah. I am busy and lazy and so like I prefer a cream that I only have to put on once a day rather than twice per day, things like that, yeah those kinds of things. **Participant 68**

There were also 19 participants (19.00%) that spoke about considering the long-term effect of treatment and how it will impact their overall health:

*The biggest thing for me is that it's not, in the long-term, harmful to me as far as my overall health and well being goes. So definitely the long-term effects of something. Whether it's internal or external, on my skin. **Participant 18***

*When you open up the fine print in the box that you've been provided, with the drugs in it, it doesn't seem to always be consistent with what allergists, dermatologists, or GP's tells you. because I'm concerned with the long term use of cortisone, that's why. That's my major concern at the moment. **Participant 43***

Anything that I am deciding on, I need to know the long-term side effects of, especially if it's medication.

*If it's medication, I want to know the side effects and long-term side effects. **Participant 80***

There were three sub-group variations. Participants with mild AD reported considering the severity of side effects (18.18% compared to 31.00% in the general cohort) They also reported considering the treatment effectiveness/evidence base less frequently than the general cohort (18.00% compared to 30.00% in the general cohort). Participants that had a high school or trade education also reported considering the treatment effectiveness/evidence base more frequently than the general cohort (42.86 compared to 30.00% in the general cohort).

Table 4.3: Considerations when making decisions

	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 considering the time that the treatment will take to administer (whether there is a large burden, for example daily creams, baths and wet dressings)	34	34.00	3	27.27	10	38.46	13	31.71	8	36.36
Participant describes considering the severity of side effects and safety	31	31.00	2	18.18	6	23.08	14	34.15	9	40.91
Participant describes considering the effectiveness of the treatment and the evidence-base (which is often just trial and error)	30	30.00	2	18.18	6	23.08	14	34.15	8	36.36
Participant describes considering the cost	27	27.00	2	18.18	7	26.92	12	29.27	6	27.27
Participant describes considering the long-term effects	19	19.00	3	27.27	6	23.08	7	17.07	3	13.64
Effect on other people/family: how much they will be burdened	10	10.00	1	9.09	5	19.23	3	7.32	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 considering the time that the treatment will take to administer (whether there is a large burden, for example daily creams, baths and wet dressings)	15	38.46	11	26.83	23	38.98	18	31.03	16	38.10
Participant describes considering the severity of side effects and safety	11	28.21	14	34.15	17	28.81	21	36.21	10	23.81
Participant describes considering the effectiveness of the treatment and the evidence-base (which is often just trial and error)	11	28.21	13	31.71	17	28.81	12	20.69	18	42.86
Participant describes considering the cost	12	30.77	10	24.39	17	28.81	18	31.03	9	21.43
Participant describes considering the long-term effects	7	17.95	5	12.20	14	23.73	12	20.69	7	16.67
Effect on other people/family: how much they will be burdened	6	15.38	6	14.63	4	6.78	7	12.07	3	7.14

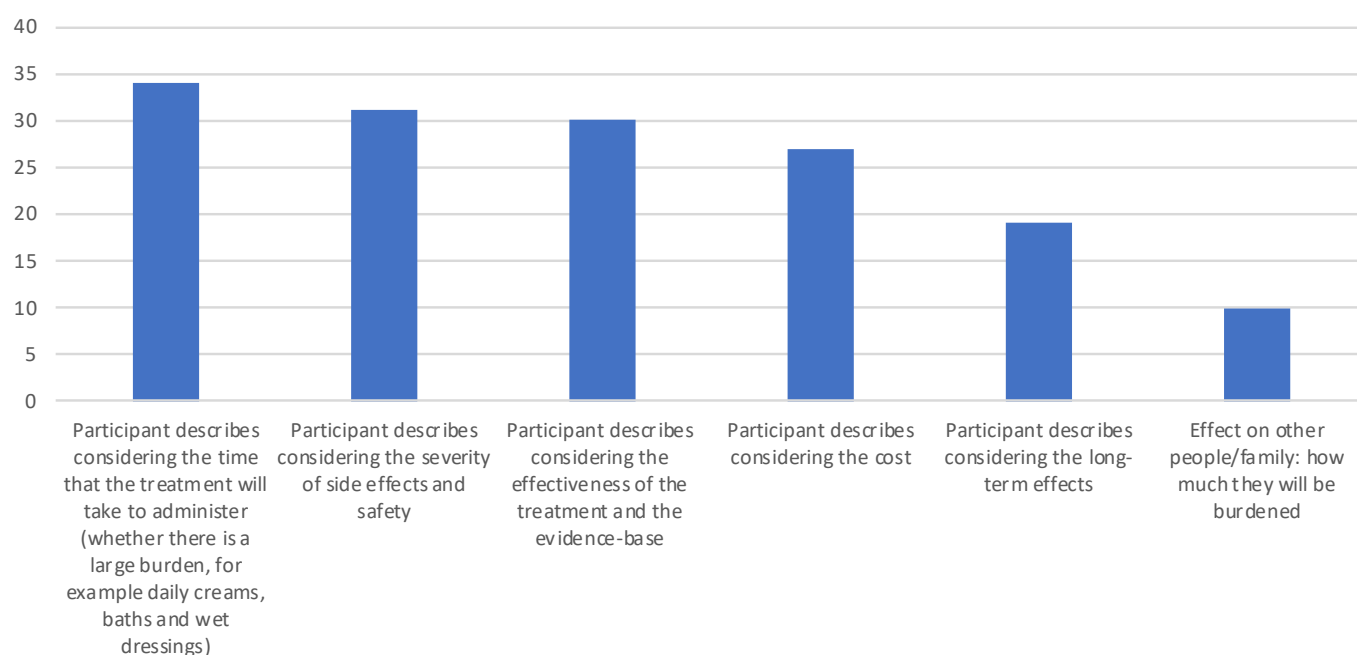


Figure 4.3: Considerations when making decisions

Changes in decision-making

In the final question about decision-making, participants were asked whether they felt the way they made decisions had changed over time since they were diagnosed. The most common theme was that participants had changed the way they made decisions (n=31, 31.00%) and this was primarily because they had become more informed and assertive:

*I think it has changed as I've gotten older. I think as I've gotten older, I'm less likely to just say yes to whatever is suggested. I'm a bit more likely to want to know the risks, the cost, the how long I'm gonna have to do it for, all those sorts of things. **Participant 33***

*Yes. Of course. I mean I've been an engineer for 20 odd years so obviously gaining that change of thinking and thought process. Yes, certainly. I'm a lot more evaluative and critical, shall I say? **Participant 41***

*I will do an awful lot of reading and research, and, of course, a lot of it has to be internet but I try not to use ridiculous sites. I try and use the sites that inform you. **Participant 70***

There were 24 participants that described changing the way they made decisions over time or as they got older. This also included taking more of an active role or interest in their condition in adulthood:

*Yes, definitely. It changes as you get older, doesn't it? It goes from being what your parents decided and then it's changed, especially because of what I do for a job, it's changed too. I have a bit more understanding and knowledge. **Participant 13***

*I think it's changed, over time. When I was, probably younger, and like, especially, teenage years, you and, you know, and when I was in my 20's, you're more vain, and worried about your looks, and your skin. And, whereas now, I'm more worried about my overall health. I'm more long-term, worried about my health, whereas when I was younger, I was more worried about my looks, and things like that. **Participant 60***

*I think they've probably changed over time especially probably for me that period of being 16, 17 up until probably 20 I was like Okay. It's not too bad. Hopefully, it'll disappear in the next couple of years. Probably, now that I'm 26 I'm getting to a point where this is actually getting really frustrating. I'm not getting frustrated with my doctors because I know they're doing what they know, but it's just frustrating. I'm getting frustrated with the whole situation. The way I question is now more how is this going to help me, when is this going to help me get rid of it effectively? **Participant 83***

A less common but notable theme was that participants felt that they needed to take decisions into their own hands, whether this meant seeking alternatives or deciding to no longer seek medical advice (n=13, 13.00%):

Yes, definitely. Definitely. but I feel like there's not enough talk about options outside of the drug world. We all know, there's no cure, right? At the moment. All we're doing, is we're trying to relieve our symptoms. Participant 43

I think perhaps after seeing the doctors the first few times, and probably being told the same things and not really being offered anything new, I guess that

affected my decision either to see a doctor. Participant 45

I suppose I was more eager to find out and try new things in the first place, but after so many failed attempts, I'm pretty over it. I just stick with steroids, because I know that that works. Participant 85

There was one sub-group variation. Participants with mild AD reported changes in the way they make decisions and becoming more informed, less frequently than the general cohort (18.18% compared to 31.00% in the general cohort).

Table 4.4: Decision-making over time

	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 change in decision-making as they have become more informed	31	31.00	2	18.18	8	30.77	12	29.27	9	40.91
Participant describes no change in decision-making	24	24.00	4	36.36	6	23.08	9	21.95	5	22.73
Participant describes changes in life-stage which affected their decisions (getting older)	21	21.00	3	27.27	6	23.08	7	17.07	5	22.73
Participant describes needing to take decisions into their own hands (often because atopic dermatitis is dismissed by clinicians or they offer few solutions)	13	13.00	0	0.00	3	11.54	6	14.63	4	18.18
Participant describes a change in decision-making based on their experience	10	10.00	2	18.18	4	15.38	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 change in decision-making as they have become more informed	13	33.33	14	34.15	17	28.81	16	27.59	15	35.71
Participant describes no change in decision-making	11	28.21	10	24.39	14	23.73	15	25.86	9	21.43
Participant describes changes in life-stage which affected their decisions (getting older)	10	25.64	9	21.95	12	20.34	14	24.14	7	16.67
Participant describes needing to take decisions into their own hands (often because atopic dermatitis is dismissed by clinicians or they offer few solutions)	3	7.69	4	9.76	9	15.25	7	12.07	6	14.29
Participant describes a change in decision-making based on their experience	2	5.13	1	2.44	9	15.25	6	10.34	4	9.52

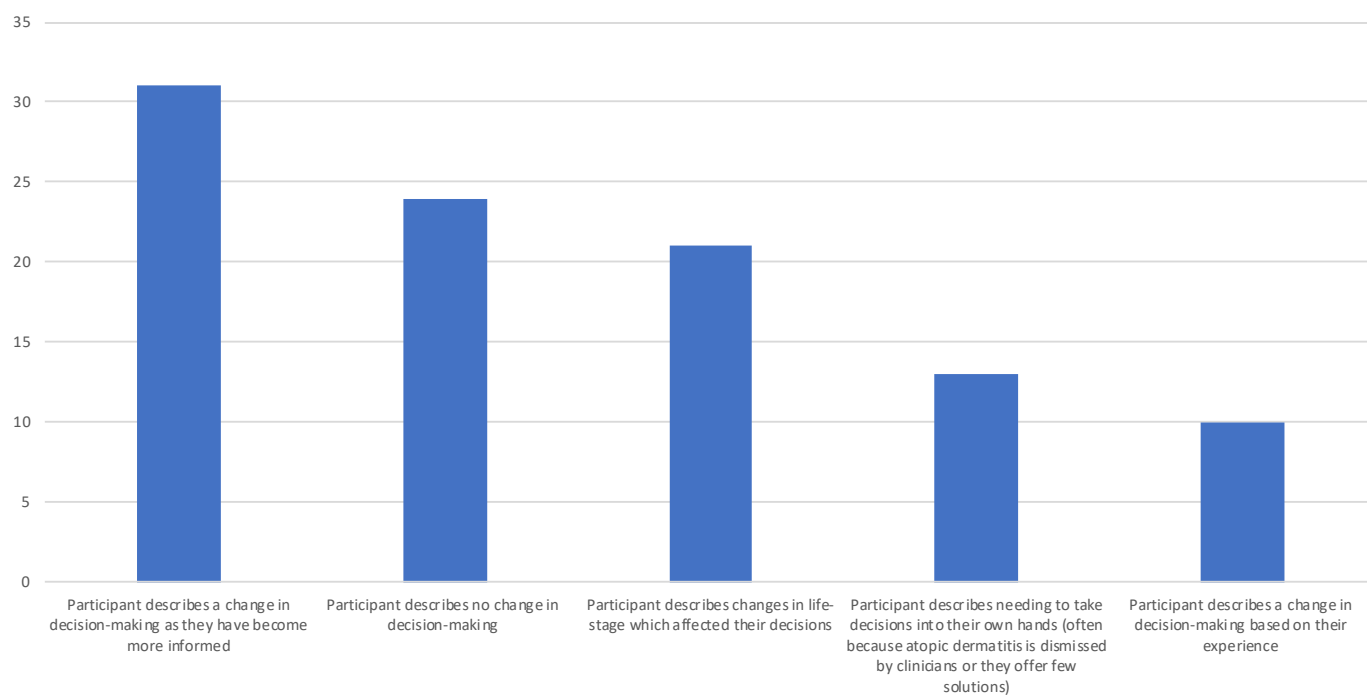


Figure 4.4: Decision-making over time

Section 5 Treatment and health service provision

Section 5: Experience of treatment and service provision

Treatments experienced

- The most common treatments reported by nearly all participants were corticosteroid creams (n=94, 94.00%). This was followed by non-prescription creams that control itching (n=61, 61.00%), antihistamines (n=61, 61.00%) and wet dressings (n=47, 47.00%). Antibiotics and calamine lotion were both reported by 40 participants (40.00%).
- Participants were asked to rate their quality of life on a scale of 1 to 7, while using each specific treatment (with 1 being 'Life was very distressing and 7 being 'Life was great'). Mean quality of life scores ranges from 2.40 to 3.62, that is, all quality of life scores were with the 'life was distressing' to 'Life was a little distressing' range. The treatments that scored the least impact on quality of life were non-prescription creams that control itching and inflammation (average score 3.62), antihistamines (average score 3.33), creams to repair cracked skin (average score 3.31), stress reduction treatments (average score 3.21) and corticosteroid creams (average score 3.03). The treatments that had the greatest impact on quality of life were antibiotics (average score 2.40), diluted bleach baths (average score 2.42) and relaxation or behaviour modification (average score 2.42).
- Participants were asked to rate how effective the participant felt the treatment was on a scale of 1 to 5 (with 1 being ineffective and 5 being very effective). All treatments scored between a range of 1.53 to 3.86, that is ineffective to moderately effective. The most effective treatments were oral or injectable corticosteroids (average score 3.86), corticosteroid creams (average score 3.42), and wet dressings (average score 3.13). The least effective treatments were calamine lotion (average score 1.53), stress reduction techniques (average score 2.21) and diluted bleach baths (average score 2.29).
- In relation to side effects that participants felt they could cope with, the main theme was that there were no significant side effects of treatment noted, but the eczema itself needed to be managed (n=47, 47.00%). There were 13 participants (13.00%) that described being able to cope with all side effects, 12 participants (12.00%) that described being able to cope with dryness and/or scarring and/or bruising, 10 participants (10.00%) that described being able to cope with dryness and/or scarring and/or bruising, and 10 participants (10.00%) that described being able to cope with the thinning of skin. There were a further 11 participants (11.00%) that did not describe any side effects that they could cope with, rather they only described side effects that were difficult.
- In relation to sub-group variations, participants with mild AD reported no significant side effects more frequently than the general cohort (63.64% compared to 47.00% in the general cohort) while participants with very severe AD reported this less frequently (31.82% compared to 47.00% in the general cohort). There were also no participants with mild AD that reported only having difficult side effects.
- For the participants that did speak about difficult side effects, there was a broad range of difficult side effects noted by participants including coping with the impact on mental health, skin dryness, cracking, bruising and thinning, and the long-term impact of treatment, however no themes were coded more than ten times. The most common theme overall was difficulty coping with the impact on mental health (n=7, 7.00%).
- While we acknowledge that there were few significant themes identified in relation to difficult side effects, it is important to note that there were six participants (6.00%) that also noted the difficulties in managing long term side effects of treatment as this is also aligned with the psychological stress associated with AD.

Adherence to medication

- The main theme noted by 23 participants (23.00%) was that they would stick to a treatment for as long as it was working for them. In relation to a specific time frame in which participants would adhere to a treatment, the main time frame was about a month (n=19, 19.00%) followed by a week or less (n=16, 16.00%) and two to three months (n=16, 16.00%).
- There was one sub-group variation where participants with mild AD reported sticking to a treatment for as long as it worked more frequently than the general cohort (36.36% compared to 20.00% in the general cohort).
- Participants were asked what needed to change for them to feel as though a treatment was working. The key theme noted by over half of the cohort was needing to have a reduction in itchiness (n=53, 53.00%).

Participants describes this as a key symptom that causes discomfort and the importance of ameliorating this. The next most common theme was that the AD needed to disappear in general (n=33, 33.00%) and there were three additional, common themes including needing to see a reduction in rash, redness or inflammation (n=26, 26.00%), needing to feel more comfortable in general (n=19, 19.00%) and a reduction on skin dryness, flakiness or skin cracking (n=18, 18.00%).

- There was one sub-group variation where there were no participants that had mild AD who reported needing the AD to disappear in general (compared to 33.00% in the general cohort).

Complementary therapies

- The main theme was that participants considered using various creams and gentle soaps as complementary therapies (n=36, 36.00%). This was followed by dietary changes that were also considered to be complementary therapies. There were 27 participants (27.00%) that described accessing naturopaths or homeopaths and 24 participants (24.00%) that described accessing Chinese medicine and acupuncture.
- There were a number of sub-group variations. Participants with mild AD reported using creams and gentle soaps more frequently than the general cohort (81.82% compared to 36.00% in the general cohort), while participants with moderate AD reported this less frequently (19.23% compared to 36.00% in the general cohort). In relation to dietary changes, participants with mild AD reported this less frequently (9.09% compared to 35.00% in the general cohort) and participants with severe AD reported this more frequently (51.22% compared to 36.00% in the general cohort). With the exception of using creams and gentle washes, participants with mild AD reported overall less use of complementary treatments over all themes.

Service provision and affordability

- The majority of patients had private healthcare insurance (n=75, 75%), and half of the participants were treated mostly as a public patient (n=50, 50%). Of those that were treated for atopic dermatitis in hospital, most were treated in a public hospital (n=39, 6.94%)
- Approximately half of the participants have never missed medical appointments due to cost (n=52, 52.00%), and have never been unable to afford prescription medications (n=49, 49.50%), however, approximately half of the participants have missed appointments or been unable to pay for medications at some point. The majority of participants have never had trouble paying for basic needs due to their diagnosis with atopic dermatitis (n=62, 62.00%).

Treatments experienced

Participants were asked in the questionnaire to identify the treatments that they had experienced. The most common treatments reported by nearly all participants were corticosteroid creams (n=94, 94.00%). This was followed by non-prescription creams that control

itching (n=61, 61.00%), antihistamines (n=61, 61.00%) and wet dressings (n=47, 47.00%). Antibiotics and calamine lotion were both reported by 40 participants (40.00%).

Table 5.1: Treatments experienced

Treatments 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)	%
Corticosteroid creams or ointments	94	94.00	7.00	63.64	25.00	96.15	40.00	97.56	22.00	100.00
Non-prescription creams that control itching and inflammation	61	61.00	6.00	54.55	15.00	57.69	24.00	58.54	16.00	72.73
Antihistamines	61	61.00	3.00	27.27	13.00	50.00	29.00	70.73	16.00	72.73
Wet dressings	47	47.00	3.00	27.27	10.00	38.46	16.00	39.02	18.00	81.82
Calamine lotion	40	40.00	3.00	27.27	7.00	26.92	19.00	46.34	11.00	50.00
Antibiotics	40	40.00	0.00	0.00	7.00	26.92	20.00	48.78	13.00	59.09
Light therapy	36	36.00	0.00	0.00	10.00	38.46	17.00	41.46	9.00	40.91
Oral or injectable corticosteroids	35	35.00	1.00	9.09	9.00	34.62	13.00	31.71	12.00	54.55
Diluted bleach baths	24	24.00	0.00	0.00	2.00	7.69	11.00	26.83	11.00	50.00
Stress reduction treatments	14	14.00	0.00	0.00	1.00	3.85	7.00	17.07	6.00	27.27
Creams to repair cracked skin	13	13.00	0.00	0.00	3.00	11.54	7.00	17.07	3.00	13.64
Relaxation or behaviour modification	12	12.00	1.00	9.09	2.00	7.69	6.00	14.63	3.00	13.64
Antidepressants	3	3.00	0.00	0.00	0.00	0.00	2.00	4.88	1.00	4.55

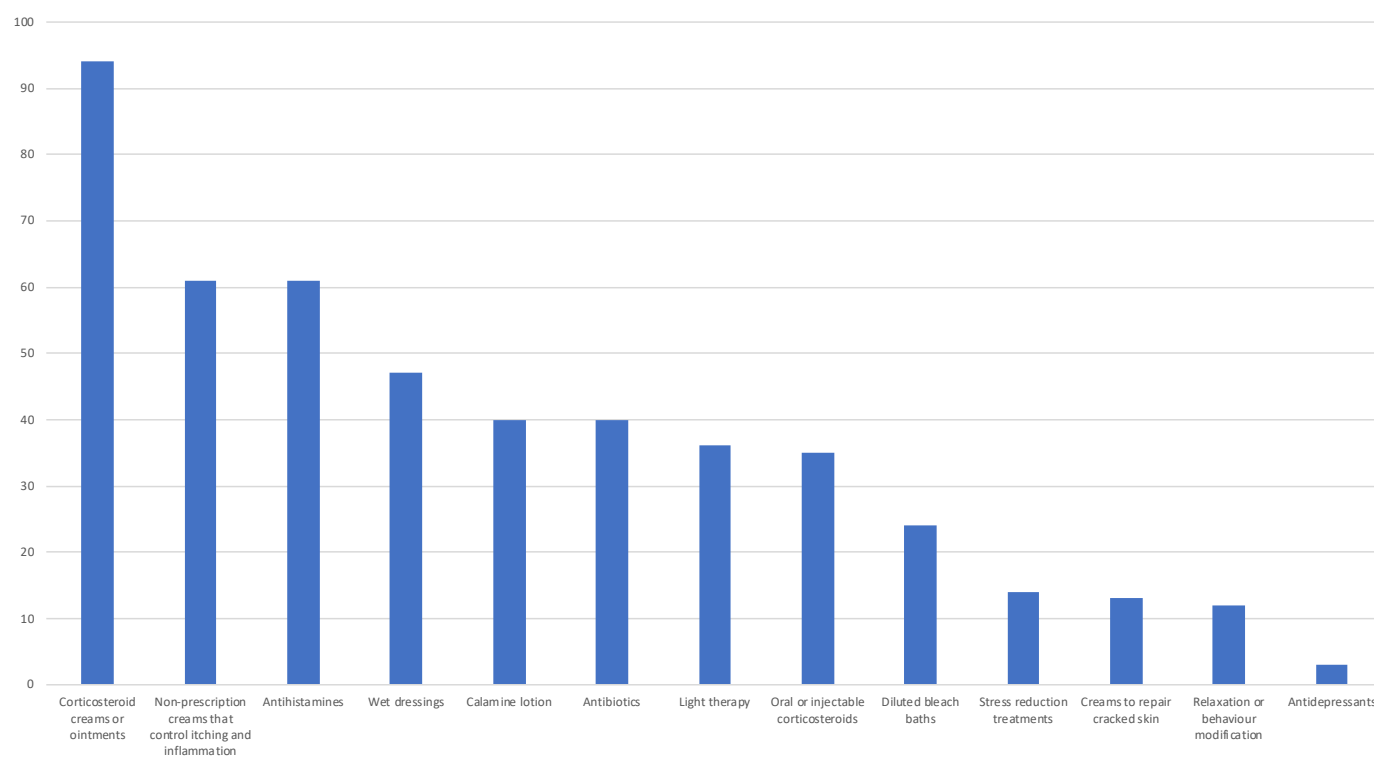


Figure 5.1: Treatments experienced (% of all participants)

As a follow-up question (within the questionnaire), participants were asked to rate their quality of life on a scale of 1 to 7, while using each specific treatment (with 1 being 'Life was very distressing and 7 being 'Life was great'). Mean quality of life scores ranges from 2.40 to 3.62, that is, all quality of life scores were with the 'life was distressing' to 'Life was a little distressing' range. The treatments that scored the least impact on quality of life were non-prescription creams that

control itching and inflammation (average score 3.62), antihistamines (average score 3.33), creams to repair cracked skin (average score 3.31), stress reduction treatments (average score 3.21) and corticosteroid creams (average score 3.03). The treatments that had the greatest impact on quality of life were antibiotics (average score 2.40), diluted bleach baths (average score 2.42) and relaxation or behaviour modification (average score 2.42).

Table 5.2: Treatments experienced and mean quality of life

Treatment	n=	%	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)	
Non-prescription creams that control itching and inflammation	61	61	1 (min) – 7 (max)	3.62	5	8.20	11	18.03	11	18.03	18	29.51	8	13.11	7	11.48	1	1.64
Antihistamines	61	61	1 (min) – 7 (max)	3.33	5	8.20	12	19.67	16	26.23	17	27.87	9	14.75	1	1.64	1	1.64
Creams to repair cracked skin	13	13	1 (min) – 5 (max)	3.31	1	7.69	2	15.38	5	38.46	2	15.38	3	23.08	0	0.00	0	0.00
Stress reduction treatments	14	14	2 (min) – 5 (max)	3.21	0	0.00	6	42.86	2	14.29	3	21.43	3	21.43	0	0.00	0	0.00
Corticosteroid creams or ointments	94	94	1 (min) – 7 (max)	3.03	18	19.15	19	20.21	17	18.09	28	29.79	7	7.45	4	4.26	1	1.06
Light therapy	36	36	1 (min) – 7 (max)	2.81	11	30.56	4	11.11	10	27.78	5	13.89	5	13.89	0	0.00	1	2.78
Calamine lotion	40	40	1 (min) – 6 (max)	2.70	8	20.00	14	35.00	7	17.50	5	12.50	5	12.50	1	2.50	0	0.00
Oral or injectable corticosteroids	35	35	1 (min) – 7 (max)	2.49	12	34.29	9	25.71	6	17.14	3	8.57	4	11.43	0	0.00	1	2.86
Wet dressings	47	47	1 (min) – 5 (max)	2.43	15	31.91	13	27.66	5	10.64	12	25.53	2	4.26	0	0.00	0	0.00
Relaxation or behaviour modification	12	12	1 (min) – 5 (max)	2.42	2	16.67	6	50.00	2	16.67	1	8.33	1	8.33	0	0.00	0	0.00
Diluted bleach baths	24	24	1 (min) – 5 (max)	2.42	8	33.33	7	29.17	3	12.50	3	12.50	3	12.50	0	0.00	0	0.00
Antibiotics	40	40	1 (min) – 5 (max)	2.40	9	22.50	16	40.00	6	15.00	8	20.00	1	2.50	0	0.00	0	0.00

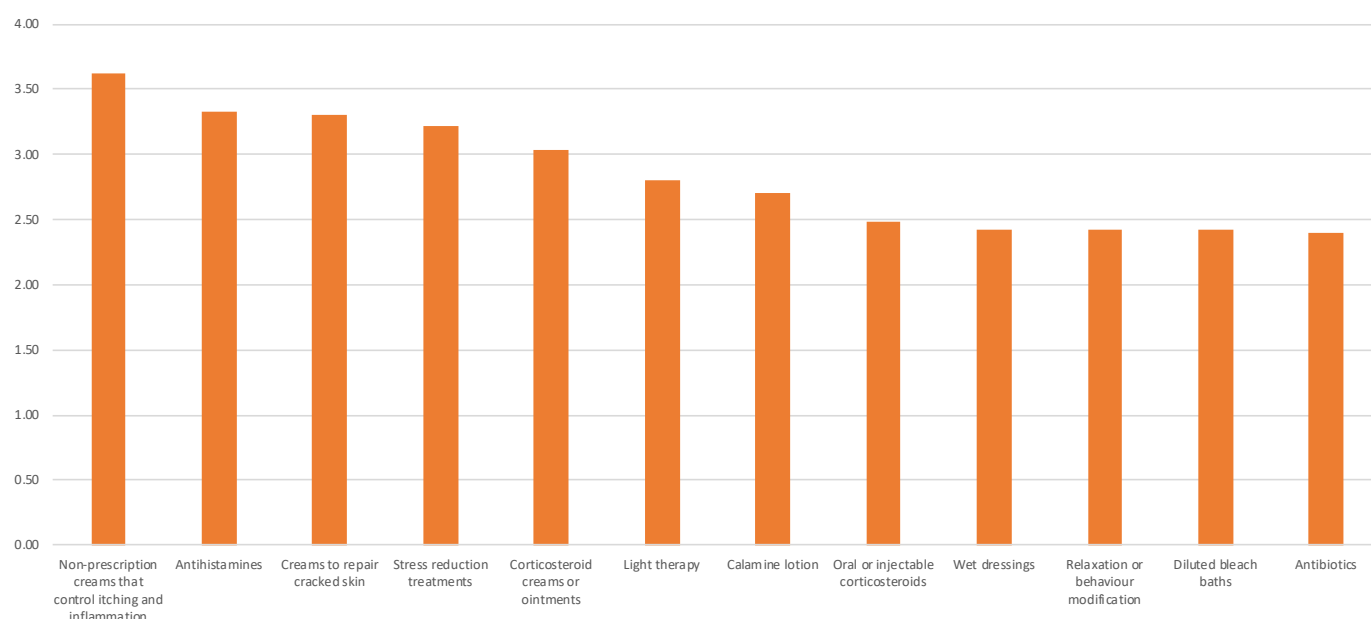


Figure 5.2: Treatments experienced and mean quality of life

A second follow-up question was asked in relation to how effective the participant felt the treatment was on a scale of 1 to 5 (with 1 being ineffective and 5 being very effective). All treatments scored between a range of 1.53 to 3.86, that is ineffective to moderately effective. The most effective treatments were oral or

injectable corticosteroids (average score 3.86), corticosteroid creams (average score 3.42), and wet dressings (average score 3.13). The least effective treatments were calamine lotion (average score 1.53), stress reduction techniques (average score 2.21) and diluted bleach baths (average score 2.29).

Table 5.3: Treatments experienced and effectiveness

Treatment	n=	Range	Mean Effective- ness score	Ineffective (Score = 1)		Somewhat effective (Score = 2)		Moderately effective (Score = 3)		Effective (Score = 4)		Very effective (Score = 5)	
				n=	%	n=	%	n=	%	n=	%	n=	%
Oral or injectable corticosteroids	35	1(min) – 5 (max)	3.86	2	5.71	3	8.57	7	20.00	9	25.71	14	40.00
Corticosteroid creams or ointments	94	1(min) – 5 (max)	3.43	5	5.32	16	17.02	24	25.53	32	34.04	17	18.09
Wet dressings	47	1(min) – 5 (max)	3.13	7	14.89	14	29.79	5	10.64	8	17.02	13	27.66
Antibiotics	40	1(min) – 5 (max)	2.98	3	7.50	13	32.50	9	22.50	12	30.00	3	7.50
Non-prescription creams that control itching and inflammation	61	1(min) – 5 (max)	2.82	7	11.48	16	26.23	23	37.70	11	18.03	4	6.56
Antihistamines	61	1(min) – 5 (max)	2.70	8	13.11	18	29.51	21	34.43	12	19.67	2	3.28
Creams to repair cracked skin	13	1(min) – 3 (max)	2.69	2	15.38	0	0.00	11	84.62	0	0.00	0	0.00
Light therapy	36	1(min) – 5 (max)	2.67	10	27.78	9	25.00	5	13.89	7	19.44	5	13.89
Relaxation or behaviour modification	12	1(min) – 4 (max)	2.42	1	8.33	7	58.33	2	16.67	2	16.67	0	0.00
Diluted bleach baths	24	1(min) – 4 (max)	2.29	6	25.00	8	33.33	7	29.17	3	12.50	0	0.00
Stress reduction treatments	14	1(min) – 4 (max)	2.21	5	35.71	3	21.43	4	28.57	2	14.29	0	0.00
Calamine lotion	40	1(min) – 4 (max)	1.53	23	57.50	14	35.00	2	5.00	1	2.50	0	0.00

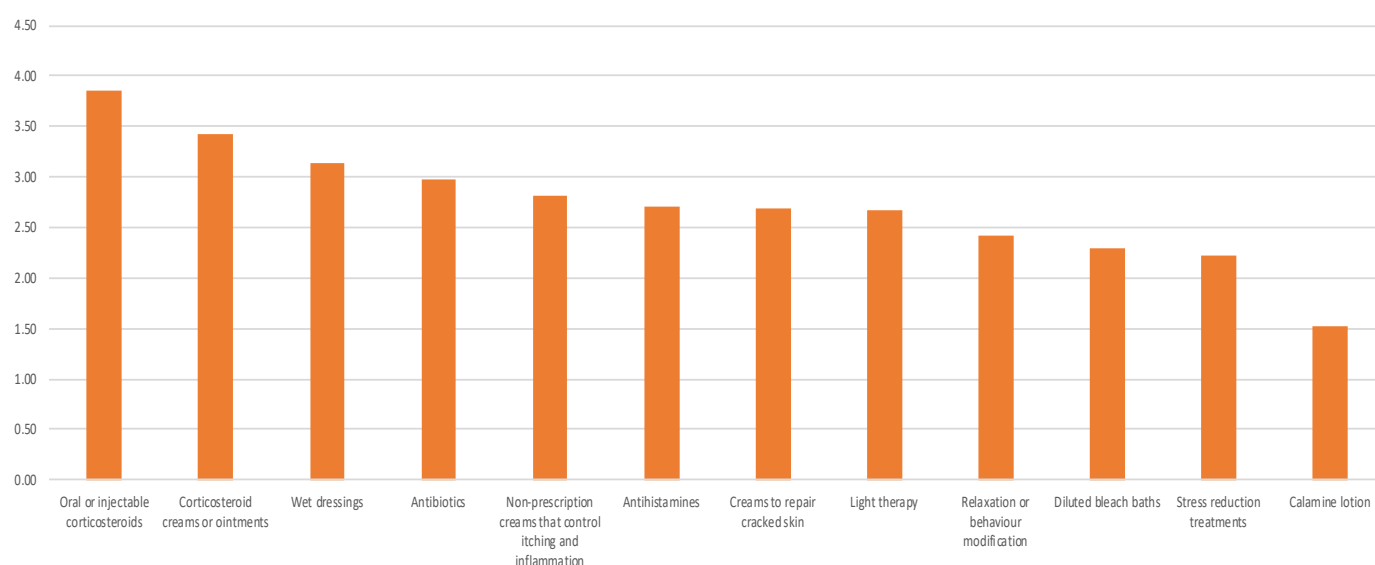


Figure 5.3: Treatments experienced and effectiveness

Side effects of treatment

Participants were guided to reflect on the side effects that they had experienced from their various treatments. They were then asked two, separate questions in relation to the side effects that they felt they could cope with, and the side effects that were very difficult to cope with. In relation to side effects that participants could cope with, the main theme was that there were no significant side effects noted, but the eczema itself needed to be managed (n=47, 47.00%). There were 13 participants (13.00%) that described being able to cope with all side effects, 12 participants (12.00%) that described being able to cope with dryness and/or scarring and/or bruising, and 10 participants (10.00%) that described being able to cope

with the thinning of skin. There were a further 11 participants (11.00%) that did not describe any side effects that they could cope with, rather they only described side effects that were difficult.

In relation to sub-group variations, participants with mild AD reported no significant side effects more frequently than the general cohort (63.64% compared to 47.00% in the general cohort) while participants with very severe AD reported this less frequently (31.82% compared to 47.00% in the general cohort). There were also no participants with mild AD that reported only having difficult side effects.

Table 5.4: Side effects that participants could cope with

	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)	
No significant side effects experienced that the participant needed to cope with - only the AD itself	47	47.00	7	63.64	13	50.00	20	48.78	7	31.82
Participant describes being able to cope with all the side effects	13	13.00	1	9.09	3	11.54	5	12.20	4	18.18
Participant describes being able to cope with dryness and/or scarring and/or bruising of skin	12	12.00	1	9.09	0	0.00	8	19.51	3	13.64
No response given/coded (only difficult side effects)	11	11.00	0	0.00	5	19.23	3	7.32	3	13.64
Participant describes being able to cope with thinning of skin (weakening)	10	10.00	1	9.09	0	0.00	5	12.20	4	18.18
Participant describes coping with side effects as there was no other option	6	6.00	0	0.00	1	3.85	3	7.32	2	9.09
Participant describes being able to cope with weight gain	6	6.00	0	0.00	1	3.85	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)	
No significant side effects experienced that the participant needed to cope with - only the AD itself	17	43.59	15	36.59	32	54.24	25	43.10	22	52.38
Participant describes being able to cope with all the side effects	5	12.82	5	12.20	8	13.56	9	15.52	4	9.52
Participant describes being able to cope with dryness and/or scarring and/or bruising of skin	5	12.82	5	12.20	7	11.86	8	13.79	4	9.52
No response given/coded (only difficult side effects)	5	12.82	5	12.20	6	10.17	6	10.34	5	11.90
Participant describes being able to cope with thinning of skin (weakening)	3	7.69	7	17.07	3	5.08	7	12.07	3	7.14
Participant describes coping with side effects as there was no other option	4	10.26	2	4.88	4	6.78	5	8.62	1	2.38
Participant describes being able to cope with weight gain	1	2.56	5	12.20	1	1.69	3	5.17	3	7.14

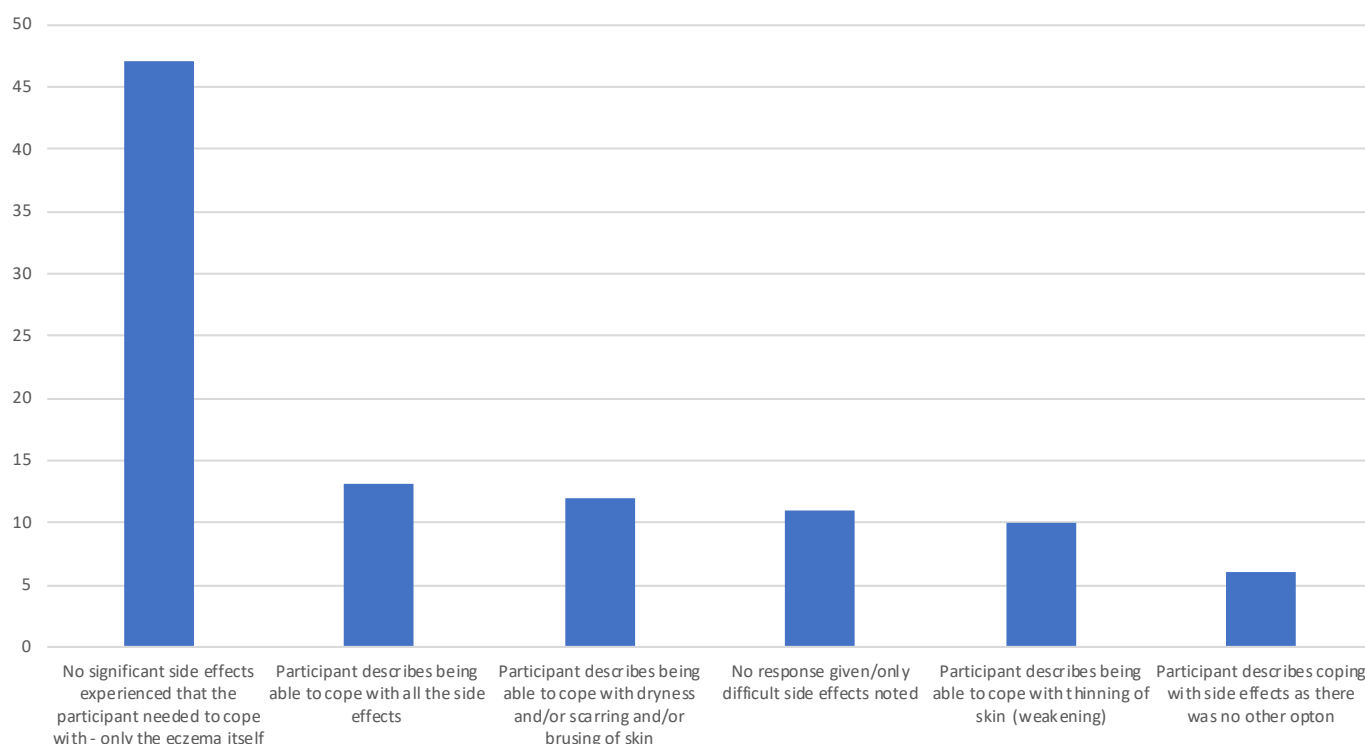


Figure 5.4: Side effects that participants could cope with (% of all participants)

For the participants that did speak about difficult side effects, there was a broad range of difficult side effects noted by participants including coping with the impact on mental health, skin dryness, cracking, bruising and thinning, and the long-term impact of treatment, however no themes were coded more than ten times. The most common theme overall was difficulty coping with the impact on mental health (n=7, 7.00%). Participants spoke about the fear they encounter in relation to the implications of being on treatment for a long period of time:

As a kid, that's traumatic. Yes, because you associate bandages with someone being really badly burnt or damaged kind of thing, so having to be wrapped like that, it does, mentally, stay with you. Also, it makes you very cold, made me shiver. Everything is wet like your beds end up. (What about the gloves on my hands?) Yes, again, that's traumatic. It's funny now thinking about, not funny but it's interesting thinking about it. It's actually quite traumatic. You're almost like there's something so wrong with you that you have to have gloves on your hands to protect yourself from yourself. It has that mental side-effect. ", "I think it's, I look back now, I think it's really the psychological ones related to the wrapping. Because it stays with you." Participant 6

I get really conscious. Yes. It's probably emotional for the part of it. It's not as if I'm not old enough now that I don't get self conscious about that stuff but as a kid I

was self conscious about looking a bit funny, I don't think that otherwise. Participant 13

I struggle mentally, more than anything. So, psychologically, with the fear, I guess, on becoming dependent of topical steroids the most. That's what I struggle with. It seems to always be in my mind, now that I've found out that it could be an issue. Let's put it to you this way. If I hadn't read six months ago that you shouldn't be using topical steroids daily, I probably still would be using them. Not necessarily daily, but whenever I noticed something flare I would just put something ... I would be living my life, and hardly noticing any side effects. For me, knowing that this might be an issue, and nobody being able to tell me, "Yes, it is an issue." Or, "No, it isn't an issue. You can relax." Is causing a lot of stress. That stress is making me sicker. That is my biggest worry. Participant 43

I think a big side effect is the fear as well. The fear of what else could be happening because one of the side-effects from the methotrexate is higher risk of getting skin cancer, and so I cover up as best as I can for that but the anxiety in those sorts of things, from using them. Participant 90

While we acknowledge that there were few significant themes identified in relation to difficult side effects, it is important to note that there were six participants (6.00%) that also noted the difficulties in managing

long term side effects of treatment as this is also aligned with the psychological stress associated with AD:

Coping with now as an older adult with this liver and osteoporosis. You can't have 50 years of that treatment without it impacting on your health. Participant 19

Well, it's a worry thinking your liver could be damaged. The fact that your immune system is getting wiped out, and what's that going to leave you with. Participant 82

They said, have I had a bone density scan? I said no. So I went to have a bone density scan. The X-ray person says to us, "You have the bone density of an 80-year-old." I'm going, holy crap. That scared me. When I

spoke to the doctors, they said she had no right to say that. That's why I've got ... An X-ray person should just take the X-ray, don't do a diagnosis sort of thing. That's probably the worrying thing, is the bones. Participant 96

They have so much damage, steroid tablets have so much damage on your bone density, and all those other things in your body as well. The fact that I had been on them for such a- I've been on them for about a year-and-a-half so that period of time, doctors were getting very, very-- because, I would do it secretly and stuff. They were getting very, very worried about me, just my body and stuff. Participant 97

Table 5.5: Side effects that participants found difficult to cope with

	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 difficulty coping with the impact on their mental health	7	7.00	1	9.09	1	3.85	3	7.32	2	9.09
Participants describes difficulty coping with skin cracking, dryness and bruising	6	6.00	0	0.00	0	0.00	4	9.76	2	9.09
Participants describes difficulty coping with itchiness	6	6.00	0	0.00	2	7.69	1	2.44	3	13.64
Participants describes difficulty coping with long term effects of treatment including osteoporosis	6	6.00	0	0.00	1	3.85	2	4.88	3	13.64
Participants describes difficulty coping with thinning of skin (weak skin)	5	5.00	2	18.18	2	7.69	1	2.44	0	0.00
Participants describes difficulty coping with dependency/addiction caused due corticosteroids (oral and topical)	4	4.00	0	0.00	1	3.85	2	4.88	1	4.55
Participants describes difficulty coping when treatment with corticosteroids is not working or it making eczema worse	4	4.00	0	0.00	0	0.00	3	7.32	1	4.55
Participants describes difficulty coping with sensitive skin	3	3.00	1	9.09	1	3.85	0	0.00	1	4.55
Participants describes difficulty coping with side effects caused by cyclosporine and methotrexate like headache, polymyalgia	3	3.00	0	0.00	1	3.85	1	2.44	1	4.55
Participants describes difficulty coping with weight gain	3	3.00	0	0.00	1	3.85	0	0.00	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 difficulty coping with the impact on their mental health	3	7.69	4	9.76	3	5.08	5	8.62	2	4.76
Participants describes difficulty coping with skin cracking, dryness and bruising	2	5.13	1	2.44	5	8.47	3	5.17	3	7.14
Participants describes difficulty coping with itchiness	3	7.69	1	2.44	5	8.47	1	1.72	5	11.90
Participants describes difficulty coping with long term effects of treatment including osteoporosis	3	7.69	6	14.63	0	0.00	6	10.34	0	0.00
Participants describes difficulty coping with thinning of skin (weak skin)	1	2.56	4	9.76	1	1.69	3	5.17	2	4.76
Participants describes difficulty coping with dependency/addiction caused due corticosteroids (oral and topical)	2	5.13	2	4.88	2	3.39	1	1.72	3	7.14
Participants describes difficulty coping when treatment with corticosteroids is not working or it making eczema worse	2	5.13	1	2.44	3	5.08	3	5.17	1	2.38
Participants describes difficulty coping with sensitive skin	2	5.13	1	2.44	2	3.39	2	3.45	1	2.38
Participants describes difficulty coping with side effects caused by cyclosporine and methotrexate like headache, polymyalgia	2	5.13	2	4.88	1	1.69	2	3.45	1	2.38
Participants describes difficulty coping with weight gain	2	5.13	3	7.32	0	0.00	2	3.45	1	2.38

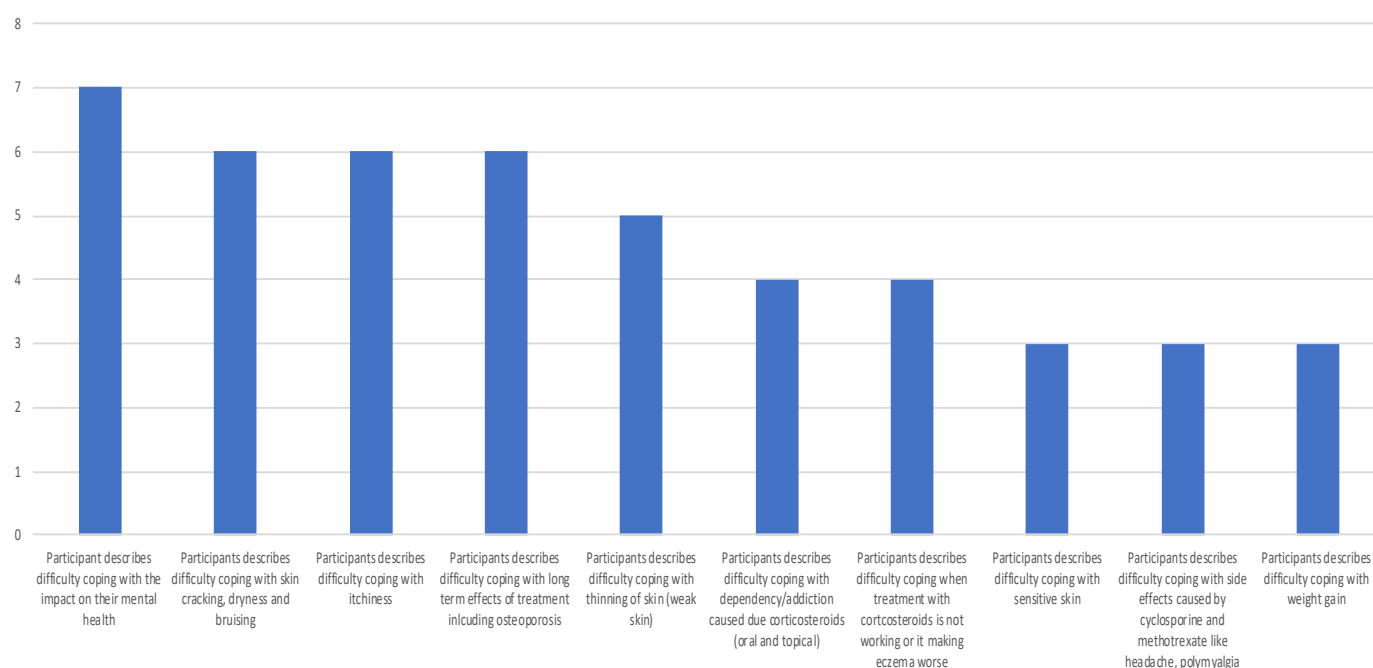


Figure 5.5: Side effects that participants found difficult to cope with (% of all participants)

Adherence to medications

Participants were asked how long they stick with a therapy before they think it might not be working or give up on it.

The main theme noted by 23 participants (23.00%) was that they would stick to a treatment for as long as it was working for them:

*This is really moisturising my skin. Especially my hands, if they're moisturised, as soon as they dry out, they hurt, they get sore, and then the crack, so it's pretty well instant sort of a thing. If something seems to be working and working well, I just keep using it until I find something else. **Participant 2***

*If it's working, I just stick with it. I've got stuck with this for 16 years. I've stuck with the other one for 50. Yes, I've got a long-range. **Participant 19***

*If it don't think it's working I'd probably give it a couple more tries just to convince myself. And then I'd stop. **Participant 95***

In relation to a specific time frame in which participants would adhere to a treatment, the main time frame was about a month (n=19, 19.00%) followed by a week or less (n=16, 16.00%) and two to three months (n=16, 16.00%).

Participant describes sticking with something for about a month

*I test for a month. Yes, about a month. You see, but because I-- for me, testing with one, two, three-day is just the beginning so you don't really see the result yet. To see a good result, you have to take that longer, so I'm giving myself a month. **Participant 14***

*I try to give it at least two to four weeks to try and get a real sense of whether it's doing anything. **Participant 66***

*I usually try and do it for about two weeks. Two weeks to maybe a month depending on what it is, depending on if I actually stick with it, how good I am with it. **Participant 83***

Participant describes sticking with something for about a week or less

*It kind of depends. If it's making it worse, I'll probably only give it about a week. If it's around the same, I'll stick with it until that container or whatever's finished. **Participant 3***

*Generally, because unfortunately I've had success with ... So it's like an impulse thing, so I've had Prednisolone act and be successful within 24 hours. Unfortunately from that I'm likely to give something three to five days to see if it works. **Participant 54***

*Not long really. Like someone gave me a cream, I might put it on for a week or so. Just be like doing nothing, and stop. That's been mostly in situations where people just have their advice about what's going to help your eczema, they give you a lotion or a cream or something. It hasn't been something that I feel like anyone's come to me with evidence. It's going to really help then I'd stick with it for a week, something like that. But, not long, just like a week or so. I'd put their cream on and give up really. **Participant 99***

Participant describes sticking with something for about 2 to 3 months

*Two or three months. I persevere. I'm quite a patient person, I guess. **Participant 30***

*Normally, I stick with them for quite a while because I know sometimes it takes quite a while for things to make a difference, so, yeah, I would say a few months I would stick with something before I gave up on it. **Participant 51***

*I would say probably two months I would hope for it to work. **Participant 75***

There was one sub-group variation where participants with mild AD reported sticking to a treatment for as long as it worked more frequently than the general cohort (36.36% compared to 20.00% in the general cohort).

Table 5.6: How long patients stick to a therapy

How long people stick with something before they give up on it	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 sticking with something for as long as it is working	23	23.00	4	36.36	5	19.23	8	19.51	6	27.27
Participant describes sticking with something for about a month	19	19.00	2	18.18	7	26.92	6	14.63	4	18.18
Participant describes sticking with something for about a week or less	16	16.00	3	27.27	3	11.54	7	17.07	3	13.64
Participant describes sticking with something for about 2 to 3 months	16	16.00	0	0.00	5	19.23	8	19.51	3	13.64
Participant describes sticking with something for about two weeks	8	8.00	0	0.00	1	3.85	6	14.63	1	4.55
Participant describes sticking with something for about 6 months	7	7.00	0	0.00	3	11.54	3	7.32	1	4.55
Participant describes sticking with something for as long as prescribed	5	5.00	0	0.00	0	0.00	1	2.44	4	18.18
Participant describes sticking with something for about a year or longer	4	4.00	0	0.00	1	3.85	2	4.88	1	4.55

How long people stick with something before they give up on it	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
Participant describes sticking with something for as long as it is working	15	38.46	8	19.51	15	25.42	13	22.41	10	23.81
Participant describes sticking with something for about a month	5	12.82	9	21.95	10	16.95	15	25.86	4	9.52
Participant describes sticking with something for about a week or less	2	5.13	9	21.95	7	11.86	9	15.52	7	16.67
Participant describes sticking with something for about 2 to 3 months	5	12.82	5	12.20	11	18.64	9	15.52	7	16.67
Participant describes sticking with something for about two weeks	4	10.26	5	12.20	3	5.08	5	8.62	3	7.14
Participant describes sticking with something for about 6 months	1	2.56	3	7.32	4	6.78	5	8.62	2	4.76
Participant describes sticking with something for as long as prescribed	2	5.13	2	4.88	3	5.08	1	1.72	4	9.52
Participant describes sticking with something for about a year or longer	1	2.56	1	2.44	3	5.08	2	3.45	2	4.76

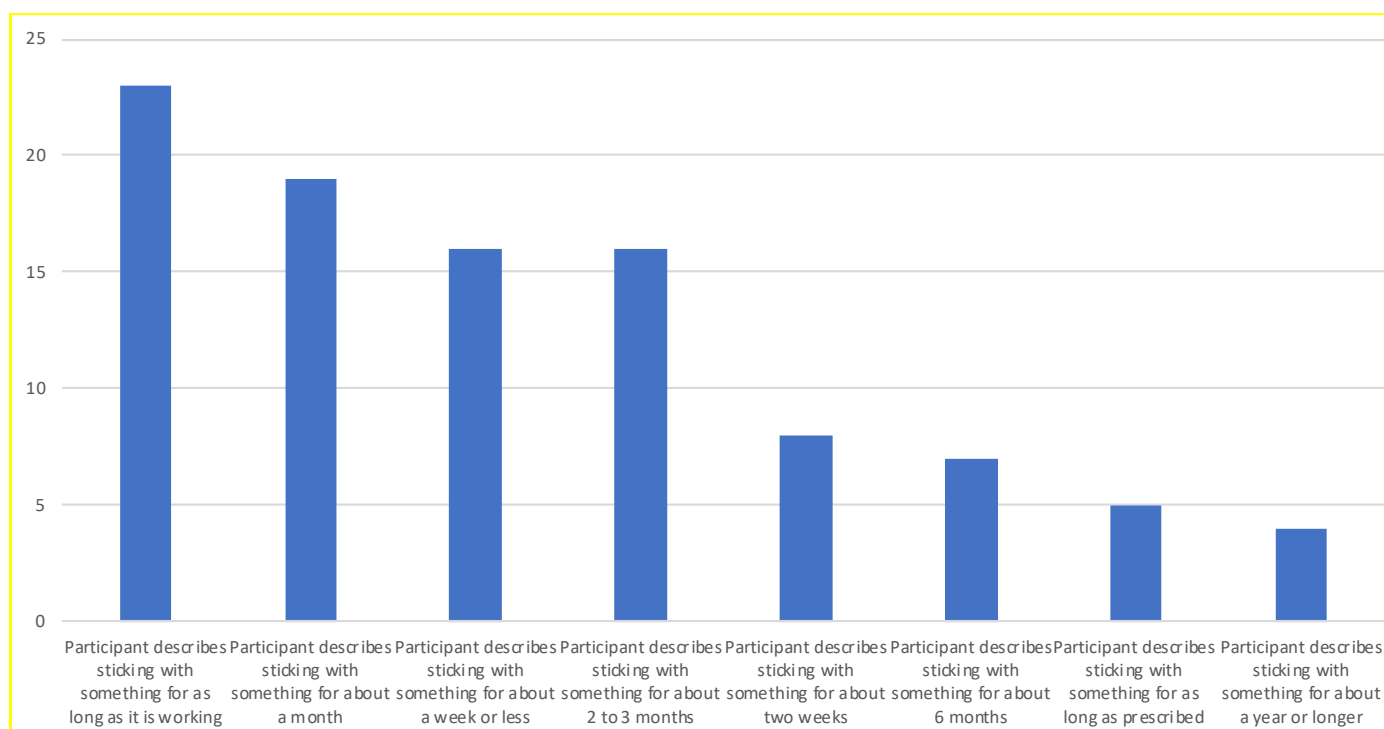


Figure 5.6: How long patients stick to a therapy (% of all participants)

Impact of treatment

Participants were asked what needed to change for them to feel as though a treatment was working. The key theme noted by over half of the cohort was needing to have a reduction in itchiness (n=53, 53.00%). Participants describes this as a key symptom that causes discomfort and the importance of ameliorating this:

The itchiness needs to improve and obviously, the actual-- it's because of my weak skin as well, but just having that patch of eczema there as well, for it to clear up and heal. Participant 16

Generally, it's just reducing the itch. Because if can reduce the itch then it stops the sores and not being able to sleep and all of that. If it reduced the itch it generally helps a lot in terms of a lot of other things. Participant 45

I need to stop itching [chuckles]. I think that's really one of the main things, is that I have been scratching and I have felt my skin tearing underneath my fingernails and still not wanted to stop. It's just awful. That's probably-- Aside from cracked hands, bleeding, pain and dry hands, so bad that I can't actually fully open my hand without my skin cracking, I'd say the itch just drives me absolutely nuts. That's probably one thing that I really look for in treatment is getting rid of that itch, which makes me pretty happy. Participant 63

The next most common theme was that the AD needed to disappear in general (n=33, 33.00%). In this theme, participants referred to their skin being clear:

If it's almost gone away. I don't think I've ever had a case where I've never had any eczema, but it's almost gone away, and I am happy with that. Participant 36

Just an, a miraculous improvement to my skin. I just, yeah, just, my skin gets better and I'm, yeah. Participant 60

Basically for the eczema to be clear- my skin to be clear. Participant 86

There were three additional, common themes including needing to see a reduction in rash, redness or inflammation (n=26, 26.00%), needing to feel more comfortable in general (n=19, 19.00%) and a reduction on skin dryness, flakiness or skin cracking (n=18, 18.00%).

Participant describes needing a reduction in rash (redness, irritation)

The redness disappears, the flakiness disappears, and the itchiness disappears. Participant 10

*The redness of the skin, really. Yeah. If I can see the redness going away and I can see the scratches actually healing, going through a healing process, then that's good enough for me. **Participant 33***

*Definitely the redness in my skin. The amount of itching, the dryness, the cracking and all the crappy stuff that goes with it. And once I've seen that happening, it's like, "Oh wow, it's getting better." **Participant 64***

Participant describes needing to feel more comfortable in general

*Just in general the itching or the sizeable, how much the eczema covers the body. Or discomfort, how much discomfort I've relieved or relief I've had from it. **Participant 73***

*My quality of life is the biggest one. I kind of prod along on my daily, whatever I'm doing and if I all of a sudden get to the end and go, oh wow I'm okay. I'm struggling with this or not too uncomfortable, I pass that as a good sign. Where, if I'm still struggling, I feel miserable and uncomfortable then that's how I decide. **Participant 90***

*I believe there has to be some relief somewhere. Has to be, whether it's a moisturising relief or if it's a anti-itch or something like that. **Participant 96***

Participant describes needing a reduction in skin dryness, flaking or cracking

*To see the effects of the treatment. It's always that anger, that heat, and that itchiness goes down, and then, working with the flakiness, or the chalkiness of my skin. **Participant 46***

*Well the flaxseed oil if I stop taking it for example if ... I stopped for 10 days just because I was slack. When I stop taking it my skin gets really flaky. I am looking at it now and it's all falling off my hands and my wrists and yeah. **Participant 77***

*Definitely the redness in my skin. The amount of itching, the dryness, the cracking and all the crappy stuff that goes with it. And once I've seen that happening, it's like, "Oh wow, it's getting better." **Participant 64***

There was one sub-group variation where there were no participants that had mild AD who reported needing the AD to disappear in general (compared to 33.00% in the general cohort)

Table 5.7: What needs to change to know a treatment has worked

What needs to improve to feel as though something is working	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 needing a reduction in itchiness	53	53.00	5	45.45	14	53.85	22	53.66	12	54.55
Participant describes needing the AD to disappear in general	33	33.00	0	0.00	9	34.62	16	39.02	8	36.36
Participant describes needing a reduction in rash (redness , irritation)	26	26.00	4	36.36	6	23.08	9	21.95	7	31.82
Participant describes needing to feel more comfortable in general	19	19.00	1	9.09	5	19.23	8	19.51	5	22.73
Participant describes needing a reduction in skin dryness, flaking or cracking	18	18.00	2	18.18	3	11.54	9	21.95	4	18.18
Participant describes needing a reduction in bleeding, oozing or weeping	4	4.00	1	9.09	0	0.00	3	7.32	0	0.00

What needs to improve to feel as though something is working	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
Participant describes needing a reduction in itchiness	13	33.33	20	48.78	33	55.93	33	56.90	20	47.62
Participant describes needing the AD to disappear in general	12	30.77	14	34.15	19	32.20	21	36.21	12	28.57
Participant describes needing a reduction in rash (redness, irritation)	8	20.51	11	26.83	15	25.42	14	24.14	12	28.57
Participant describes needing to feel more comfortable in general	11	28.21	8	19.51	11	18.64	13	22.41	6	14.29
Participant describes needing a reduction in skin dryness, flaking or cracking	7	17.95	5	12.20	13	22.03	9	15.52	9	21.43
Participant describes needing a reduction in bleeding, oozing or weeping	1	2.56	2	4.88	2	3.39	4	6.90	0	0.00

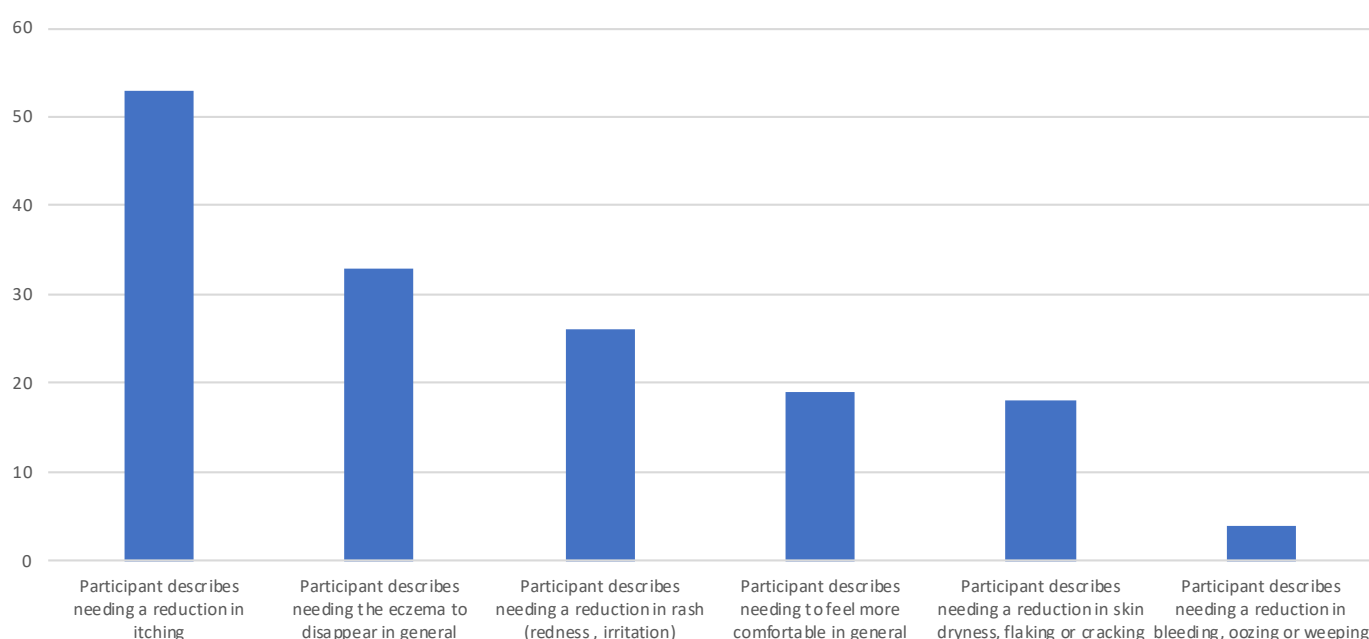


Figure 5.7: What needs to change to know a treatment has worked

Use of complementary therapies

Participants were asked whether they had used any complementary therapies. The main theme was that participants considered using various creams and gentle soaps as complementary therapies (n=36, 36.00%). This was followed by dietary changes that were also considered to be complementary therapies:

The past year, I'd say, I've had the most luck with my eczema. It's the most controlled. I would cutting out certain foods from my diet. I did a bit of my own type of elimination diet, put it that way, cutting out certain foods. Participant 12

Diet, elimination diet, dairy, eggs, all sorts of things. I've tried all the creams that people suggested, goat's milk, and honey, stuff like that. Participant 42

Well, like I've said, I have tried just about everything known to man, I would say. I've tried every sort of moisture cream, bath oil, and everything on the market....vitamin C, vitamins, and minerals. I get the activated Vitamin B....I've tried the - I went to the METROPOLITAN hospital, went with the nutritionist, and went on their diet for eighteen months. I've not the slightest bit of difference, but you just keep on it to try and you never know it might kick in tomorrow. Participant 82

There were 27 participants (27.00%) that described accessing naturopaths or homeopaths and 24 participants (24.00%) that described accessing Chinese medicine and acupuncture.

Participant describes seeing an naturopath/homeopath

*I went to a natural person who pretty much put me on a cleaning- a cleansing diet. That was there and that was hard. Definitely the hardest thing I've done as an adult in my life. I sort that out myself. They took hair samples, blood samples, urine samples. I did everything. They did a whole mark up of every of everything that was going on in my body which is nothing that the doctor ever did. **Participant 55***

*Yes. I have tried some homeopathic, for a long time, was really good. To control my anxiety, there was very good because we have such a busy life and at the end I saw that was getting too stressed with everything. When I realized, I was already itching myself. Then it was like, Oh God its stress, it's something that I relate a lot to my eczema. Was it the same acupuncture, he was homeopathic as well. He was like, "Let's do something nice for you" and was great at the time and I had to see a homeopathic here in Australia as well. **Participant 57***

*I have been to a naturopath and that was probably during my first month of topical steroid withdrawal and I have to say I think they prescribed some natural creams and tablet as well. I have to say, I don't think any of those really worked not because they're ineffective but it's more that my body was in such a shock from steroid creams, from the withdrawal of steroid creams, that nothing would have worked anyway. It just I felt that my body just needed time to just heal by itself and anything external just wasn't gonna help anyway. **Participant 67***

Participant describes using acupuncture and Chinese medicine

*So, from now I go, for example with the Chinese herbs, I've been using that intermittently over three years. And, she gone at lots of different angles. Whether it's eczema or I get cracks in my knuckles or in my hands or wrist or rash on my back. So, with different things that I've had pop up over the years seeing her, I've sort of stuck with it. If that makes sense. **Participant 18***

*I've tried a few different things. I had some copying and other Chinese medicine things. The herbal tea and the needles, what's it called? Acupuncture, yes. I had that - all unsuccessfully. (Interviewer: You mentioned herbs, so that was from the Chinese medicine?) Yes. That was all from Chinese medicine got no idea what was in that. **Participant 22***

*Well, just about three weeks ago, I went to a Chinese doctor thinking that maybe they could help me because I couldn't do that trial thing. We did an acupuncture with the electricity through it, and then she made me these two things, one thing to put on my skin and then this other stuff that I had to mix in the microwave with water and drink and it was like sludge. I had to do that twice a day. I had to ring her back and said, "I'm not coming back. I can't do this." Couldn't do it. I thought I'd try, but I just couldn't do it. **Participant 39***



Figure 5.8: Various creams and gentle washes considered to be complementary therapies

There were a number of sub-group variations. Participants with mild AD reported using creams and gentle soaps more frequently than the general cohort (81.82% compared to 36.00% in the general cohort), while participants with moderate AD reported this less frequently (19.23% compared to 36.00% in the general cohort). In relation to dietary changes, participants

with mild AD reported this less frequently (9.09% compared to 35.00% in the general cohort) and participants with severe AD reported this more frequently (51.22% compared to 36.00% in the general cohort). With the exception of using creams and gentle washes, participants with mild AD reported overall less use of complementary treatments over all themes.

Table 5.8: Use of complementary therapies

Use of complementary therapies	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 using various creams and ointments/gentle soaps	36	36.00	9	81.82	5	19.23	11	26.83	11	50.00
Participants describes making dietary changes	35	35.00	1	9.09	7	26.92	21	51.22	6	27.27
Participant describes see an naturopath/homeopath	27	27.00	1	9.09	7	26.92	14	34.15	5	22.73
Participants describes using Acupuncture and/or Chinese medicine	24	24.00	1	9.09	5	19.23	14	34.15	4	18.18
Participant describes not using any complementary therapies	13	13.00	0	0.00	8	30.77	3	7.32	2	9.09
Psychological support and/or counselling	7	7.00	0	0.00	1	3.85	4	9.76	2	9.09

Use of complementary therapies	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/ Trade educated (n=42)	
Participant describes using various creams and ointments/gentle soaps	11	28.21	16	39.02	20	33.90	16	27.59	20	47.62
Participants describes making dietary changes	13	33.33	14	34.15	21	35.59	23	39.66	12	28.57
Participant describes see an naturopath/homeopath	11	28.21	11	26.83	16	27.12	16	27.59	11	26.19
Participants describes using Acupuncture and/or Chinese medicine	8	20.51	8	19.51	16	27.12	14	24.14	10	23.81
Participant describes not using any complementary therapies	6	15.38	7	17.07	6	10.17	9	15.52	4	9.52
Psychological support and/or counselling	2	5.13	2	4.88	5	8.47	5	8.62	2	4.76

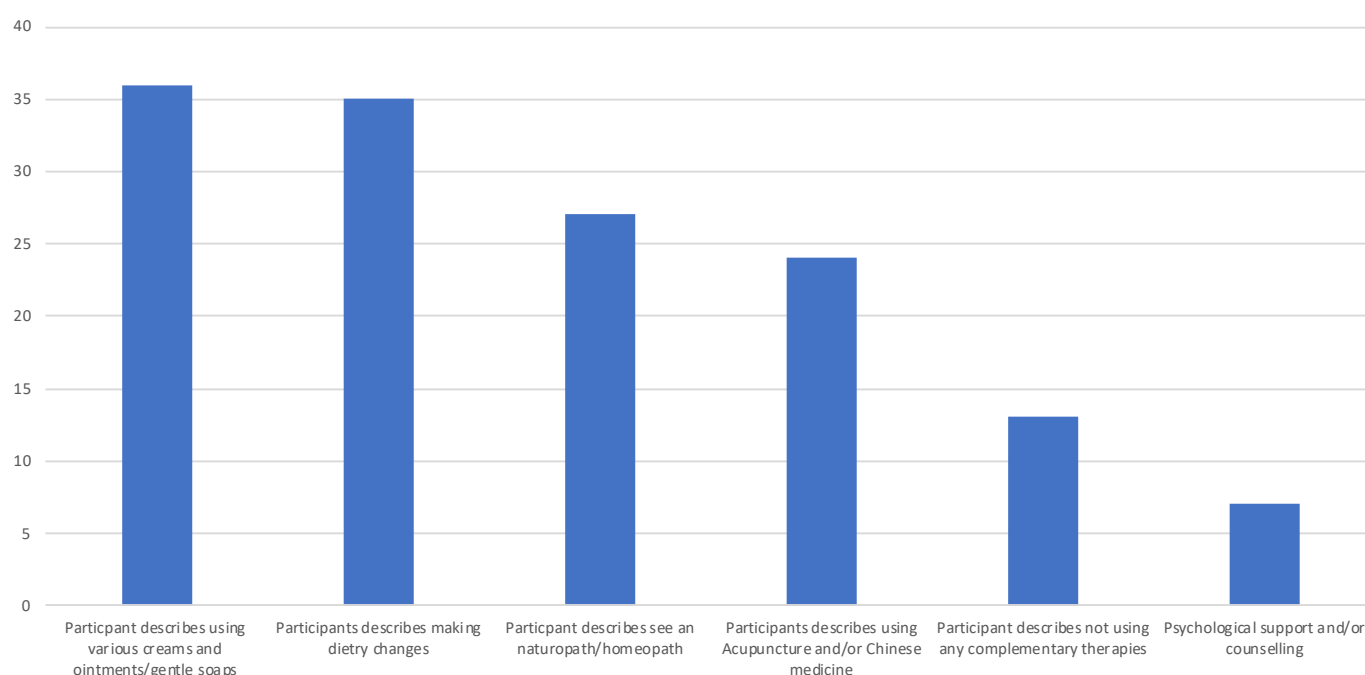


Figure 5.9: Use of complementary therapies (% of all participants)

Service provision and affordability

Details about the healthcare system where participants were treated for eczema and financial complications from treatment are listed in Tables 5.9 to 5.10.

The main provider of treatment for the majority of patients is a general practitioner (n=64, 64.65%) followed by dermatologists (n=24, 24.24%), however, more than three quarters of participants have had access to dermatologists for their atopic dermatitis (n=78, 78%) (Table 5.9).

The majority of patients had private healthcare insurance (n=75, 75%), and half of the participants were treated mostly as a public patient (n=50, 50%). Of those that were treated for atopic dermatitis in hospital, most were treated in a public hospital (n=39, 6.94%) (Table 5.10).

Approximately half of the participants have never missed medical appointments due to cost (n=52, 52.00%), and have never been unable to afford prescription medications (n=49, 49.50%), however, approximately half of the participants have missed appointments or been unable to pay for medications at some point (Table 5.10). The majority of participants have never had trouble paying for basic needs due to

their diagnosis with atopic dermatitis (n=62, 62.00%) (Table 5.10).

Additional costs were described in terms of needing carers, changes to work status and out of pocket expenses. Very few needed to pay for a carer for either themselves or their family as a result of atopic dermatitis (n=8, 8.00%) (Table 5.10). The majority had no change to their work status (n=64, 64.00%), and the majority of carers or partners did not need to change

their work status (n=89, 89.00%) (Table 5.10). The range of out of pocket monthly expenses reported was between \$0 and more than \$1000 (Table 5.10). For some, this cost was not significant at all (n=39, 39.00%), however for more than half of the participants the cost was a somewhat, moderately or extremely significant burden to them (Table 5.10).

Table 5.9: Health professionals providing services for eczema

Main provider of treatment (n=99)	N=	%
General Practitioner	64	64.65
Dermatologist	24	24.24
Naturopath	3	3.03
Self	3	3.03
Immunologist	2	2.02
Chinese medicine/herbalist	2	2.02
Other	1	1.01
Health professionals accessed for eczema (n=100)		
General Practitioner	95	95.00
Dermatologist	78	78.00
Immunologist	30	30.00
Alternative health practitioners	17	17.00
Dietician	16	16.00
Counselling or psychological support	14	14.00
Paediatrician	13	13.00
Registered Nurse	12	12.00
Allergy specialist	3	3.00
Psychiatrist	3	3.00
Physiotherapy	2	2.00
Endocrinologist	1	1.00
Nurse Care Coordinator	1	1.00

Table 5.10: Service provision and affordability

Private health insurance (n=100)	N=	%
Yes	75	75.00
No	25	25.00
Treated as public or private patient (n=100)		
Equally public and private	17	17.00
Private	27	27.00
Public	50	50.00
Don't know	6	6.00
Primary hospital system treated in (n=64)		
Both public and private	16	25.00
Private	9	14.06
Public	39	60.94
(Not treated at hospital)	(36)	
Had to delay or cancel healthcare appointments due to affordability (n=100)		

Never	52	52.00
Rarely	15	15.00
Sometimes	24	24.00
Often	7	7.00
Very often	2	2.00
Unable to fill prescription due to cost (n=99)		
Never	49	49.50
Rarely	17	17.17
Sometimes	24	24.24
Often	8	8.08
Very often	1	1.01
Difficult to pay for basic needs as a result of eczema diagnosis (n=100)		
Never	62	62.00
Rarely	18	18.00
Sometimes	15	15.00
Often	2	2.00
Very often	3	3.00
Had to pay for additional carers due to eczema (n=100)		
Yes	8	8.00
No	92	92.00
Change in employment due to eczema (can choose more than one option) (n=100)		
I have had to quit my job	6	6.00
I have reduced the number of hours i work	13	13.00
I have taken leave with pay	18	18.00
I have taken leave without pay	9	9.00
I was retired or did not have a job when diagnosed	4	4.00
My work status has not changed	64	64.00
I have accessed my super	2	2.00
Change in carer job status (can choose more than one option) (n=100)		
My carer had to quit their job	1	1.00
My carer has reduced the number of hours they work	5	5.00
My carer has taken leave with pay	2	2.00
My carer has taken leave without pay	4	4.00
My carer was retired or did not have a job when diagnosed	5	5.00
My carers work status has not changed	89	89.00
Amount spent per month (n=100)		
		percent
\$0	4	4.00
\$1 -\$50	46	46.00
\$51-\$100	12	12.00
\$101-\$250	15	15.00
\$251-\$500	5	5.00
\$501-\$1000	5	5.00
\$1000 plus	4	4.00
don't know	9	9.00
Out of pocket expenses burden (n=100)		
Very significant	14	14.00
Moderately significant	21	21.00

Somewhat significant	17	17.00
Slightly significant	9	9.00
Not significant at all	39	39.00

Medications/Clinical Trials

Participants were asked about the last time they had a medication review with their doctor, almost half had one within the last year (n=46, 46.00%), and 30 (30.00%) participants had never had a medication review (Table 5.11). In addition, participants were

asked about their experience of clinical trials, almost all participants did not have any discussion about clinical trials (n=95, 95.00%) (Table 5.12). Very few have participated in clinical trials (n=5, 5.00%), however more than three quarters would like to participate in a clinical trial if one was suitable (N=76, 76.00%) (Table 5.12).

Table 5.11: Time since last medication review

Time since last medication review (n=100)		%
With last year	46	46.00%
1 to 2 years ago	7	7.00%
2 to 3 years ago	8	8.00%
3 to 4 years ago	1	1.00%
4 to 5 years ago	1	1.00%
More than 5 years ago	7	7.00%
No medication review	30	30%

Table 5.12: Clinical trials discussion and experience

Discussed clinical trials for eczema with doctor? (n=100)	N=	%
I brought up the topic of clinical trials with my doctor for discussion	3	3
My doctor brought up the topic of clinical trials for discussion	2	2
No one has ever spoken to me about clinical trials	95	95
Participation in a clinical trial for eczema (n=100)		
I have not participated in a clinical trial and do not want to	19	19
I have not participated in a clinical trial but would like to if there is one for me	76	76
I have participated in a clinical trial	5	5

Section 6 Information and communication

Section 6: Information and communication

Access to information

- The majority of participants (n=75, 75.00%) described the internet as their main source of information. There was a large gap between this main theme and the next most common theme of accessing information through their treating clinician which was noted by 25 participants (25.00%).
- There were a number of sub-group variations. Participants with very severe AD described accessing information through their treating clinician less frequently than the general cohort (9.09% compared to 25.00% in the general cohort), while those with moderate AD accessed information this way more frequently (42.31% compared to 25.00% in the general cohort). There were also no participants with very severe AD that did not seek information about their condition, compared to 12.00% in the general cohort.
- Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. Almost half of the participants (n=48, 48.00%) described a preference for talking to someone. Of those that described a preference for a talking to someone 27 participants preferred this along with written or online material.

Information that was helpful

- 21 participants (21.00%) felt that was that no information or little information was particularly helpful. This primarily referred to participants feeling as though there were no concrete answers or that information did not offer anything beyond what they already knew. There were 14 participants that described information about diet as being a useful topic and 14 participants (14.00%) that described information about other people's experience as helpful. There were 13 participants (13.00%) that described the internet being a useful source of information. Some of the specific topics that participants described as being useful, in addition to diet, were information about treatments (n=10, 10.00%) and information about allergies and triggers (n=9, 9.00%).
- In relation to sub-group variations, participants with mild AD described dietary information as being helpful more frequently than participants in the general cohort (36.36% compared to 14.00% in the general cohort) and however overall, this group reported the various types of information as being useful, less frequently than the general cohort.

Information that was not helpful

- The main theme in this section was that there was not information that was not helpful (n=28, 28.00%). There were 15 participants (15.00%) that described being confident in deciding whether or not information was credible in relation to determining if it was useful. The next most common theme was that information based on the experience of others was not helpful (n=13, 13.00%). Information provided by general practitioners or specialists was described as not being helpful by 11 participants (11.00%). The final theme in this section was in relation to a lack of new information (n=10, 10.00%).
- There were two sub-group variations. Participants with mild AD reported no information as being unhelpful more frequently than the general cohort (54.55% compared to 28.00% in the general cohort) and also reported receiving conflicting information more frequently than the general cohort (18.18% compared to 4.00% in the general cohort).

Timing of information

- The two most common themes were being most receptive to information when AD becomes worse (during flares) (n=22, 22.00%) and the same number of people had no particular time in which they could absorb information better. The next most common theme was that participants were most receptive to information when they were well and not too busy (n=17, 17.00%). Participants described that the time during flares and when life is busy, is too distracting to take in information.
- Participants with mild AD reported having a preference for information during flares, more frequently than the general cohort (45.45% compared to 22.00% in the general cohort). This sub-group also reported having no preference in relation to timing of information less frequently (9.09% compared to 22.00% in the general cohort) and receiving information at times when they are not too busy, less frequently (9.09% compared to 22.00% in the general cohort). Participants with moderate AD reported a preference for

receiving information at times when they are not too busy, more frequently (30.77% compared to 17.00% in the general population and participants with very severe AD reported this less frequently (4.55% compared to 17.00% in the general population).

Health professional communication

- The main theme described by close to half of all participants (n=48, 48.00%) was that they felt their AD was dismissed by health professionals in general. The next most common theme was that communication was overall positive (n=32, 32.00%). There were also 15 participants that spoke about health professionals not understanding AD and therefore, not always providing accurate information.
- In relation to sub-group variations, participants with mild AD and moderate AD reported overall positive communication (holistic) more frequently than the general cohort (45.45% and 46.15% compared to 32.00% in the general cohort) while participants with severe and very severe AD reported this less frequently (26.83% and 16.16% compared to 32.00% in the general cohort).

Respect shown to patients

- The majority of participants (n=51, 51.00%) reported that they had been treated with respect. There were 35 participants (35.00%) that reported that they were treated with respect however, they also felt that they were often dismissed and/or that their AD was not being taken seriously
- In relation to sub-group variations, participants with mild AD reported being treated respectfully more frequently (72.73%) while participants with very severe AD reported this less frequently (31.82%) than the general cohort (51.00%). Participants with mild AD reported not being heard or feeling like there was a lack of knowledge about AD, less frequently (18.18%) while participants with very severe AD reported this more frequently (45.45%) than the general cohort (35.00%). Participants with very severe AD also reported not being treated respectfully more frequently than the general cohort (22.73% compared to 11.00% in the general cohort).

Knowledge and confidence

The Partners in Health questionnaire (PIH) measures an individual's knowledge and confidence for managing their own health. The Partners in Health comprises a global score, 4 sub scales; knowledge, treatment, symptoms and coping. A higher score denotes a better outcome.

- Overall, the participants scored in the top quintile for, adherence to treatment, and management of symptoms, indicating very good outcomes; the overall median score for knowledge, and mean score for coping and total score were all in the second highest quintile indicating outcomes.
- Participants with very severe disease scored lower compared to all other groups in the PIH coping and PIH total score.
- There were no differences observed in PIH subscales by comorbid depression and anxiety, location and education status.

Information given by healthcare professionals and searched for independently.

- Information about treatment options (77.00%), disease management (41.00%) and dietary information (27.00%) were most frequently given to participants by healthcare professionals, and information about clinical trials (3.00%) and psychological support (2.86%) were given least often.
- Information about treatment options (74.00%), disease cause (58.00%), and disease management (57.00%) were most often searched for independently by participants, and clinical trials (14.00%) and how to interpret test results (16.00%) were least searched for.

Most trusted information sources

- Across all participants, information from the not for profit or charitable organisations was most trusted followed by participants' hospital or clinic, then government, and then pharmaceutical companies. This order of trusted information source was the same for all of the subgroups (disease severity, comorbid depression and anxiety, location and education) with the exception of those with moderate disease. Those with moderate disease most trusted information from government.

Access to information

Participants were asked what information they had accessed in relation to AD. There was one key theme in relation to accessing information via the internet. The majority of participants (n=75, 75.00%) described the internet as their main source of information. There was a large gap between this main theme and the next most common theme of accessing information through their treating clinician which was noted by 25 participants (25.00%).

There were a number of sub-group variations. Participants with very severe AD described accessing information through their treating clinician less frequently than the general cohort (9.09% compared to 25.00% in the general cohort), while those with moderate AD accessed information this way more frequently (42.31% compared to 25.00% in the general cohort). There were also no participants with very severe AD that did not seek information about their condition, compared to 12.00% in the general cohort.

Table 6.1: Access to information

Access to information	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 described accessing information through the internet in general	73	73.00	8	72.73	18	69.23	28	68.29	19	86.36
Participant described primarily accessing information through treating clinician	25	25.00	2	18.18	11	42.31	10	24.39	2	9.09
Participant describes not seeking / researching information extensively	12	12.00	3	27.27	5	19.23	4	9.76	0	0.00
Participant described primarily accessing information through other patient's experience	10	10.00	0	0.00	2	7.69	4	9.76	4	18.18
Participant described accessing information primarily through journals (research articles)	8	8.00	1	9.09	0	0.00	4	9.76	3	13.64
Participant describes receiving information from books and newsletters	8	8.00	0	0.00	1	3.85	5	12.20	2	9.09
Participant described accessing information primarily through Facebook	5	5.00	1	9.09	0	0.00	2	4.88	2	9.09
Participant describes receiving information from chemist /pharmacist	5	5.00	0	0.00	1	3.85	3	7.32	1	4.55

Expectations of health professional communication	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/ Trade educated (n=42)	
Participant described accessing information through the internet in general	30	76.92	31	75.61	42	71.19	41	70.69	32	76.19
Participant described primarily accessing information through treating clinician	10	25.64	10	24.39	15	25.42	16	27.59	9	21.43
Participant describes not seeking / researching information extensively	2	5.13	3	7.32	9	15.25	7	12.07	5	11.90
Participant described primarily accessing information through other patient's experience	4	10.26	5	12.20	5	8.47	5	8.62	5	11.90
Participant described accessing information primarily through journals (research articles)	2	5.13	3	7.32	5	8.47	6	10.34	2	4.76
Participant describes receiving information from books and newsletters	3	7.69	3	7.32	5	8.47	3	5.17	5	11.90
Participant described accessing information primarily through Facebook	3	7.69	3	7.32	2	3.39	3	5.17	2	4.76
Participant describes receiving information from chemist /pharmacist	3	7.69	3	7.32	2	3.39	2	3.45	3	7.14

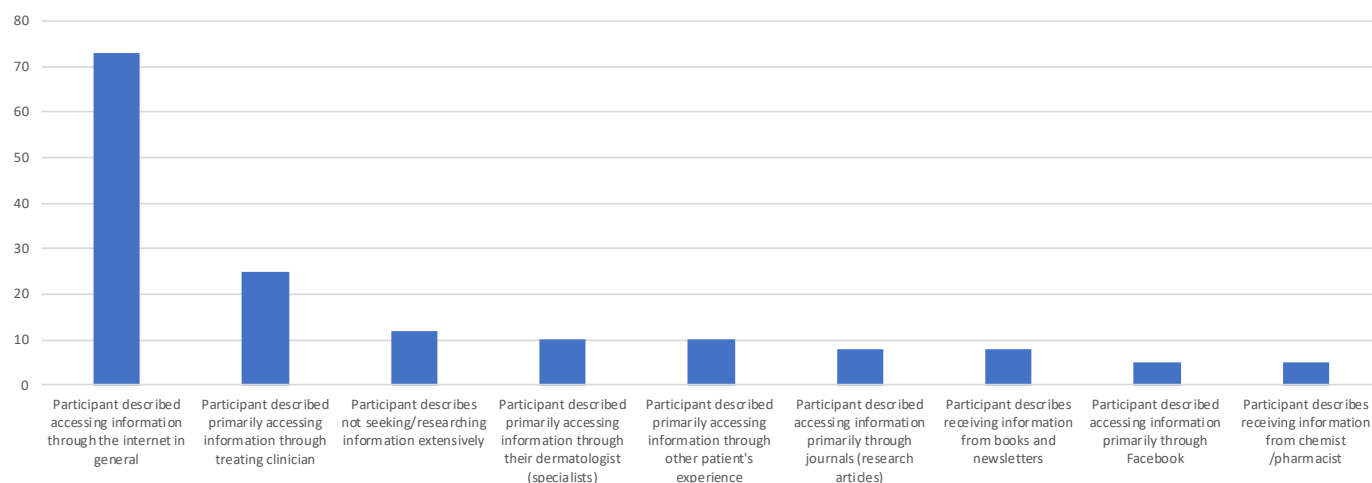


Figure 6.1: Access to information (% of all participants)

Information that was helpful

After talking about all of the information that participants had received, they were then asked what information had been helpful. There were a number of themes identified, however the main theme described by 21 participants (21.00%) was that no information or little information was particularly helpful. This primarily referred to participants feeling as though there were no concrete answers or that information did not offer anything beyond what they already knew:

At some point, there was just following certain things like making sure when you head to showers you put on your moisturizer and those sort of things. But I haven't really been able to find a specific, anything really that has been helpful, or that I would have gone to the doctor and said, "Can you look at this?". **Participant 45**

Not really. I mean, I've read things, and it says, you know, you really should keep your skin really moisturised; that's the best thing for eczema, and things like that. Then I; but that doesn't necessarily help me. I sort of feel, lot of things I read, that, everyone's different with their eczema. And we'll, we have different ways to, to heal it, to make us feel better. And, we all have different triggers. So, I sort of, a lot of the information is quite generic. And, I don't - ... just always the same. You've got dry skin, put, put moisturiser on it. And -... and to me, that doesn't - ... necessarily help. **Participant 60**

Not a lot, actually. Because no one can really tell me why I've got eczema. Because no one else in my family has it except myself. **Participant 84**

There were 14 participants that described information about diet as being a useful topic, particularly in

relation to understanding how diet can impact or trigger AD:

I think the most helpful thing for me have been the...to make the connection between eczema and my gut health, because I really-- over the past two years or so, I really started to eat a lot better and really-- I've been exercising a lot and looking at my diet and eating a lot of fresh healthy food, because of my eczema. Avoiding things such as dairy or gluten, because I know that they're inflammatory to eczema. I've just been looking up from a diet perspective, "What can I do?" Because from my perspective, "Steroid cream's not working, cortisol injections aren't working. What can I do in order to help myself?" But again, I haven't seen any massive improvements with that. **Participant 38**

Well, yes. I was actually walking home one day, and I crazily had the universe as my call light. I just read a book called The Eczema Diet. I was originally just sitting straight on the road. I was like, "Wow, that's strange. Picked it up, and I've just kind of been reading it like crazy. Just, I mean, the things ... That are in her book sound really helpful, and it's really well written. It's like the elimination diet as well. That's something that ... I think stuck with me. **Participant 58**

There was a book that came out ... Actually two books. And you'd be surprised, they're cook books. Which is what I do. So yeah, one was super ... Something Super Food Grain ... But before that, Super Food brand came out. It was super food ... It told you all about yeah ... Different foods that ... different nutrients and I just kind of, "Oh yeah, this is what could be a problem for me." And then same with Gluten Free cook books. They give you a big blurb about the damaging effects of gluten on your diet and on your tummy. So I've then looked into bio-immune stuff and got help. **Participant 61**

Another theme noted by 14 participants (14.00%) was that information about other people's experience was helpful. This was in relation to being able to see what other people have tried, what has worked and what has not worked:

Probably, as I said, Doctor Google. Looking, reading other people's experiences online. What's worked for them, seeing if it works for me. Trial and error. **Participant 12**

I think that chats that people ... because we're now on the Internet, people chat and say back, like on the Facebook sites and Twitter and all that. Here are the people's stories and what they've tried. It might not help much, but it's just a journey that you realise that you're not actually the only one. And- Yeah. And perhaps someone's tried something completely stupid, and you might have suspected it was completely stupid, but now they've told you it didn't work. And so you go, "No, I'll put a nail in it." **Participant 32**

I think the real life stories because I've been in the same situation myself. And they've had success or something, then that's what I find helpful. **Participant 51**

There were 13 participants (13.00%) that described the internet being a useful source of information, particularly because of its convenience and wide range of information:

The first time I got information for it, the doctor gave me an information from the Better Health channel. So, that was descriptive. And then later on I found the eczema remedy type of thing. It was just tips, a guide or something like that. And then on a Juvie website I think it was, and then another similar Better Health channel. It was like a health guide type of thing. I think it was more like a dermatologist website or something- ... And then it shows what not to use and what to use. That type of thing, yeah. **Participant 21**

Yes, I believe it is good because nowadays it's so easy to have access to information through the internet. It's not everything that you can trust because I've tried so many different treatments and it just got worse like, "It's good for your skin to find some coconut oil." It's a lie because of all your blogs, your skin should breathe and information like blood. Once you collate and the oil blocks. I got such a bad inflammation at that time. I had to be careful with what I read and with what I try in my body. **Participant 57**

I found the internet to be really helpful just because you get access to a wide variety of voices and you can really

get both sides of whether it works for someone or doesn't work for someone. You can kind of balance that but, it's a huge wealth of information that you can access. My GP, they haven't been a huge help. All they do is prescribe me steroid cream, that's it. So, they haven't been wonderful. Yeah, I'm going to say the internet because that's where I read up on a few coping mechanisms and a few things to try that have actually worked for me so, I'll say that that's been the best resource. **Participant 66**

Some of the specific topics that participants described as being useful, in addition to diet, were information about treatments (n=10, 10.00%) and information about allergies and triggers (n=9, 9.00%):

Participant describes information about specific treatments as being useful

Well, obviously, consumer information for medications. If I'm prescribed anything, I always check it out for consumer information that's relevant. It's always helpful to some point, sometimes it's alarming because it tells you all the things that could go wrong. But that's important to know anyway. **Participant 20**

What's been helpful? Probably information on antihistamines, and managing the allergy sides of things, to then cope with the eczema. Yeah, knowing about the side effects, for example the steroids I'd have to take, so I could try and put things in place and just know what was coming up beforehand. **Participant 34**

The medical information and recently the consumer information. **Participant 40**

Participant describes information about allergies/potential triggers as useful

Here, I have to say, that not a lot of that has been helpful because probably I don't know that my eczema severe enough. It's probably been more helpful around links back with other things, like my allergies. That's probably where I've found information that's been very helpful. Yeah. **Participant 8**

Yeah, it was. I was probably more helpful, again, because it was something I could control myself. It took a bit of time to do because it's quite different ... Like, it's not hard but, again, it's something to try and you commit through the day. That you try and maintain what you're eating all the time and that that's the good stuff. And, usually it's not particularly exciting food, it's relatively bland. And, things like, I suppose, what I'm wearing. So, I only wear cotton clothes. I don't wear

*synthetics. And, things like in my room, I'm always vacuuming dust. So about maintaining my home lifestyle as well. Just reading about, need to know irritants like that can effect you, even though it doesn't effect that. **Participant 18***

*What's been helpful? Probably information on antihistamines, and managing the allergy sides of things, to then cope with the eczema. **Participant 34***

In relation to sub-group variations, participants with mild AD described dietary information as being helpful more frequently than participants in the general cohort (36.36% compared to 14.00% in the general cohort) and however overall, this group reported the various types of information as being useful, less frequently than the general cohort.

Table 6.2: Information that was helpful

Information that has been helpful	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 no or very limited information has been helpful	21	21.00	3	27.27	3	11.54	9	21.95	6	27.27
Participant describes dietary information being helpful	14	14.00	4	36.36	2	7.69	6	14.63	2	9.09
Participant describes being able to read or learn about other patient's experience as helpful (Knowing they aren't alone)	14	14.00	1	9.09	5	19.23	5	12.20	3	13.64
Participant describes information from internet which was helpful	13	13.00	0	0.00	4	15.38	5	12.20	4	18.18
Participant describes information about specific treatments as being useful	10	10.00	0	0.00	4	15.38	3	7.32	3	13.64
Participant describes information about allergies/potential triggers as useful	9	9.00	1	9.09	2	7.69	4	9.76	2	9.09
Participant describes information from GP or specialist as being helpful	9	9.00	1	9.09	5	19.23	3	7.32	0	0.00
Participant describes information about alternatives to corticosteroids as being helpful	8	8.00	0	0.00	1	3.85	4	9.76	3	13.64
Participant describes information about the underlying cause of AD as being helpful	7	7.00	1	9.09	1	3.85	1	2.44	4	18.18
Participant describes all information as helpful	6	6.00	0	0.00	3	11.54	2	4.88	1	4.55

Information that has been helpful	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/ Trade educated (n=42)	
Participant describes no or very limited information has been helpful	8	20.51	8	19.51	13	22.03	10	17.24	11	26.19
Participant describes dietary information being helpful	5	12.82	4	9.76	10	16.95	7	12.07	7	16.67
Participant describes being able to read or learn about other patient's experience as helpful (Knowing they aren't alone)	5	12.82	8	19.51	6	10.17	9	15.52	5	11.90
Participant describes information from internet which was helpful	5	12.82	7	17.07	6	10.17	5	8.62	8	19.05
Participant describes information about specific treatments as being useful	4	10.26	3	7.32	7	11.86	6	10.34	4	9.52
Participant describes information about allergies/potential triggers as useful	4	10.26	3	7.32	6	10.17	4	6.90	5	11.90
Participant describes information from GP or specialist as being helpful	3	7.69	2	4.88	7	11.86	7	12.07	2	4.76
Participant describes information about alternatives to corticosteroids as being helpful	3	7.69	4	9.76	4	6.78	7	12.07	1	2.38
Participant describes information about the underlying cause of AD as being helpful	3	7.69	2	4.88	5	8.47	3	5.17	4	9.52
Participant describes all information as helpful	2	5.13	0	0.00	6	10.17	4	6.90	2	4.76

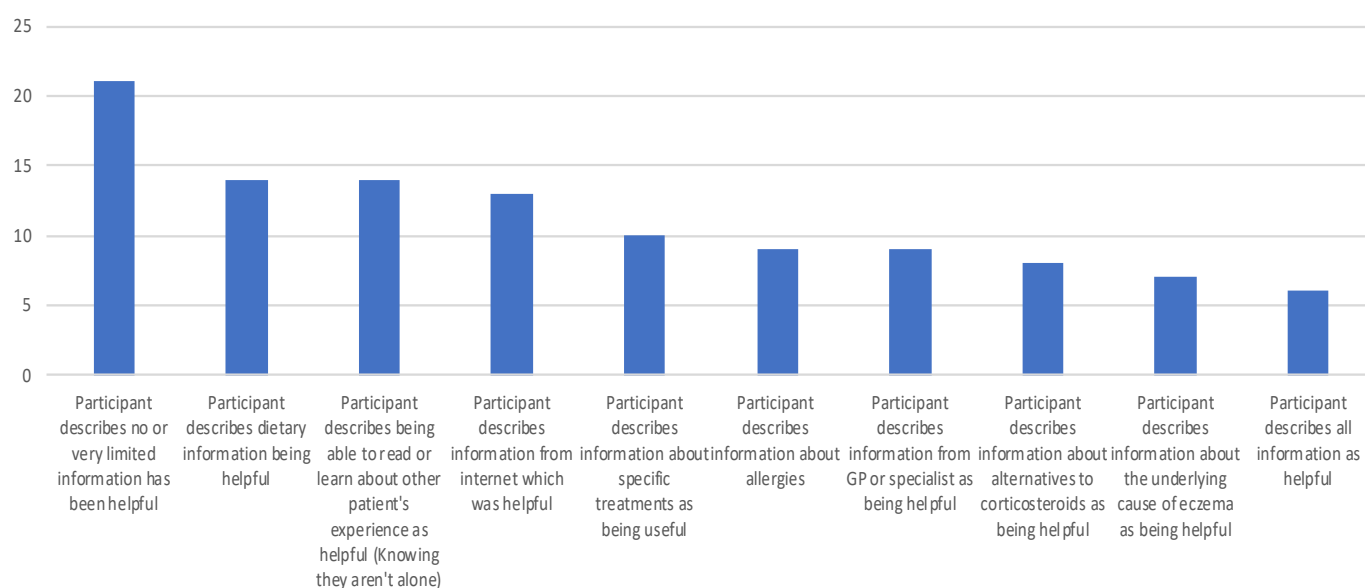


Figure 6.2: Information that was helpful

Information that was not helpful

Participants were asked whether there was any information they had come across that was not helpful. The main theme in this section was that there was not information that was not helpful (n=28, 28.00%). Within this theme, participants spoke about their openness to new information, driven by the willingness to try new things to manage their AD:

*I'm not too sure I could say with that one, either, because pretty much everything I come across, I'm willing to give it a go. **Participant 3***

*I suppose that, no, because it's all learning. Everything that I tried, and I thought come to a bit like a woman going ... I feel like it got me where I am now. Because I feel maybe it's not something that I found useful, but it could be for someone else. **Participant 58***

*I've found all sorts of sites. Nothing is really not been helpful. I've tried every therapy or alternate therapy that there has been. Now, I'm about to go into the acupuncture and hypnosis to see if I can stop scratching. **Participant 89***

There were 15 participants (15.00%) that described being confident in deciding whether or not information was credible in relation to determining if it was useful:

*No, no. But I'm smart enough about my health to realise that there are things I control and not to do, like, eat less dairy and so on, and don't get hot unnecessarily. And wear your clothes that's all cotton, not synthetic, all that. If I was really struggling, I'd be mindful, but I'm not struggling in my eczema. **Participant 30***

*I don't know about that. No, I don't know that I have come across information that isn't helpful ... apart from, I guess you could say, rubbish users. All that woman's day rubbish. None of that's helpful to anybody. Yeah, and all that marketing for goat's milk cream or ... You know. Yeah. None of that I feel is helpful, but I don't pay much attention to it. But I suspect in the wider community, if you weren't educated, you might spend a lot of money trying a lot of products that weren't helpful. But no, I'm not interested. **Participant 32***

You read a lot of shit out there. Yeah, there's a lot of good stuff published, and there's a lot of rubbish as well. But you've got to read them all, try other things and decide for yourself if it works for you or not. And then you decide if well that was good information or it wasn't. And as I said, what is bad information for me

*might be good information for someone else because it'll work for them but it won't work for me. That's the problem with eczema. So everything is different. People react to one thing like pet dander. And others won't. But to look at the two people side by side without their clothes on they've still got the same thing. One will enter into the room, one person will freak and the other person will start petting it. So yeah, so there's good and bad out there. As I said, you don't know it's good until you try it, you don't know it's bad until you try it. **Participant 95***

The next most common theme was that information based on the experience of others was not helpful (n=13, 13.00%). Within this theme there was a sense of fatigue in relation to being told what worked for other people, particularly if they did not really understand the potential severity of AD:

*More of anecdotal things that a random old lady or something will tell you. They don't do any harm, but it won't do any good either. They probably work for very mild eczema. **Participant 42***

*Probably the most unhelpful is, maybe, the people that tell you something that worked for ... Or gave you for eczema that was there for, like, a week. I don't know how to explain it. **Participant 51***

*I think people's personal stories are not usually helpful. If someone else had eczema or I used this, it's really great and cleared up my eczema in three days. I think other people's personal journeys and how their eczema has been cleared doesn't really help someone else in the same situation. Not everyone's experience has been the same. Like I said, you give things a try because other people recommend them but it doesn't necessarily mean that their information helpful to you whatsoever. **Participant 55***

Information provided by general practitioners or specialists was described as not being helpful by 11 participants (11.00%). Participants described frustration in the lack of information provided, particularly in relation to treatment options:

*Plenty of information hasn't been helpful. Just from doctors, I just don't feel like they really understand my condition or what they can do for me or what-- any alternatives are. I just don't feel like the information or lack thereof. What they give me is really helpful, I don't think it is, because they'll just say, "You've got this for life. You've just got a used steroid creams" or something like that. That's not helpful. **Participant 38***

Anyone who says, don't itch. [laughs]The information that I receive from the dermatologist has not been helpful. Those huge things like I said all for an appointment they'll say, "You have this mirror. Here's some steroid cream. Put it on for two weeks twice a day and then taper off." That's about as much as they say and they don't give much more advice than that. That's really unhelpful to receive basic information about medication which is actually really strong, those medications really strong. It screwed up like my whole endocrine system. It's not something that should have been taken lightly and in the way that they talk about it, the way they move you in and out of an appointment in 15 minutes. It makes you feel like actually the medication's fine, there's nothing, it's no big deal and funny now that we know that to go through this process that it's really mucked up everything. I'd have to say that insufficient information given about steroids and their side effects. **Participant 80**

Just the information from my doctors, basically. Just saying that there's nothing I can do. **Participant 98**

The final theme in this section was in relation to a lack of new information (n=10, 10.00%). Participants spoke about the repetitive nature of information provided that gave no new advice or treatment options:

I'm not sure. Maybe just the repetitive things, so when you ... Generally, when doctors talk to you about treatment, they say wet dressings, steroid creams. It's quite repetitive, there doesn't seem to be any new information coming up. So, probably that's been unhelpful because it's stuff I know anyway. **Participant 34**

Basically information that just tells me to keep doing what I'm doing, or information that's so general and basic that it doesn't tell me anything about why what I'm doing is not working, or why my body's responding the way it is to a certain treatment. **Participant 92**

Well, I don't think I've tried anything that's been a disaster. I haven't read anything or seen anything and tried it and it's just been the doctor that set me on some track. But I think it's the lack of information. Just the lack of information that you're given through doctors, or through sources where you go to seek what you would think is kind of expert advice on something. They just don't give you any helpful information. Just giving you the cortisone cream. They're saying that that's going to help. That hasn't been helpful because it hasn't actually really worked. It's hard to say because I don't think I've really found anything terribly helpful but on

the opposite unhelpful because I haven't really found much that's helpful. **Participant 99**

There were two sub-group variations. Participants with mild AD reported no information as being unhelpful less frequently than the general cohort (54.55% compared to 28.00% in the general cohort) and also reported receiving conflicting information more frequently than the general cohort (18.18% compared to 4.00% in the general cohort).

Table 6.3: Information that was not helpful

Information that has not been helpful	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 no information as being unhelpful	28	28.00	6	54.55	7	26.92	12	29.27	3	13.64
Participant describes feeling confident in deciding if something is not helpful (or not credible)	15	15.00	1	9.09	2	7.69	7	17.07	5	22.73
Participant describes experiences and suggestions of other people as being unhelpful	13	13.00	1	9.09	2	7.69	6	14.63	4	18.18
Participant describes the GP/specialist as being unhelpful	12	12.00	0	0.00	6	23.08	2	4.88	4	18.18
Participant describes lack of new information as unhelpful	10	10.00	0	0.00	1	3.85	4	9.76	5	22.73
Participant describes conflicting information as not helpful	4	4.00	2	18.18	1	3.85	0	0.00	1	4.55
Participant describes complementary therapies as being unhelpful	4	4.00	1	9.09	2	7.69	1	2.44	0	0.00

Information that has not been helpful	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
Participant describes no information as being unhelpful	12	30.77	4	9.76	24	40.68	13	22.41	15	35.71
Participant describes feeling confident in deciding if something is not helpful (or not credible)	7	17.95	9	21.95	6	10.17	9	15.52	6	14.29
Participant describes experiences and suggestions of other people as being unhelpful	3	7.69	9	21.95	4	6.78	9	15.52	4	9.52
Participant describes the GP/specialist as being unhelpful	7	17.95	6	14.63	6	10.17	7	12.07	5	11.90
Participant describes lack of new information as unhelpful	3	7.69	6	14.63	4	6.78	4	6.90	6	14.29
Participant describes conflicting information as not helpful	2	5.13	2	4.88	2	3.39	2	3.45	2	4.76
Participant describes complementary therapies as being unhelpful	1	2.56	2	4.88	2	3.39	3	5.17	1	2.38

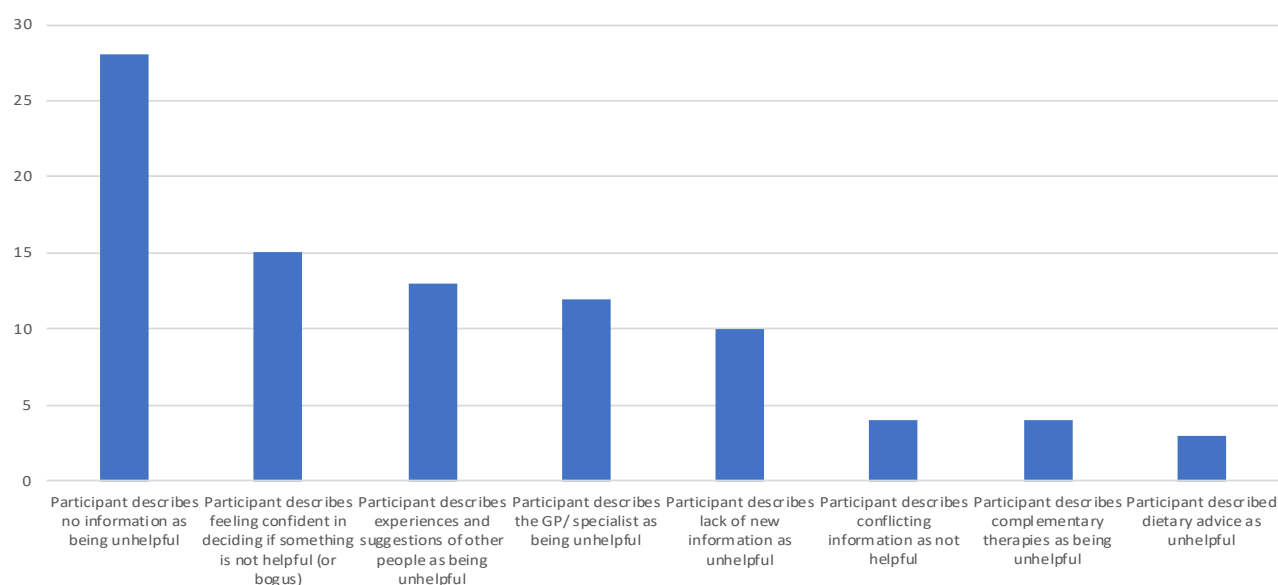


Figure 6.3: Information that was not helpful (% of all participants)

Information preferences (Format of information)

Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. Almost half of the participants (n=48, 48.00%) described a preference for talking to someone. Of those that described a preference for a talking to someone 27 participants preferred this along with written or online material.

The second most common theme was accessing information online (n=35, 35.00%). Written information was preferred by 4 participants (4.00%) and phone apps by 3 participants (3.00%)

In relation to talking to someone, patients also described the preference of talking to someone as it is easier to show someone their skin and discuss it, so that they are not dismissed:

If someone does thingslike if someone doesn't know what they are talking about, I prefer in person because I can show them the way my skin is like that has been the dermatologist that was really good. But I was like, "I prefer to go in person and talk and show them".

Participant 57

I think in-- When it gets really that bad to the point where I'm so badly scratching my hands and bleeding every day, I want to talk to somebody face-to-face. To be able to probably just show them how severe it's getting as well. I think sometimes when you just say eczema, dermatitis or something like that people go, "Yes." They just think of a couple of little spots of red rash and then that's it. I find when it's really bad, it's just better to talk to somebody face-to-face because you can actually show them how bad things are getting. **Participant 63**

Talking to someone. Well, you're the first person that I've talked to. I thought about this. You're the first person I've talked to about eczema for a very, very long time. Very long time. I cannot remember when I last had a proper chat. **Participant 32**

The preference for online information was primarily related to ease in which it can be accessed and also the breadth of information available:

My preference is online. Yeah. Yeah, purely for convenience. I can sit down and have my lunch, and I can search something out and do a bit of reading on it while I have lunch or the kids are quiet. Yeah, purely for convenience. I can sit down and have my lunch, and I can search something out and do a bit of reading on it while I have lunch or the kids are quiet. **Participant 2**

I think online, or an app, or whatever, would be fine. I think it's pretty hard to actually get to talk to somebody. And I think this interview today would be the first time I've spoken with anybody at this length about it. It's tended to be something to figure outthe snippets that you get, and they're from the specialists, you can find online. **Participant 62**

Online for me works best because I can access it anywhere. I've done a little bit of research myself or what I can get access to. That's just convenient as I can read it on the bus or I can read at home, I can read it, probably not work. That's probably not good. How about possibly wouldn't like that? I can read in my time.

Participant 83

Table 6.4: Information preferences (Format)

	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 preference for talking to someone	48	48.00	4	36.36	13	50.00	20	48.78	11	50.00
Of those that described a preference for a talking to someone along - these participants preferred this along with written or online material	27	27.00	3	27.27	5	19.23	10	24.39	9	40.91
Participant describes a preference for online information	35	35.00	5	45.45	10	38.46	12	29.27	8	36.36
Participant describes a preference for written information (newsletters, booklets, pamphlets)	11	11.00	0	0.00	5	19.23	5	12.20	1	4.55
Participant describes a preference for a phone app	7	7.00	1	9.09	1	3.85	4	9.76	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 a preference for talking to someone	20	51.28	23	56.10	25	42.37	27	46.55	21	50.00
Of those that described a preference for a talking to someone along - these participants preferred this along with written or online material	12	30.77	10	24.39	17	28.81	14	24.14	13	30.95
Participant describes a preference for online information	12	30.77	13	31.71	22	37.29	23	39.66	12	28.57
Participant describes a preference for written information (newsletters, booklets, pamphlets)	4	10.26	3	7.32	8	13.56	6	10.34	5	11.90
Participant describes a preference for a phone app	3	7.69	3	7.32	4	6.78	5	8.62	2	4.76

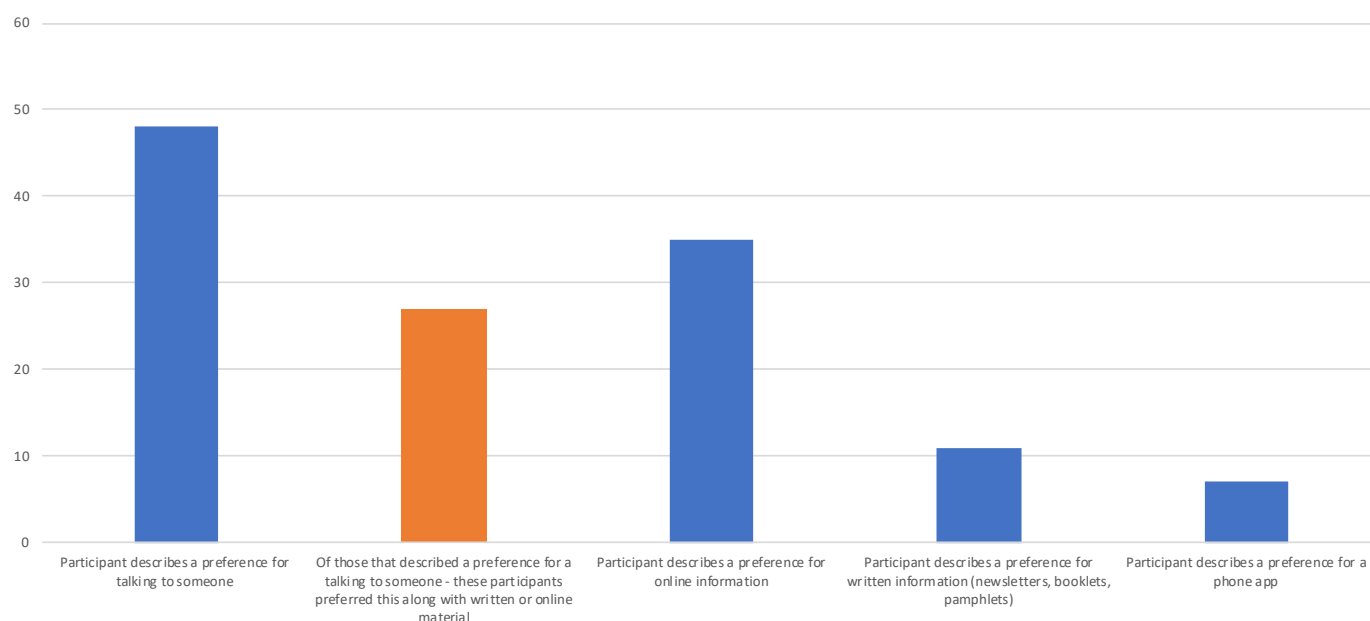


Figure 6.4: Information preferences – Format (% of all participants)

Information preferences (Timing of information)

Participants were asked to reflect on their experience and think about when they were most receptive to receiving information, not when they actually received the information, but when they felt they could take it all in. There was a wide range of responses across six key themes.

The two most common themes were being most receptive to information when AD becomes worse (during flares) (n=22, 22.00%) and the same number of people had no particular time in which they could absorb information better.

Participant describes a preference for receiving information when their eczema has become worse (Flare)

Probably when the eczema's bad then you would probably look back at it. So, yeah not straight away, if you just get you probably wouldn't when its bad then you'd go and look at it again. Or re read it, or reuse it or whatever. Participant 27

I think for me, personally, it would depend on why I thought the flare up occurred. If it was due to stress, and those sorts of things, then I would be looking at how to alleviate the stress, as well as how to deal with the eczema. So, I'd probably want the information then. I don't think after the fact would help me, because I'd want the information to help get the flare up under control. As opposed to ... Well, I guess it depends on what sort of the information was. Whether it was how to stop it happening again, or an ongoing treatment plan. If it was an ongoing treatment plan, then I'd want it at the time of the flare up. Whereas if it was sort of how to stop it occurring again, or how to lessen the flare up in the first place, then sort of after the event would be okay. Participant 37

It's usually when I'm at a low point, and so when you're physically low so you're just suffering from all this inflammation, your brain, you can't function, you can't sleep. It's usually those times when you start to ... When you say receive information, it's like you're not receiving any information unless you're looking for it, so you don't have someone trying to tell you about this, that and the other and you should try this and you should try that, unless you're participating in those conversations or in those groups, so I guess it would be when you're really looking for it, which is when I'm really low physically and then that becomes obviously a mental and emotional low as well as the result. Yeah and for me it's usually when I'm having a really bad flare. Participant 91

Participant describes having no real preference for the timing of information

Look, I don't think there is a most-- if I make sense of I had some conversations with the dermatologists that had been fruitful in the sense of my understanding. Usually, it's only one or two points which are significant but otherwise, I would probably, apart from those occasions, I would probably get those from internet sources. Participant 20

I normally jump in without thinking, if it's something I think - I'm not someone who has to research something to the hilt before they start it. Like if I get A sniff of the information and thing 'Geez wow', let's go and I'll just go and buy the thing or do it or whatever. Typically, if I think that there is some merit to it, it's fine. Participant 39

Really any time. There will be times I'll sit down and I'll just read through and go through all these sites and read everybody's experiences and things like that. So I'm sort of open to that all the time. Participant 95

The next most common theme was that participants were most receptive to information when they were well and not too busy (n=17, 17.00%). Participants described that the time during flares and when life is busy, is too distracting to take in information:

Probably, when it's cleared up. If it's all infected and awful, you just want it rid of. But if there's clear skin, which I do have now, it's a lot easier. You're rested. You're not worrying about the itch and you're not-- all of that stuff. Participant 16

I think when the crisis is over. When you can look back on it and go, "Yes, I understand what they were saying now. Or if their information is really helpful." Now hopefully I can move on with that and it won't happen again. Participant 55

After my treatments. After I've started to improve or get past being at the worst point. Because yeah, I can reflect on what works for me or maybe try it different or using the symptoms I've had to compare stuff. Participant 73

The final theme in this section was that participants absorbed information when they were a teen or adult (n=8, 8.00%). In this theme participants spoke about this being the time when they took an active interest in/need to managing their AD:

*When you're a bit younger, you either ignore it or you don't want to listen to your mother. [laughs] As I've gotten older, I've gone out into the world. It affects how you look and your day-to-day life. **Participant 12***

*Yes, it was probably in the last year or so. When I've turned 22. I've just matured a little bit more and decided to take more responsibility for my health. If that makes sense? **Participant 29***

*Yes. Look, I think, probably, it started in the mid-teen years for me. I think, as a child-- as a kid, you just follow what your parents recommend. I think, I hit about 14 or so, and from there, it's just been pretty consistent, in terms of being receptive to info. I'm now 24. Good ten years of learning. **Participant 46***

Participants with mild AD reported having a preference for information during flares, more frequently than the general cohort (45.45% compared to 22.00% in the general cohort). This sub-group also reported having no preference in relation to timing of information less frequently (9.09% compared to 22.00% in the general cohort) and receiving information at times when they are not too busy, less frequently (9.09% compared to 22.00% in the general cohort.) Participants with moderate AD reported a preference for receiving information at times when they are not too busy, more frequently (30.77% compared to 17.00% in the general population and participants with very severe AD reported this less frequently (4.55% compared to 17.00% in the general population).

Table 6.5: Information preferences (Timing)

	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 preference for receiving information when their AD has become worse (Flare)	22	22.00	5	45.45	5	19.23	7	17.07	5	22.73
Participant describes having no real preference for the timing of information	22	22.00	1	9.09	5	19.23	10	24.39	6	27.27
Participant describes a preference for receiving information at times when they are well, not too busy with life in general and can take the information.	17	17.00	1	9.09	8	30.77	7	17.07	1	4.55
Participant describes being more receptive to information as a teen or adult	8	8.00	0	0.00	1	3.85	4	9.76	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 preference for receiving information when their AD has become worse (Flare)	7	17.95	3	7.32	19	32.20	15	25.86	7	16.67
Participant describes having no real preference for the timing of information	11	28.21	9	21.95	13	22.03	13	22.41	9	21.43
Participant describes a preference for receiving information at times when they are well, not too busy with life in general and can take the information.	6	15.38	10	24.39	7	11.86	10	17.24	7	16.67
Participant describes being more receptive to information as a teen or adult	5	12.82	4	9.76	4	6.78	4	6.90	4	9.52

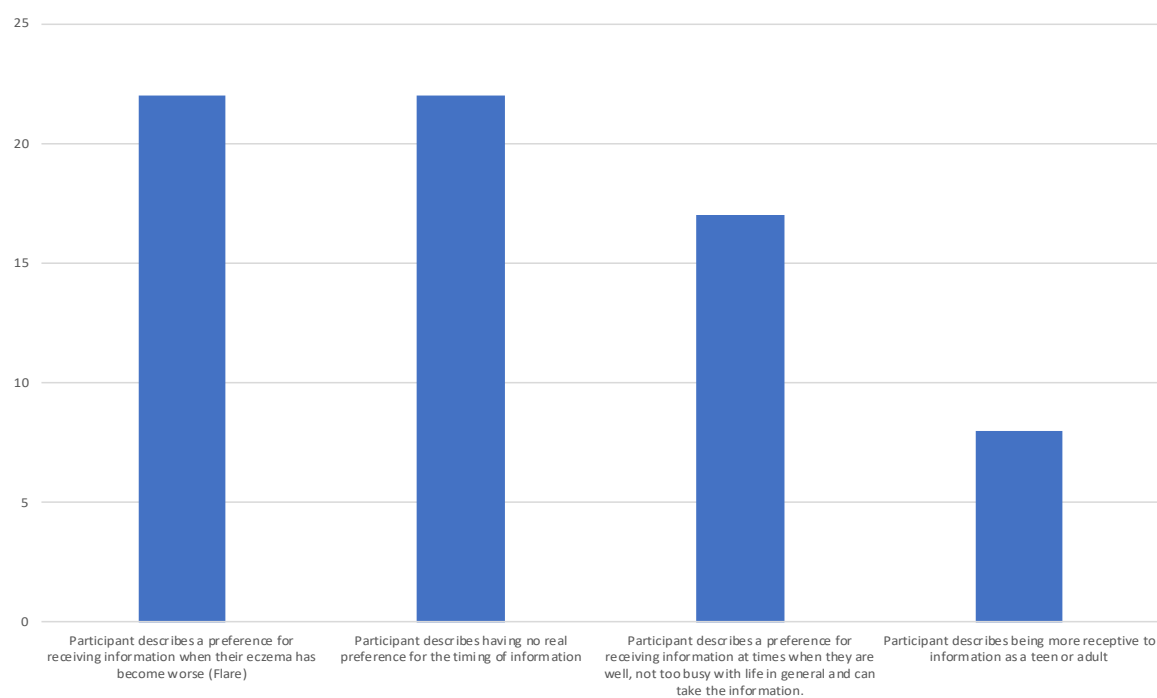


Figure 6.5: Information preferences – Timing (% of all participants)

Communication with health professionals

Participants were asked to describe the communication that they had had with health professionals throughout their experience. The main theme described by close to half of all participants (n=48, 48.00%) was that they felt their AD was dismissed by health professionals in general:

Minimal and dismissive. It's pretty much just, "Here's the prescription, go away". **Participant 1**

They kind of just say like, "Do this, do that." I don't know whether my GP I go to. They're pretty busy, at times, to try and get you in, do it, get you out. The ones I spoke to, a couple hundred bucks try this cream really. Again, that was all about five years ago. They might change now, but I just gave up after that and thought "Buggar it, I'll just look after it myself". **Participant 12**

The only healthcare professional that's really helped me is my GP that was able to give me the hydrocortisone and cortisone creams. Skin specialists, I've seen so many skin specialists in my life, and they just look at me and say "There's nothing we can do." There's no magic pill. **Participant 28**

Then she put me onto another GP in her clinic who I started to see. She was really unhelpful, was not willing to talk about options, was not willing to do anything other than prescribe steroids for me. Just said, in the end well after a year of meeting her periodically, we just basically had a personality clash and she said, "I think you should probably see one of the other GP's in the clinic." I said, "Well, I was going to offer you that same thing today." [laughs] **Participant 47**

She just tells me, "You've got to do this, you can't do that". I'm not really, really happy about it, what she ... She doesn't do a lot for me. When I go to the doctor, she never says anything, all she says is "Stop scratching." That's the doctor. She wouldn't say "Have you tried this?", or "Have you been back to the specialist?" No, she doesn't say a word. I don't get a lot of help. You don't get a lot of help, you're on your own, really. You're on your own to really try and help yourself. **Participant 93**

The next most common theme was that communication was overall positive (n32, 32.00%). Where communication was positive, this was often because a two-way conversation, where options had been provided, was held:

They are all pretty good. There's been tons. It's because I've had it for years, I can tell when doctors know the

stuff or not know the stuff or maybe it's more around having to care for the patient. If the experience I felt that, "Yes. The doctor didn't care or she didn't care." Then I wouldn't go back to that professional, because you can get that vibe. Their lack of knowledge, I can accept that. Yes. If I'm happy with the service or the information that was there or the treatment-- not treatment, advice. Then, yes, I'd just take my business elsewhere or get a second opinion. Yes, I'm one of those people that, if I didn't like what heard or wasn't completely happy or second guessing what they said, then I go get a second opinion. **Participant 15**

My GP is quite up to date ... Well, I assume is quite up to date with her suggestions. She'll sort of have a look through my file and go, "Okay, well this is what worked last time. Are we gonna try that again? Or are you looking to try something new?" I guess I'm very much, "Well, this worked last time, let's try this again." I guess, A, because I'm comfortable with just applying a lotion. I know it's not ... Or a cream, or whatever, it's probably not the best way to do it. I probably should look a bit further into my diet and things. But, yeah. She's quite happy to ask me what I think, and then sort of say, "Yeah, I think you're on the right track", or, "I think we should try something new." Or those sorts of things. Whether it be for eczema, or whether it be for the celiac disease, or asthma, or whatever. So I'm acutely aware that sort of all our body systems are all incredibly interactive ... Interlaced, and just dealing with eczema in isolation, probably isn't gonna fix the problem. That it's got to do with my diet, that it's got to do with my lifestyle, and my environment, and all the rest of it. There's no point in just going, "Here's the cream, that'll fix it." Sometimes it is if I just come into contact with wool, or whatever, and I just need something to stop a flare up. But then other times I sort of struggle to find the reason why it's flared up. And it might even be that I've been stressed about something, but I haven't realised exactly how stressed I've been about it. Yeah, very much so. It's only when you sort of look back at it in hindsight you kinda go, "Oh, that's probably why that happened" sort of thing. My GP, as far as my eczema's concerned. But I'm also lucky, I've got a fabulous physio, for sports injuries and things, which happens on a fairly regular basis. **Participant 37**

It's always been pretty good. [laughs] My GP is really, really good with me. He gets me to try new things and whatever. We've got a new cream or this or that. I'm a creature of habit, I like the cream that works. That's what I stick to. I don't generally. I don't like to be looking scabby and red and horrible. **Participant 64**

There were also 15 participants that spoke about health professionals not understanding AD and therefore, not always providing accurate information:

Some of them, they didn't have as much information or the information they're telling me doesn't correspond to the-- some of the stuff I may have already read up on or already know about my condition. Then some of them-- I don't know. Maybe their job, I can sense from them that they just want to get me out of there quick like, "Get over it." Yes. Get the appointment over with..

Participant 15

So I think there's definitely a lack of understanding, lack of knowledge on their part about information, about information that eczema, none of them can really explain to me what eczema is, none of them can really explain to me even just basic stuff, basic information about side effects on steroid creams, side effects on oral steroids. No one mentioned anything about side effects so very little knowledge, very little education to the patient, very disappointing and unwillingness to even just listen really. **Participant 67**

The first time I went and seen a new doctor. He, actually, told me I had scabies. I refused to see that doctor ever again. It's quite difficult because I don't like to show my eczema because I am very embarrassed by it. It is hard for me to go and see someone and discuss my eczema with somebody. **Participant 84**

In relation to sub-group variations, participants with mild AD and moderate AD reported overall positive communication (holistic) more frequently than the general cohort (45.45% and 46.15% compared to 32.00% in the general cohort) while participants with severe and very severe AD reported this less frequently (26.83% and 16.16% compared to 32.00% in the general cohort).

Table 6.6: Communication with health professionals

Communication with health professionals	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 healthcare professional being dismissive about AD and about exploring treatment options ('Nothing we can do'/One way conversation)	47	47.00	4	36.36	9	34.62	22	53.66	12	54.55
Participant describes overall positive communication (holistic, two way conversations)	32	32.00	5	45.45	12	46.15	11	26.83	4	18.18
Participant describes that healthcare professionals don't understand AD	15	15.00	0	0.00	4	15.38	5	12.20	6	27.27
Participant describes feeling as though healthcare professionals don't have a lot of time for them	10	10.00	0	0.00	4	15.38	5	12.20	1	4.55
Participant describes negative communication	6	6.00	0	0.00	2	7.69	3	7.32	1	4.55
Participant does not regularly speak to a healthcare professional about their AD	5	5.00	1	9.09	2	7.69	2	4.88	0	0.00

Communication with health professionals	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
Participant describes a healthcare professional being dismissive about AD and about exploring treatment options ('Nothing we can do'/One way conversation)	19	48.72	15	36.59	32	54.24	25	43.10	22	52.38
Participant describes overall positive communication (holistic, two way conversations)	15	38.46	14	34.15	18	30.51	22	37.93	10	23.81
Participant describes that healthcare professionals don't understand AD	3	7.69	8	19.51	7	11.86	10	17.24	5	11.90
Participant describes feeling as though healthcare professionals don't have a lot of time for them	4	10.26	3	7.32	7	11.86	7	12.07	3	7.14
Participant describes negative communication	4	10.26	1	2.44	5	8.47	4	6.90	2	4.76
Participant does not regularly speak to a healthcare professional about their AD	0	0.00	3	7.32	2	3.39	3	5.17	2	4.76

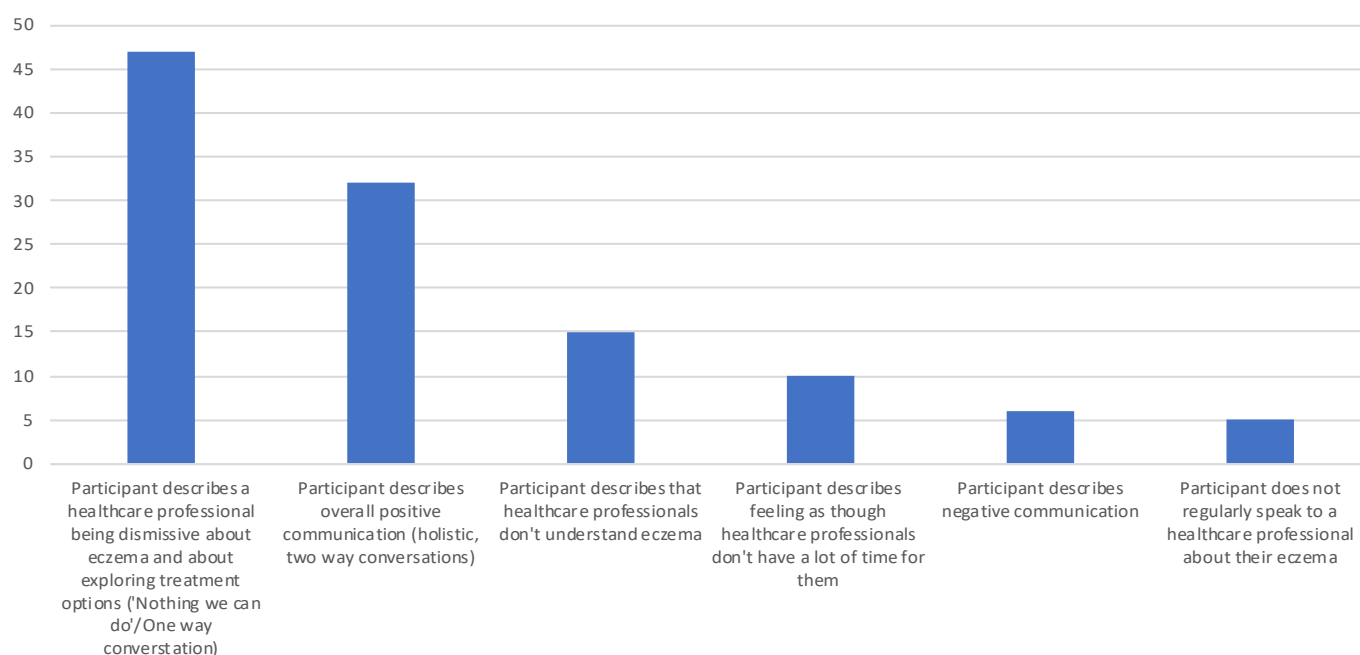


Figure 6.6 : Communication with health professionals (% of all participants)

Who patients talk to about their condition

Participants were asked who they talk to the most about their condition. The majority of participants reported that they mostly speak to their general practitioner (n=42, 42.00%) followed by their dermatologist (n=29, 29.00%). There were also 12

(12.00%) participants that described not having a regular health professional that they spoke to about their AD and ten (10.00%) participants that described not having a preference or not speaking to any, one health professional in particular.

Table 6.7: Who patients talk to

Who patients talk to about treatment	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 trusting their General Practitioner	42	42.00	6	54.55	13	50.00	14	34.15	9	40.91
Participant describes trusting their dermatologist	29	29.00	1	9.09	7	26.92	14	34.15	7	31.82
Participant describes not having a regular health professional that they talk to.	12	12.00	0	0.00	2	7.69	6	14.63	4	18.18
Participant describes trusting a different healthcare professional (Psychiatrist, pharmacist, chiropractor, naturopath, immunologist, nurse)	10	10.00	1	9.09	4	15.38	4	9.76	1	4.55
Participant describes trusting all/no specific healthcare professional	10	10.00	0	0.00	3	11.54	5	12.20	2	9.09

Who patients talk to about treatment	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
Participant describes trusting their General Practitioner	18	46.15	18	43.90	24	40.68	19	32.76	23	54.76
Participant describes trusting their dermatologist	10	25.64	15	36.59	14	23.73	21	36.21	8	19.05
Participant describes not having a regular health professional that they talk to.	7	17.95	4	9.76	8	13.56	9	15.52	3	7.14
Participant describes trusting a different healthcare professional (Psychiatrist, pharmacist, chiropractor, naturopath, immunologist, nurse)	3	7.69	2	4.88	8	13.56	5	8.62	5	11.90
Participant describes trusting all/no specific healthcare professional	4	10.26	5	12.20	5	8.47	6	10.34	4	9.52

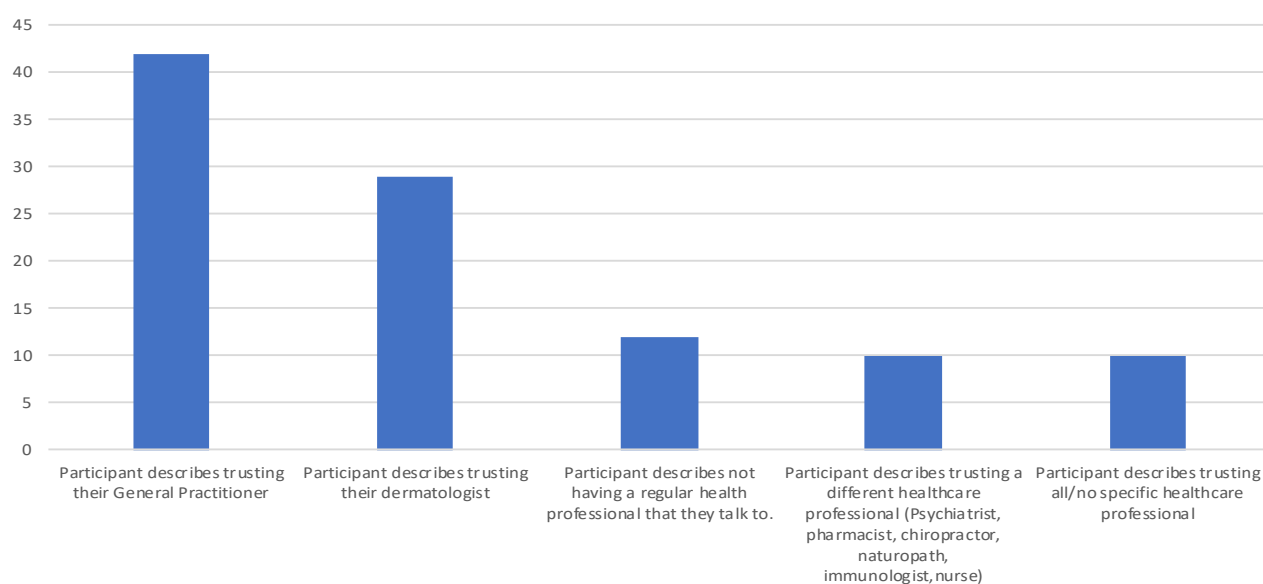


Figure 6.7: Who patients talk to (% of all participants)

Respect shown to patients in the health system

Participants were asked whether they had been treated with respect throughout their experience in the health system. The majority of participants (n=51, 51.00%) reported that they had been treated with respect. There were 35 participants (35.00%) that reported that they were treated with respect however, they also felt that they were often dismissed and/or that their AD was not being taken seriously:

I think it's both. I think they dismiss Eczema as the real problem, like you said. I think they dismiss me as a person, because I'm quiet. I'm a young girl. Participant 38

For the most part. The only thing that's a bit bothersome is, sometimes, you just feel rushed when they're just like, "Yes, eczema." They just prescribe you anything. I understand that doctors are very time-poor. Participant 42

Most of the time, yes. I have had instances where I felt, "Buddy, you don't know what you're talking about"

kind of things. But it's more of, I feel with some of the GP's, I've had this my whole life, so I know more than they know. Participant 43

Not all the time. Sometimes, some of the doctors didn't understand my knowledge of it already, and just treat me like it was something new to me, when it's apparently not. Participant 51

In relation to sub-group variations, participants with mild AD reported being treated respectfully more frequently (72.73%) while participants with very severe AD reported this less frequently (31.82%) than the general cohort (51.00%). Participants with mild AD reported not being heard or feeling like there was a lack of knowledge about AD, less frequently (18.18%) while participants with very severe AD reported this more frequently (45.45%) than the general cohort (35.00%). Participants with very severe AD also reported not being treated respectfully more frequently than the general cohort (22.73% compared to 11.00% in the general cohort).

Table 6.8: Respect shown to patients

Respect shown to patients	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 being treated respectfully	51	51.00	8	72.73	13	50.00	23	56.10	7	31.82
Participant describes being treated respectfully however at the same time being dismissed, not heard or feeling like there was a lack of knowledge about AD	35	35.00	2	18.18	9	34.62	14	34.15	10	45.45
Participant describes not being treated respectfully	11	11.00	1	9.09	3	11.54	2	4.88	5	22.73

Respect shown to patients	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
Participant describes being treated respectfully	22	56.41	24	58.54	27	45.76	31	53.45	20	47.62
Participant describes being treated respectfully however at the same time being dismissed, not heard or feeling like there was a lack of knowledge about AD	12	30.77	12	29.27	23	38.98	17	29.31	18	42.86
Participant describes not being treated respectfully	3	7.69	5	12.20	6	10.17	7	12.07	4	9.52

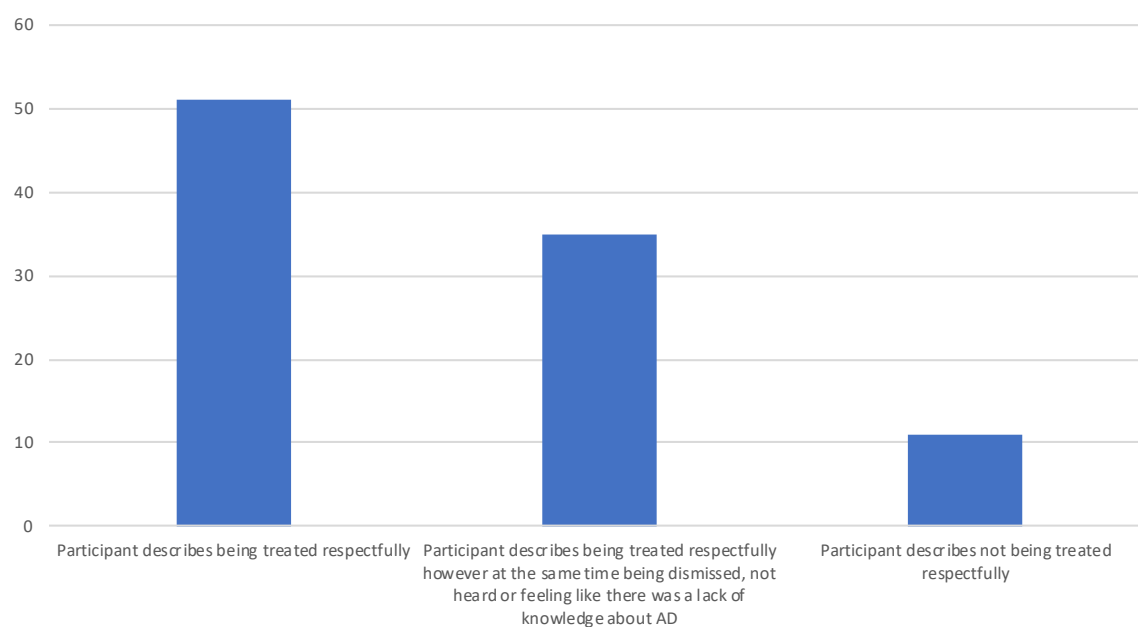


Figure 6.8: Respect shown to patients (% of all participants)

Knowledge and confidence

The Partners in Health questionnaire (PIH) measures an individual's knowledge and confidence for managing their own health. The Partners in Health comprises a global score, 4 sub scales; knowledge, treatment, symptoms and coping. A higher score denotes a better outcome. Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 6.9. Overall, the participants scored in the top quintile for adherence to treatment (Median=14.00, IQR =4.00), management of symptoms (Median=20.00, IQR = 4.00), indicating very good outcomes. The scores for knowledge (Median=25.00, IQR = 7.00), coping (Mean=17.00, sd = 7.25) and total score

(Median=76.00, IQR = 18.25) were all in the second highest quintile indicating good outcomes.

Box plots display each of the Partners in Health sub-scales by disease severity, comorbid depression and anxiety, location of participants, and education status (Figures 6.9 – 6.28)

Comparisons of PIH global and sub scales have been made based on disease severity (Figures 6.9 to 6.13, Tables 6.10 to 6.14), comorbid depression and anxiety (Figures 6.14 to 6.18, Table 6.15), location (Figures 6.19 to 6.23, Table 6.16), and education status (Figures 6.24 to 6.28, Table 6.17).

Table 6.9: Summary statistics all participants Partners in Health

Scale	Median	IQR	Possible range
Knowledge	25.00	7.00	0-32
Adherence to treatment	14.00	4.00	0-16
Management of symptoms	20.00	4.00	0-24
Coping*	17.00	7.25	0-24
Total score*	76.00	18.25	0-96

*Normal distribution, Mean and SD reported

Comparisons of PIH sub scales by disease severity

Comparisons of PIH subscales were made disease severity. Summary statistics are listed in Tables 6.10 and 6.13. A one-way ANOVA test was used when assumptions for normality and variance were met (Table 6.11), or when assumptions for normality and variance were not met, a Kruskal-Wallis test sum correction test was used (Table 6.13).

A one way ANOVA test indicated a significant difference in the PIH coping scale between groups [$F(3,96) = 18.36, p < 0.0001$] (Table 6.11). Post hoc

comparisons using the Tukey HSD test indicated that the mean score for those with very severe disease was significantly lower than any other group (Table 6.12).

A Kruskal-Wallis test was indicated a significant difference between severity for the PIH total score, $X^2(3) = 18.31, p = 0.0004$ (Table 6.13). Post hoc pairwise comparisons using Wilcoxon rank sum test indicated that the median coping score was significantly lower for the very severe group compared to all other groups (Table 6.14).

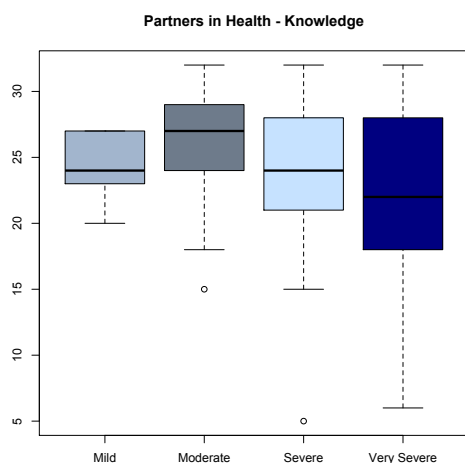


Figure 6.9: Boxplot of PIH knowledge by disease severity

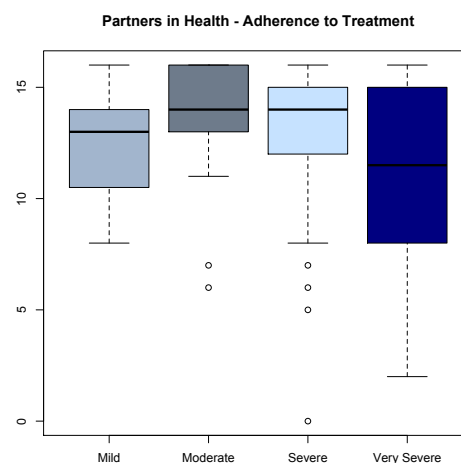


Figure 6.10: Boxplot of PIH adherence to treatment by disease severity

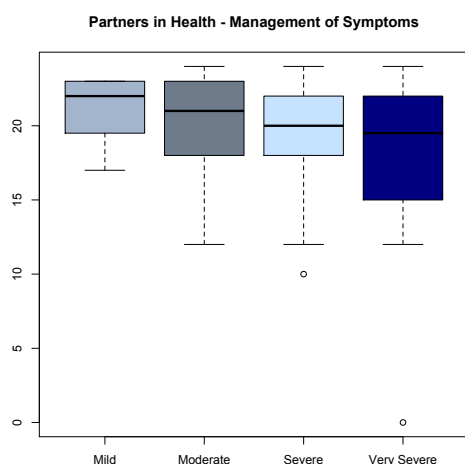


Figure 6.11: Boxplot of PIH management of symptoms by disease severity

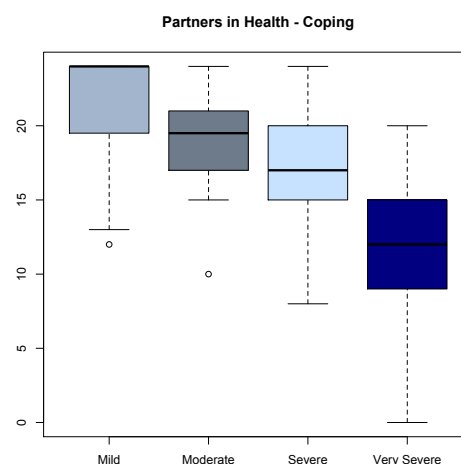


Figure 6.12: Boxplot of PIH coping by disease severity

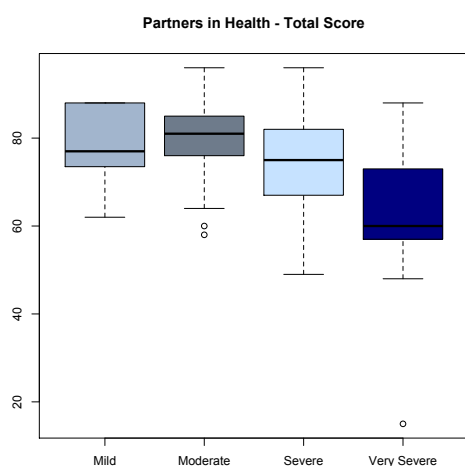


Figure 6.13: Boxplot of PIH total score by disease severity

Table 6.10: Summary statistics PIH coping scale by disease severity

PIH Scale	Group	Count	Mean	Sd
Coping	Mild	11	20.80	4.51
	Moderate	26	19.20	3.23
	Severe	41	17.40	4.04
	Very severe	22	11.60	4.82

Table 6.11: ANOVA table for PIH coping scale by disease severity

PIH Scale		Sum of squares	Df	Mean square	F	P
Coping	Between Groups	920	3	306.66	18.36	<0.0001*
	Within Groups	1604	96	16.71		
	Total	2524	99			

* Statistically significant at $p < 0.05$

Table 6.12: Post hoc Tuckey HSD test for PIH coping scale by disease severity

PIH Scale	Comparison	Mean difference	Lower	Upper	P adjusted
Coping	Moderate -Mild	-1.66	-5.51	2.18	0.6707
	Severe-Mild	-3.43	-7.06	0.20	0.0712
	Very severe – Mild	-9.18	-13.13	-5.24	<0.0001*
	Severe-Moderate	-1.76	-4.44	0.92	0.3185
	Very Severe-Moderate	-7.52	-10.61	-4.42	<0.0001*
	Very Severe-Severe	-5.75	-8.58	-2.93	<0.0001*

* Statistically significant at $p < 0.05$

Table 6.13: Summary statistics and Kruskal-Wallis rank sum test by disease severity

PIH Scale	Group	Count	Median	IQR	X ²	Df	P
Knowledge	Mild	11	24.00	4.00	4.45	3	0.2170
	Moderate	26	27.00	4.75			
	Severe	41	24.00	7.00			
	Very severe	22	22.00	20.00			
Adherence to Treatment	Mild	11	13.00	3.50	4.70	3	0.1949
	Moderate	26	14.00	2.75			
	Severe	41	14.00	3.00			
	Very severe	22	11.50	6.75			
Management of symptoms	Mild	11	22.00	3.50	4.34	3	0.2268
	Moderate	26	21.00	5.00			
	Severe	41	20.00	4.00			
	Very severe	22	19.50	6.50			
Total Score	Mild	11	77.00	14.50	18.31	3	0.0004*
	Moderate	26	81.00	8.50			
	Severe	41	75.00	15.00			
	Very severe	22	60.00	15.50			

* Statistically significant at $p < 0.05$

Table 6.14 **Post hoc** pairwise comparisons using Wilcoxon rank sum test, p-values

PIH scale	Group	Mild	Moderate	Severe
Total score	Moderate	0.8678		
	Severe	0.2267	0.0811	
	Very severe	0.0069*	0.0009*	0.0122*

* Statistically significant at $p < 0.05$

Comparisons of PIH sub scales by depression and anxiety status

Comparisons of PIH sub scales were made between participants comparing those with comorbid depression and anxiety and those that do not. Boxplots are displayed in Figures 6.14 to 6.18. Two sample t-test assumptions for normality and variance were not met,

a Wilcoxon rank sum test with continuity correction was used (Table 6.15). No statistically significant differences were observed between these two groups for any PIH sub scale (Tables 6.15).

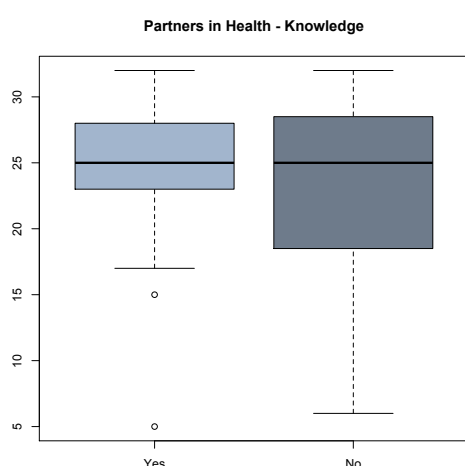


Figure 6.14: Boxplot of PIH knowledge by depression and anxiety status

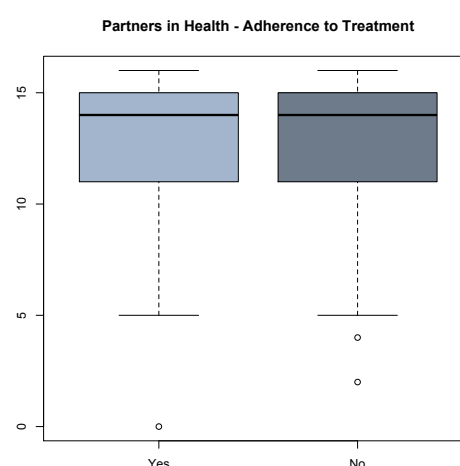


Figure 6.15: Boxplot of PIH adherence to treatment by depression and anxiety status

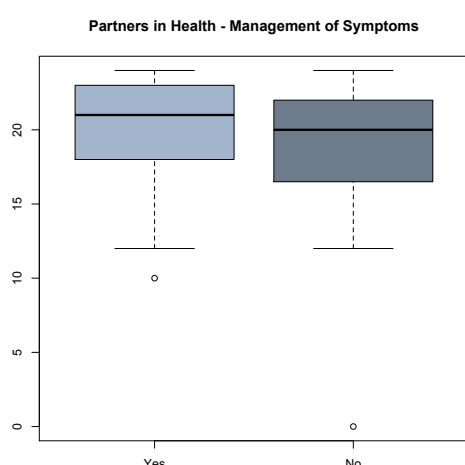


Figure 6.16: Boxplot of PIH management of symptoms by depression and anxiety status

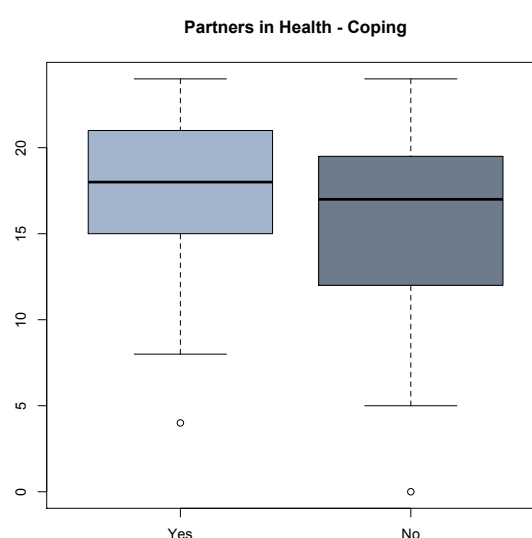


Figure 6.17: Boxplot of PIH coping by depression and anxiety status

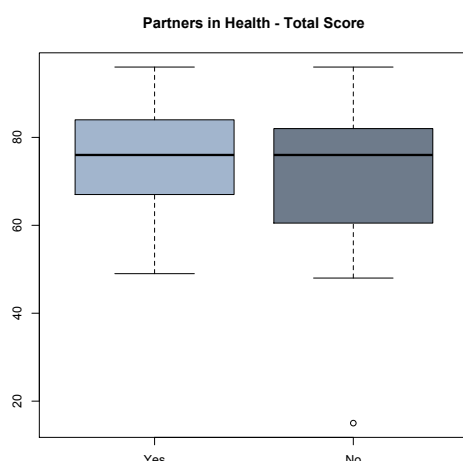


Figure 6.18: Boxplot of PIH total score by depression and anxiety status

Table 6.15: Summary statistics Wilcoxon rank sum test with continuity correction PIH subscales by comorbid depression and anxiety

PIH subscale	Both depression and anxiety	Count	Median	IQR	W	P
Knowledge	No	61	25.00	5.00	1266.00	0.5899
	Yes	39	25.00	10.00		
Adherence to treatment	No	61	14.00	4.00	1172.50	0.9060
	Yes	39	14.00	4.00		
Management of symptoms	No	61	21.00	5.00	1301.50	0.4279
	Yes	39	20.00	5.50		
Coping	No	61	18.00	6.00	1380.00	0.1780
	Yes	39	17.00	7.50		
Total score	No	61	76.00	17.00	1340.5	0.2871
	Yes	39	76.00	21.50		

Comparisons of PIH sub scales by location

Comparisons of PIH sub scales were made between participants between those that live in metropolitan areas and those that live in regional or rural areas. Boxplots are displayed in Figures 6.19 to 6.23 . Two

sample t-test assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.17). No statistically significant differences were observed between these two groups for any PIH sub scale (Table 6.17).

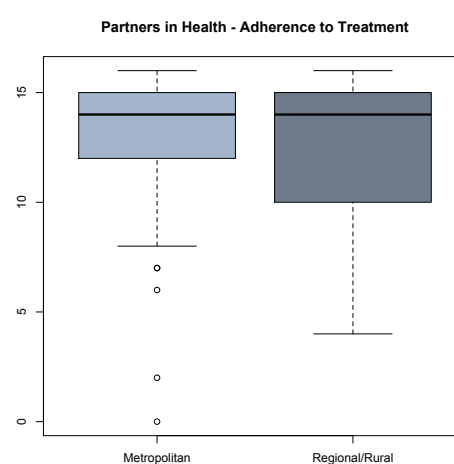
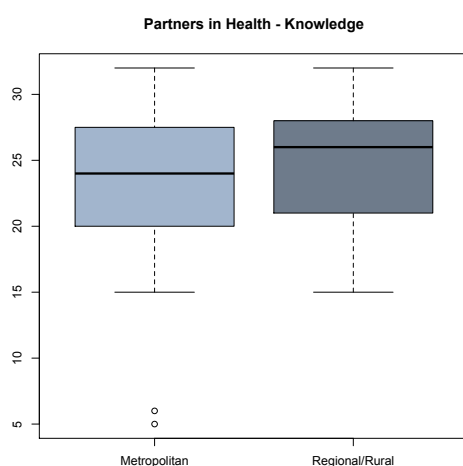


Figure 6.19: Boxplot of PIH knowledge by location

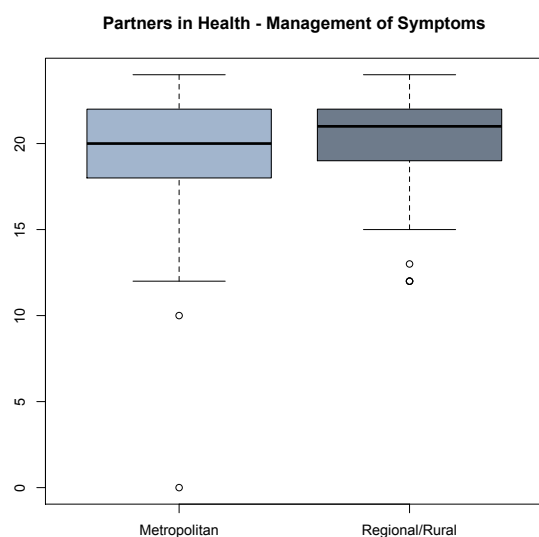


Figure 6.20: Boxplot of PIH adherence to treatment by location

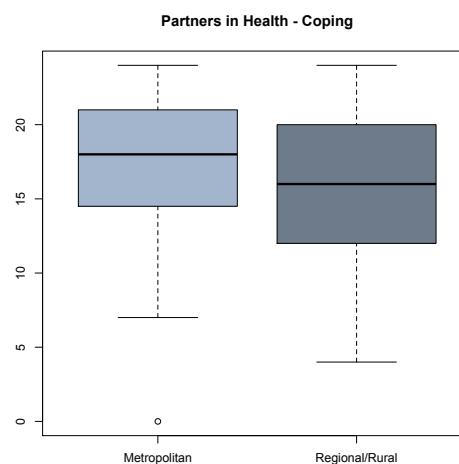


Figure 6.21: Boxplot of PIH symptoms by location

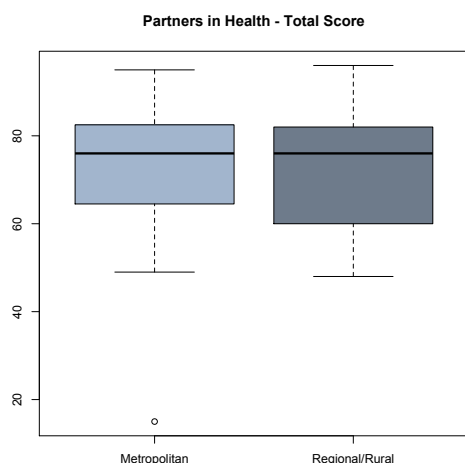


Figure 6.22: Boxplot of PIH coping by location

Figure 6.23: Boxplot of PIH total score by location

Table 6.16: Summary statistics Wilcoxon rank sum test with continuity correction PIH subscales by location

PIH subscale	Location	Count	Median	IQR	W	p
Knowledge	Metropolitan	59	24.00	7.50	1063.00	0.3045
	Regional/Remote	41	26.00	7.00		
Adherence to treatment	Metropolitan	59	14.00	3.00	1286.50	0.5870
	Regional/Remote	41	14.00	5.00		
Management of symptoms	Metropolitan	59	20.00	4.00	1047.50	0.2548
	Regional/Remote	41	21.00	3.00		
Coping	Metropolitan	59	18.00	6.50	1400.00	0.1816
	Regional/Remote	41	16.00	8.00		
Total score	Metropolitan	59	76.00	18.00	1209.05	1.000
	Regional/Remote	41	76.00	22.00		

Comparisons of PIH sub scales by Education

Comparisons of PIH sub scales were made between participants based on highest education levels obtained; high school/trade or university. Boxplots are displayed in Figures 6.24 to 6.28. Two sample t-test

assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.17). No statistically significant differences were observed between these two groups for any PIH sub scale (Tables 6.17).

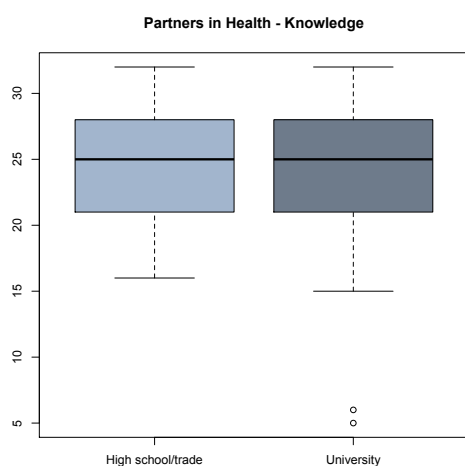


Figure 6.24: Boxplot of PIH knowledge by education status

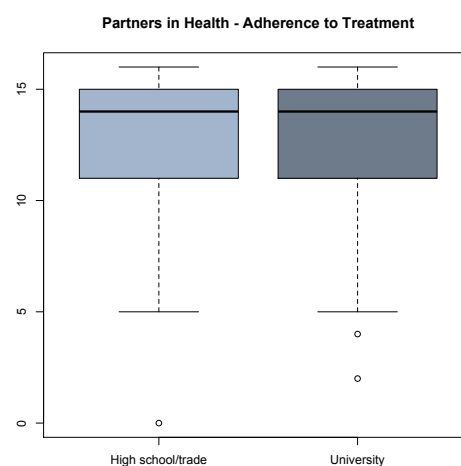


Figure 6.25: Boxplot of PIH adherence to treatment by education status

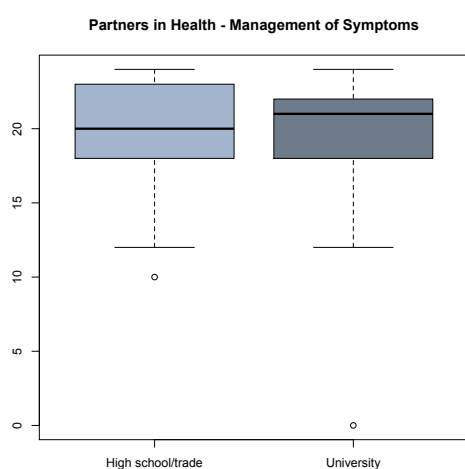


Figure 6.26: Boxplot of PIH symptoms by education status

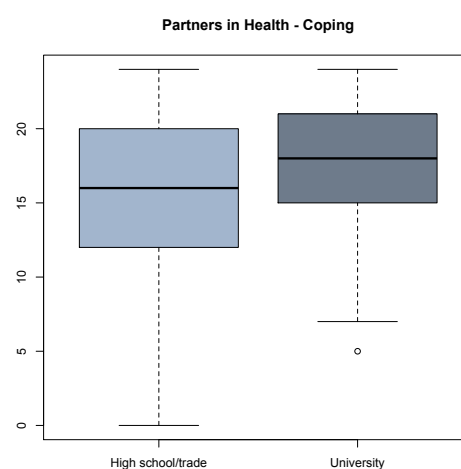


Figure 6.27: Boxplot of PIH coping by education status

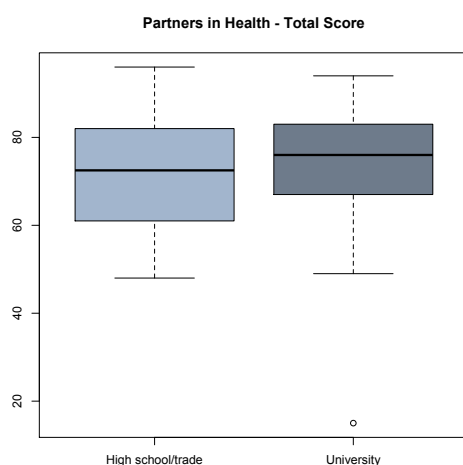


Figure 6.28: Boxplot of PIH total score by education status

Table 6.17: Summary statistics Wilcoxon rank sum test with continuity correction PIH subscales by education

PIH subscale	Group	Count	Median	IQR	W	P
Knowledge	Trade or high school	42	25.00	7.00	1235	0.9079
	University	58	25.00	7.00		
Adherence to treatment	Trade or high school	42	14.00	4.00	1206	0.9351
	University	58	14.00	4.00		
Management of symptoms	Trade or high school	42	20.00	4.75	1081.50	0.3392
	University	58	21.00	4.00		
Coping	Trade or high school	42	16.00	8.00	1037.5	0.2073
	University	58	18.00	6.00		
Total score	Trade or high school	42	72.50	20.20	1087	0.3616
	University	58	76.00	15.80		

Information given by healthcare professionals and searched for independently.

Participants were asked about what type of information they were given by healthcare professionals and what type of information they searched for independently. Information about treatment options (77.00%), disease management (41.00%) and dietary information (27.00%) were most frequently given to participants by healthcare professionals, and information about clinical trials (3.00%) and psychological support (2.86%) were given

least often (Figure 6.29). Information about treatment options (74.00%), disease cause (58.00%), and disease management (57.00%) were most often searched for independently by participants, and clinical trials (14.00%) and how to interpret test results (16.00%) were least searched for (Figure 6.30). Information given to participants by was similar for by disease severity, comorbid depression and anxiety, loction and education. (Figures 6.31 and 6.38). Information given and searched for independently was generally similar for all subgroups (Figures 6.31 and 6.38).

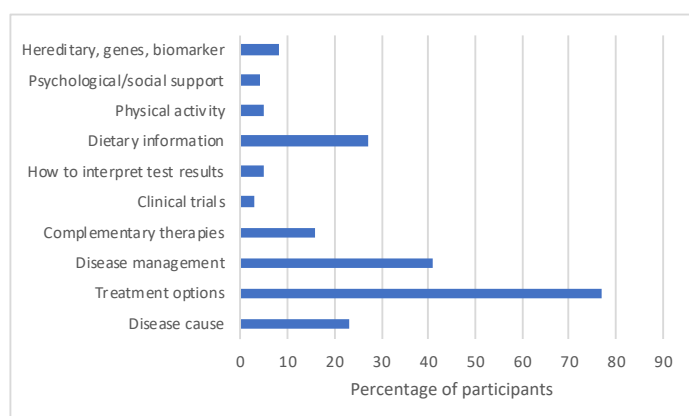


Figure 6.29: Information given by healthcare professionals: all participants

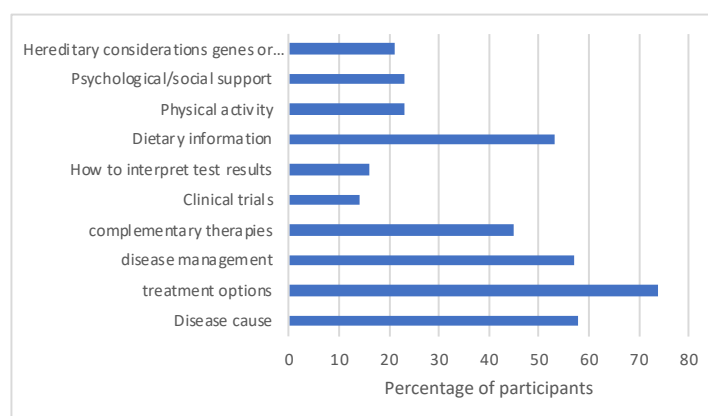


Figure 6.30: Information searched for independently: all participants

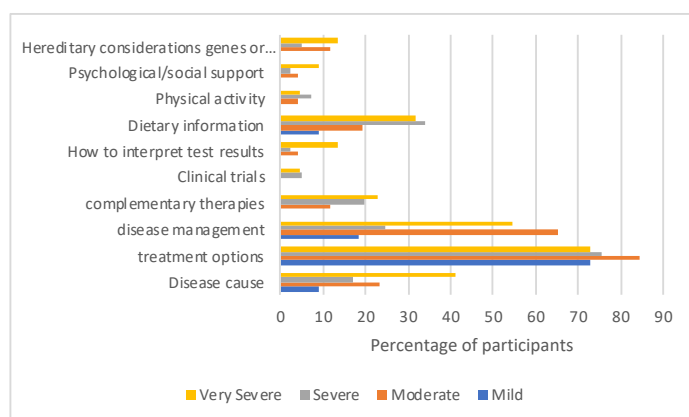


Figure 6.31: Information given by healthcare professionals by disease severity

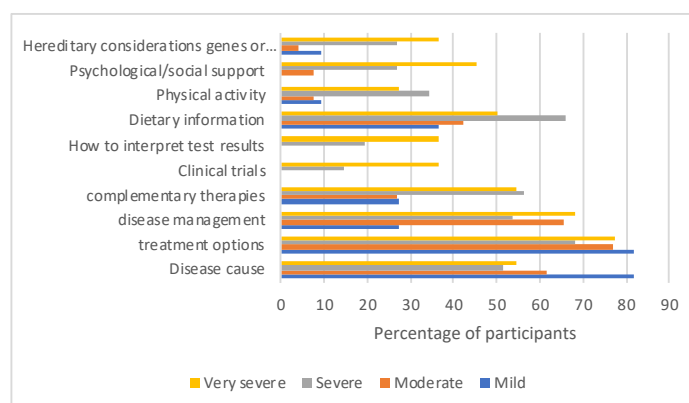


Figure 6.32: Information searched for independently by disease severity

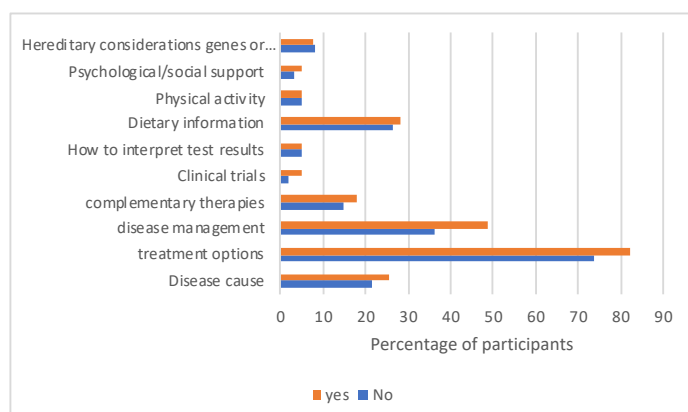


Figure 6.33: Information given by healthcare professionals by comorbid depression and anxiety

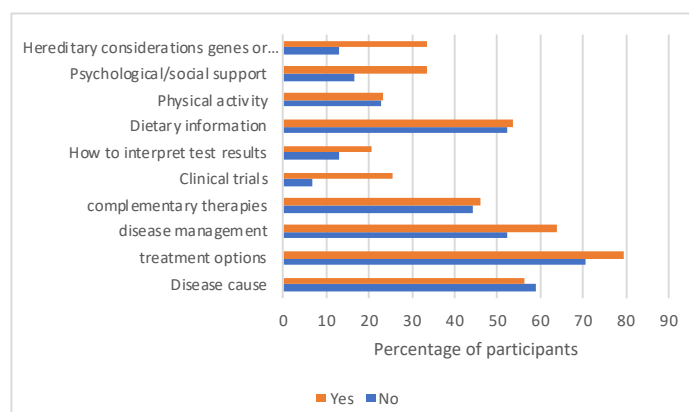


Figure 6.34: Information searched for independently by comorbid depression and anxiety

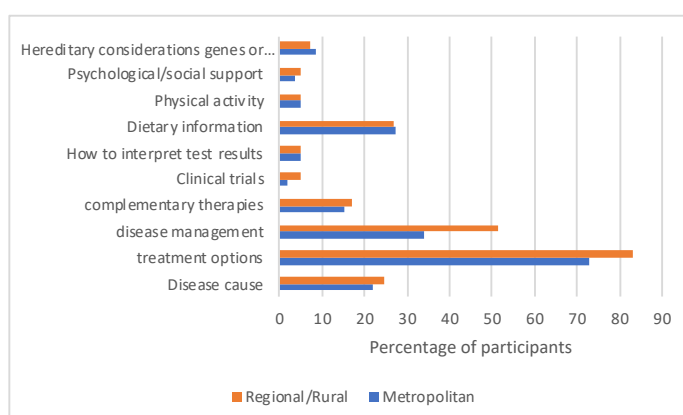


Figure 6.35: Information given by healthcare professionals by location

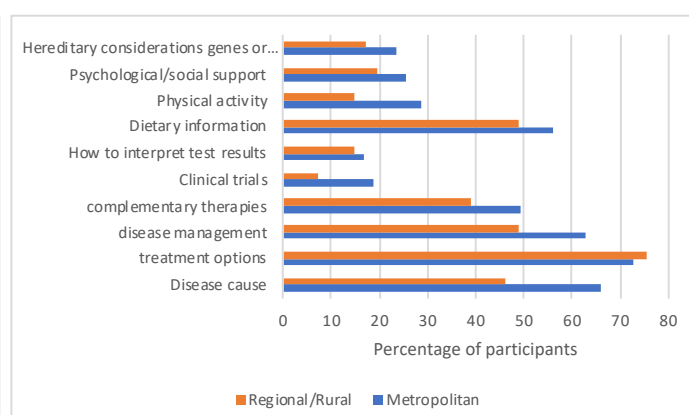


Figure 6.36: Information searched for independently by location

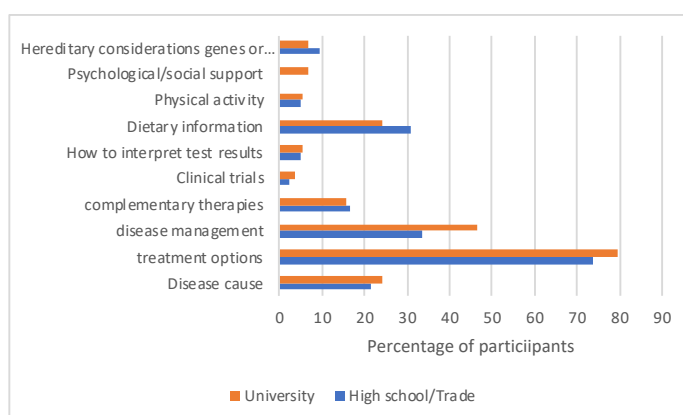


Figure 6.37: Information given by healthcare professionals by education

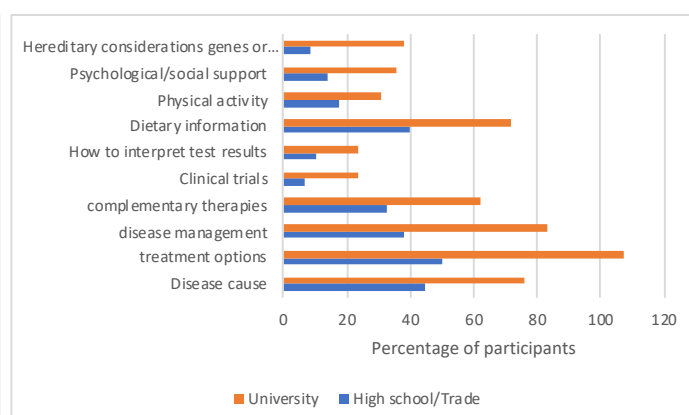


Figure 6.38: Information searched for independently by education

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were for clinical trials (85.00%), how to interpret test results (80.00%), physical activities (75.00%), and psychological/social support (75.00%)

(Figure 6.39). Participants were given most information either from healthcare professionals or independently for treatment options (91.00%) and disease cause (72.00%) (Figure 6.39). Disease cause was the topic that was most searched for independently following no information from health professionals (49.00%) (Figure 39).

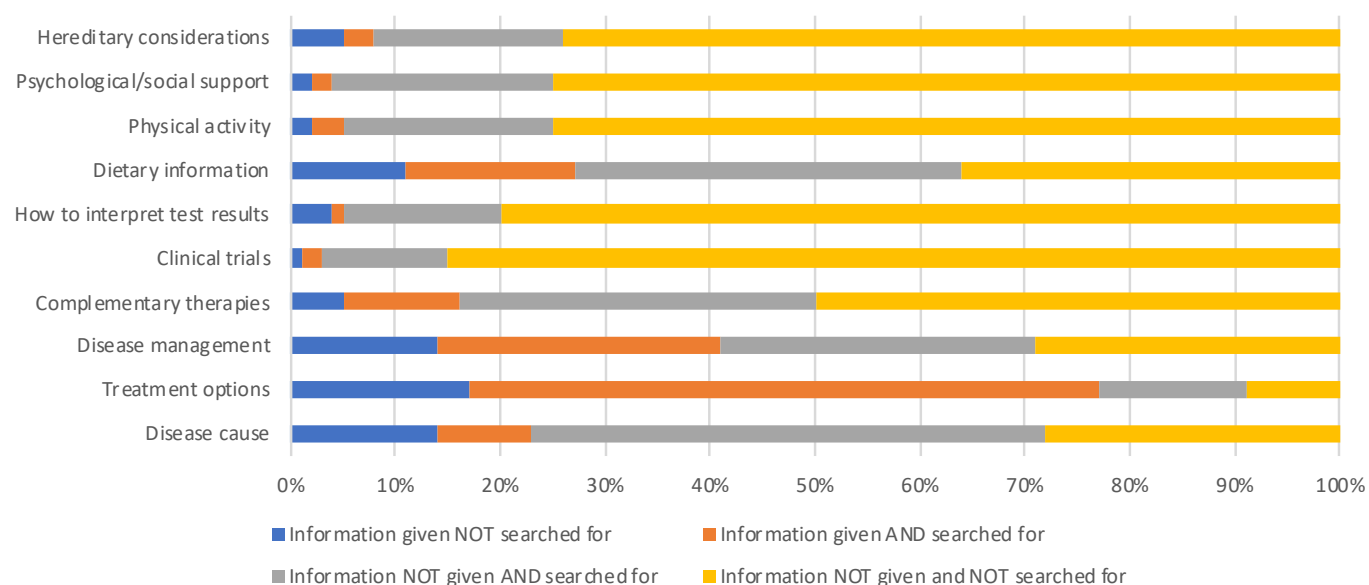


Figure 6.39: Proportion of information given by health care professionals and searched for independently.

Most trusted information sources

Participants were asked to rank which information source that they most trusted, where 1 is the most trusted and 4 is the least trusted. A weighted average is presented in Figure 6.40. With a weighted ranking, the higher the score, the more trusted the source of information to the participant. Across all participants, information from the not for profit or charitable

organisations was most trusted followed by participants' hospital or clinic, then government, and then pharmaceutical companies (Figure 6.40). This order of preference was the same for all sub-groups with the exception of those with moderate disease that trusted information from participants' hospital or clinic, the from not for profit or charitable organisations (Figures 6.41 – 6.4

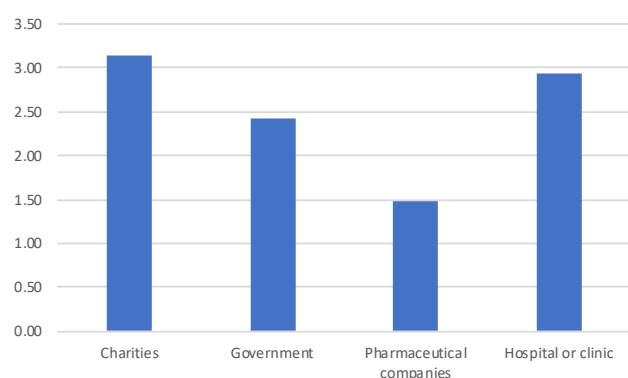


Figure 6.40: Most trusted information sources

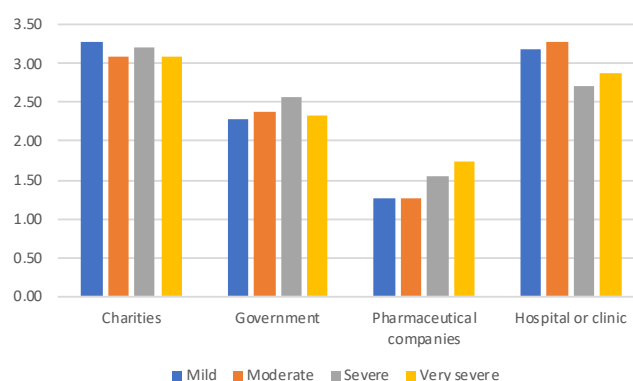


Figure 6.41: Most trusted information sources by disease severity

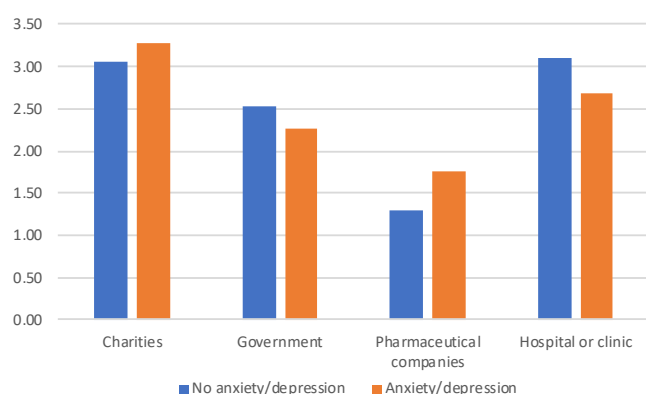


Figure 6.42: Most trusted information sources by comorbid depression and anxiety

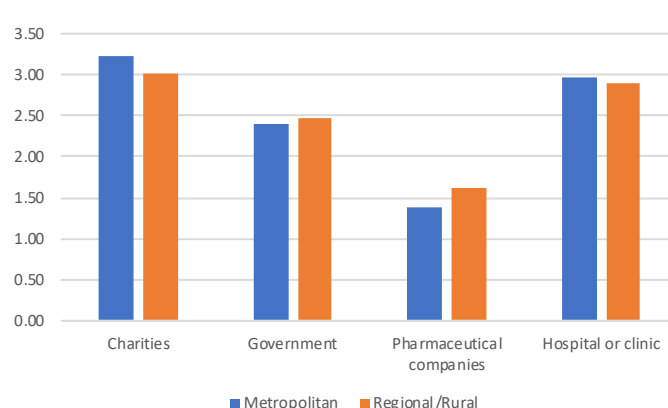


Figure 6.43: Most trusted information sources by location

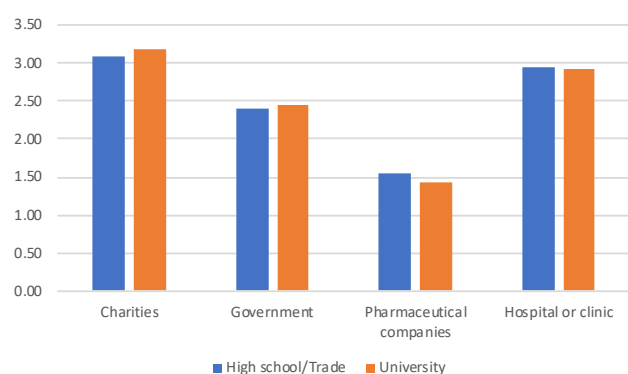


Figure 6.44: Most trusted information sources by education

Section 7 Care and support

Section 7: Experience of care and support

Coordination of care

- Overall the entire cohort had a mean communication score of 38.06, total score of 64.06, a median score of 5.00 for care co-ordination and 6.00 for care received; these scores fall in the middle of the scale. The median score for navigation was 26.00, this falls in the second highest quintiles indicating good navigation.
- The care coordination navigation scores and total scores were better for those with moderate disease compared to those with either severe or very severe; and the care coordination communication scores were better for those with moderate disease compared to those with very severe disease.
- There was a significant difference between those that live in metropolitan areas compared with those that live in regional/rural areas for care coordination. Those that live in regional/rural areas had a higher score.
- There were no significant differences in care coordination between the comorbid depression and anxiety subgroups or the education status subgroups.

Care and support

- Participants were asked what care and support they had received throughout their experience. The majority of participants described care and support coming from family and friends (n=76; 76.00%), and this was the most common theme followed by care and support accessed from the hospital or clinical setting (n=27; 27.00%). There were also 16 (16.00%) participants that described feeling as though they did not need additional support, however, participants that had severe AD were stated this less frequently (9.09% compared to 16.00% in the general cohort). This was also stated less frequently by participants that had a high school/trade education (7.14 compared to 16.00% in the general cohort).

Experience of coordination of care

A Care Coordination questionnaire was completed. The Care Coordination questionnaire comprises a total score, 2 sub scales (communication and navigation), and a single question for each relating to care-coordination and care received. A higher score denotes better care outcome. Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 7.1. Overall the entire cohort had a mean communication score of 38.06, total score of 64.06, a median score of 5.00 for care co-ordination and 6.00 for care received; these scores fall in the middle of the scale. The median score for

navigation was 26.00, this falls in the second highest quintiles indicating good navigation.

Box plots display each of the Care Coordination scores by disease severity, comorbid depression and anxiety, location of participants, and education status (Figures 7.1 to 7.20).

Comparisons of Care Coordination scores have been made based on disease severity (Figures 7.1 to 7.5, Tables 7.2 to 7.5), comorbid depression and anxiety (Figures 7.6 to 7.10, Table 7.6), location (Figures 7.11 to 7.15, Tables 7.7 and 7.8), and education status (Figures 7.16 to 7.20, Tables 7.9 and 7.10).

Table 7.1: Summary statistics Total score - Communication and Navigation

Scale	Mean	SD	Median	IQR	Possible range
Total score*	64.06	11.69	65.50	16.00	20-100
Communication*	38.06	8.49	39.00	11.00	13- 65
Navigation	26.00	5.87	26.00	9.25	7-35
Care co-ordination	5.21	2.35	5.00	4.00	1-10
Care received	5.89	2.18	6.00	4.00	1-10

*Normal distribution, use mean and sd as central measure

Comparisons of Care Coordination scores by disease severity

Comparisons of Care Coordination subscales were made by disease severity. Summary statistics are listed in Table 7.2. A one-way ANOVA test was used when assumptions for normality and variance were met (Table 7.3), or when assumptions for normality and variance were not met, a Kruskal-Wallis test sum correction test was used (Table 7.4).

A one way ANOVA test indicated a significant difference in the care coordination total score between groups [$F(3,96) = 6.53$, $p = 0.0005$], and a difference in the care coordination -navigation scores between groups [$F(3,96) = 5.89$, $p = 0.0010$] (Table 7.3). Post hoc comparisons using the Tukey HSD test indicated that

the mean score for those with moderate disease had a significantly higher score than those with severe or very severe disease for both of these scales (Table 7.4).

A one way ANOVA test indicated a significant difference in the Care coordination - communication score between groups [$F(3,96) = 3.24$, $p = 0.0257$] (Table 7.3). Post hoc comparisons using the Tukey HSD test indicated that the mean score for those with moderate disease had a significantly higher score than those with very severe disease (Table 7.4).

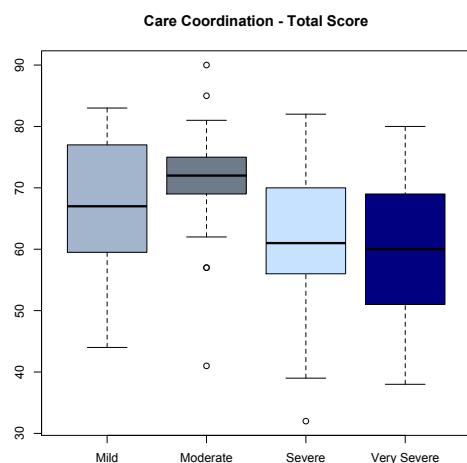


Figure 7.1: Boxplot of Care coordination total score by disease severity

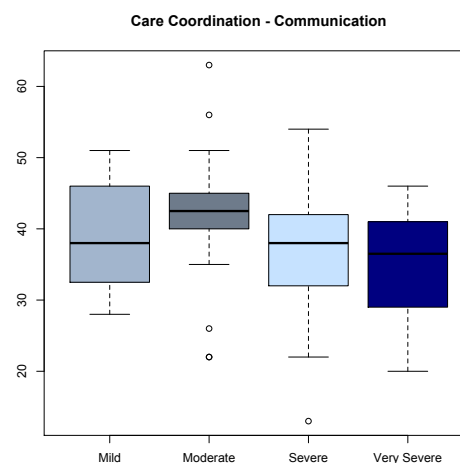


Figure 7.2: Boxplot of Communication sub scale disease severity

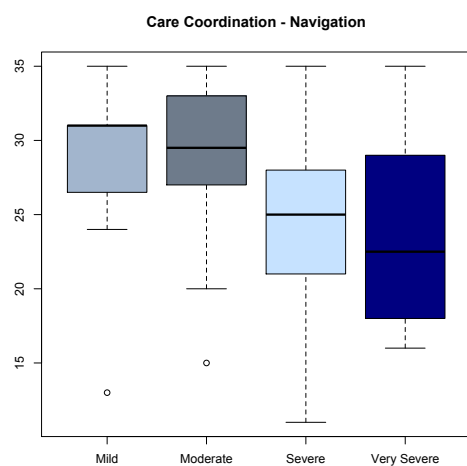


Figure 7.3: Boxplot of Navigation sub scale disease severity

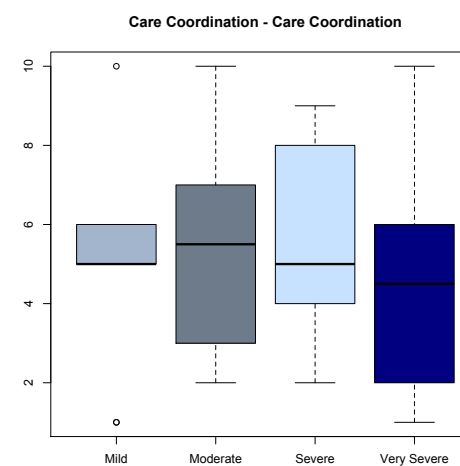


Figure 7.4: Boxplot of Care coordination question disease severity

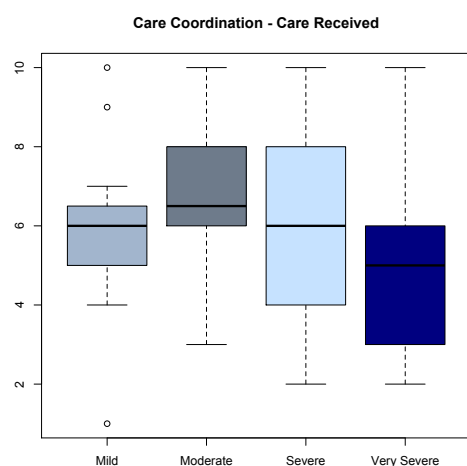


Figure 7.5: Boxplot of Care received disease severity

Table 7.2: Summary statistics by disease severity

Care coordination scale	Group	Count	Mean	Sd
Total score	Mild	11	67.50	11.80
	Moderate	26	71.10	9.52
	Severe	41	61.60	10.70
	Very severe	22	58.70	11.90
Communication	Mild	11	39.20	7.97
	Moderate	26	41.80	8.84
	Severe	41	37.20	8.32
	Very severe	22	34.70	7.34
Navigation	Mild	11	28.30	5.95
	Moderate	26	29.30	5.11
	Severe	41	24.40	5.14
	Very severe	22	24.00	6.23
Care received	Mild	11	5.91	2.39
	Moderate	26	6.62	1.72
	Severe	41	5.88	2.37
	Very severe	22	5.05	2.01

Table 7.3: ANOVA table Care coordination scale by disease severity

Care coordination scale		Sum of squares	Df	Mean square	F	P
Total Score	Between Groups	2294	3	764.80	6.53	0.0005*
	Within Groups	11245	96	117.10		
	Total	13539	99			
Communication	Between Groups	656	3	218.60	3.24	0.0257*
	Within Groups	6488	96	67.58		
	Total	7144	99			
Navigation	Between Groups	529.80	3	176.60	5.886	0.0010*
	Within Groups	2880.20	96	30.00		
	Total	3410.00	99			
Care received	Between Groups	29.40	3	9.80	2.14	0.1010
	Within Groups	440.40	96	4.59		
	Total	469.80	99			

* Statistically significant at $p < 0.05$

Table 7.4: Post hoc Tukey HSD test Care coordination by disease severity

Care coordination scale	Comparison	Mean difference	Lower	Upper	P adjusted
Total score	Moderate -Mild	3.62	-6.56	13.80	0.7886
	Severe-Mild	-5.87	-15.48	3.74	0.3852
	Very severe – Mild	-8.77	-19.22	1.68	0.1320
	Severe-Moderate	-9.49	-16.59	-2.40	0.0039*
	Very Severe-Moderate	-12.40	-20.59	-4.20	0.0008*
	Very Severe-Severe	-2.90	-10.38	4.58	0.7410
Communication	Moderate -Mild	2.63	-5.11	10.36	0.8110
	Severe-Mild	-2.01	-9.31	5.29	0.8887
	Very severe – Mild	-4.45	-12.39	3.48	0.4611
	Severe-Moderate	-4.64	-10.03	0.75	0.1174
	Very Severe-Moderate	-7.08	-13.31	-0.85	0.0192*
	Very Severe-Severe	-2.44	-8.12	3.24	0.6752
Navigation	Moderate -Mild	1.00	-4.15	6.15	0.9575
	Severe-Mild	-3.86	-8.72	1.00	0.1689
	Very severe – Mild	-4.32	-9.61	0.97	0.1495
	Severe-Moderate	-4.85	-8.44	-1.26	0.0035*
	Very Severe-Moderate	-5.31	-9.46	-1.17	0.0063*
	Very Severe-Severe	-0.46	-4.24	3.32	0.9888

* Statistically significant at $p < 0.05$

Table 7.5: Summary statistics and Kruskal-Wallis rank sum test

PIH Scale	Group	Count	Median	IQR	X ²	Df	P
Care coordination	Mild	11	5.00	1.00	3.32	3	0.3445
	Moderate	26	5.50	3.75			
	Severe	41	5.00	4.00			
	Very severe	22	4.50	3.50			

Comparisons of Care Coordination scores by depression and anxiety

Comparisons of Care Coordination scores were made between those that have comorbid depression and anxiety and those that do not. Boxplots for each of the

care coordination scales are displayed in Figures 7.6 to 7.10. Assumptions for normality and variance were met, a two sample t-test was used (Table 7.6). There were no statistically significant differences between these groups.

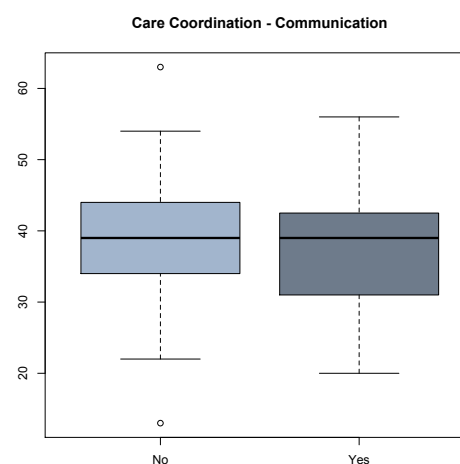
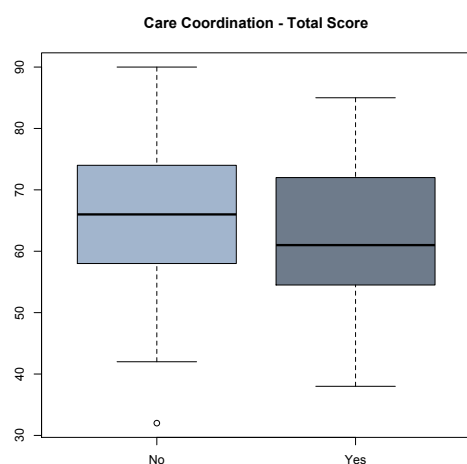
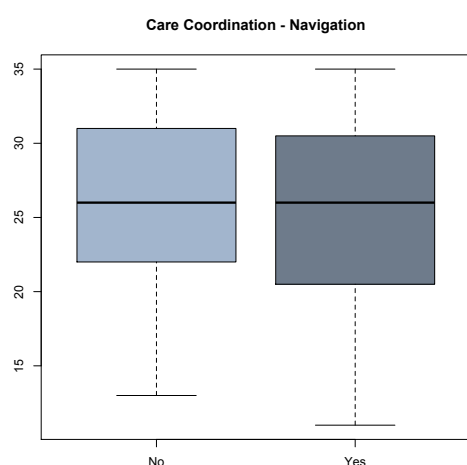


Figure 7.6: Boxplot of Care coordination total score depression and anxiety



7.7: Boxplot of Care coordination Communication depression and anxiety

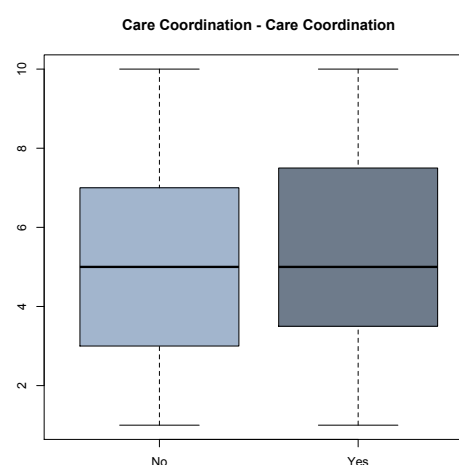


Figure 7.8: Boxplot of Care coordination Navigation depression and anxiety

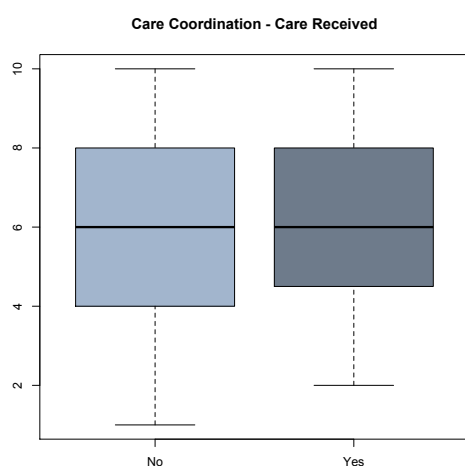


Figure 7.9: Boxplot of Care coordination question depression and anxiety

Figure 7.10: Boxplot of Care Received depression and anxiety

Table 7.6: Summary statistics and two sample t-test care coordination scales by depression and anxiety status

Care coordination scale	Depression and Anxiety	Count	Mean	SD	t	df	p
Total score	No	61	65.20	11.20	1.18	98	0.2397
	Yes	39	62.30	12.40			
Communication	No	61	38.90	8.64	1.22	98	0.2262
	Yes	39	36.80	8.21			
Navigation	No	61	26.30	5.39	0.59	98	0.5553
	Yes	39	25.60	6.60			
Care coordination	No	61	5.13	2.26	-0.42	98	0.6769
	Yes	39	5.33	2.51			
Care received	No	61	5.84	2.13	-0.31	89	0.7586
	Yes	39	5.97	2.28			

Comparisons of Care Coordination scores by Location

Comparisons of Care Coordination scores were made between participants that live in metropolitan areas compared to those that live in regional/rural. A two-sample t-test was used when assumptions for normality and variance were met (Table 7.7), or when

assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.8). There was a significant difference between those that live in metropolitan areas compared with those that live in regional/rural areas for care coordination [$W=925.00$, $p=0.0445$] with those that live in regional/rural areas having a higher score.

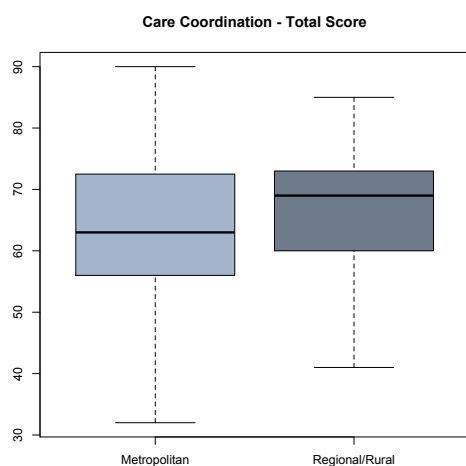
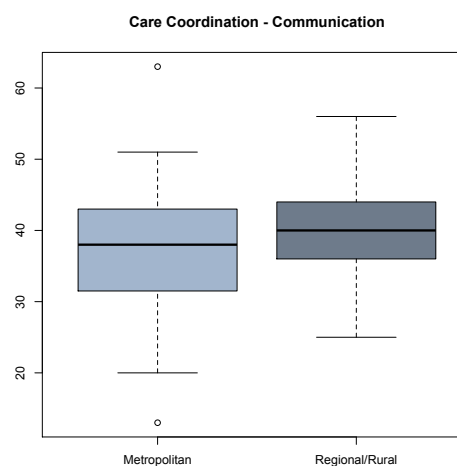


Figure 7.11: Boxplot of Care coordination total score by location



7.12: Boxplot of Care coordination Communication by location

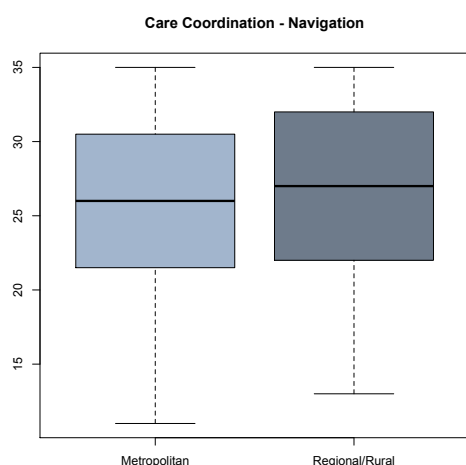


Figure 7.13: Boxplot of Care coordination Navigation by location

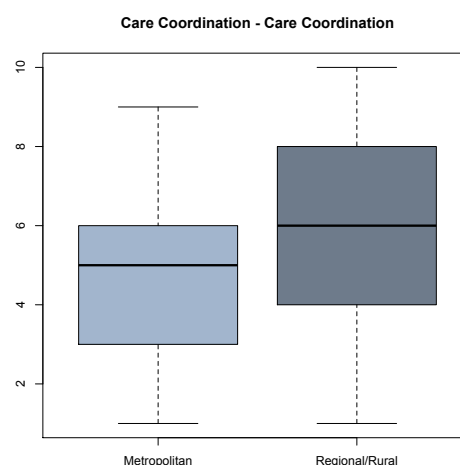


Figure 7.14: Boxplot of Care coordination question by location

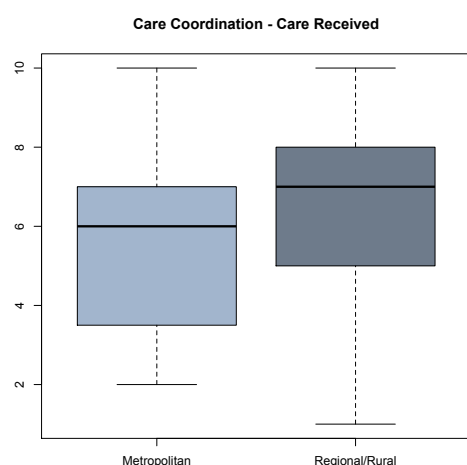


Figure 7.15: Boxplot of Care Received by location

Table 7.7: Summary statistics and Two sample t test by location

Care Coordination	Location	Number	Mean	SD	T	df	P
Total Score	Metropolitan	59	62.90	12.40	-1.18	98	0.2422
	Regional/Rural	41	65.70	10.6			
Communication	Metropolitan	59	37.10	9.13	-1.43	98	0.1551
	Regional/Rural	41	39.50	7.36			
Navigation	Metropolitan	59	25.90	5.86	-0.28	98	0.7832
	Regional/Rural	41	26.20	5.95			

Table 7.8: Summary statistics Wilcoxon rank sum test with continuity correction by location

Care Coordination	Group	Number	Median	IQR	W	P
Care coordination	Metropolitan	59	5.00	3.00	925.00	0.0445*
	Regional/Rural	41	6.00	4.00		
Care received	Metropolitan	59	6.00	3.50	947.50	0.0642
	Regional/Rural	41	7.00	3.00		

Comparisons of Care Coordination scores by education

Comparisons of Care Coordination scores were made between participants education levels, comparing those with high school or trade with those with university education. A two-sample t-test was used

when assumptions for normality and variance were met (Table 7.9), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.10). No statistically significant differences were observed between these two groups for any Care Coordination scores (Tables 7.9 and 7.10).

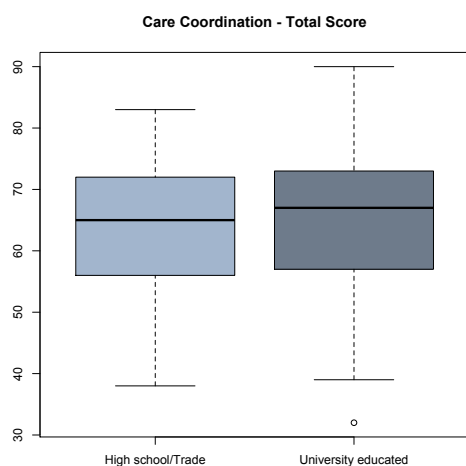
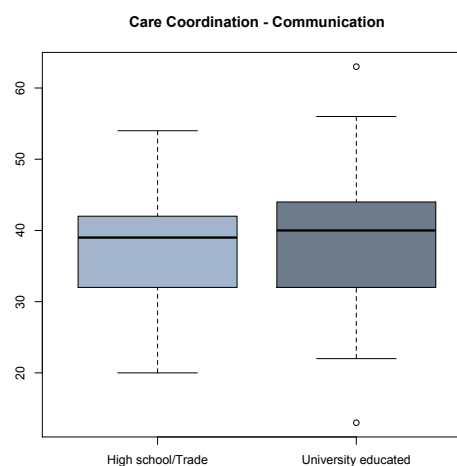


Figure 7.16: Boxplot of Care coordination total score by education



7.17: Boxplot of Care coordination Communication by education

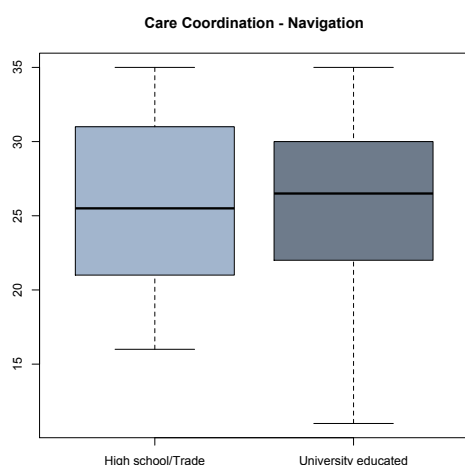


Figure 7.18: Boxplot of Care coordination Navigation by education

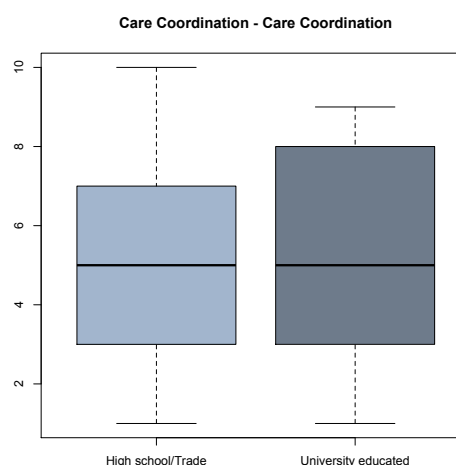


Figure 7.19: Boxplot of Care coordination question by education

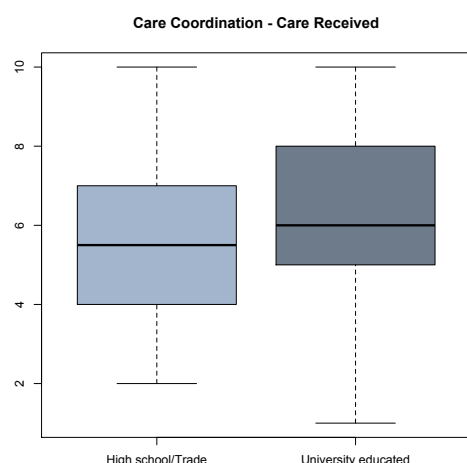


Figure 7.20: Boxplot of Care Received by education

Table 7.9: Summary statistics and Two sample t test by education status

Care Coordination	Group	Number	Mean	SD	T	df	P
Total Score	High school/Trade	42	64.00	11.10	-0.04	98	0.9654
	University	58	64.10	12.20			
Communication	High school/Trade	42	38.00	7.45	-0.11	98	0.9148
	University	58	38.10	9.24			

Table 7.10: Summary statistics Wilcoxon rank sum test with continuity correction by education status

Care Coordination	Group	Number	Median	IQR	W	P
Navigation	High school/Trade	42	25.50	9.75	1204	0.9247
	University	58	26.50	8.00		
Care coordination	High school/Trade	42	5.00	3.50	1193	0.8629
	University	58	5.00	4.75		
Care received	High school/Trade	42	5.50	3.00	1078	0.3251
	University	58	6.00	3.00		

Experience of care and support

Participants were asked what care and support they had received throughout their experience. The majority of participants described care and support coming from family and friends (n=76; 76.00%), and this was the most common theme followed by care and support accessed from the hospital or clinical setting (n=27; 27.00%). There were also 16 (16.00%) participants that described feeling as though they did

not need additional support, however, participants that had severe AD were stated this less frequently (9.09% compared to 16.00% in the general cohort). This was also stated less frequently by participants that had a high school/trade education (7.14 compared to 16.00% in the general cohort).

Table 7.14: Care and support received

	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 primarily receiving support and care from family and friends	76	76.00	9	81.82	21	80.77	29	70.73	17	77.27
Participant describes only receiving care from health professionals/clinical setting	27	27.00	2	18.18	6	23.08	12	29.27	7	31.82
Participant describes not needing or approaching any kind of support	16	16.00	2	18.18	4	15.38	8	19.51	2	9.09
Participant describes receiving support from support groups (online pages like Facebook)	8	8.00	0	0.00	0	0.00	3	7.32	5	22.73
	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
Participant describes primarily receiving support and care from family and friends	30	76.92	31	75.61	45	76.27	39	67.24	37	88.10
Participant describes only receiving care from health professionals/clinical setting	10	25.64	14	34.15	13	22.03	16	27.59	11	26.19
Participant describes not needing or approaching any kind of support	6	15.38	5	12.20	11	18.64	13	22.41	3	7.14
Participant describes receiving support from support groups (online pages like Facebook)	2	5.13	5	12.20	3	5.08	3	5.17	5	11.90

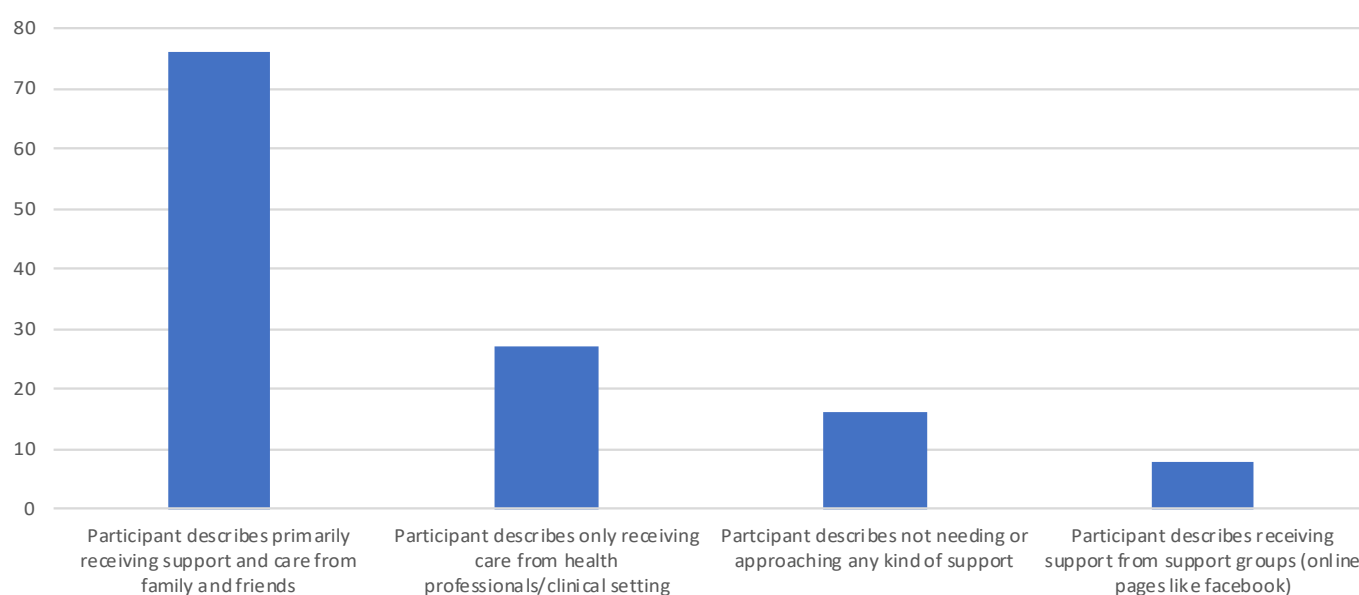


Figure 7.36: Care and support received (% of all participants)

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

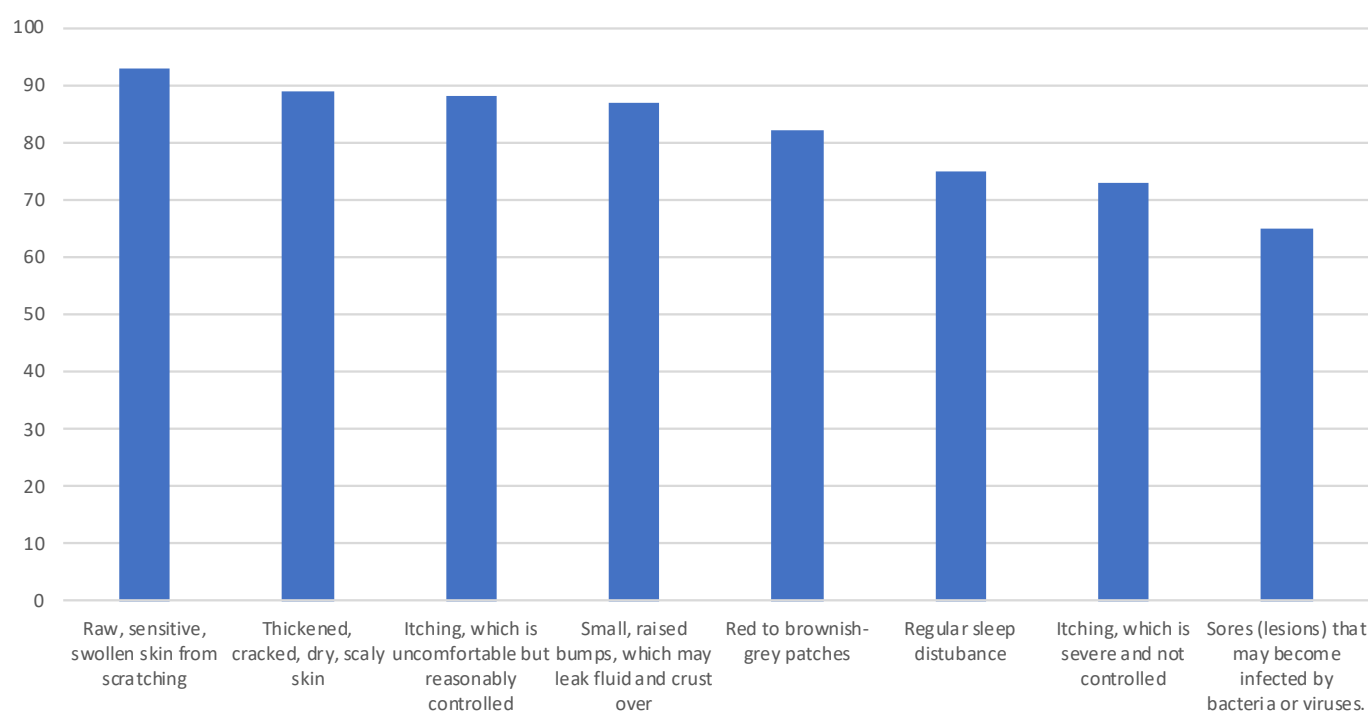


Figure 8.1: Quality of life (% of all participants)

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

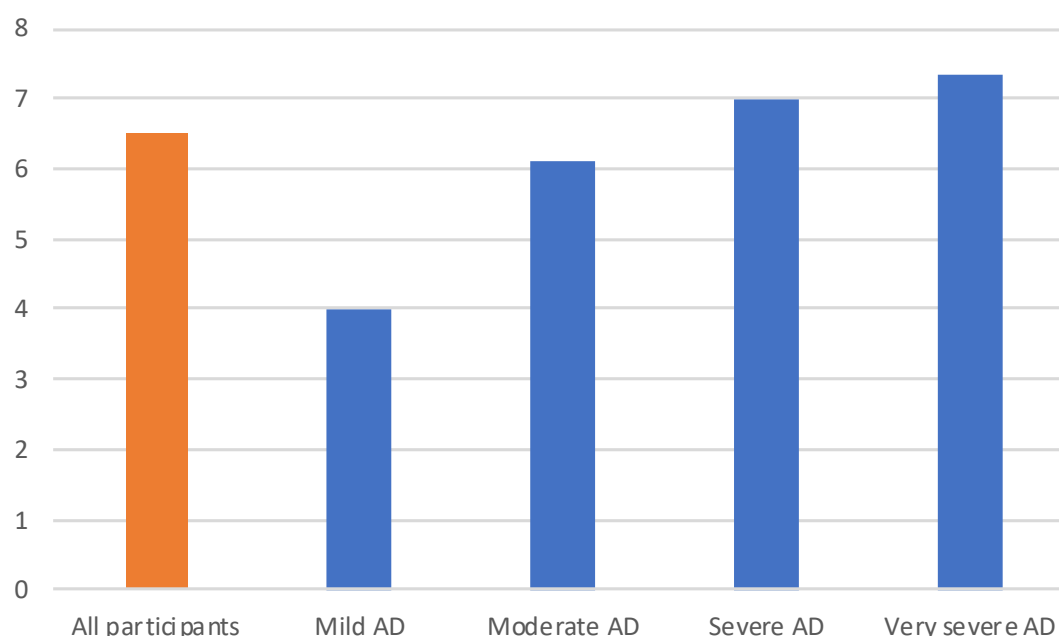


Figure 8.2: Number of symptoms per participant (Mean)

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

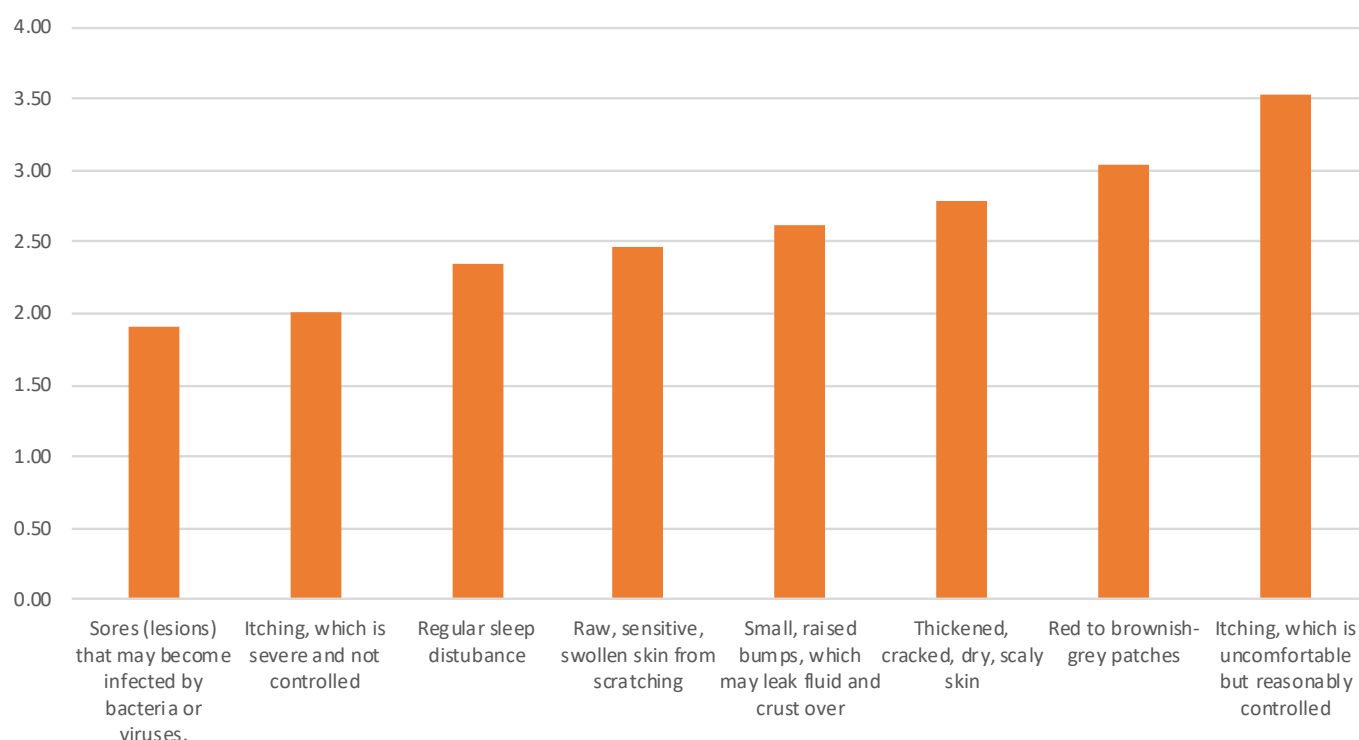


Figure 8.3: Quality of life while experiencing symptoms

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

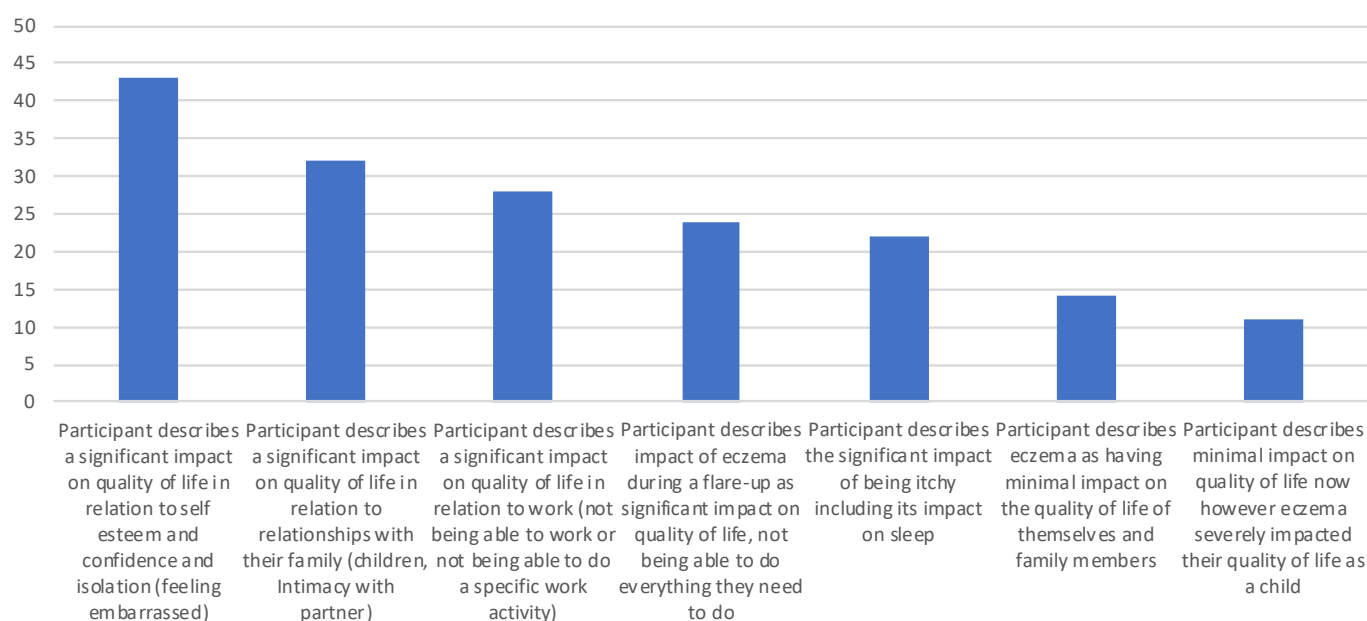


Figure 8.4: Impact on quality of life

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

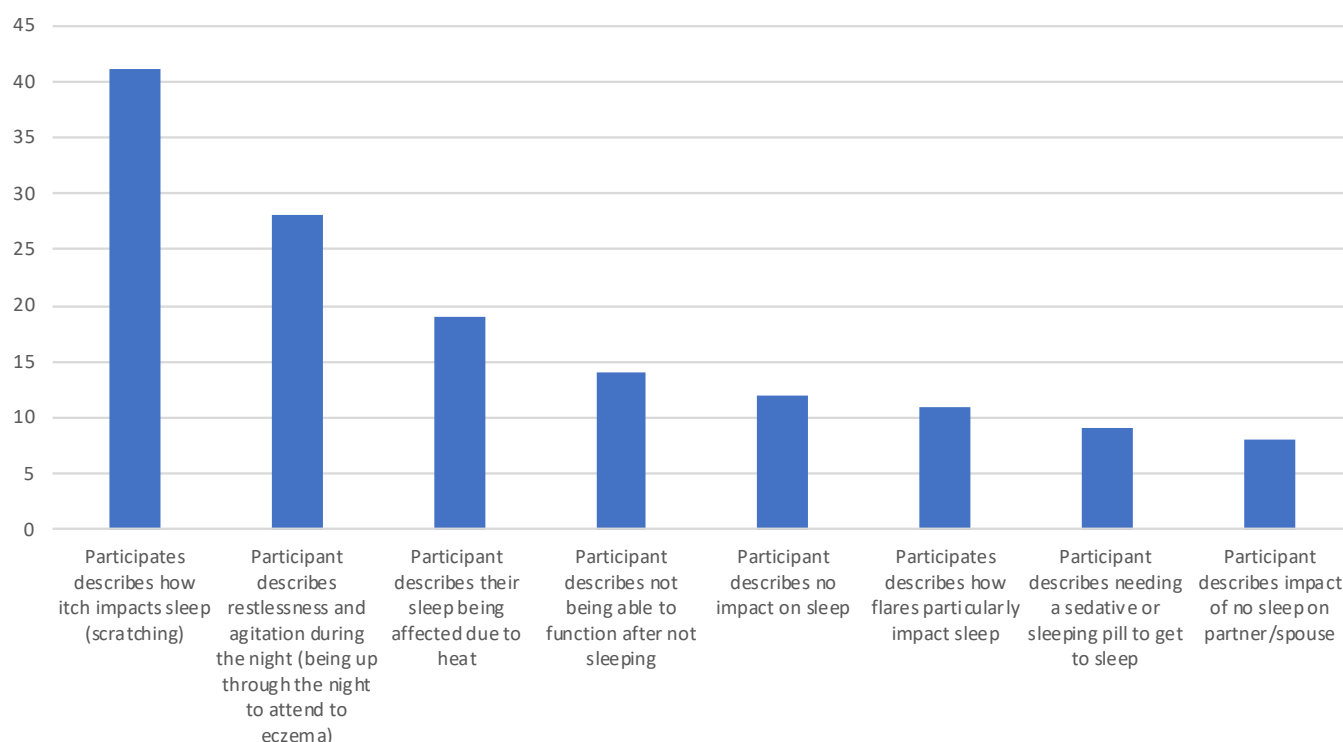


Figure 8.5: Impact on sleep

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

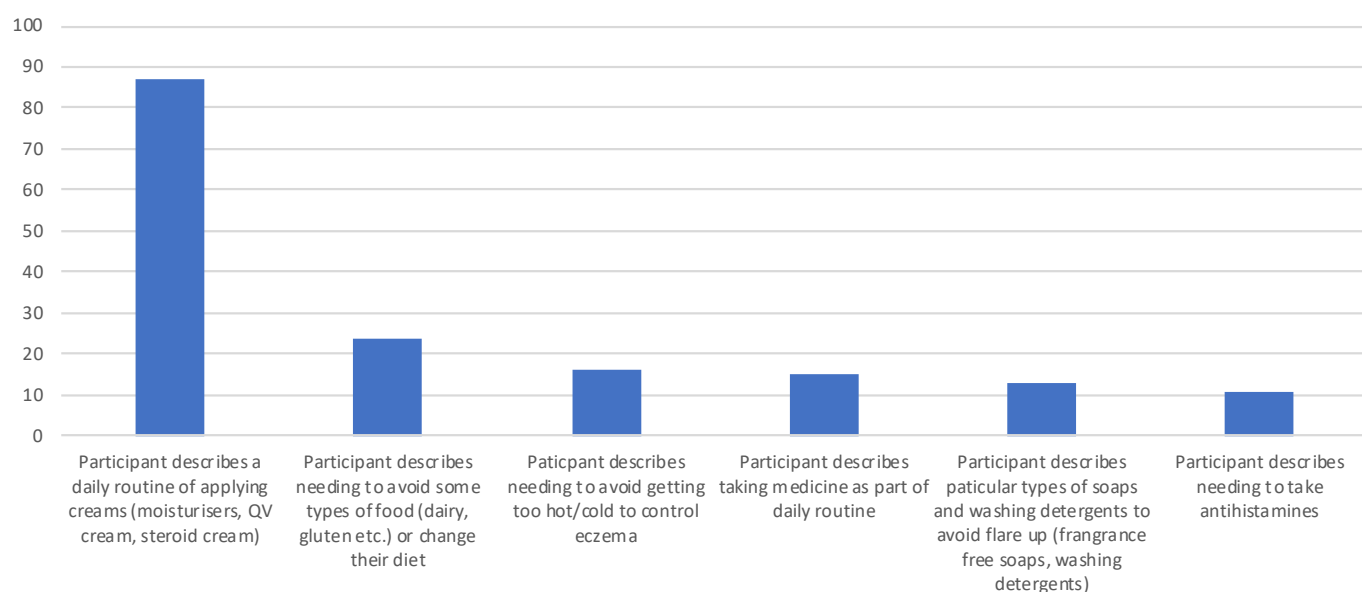


Figure 8.6: Everyday activities to manage health (% of all participants)

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

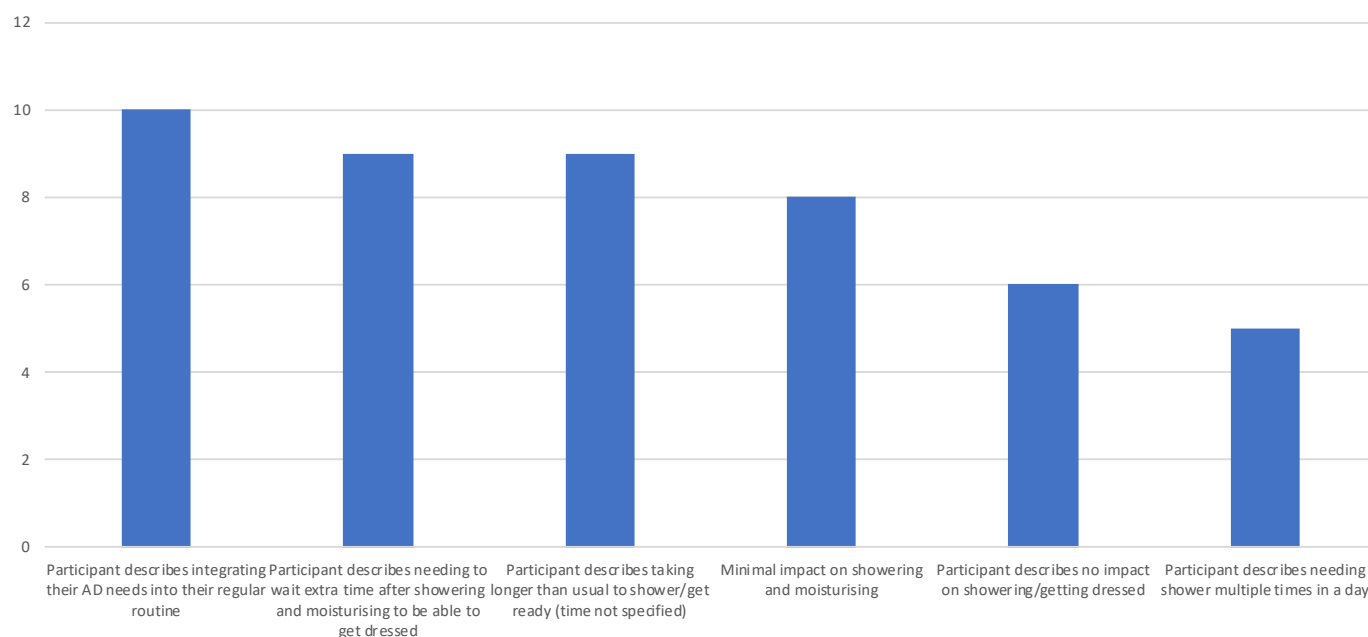


Figure 8.7: Showering/morning routine

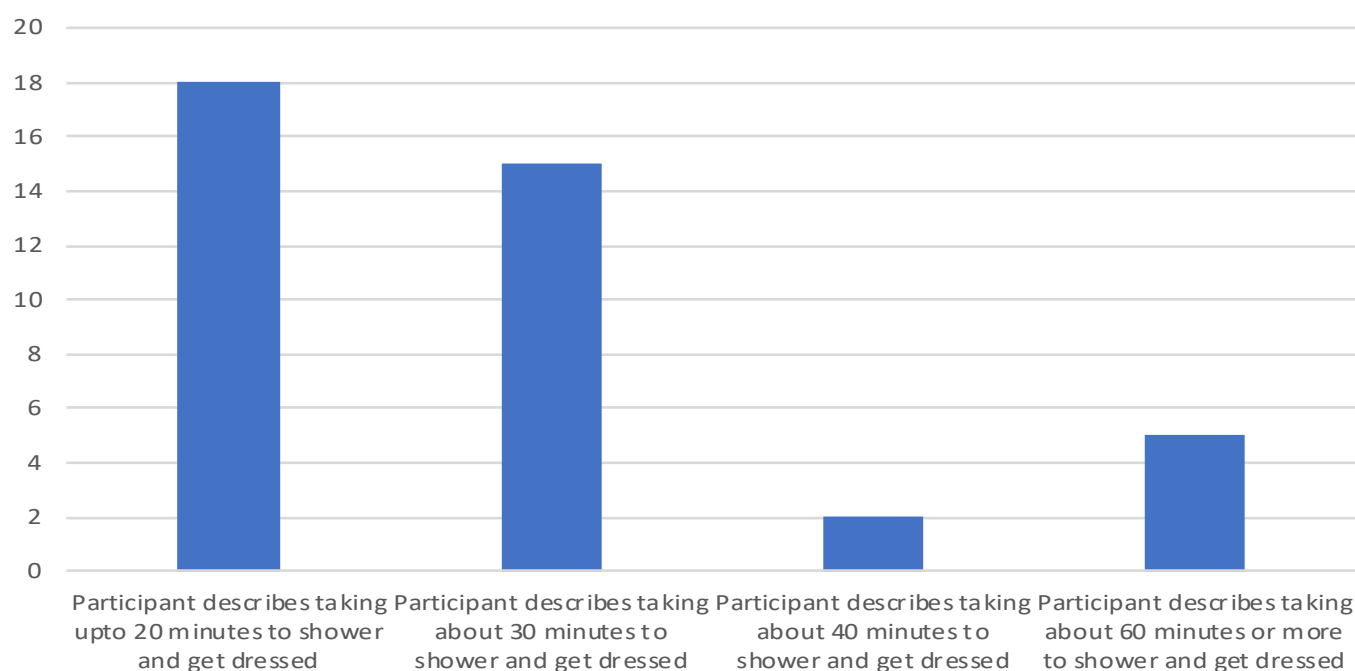


Figure 8.8: Showering/morning routine (Time)

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

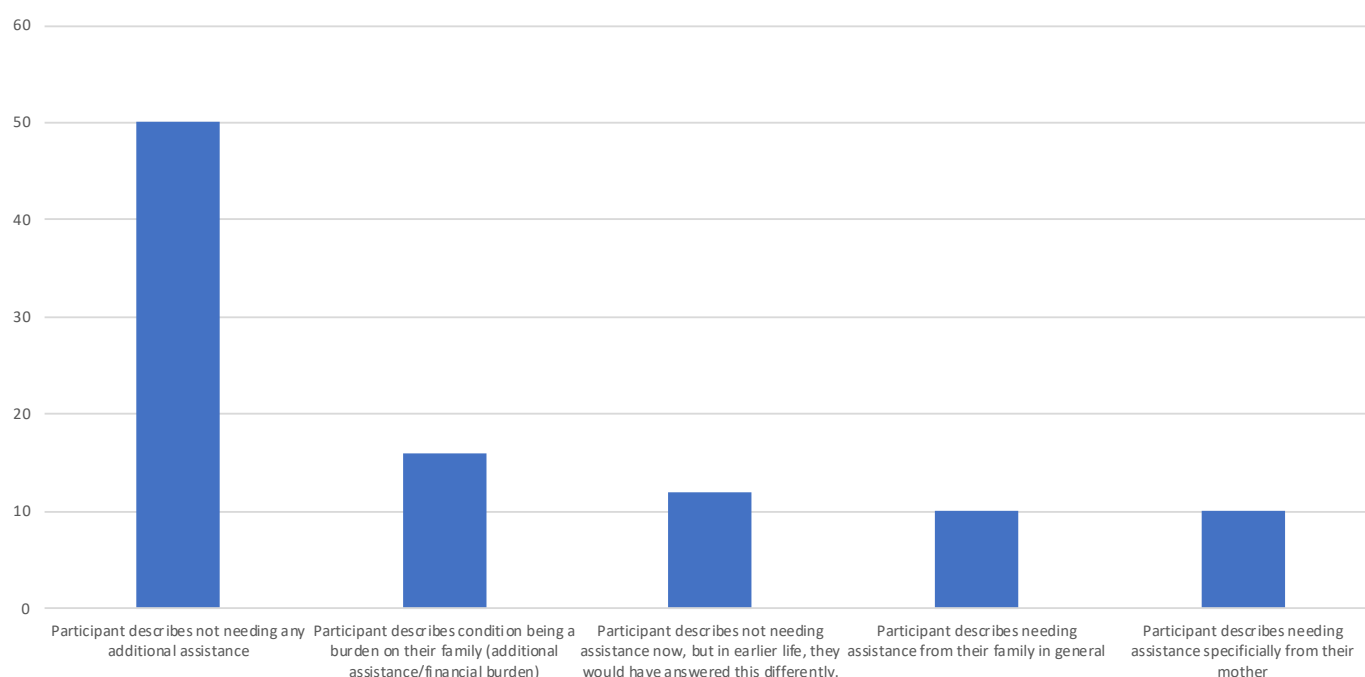


Figure 8.9: Burden on family (% of all participants)

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

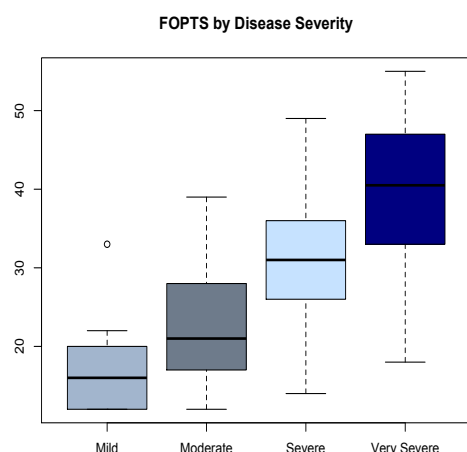


Figure 8.10: Boxplot of FOPTS by disease severity

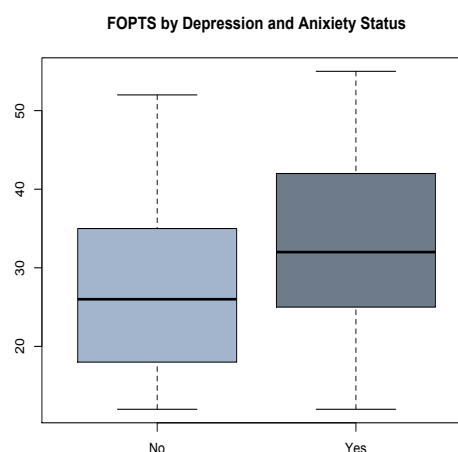


Figure 8.11: Boxplot of of FOPTS by depression and anxiety status

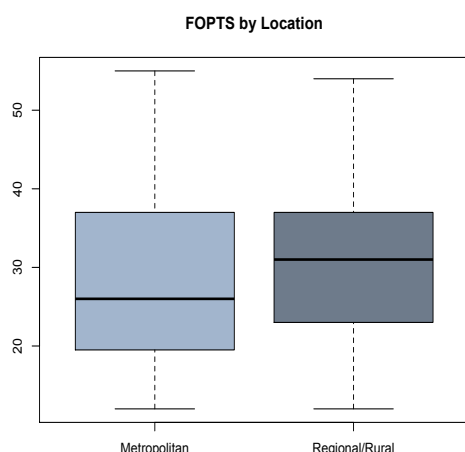


Figure 8.12: Boxplot of FOPTS by location

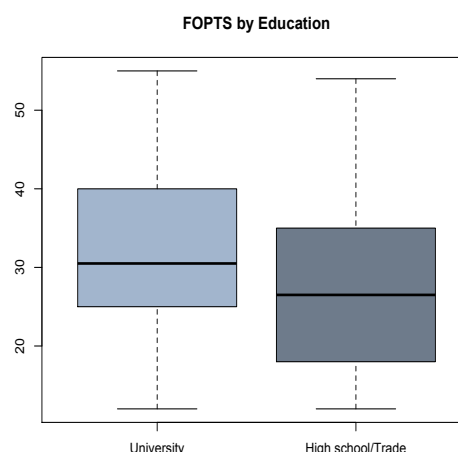


Figure 8.13: Boxplot of FOPTS by education

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		

Section 9 Expectations and messages

Section 9: Expectations of future treatment, care and support, information and communication

Expectations of future treatment

- When asked about their expectations of future treatment, there were a number of themes that emerged. The most common single theme (n=27, 27.00%) was that there should be a more holistic approach to treatment and this included access to different treatment options. There were two similar themes in relation to the expectation or hope that treatments would make the eczema go away (n=19, 19.00%) and that treatments would offer a cure (n=18, 18.00%). In relation to treatments that would make eczema go away, there was an underlying acknowledgement that eczema would always be part of the person's life. This differentiated the theme from treatments that would offer a cure where the hope or expectation was there, however the participants realised it was potentially unrealistic.
- There were 15 participants (15.00%) that described the expectation or hope that treatments would be affordable or less costly. The final theme noted by 15 participants (15.00%) was in relation to the severity of side effects. Participants described the expectation that treatments would be safe and not be detrimental to their long-term health.
- Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it. The most important aspects reported were severe and uncontrolled itching and raw sensitive swollen skin from scratching, the least important sleep disturbance and sores that may become infected.
- Participants were asked to rank what is important for them overall when they make decisions about treatment and care. The most important aspects were safety of treatment/weighing up risks and benefits, severity of side effects and impact on quality of life. The least important were cost, ability to stick to treatment and including family in decision-making.
- Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care. The two most important values were quality of life and access for all patients to all treatments and services, the least important was economic value to government.

Expectation of future information provision

- Participants were asked what they would like to see in the future in relation to information provision. The most frequent theme was that participants would like information to be more available and easy to access (n=39, 39.00%). This theme included being able to know where to find information, which is not always obvious. There were 19 participants (19.00%) that were not able to provide recommendations on future information. Within these comments there was a sense of apathy that, because there were no cures or they did not think there were any advancements in treatments, there was little point in offering more information. Some of the specific topics that participants identified for future information provision were in relation to the causes of AD (n=10, 10.00%) and also how to identify and manage flares (n=10, 10.00%).

Expectation of future healthcare professional communication

- In relation to what participants would like to see improved in relation to the way that health professionals communicate with patients, the most frequent theme was the expectation that health professionals communicate with more compassion, empathy and to take their condition seriously (n=28, 28.00%). There were 20 participants (20.00%) that described the need for more accurate information and for health professionals to have more expertise in the field. An additional theme identified was that participants expect health professionals to listen to the patient, as they know their body best (n=14, 14.00%). This was followed by the expectation to have a care plan or structured follow-up (n=12, 12.00%) and finally, the expectation that health professionals should offer information about all treatments, medical and complementary (n=10, 10.00%).

Expectation of future care and support

- Participants were asked whether there was anything they would like to see in relation to the way the care and support they receive. There were two main themes identified including recommendations to develop opportunities to understand their condition, whether it is in relation to allergies, triggers or how to manage

their condition (n=18, 18.00%). The second main theme was the recommendation for specialist services, either a clinic or telephone support line that is accessible to people diagnosed with AD (n=13, 13.00%).

Messages

- Participants were asked what their message to people who make decisions about their condition would be. There was one main theme noted by over half of the cohort (n=56, 56.00%) where participants had the message that their condition should be taken seriously and that there is a need for compassion and to actively listen to patients. This included that their condition can be debilitating and that it is life-long. There were 34 participants that whose message was to treat the condition holistically, including emotional support, having a care plan and being told about treatment options. An additional 15 participants (15.00%) had the message that there needs to be more funding, not only for research but to develop health professionals to have more understanding and knowledge of the condition. The final theme was a message to consider the cost of treatments and financial burden patients often face (n=11, 11.00%).

Expectations of future treatment

Participants were asked a series of questions about their expectations for future treatments, information, health professional communication, and care and support.

When asked about their expectations of future treatment, there were a number of themes that emerged. The most common single them (n=27, 27.00%) was that there should be a more holistic approach to treatment and this included access to different treatment options:

For new treatments, I'd like to see the patient looked at holistically and the genetic testing is probably a good start with that. Looking at lifestyle, looking at even the climate in which there is like the holistic thing about everything about persons in the environment. Not just looking at it from a disease but looking at it skin tone from of something else. I don't know because I haven't been medically diagnosed with celiac. I get ignored up by doctors all at the time but I refuse to go back on the gluten. I don't get along with doctors very well on the eczema part of it. **Participant 19**

I'd like to see new research and new strategies coming out. I feel like the steroid creams and the wet dressings, they've been doing that for the last two decades, and I feel like they're still doing that. And there doesn't seem to be much movement there. So, I'd like to see new things being tried out, and maybe more research into the cause of it, and trying to find the root of where it stems from, and trying to treat it like that. I feel like a lot of the treatment now is just sort of putting a bandaid on it for the time being, rather than actually treating it long term. I'm not sure. I think they need to target more of a holistic perspective. Yeah, in terms of not just focusing on wet dressings, but looking at your diet and your lifestyle. And bringing that all together more. I feel like now-- ... things. **Participant 34**

I'd like to have a doctor after 30 years, plus 40 years probably going on now. I'd like to have a doctor that actually wants to approach it holistically, and would want to actually work on it like as a case, want to get to the bottom of it, or help me get to the bottom of it - That's a doctor who can listen to me and hear me and actually work on how can we approach treatment based on what you've told me, what we know. I'd also like to be heard and have a responsive doctor, what I feel is a responsive doctor to what they've heard. **Participant 99**

There were two similar themes in relation to the expectation or hope that treatments would make the eczema go away (n=19, 19.00%) and that treatments would offer a cure (n=18, 18.00%). In relation to treatments that would make eczema go away, there was an underlying acknowledgement that eczema would always be part of the person's life. This differentiated the theme from treatments that would offer a cure where the hope or expectation was there, however the participants realised it was potentially unrealistic.

Participant describes the expectation of treatments that make the eczema go away

Look, I get ... I'd probably like something that stops it from happening all together. I know it's probably an impossible dream but I guess, something that actually stops it from breaking out in the first place. So, that you don't actually get it. It would be good. **Participant 8**

A magic pill that I could take once a day and keep it all under-wrapped. Something that's quick and easy and-- (side effects, symptoms) I don't know how to say it. Don't want to have a \$70 cream for a small patch. My main thing is like the redness and dryness and when it goes scaly, my hands like flake. Man, it hurts obviously, to touch things and even bend my fingers. At the moment I've got formed slits across my knuckle and one of my fingers-- one of the finger beds. I've scratched everything in my sleep, I think and it's cracked on my fingertips. **Participant 12**

I think, oh, I, I don't know, with the solutions - ... that cover treatment. Okay. I mean, if there's this magic tablet, I could take every day, and not have any eczema, and, not have any other serious detrimental side effects to my body, then I would definitely take that every day - ... sorta thing. Yeah. Well - ... kind of. I, I just know, that there are different types of medications out there, that must, I don't know what they block, within your system, to help you, your skin improve. But the, you know, dermatologists say, we can, you know, this is the only thing that's gonna make your skin, really, you know, much better. But, I've - there's no way, I would go on something long term; like, they're long term with, with side effects. So, if there's - ... I'm happy to take something long term, as long as there's no side effects. ... and, yeah, if there's other magic creams out there, that can help, that would be great, or, things to stop me being itchy that, you know, other than antihistamines. 'Cause they're not always that great. **Participant 60**

Participant describes the expectation of a cure

What would I like to see from new treatment? Longer lasting effect. Because yeah. And not having to go ... Having to do something minimally, but with a longer effect. I'd love to see a cure, but - That'll be the day.

Participant 61

Something to completely cure it. Maybe if there was a vaccine or I don't know, something like that. Or just a really powerful ointment that would take it out within a week and not have to wait over a month or something like that....or something to just prevent it from ever happening. **Participant 75**

A cure would be good. I know a cure is not...they don't put the money on it... I've always said there are worst things in this world that you can have. Sometimes, you just need to take a step back and go "You know what actually this is actually kind of shit having eczema". I think something that just improves the quality of life would be nice. I'm not expecting that there's going to be a cure anytime soon but just something where I can at least manage it. I don't care if it's medication that I have to take. But I would prefer to not have use creams and to not have to be waking up in the middle of the night scratching or having the air conditioner on the whole day, cracking up my electricity bills because I just need to have it cold. It would be nice to be able to actually want to go to the beach, for once, and to not have to worry about what it's going to do to my skin. **Participant 83**

There were 15 participants (15.00%) that described the expectation or hope that treatments would be affordable or less costly. This was primarily referenced to the costs that they currently incur with their treatment:

I don't know. I don't know what I'd like to see. I think something that would just off it completely. Oh, cost-wise, definitely. You go and you get creams and I could go and spend \$50 at the chemist in a heartbeat, you

know? But it's a very ... Yeah, it's one of those things where you can drop quite a bit of money on it very easily. **Participant 2**

It is expensive, but I'm lucky in that, you pay the bill and off we go. For some who are on a pension or something, I could see this could be tricky. Although if you're on a pension, you get your medicines a lot cheaper anyway. **Participant 32**

It has been manageable obviously, but you got to spend your money on other stuff. I mean when you get a tube of ointment that costs \$40 every three or four weeks and moisturizers and special soaps and stuff and then antibiotics etcetera, etcetera. **Participant 41**

The final theme noted by 15 participants (15.00%) was in relation to the severity of side effects. Participants described the expectation that treatments would be safe and not be detrimental to their long-term health:

I think, oh, I, I don't know, with the solutions - ... that cover treatment. Okay. I mean, if there's this magic tablet, I could take every day, and not have any eczema, and, not have any other serious detrimental side effects to my body, then I would definitely take that every day. **Participant 60**

I would like to see more, preferably treatments that have less or no side effects in the long-term. I would like to see treatments that are more, that, for which doctors are more educated on so that they can actually impart some of that information to patients. **Participant 67**

Well, I'd like to see if they're going to design a tablet or something like that other one that I had, that you can take without being, you know, dangerous. Something like that. That you can just take these tablets on a regular basis and it keeps the skin clear. That's what I'd like to see them design. Because all the creams and the moisturisers, yeah, sure, you need moisturising, but the cortisone creams aren't good for you all the time. **Participant 93**

Table 9.1: Expectations of future treatment

Expectations of future treatment	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 the expectation of a more holistic approach to treatment	27	27.00	2	18.18	11	42.31	9	21.95	5	22.73	10	25.64
Participant describes the expectation of treatments that make the eczema go away	19	19.00	5	45.45	4	15.38	7	17.07	3	13.64	6	15.38
Participant describes the expectation of a cure	18	18.00	1	9.09	5	19.23	8	19.51	4	18.18	8	20.51
Participant describes the expectation of treatments to be of lesser cost	15	15.00	1	9.09	3	11.54	7	17.07	4	18.18	8	20.51
Participant describes the expectation of treatments having lesser or no side effects	15	15.00	0	0.00	1	3.85	7	17.07	7	31.82	7	17.95
Participant describes the expectation of treatments that reduce itchiness	11	11.00	4	36.36	1	3.85	5	12.20	1	4.55	2	5.13
Participant describes the expectation of reducing flares	9	9.00	3	27.27	3	11.54	1	2.44	2	9.09	2	5.13

Expectations of future treatment	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
Participant describes the expectation of a more holistic approach to treatment	10	25.64	14	34.15	13	22.03	15	25.86	12	28.57
Participant describes the expectation of treatments that make the eczema go away	6	15.38	7	17.07	12	20.34	13	22.41	6	14.29
Participant describes the expectation of a cure	8	20.51	8	19.51	10	16.95	9	15.52	9	21.43
Participant describes the expectation of treatments to be of lesser cost	8	20.51	6	14.63	9	15.25	11	18.97	4	9.52
Participant describes the expectation of treatments having lesser or no side effects	7	17.95	6	14.63	9	15.25	9	15.52	6	14.29
Participant describes the expectation of treatments that reduce itchiness	2	5.13	3	7.32	8	13.56	7	12.07	4	9.52
Participant describes the expectation of reducing flares	2	5.13	2	4.88	7	11.86	3	5.17	6	14.29

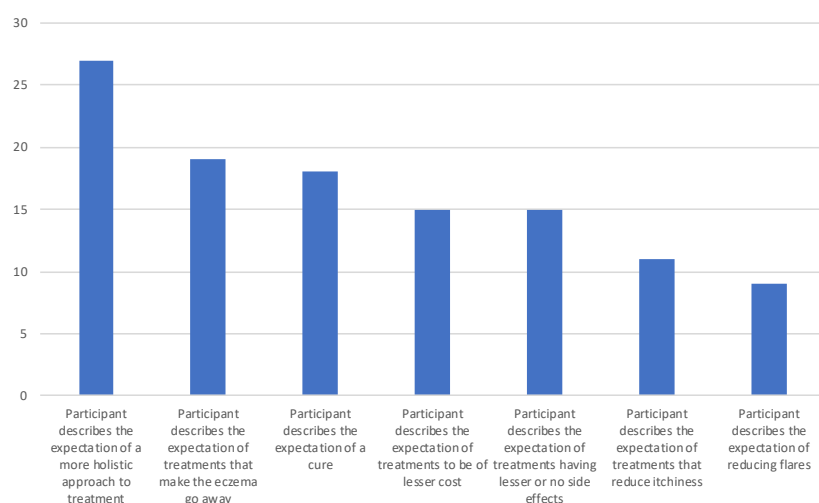


Figure 9.1: Expectations of future treatment (% of all participants)

Values when making decisions about treatment

Symptoms/aspects of quality of life important for treatments

Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it, where 1 is the most important and 10 is the least important. A weighted average is presented in Figure 9.2. With a weighted ranking, the higher the score, the greater value it is to participants. The most important aspects reported were severe and not controlled

itching, and raw sensitive swollen skin from scratching; the least important were sleep disturbance and sores that may become infected. Figures 9.3 and 9.4 show the weighted rank by disease severity and location, the symptoms and aspects of quality of life are similar within sub groups for location. For disease severity, severe and uncontrolled itching is the most important aspect for all groups, and raw and sensitive skin the second most important for moderate, severe and very severe participant, while for mild this is less important than red patches and thickened skin.

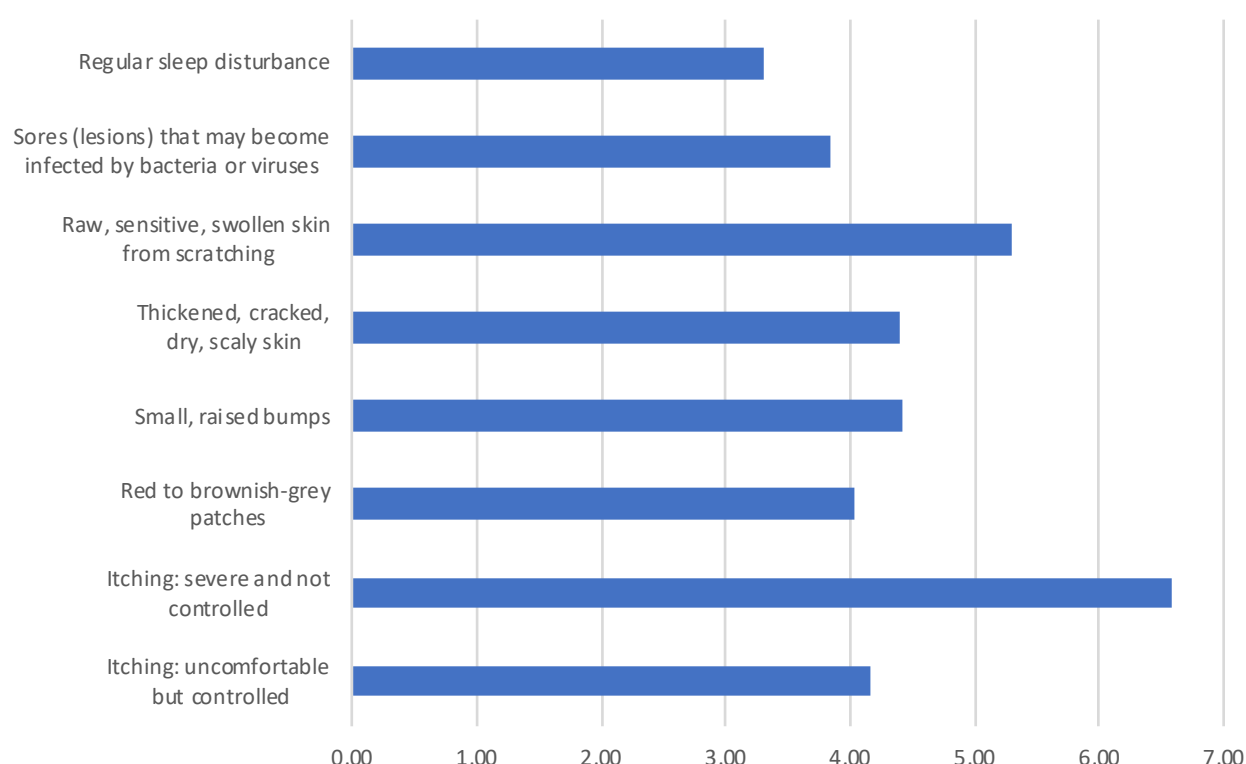


Figure 9.2: Symptoms/aspects of quality of life important for treatments all participants (weighted rank)

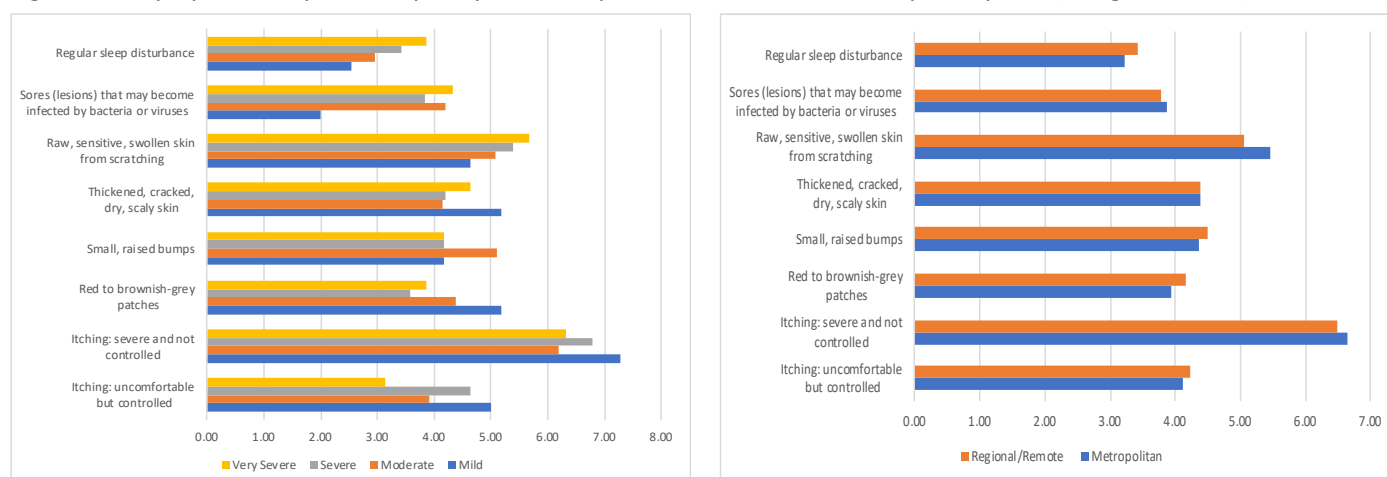


Figure 9.3: Symptoms/aspects of quality of life important for treatments by disease severity

Figure 9.4: Symptoms/aspects of quality of life important for treatments by disease class

Values that are important to patients when making decisions

Participants were asked to rank what is important for them overall when they make decisions about treatment and care, where 1 is the most important and 8 is the least important. A weighted average is presented in Figure 9.5. With a weighted ranking, the higher the score, the greater value it is to participants.

The most important aspects were safety of treatment/weighing up risks and benefits, severity of side effects and impact on quality of life. The least important were cost, ability to stick to treatment and including family in decision-making. Figures 9.6 and 9.7 show the weighted rank by disease severity and Location, the values for making treatment decisions are similar within sub groups and are similar to the overall cohort.

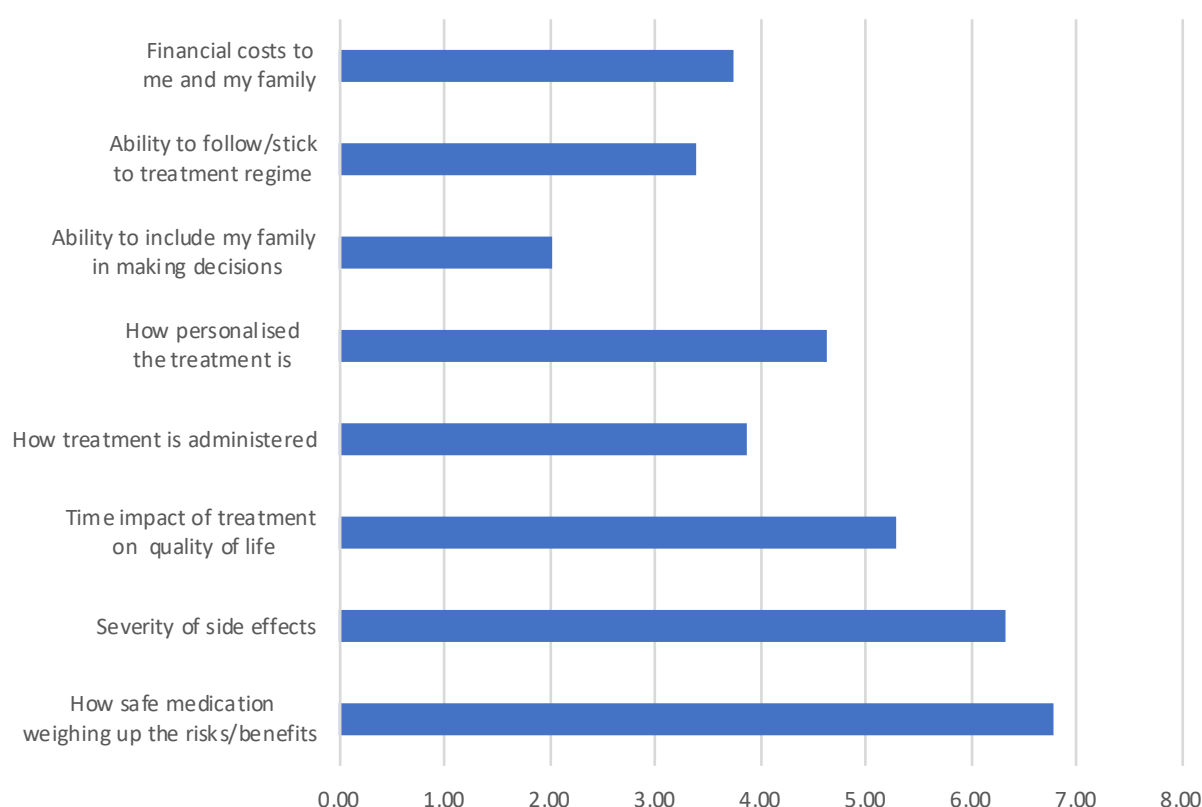


Figure 9.5: Values important when making decisions (weighted rank)

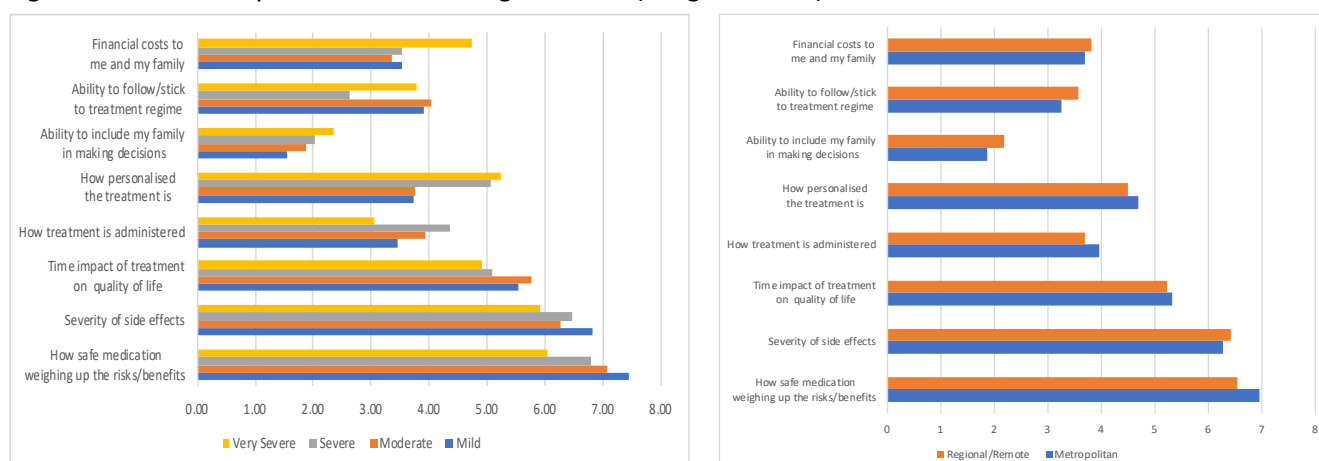


Figure 9.6: Values important when making decisions (by stage of disease)

Figure 9.7: Values important when making decisions (by location)

Values that are important to patients when others are making decisions on their behalf

Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care, where 1 is the most important and 5 is the least important. A weighted average is presented in Figure 9.8. With a weighted

ranking, the higher the score, the greater value it is to participants. The two most important values were quality of life and access for all patients to all treatments and services, the least important was economic value to government. Figures 9.9 and 9.10 show the weighted rank by disease severity and location, the values for making decisions on their behalf are similar within sub groups and are similar to the overall cohort.

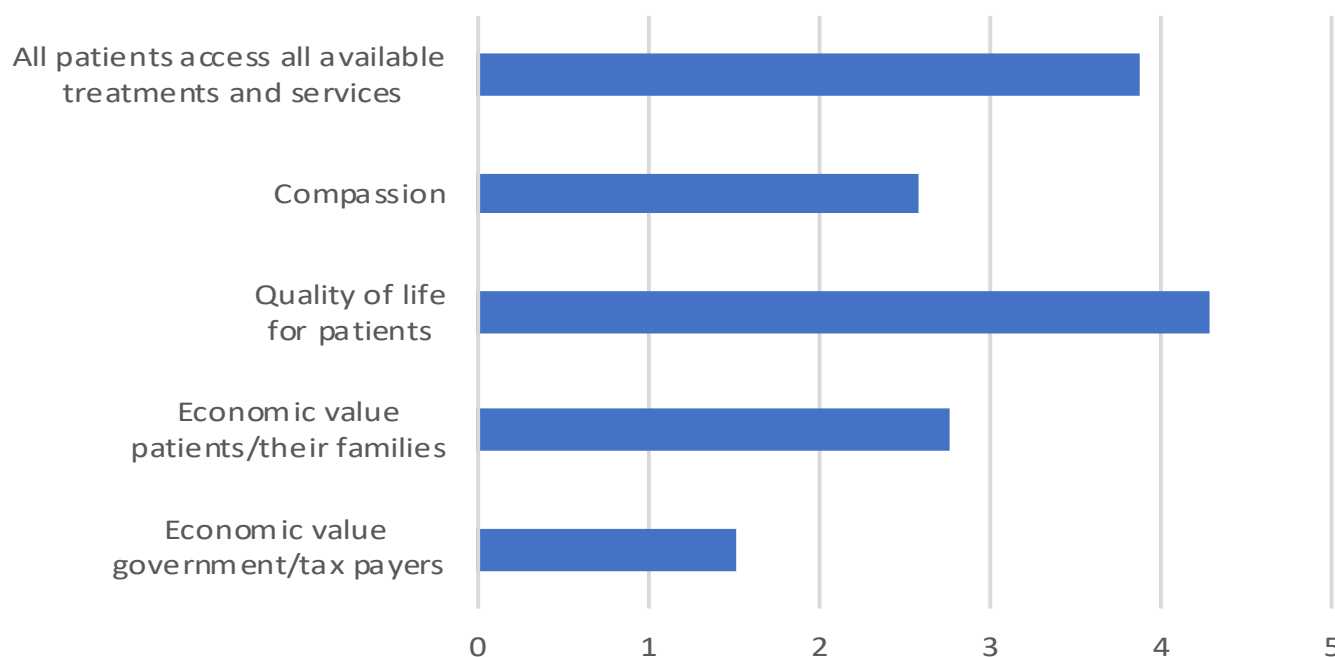


Figure 9.8: Values to consider on behalf of patients/families (weighted rank)

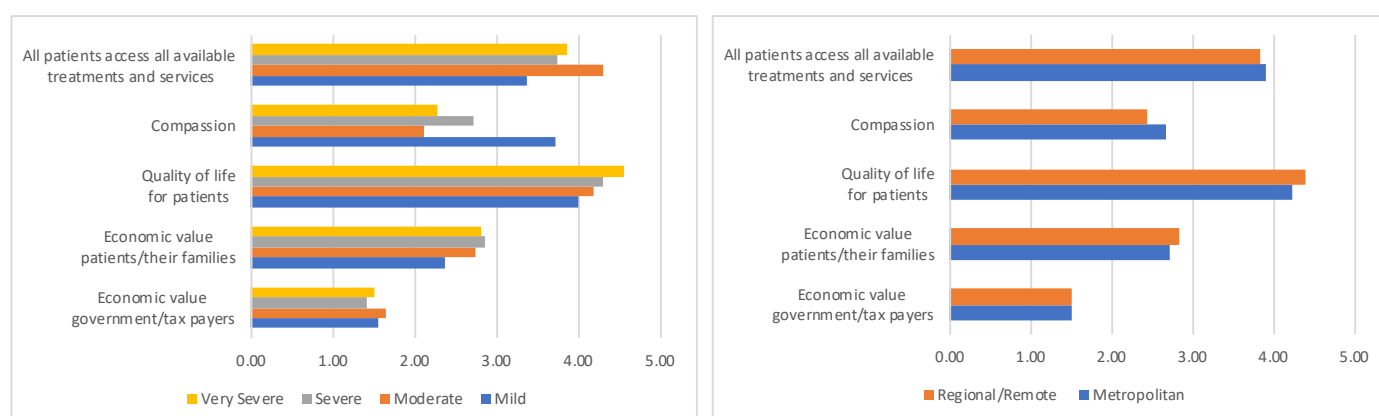


Figure 9.9: Values to consider on behalf of patients/families (weighted rank by disease severity)

Figure 9.10: Values to consider on behalf of patients/families (weighted rank by location)

Expectation of information provision

Participants were asked what they would like to see in the future in relation to information provision. The most frequent theme was that participants would like information to be more available and easy to access (n=39, 39.00%). This theme included being able to know where to find information, which is not always obvious:

It seems like there is not really a consistent source of good quality information that is easily accessible for everyday people, not well advertised, it maybe but I don't know about it. I would have liked to be taught things that are helpful before I had to figure them myself. I guess the public doesn't really...they just say, "You've got a bit of dermatitis" but they don't understand what it's like to have it all the time and for it not to go away. **Participant 13**

I don't think there was anything that wasn't covered but I think it would be good if there is research and there is things happening with eczema that would, if it was more known, cause I don't know about it. You don't see it mainstream. You have to look up things for it. In the chemist there might be a general brochure, or the doctor's, there might be a general brochure on what eczema is but more specific. Yeah, and what's being done. Is there any research or .. I've never heard of anything that's dramatically changed. **Participant 27**

I guess to be honest, I haven't really had much information given to me, other than orally from the GP. And just sort of spoken about things. I can't say that I've had ... I guess with the asthma, I've had information for asthma clinics, and the asthma nurse at the hospital where my son was diagnosed, and those sorts of things. But I haven't gone looking for that sort of information for eczema, so I don't know whether it's out there or not. But probably, simple things that you could do, to ease the eczema, or to ease the itch, or fabrics to avoid in clothing. Sort of things that sort of people are general knowledge in the eczema community for one of the better terms, are things that are likely to flare up eczema, that sort of, someone whose newly diagnosed might not know. So something like, the collective wisdom of people in Australia, of things that set you off. **Participant 37**

There were 19 participants (19.00%) that were not able to provide recommendations on future information. Within these comments there was a sense of apathy that, because there were no cures or they did not think

there were any advancements in treatments, there was little point in offering more information:

Not that I can think of. After all the bits and pieces that I've read over the years, I don't really think that there's too much more, unless that they find there's something new. I don't think there's too much more really. **Participant 2**

Well, I don't really know because I haven't really looked. Honestly, I really haven't and this is going to make me go on the computer tonight and have a look because I don't know that. Because honestly, I have never really looked at what other treatment is available other than cortisone cream. How crazy is that? **Participant 64**

That's a good question. No, probably not. I think this is where the one on one consultations are important because every condition is specific to a person and information on paper is quite generic so no, probably not. **Participant 71**

Some of the specific topics that participants identified for future information provision were in relation to the causes of AD (n=10, 10.00%) and also how to identify and manage flares (n=10, 10.00%).

Participant describes information about the cause of eczema

I find the doctors especially, they're all very just medication and cream-focused. I only learned about other things. I can do diet things, just from looking it up myself. Instead of just treating the problem, focusing on the cause and how to minimize the cause. **Participant 12**

Good question. I think some more research into the cause of it and then educating us what causes it. Because we're all told, "It could be hereditary. It could be environmental. It could be the food you're eating. It could be stress." It's so general. I don't know if that's also linked to the fact that there is no cure. They can't detect or pinpoint a cause. I know everyone is different. Yes, totally. Yes, definitely, yes. Some new information, some research into it. Some new facts, case studies, new findings. Yes, I would love to hear something new. **Participant 15**

Well, I feel like- I'm not using very particular terms with all of this and I feel like just even knowing what the common causes are for eczema. Usually you just go

online and it's just like a dry skin, but it isn't looked after and a lot of people just think oh you're just not moisturising enough, but it's a lot harder than that. So, I think that people who do have it can educate themselves and then educate other people as well, but just knowing the deeper causes of it, not just your given, it could be your family. It's like well, okay then what's the reason behind all that then too. So if it's in a gut health thing that's going on at all, whatever it might be so that, there's lots of reasons people have eczema in this world so. Yeah, so I think just even looking at the I think layers of the skin as well would be interesting, like as a diagram, just so we can see like whether it's just how deep it goes, if it is from the gut health and how that travels up to the skin. Cause isn't the skin like your biggest organ? **Participant 79**

Participant describes information about ways to identify flares or prevent flares or eczema in general

A format on how it's presented with a regime of how not to get it to flare up, the preventatives along with a care plan. **Participant 17**

I wouldn't say before the eczema gets really bad and it gets cracks and it's weeping or flaking or you got that

skin...there was things that happened prior to getting that bad that you might fail to notice. I think there needs to be some sort of "okay if you start feeling this on your skin or if you start seeing is this" - this is actually the action that you need to take straight away so it doesn't get to this point. There needs to be some sort of an action plan or I think to get more information per se so hopefully it can be some sort of specialist and attract somewhere that you just possibly go to a website and can go this is happening to my skin what can you say? The information out there because it is hard to find. Like you can google the stuff and there is lots of information out there but I think it tries to pigeonhole every person with eczema into a same box and I don't think you can. **Participant 55**

More accessibility the information would be great. And having it presented in a scientific way, but still fairly plain English style, easy to understand. More of a why does this happen than just a oh, it happens kind of format; because, yeah, I tend to find that they just say, "This is what happens. This is it", and they never explain why. So, I'd love to see a why, more of the reasons behind what we know about eczema and why it does what it does. **Participant 92**

Table 9.3: Expectations of information provision

Expectations of future information provision	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 information that is more available and easy to access	39	39.00	1	9.09	12	46.15	14	34.15	12	54.55
Participant describes not being able to recommend any additional information	19	19.00	5	45.45	4	15.38	8	19.51	2	9.09
Participant describes information about the cause of eczema	10	10.00	0	0.00	3	11.54	2	4.88	5	22.73
Participant describes information about ways to identify flare-ups or prevent flare-ups or eczema in general	10	10.00	0	0.00	4	15.38	4	9.76	2	9.09
Participant describes information about more holistic approaches to eczema	6	6.00	5	45.45	0	0.00	1	2.44	0	0.00
Participant describes information about adult eczema (including that there is a lot about childhood eczema)	6	6.00	0	0.00	1	3.85	2	4.88	3	13.64
Participant describes information about the side effects of treatments	6	6.00	0	0.00	3	11.54	1	2.44	2	9.09
Participant describes information about genes, genetic causes and hereditary links to eczema	4	4.00	0	0.00	0	0.00	3	7.32	1	4.55
Participant describes information about mental health and emotional support	4	4.00	0	0.00	1	3.85	2	4.88	1	4.55

Expectations of future information provision	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
Participant describes information that is more available and easy to access	16	41.03	19	46.34	20	33.90	18	31.03	21	50.00
Participant describes not being able to recommend any additional information	8	20.51	7	17.07	12	20.34	13	22.41	6	14.29
Participant describes information about the cause of eczema	2	5.13	5	12.20	5	8.47	6	10.34	4	9.52
Participant describes information about ways to identify flare-ups or prevent flare-ups or eczema in general	4	10.26	5	12.20	5	8.47	6	10.34	4	9.52
Participant describes information about more holistic approaches to eczema	0	0.00	1	2.44	5	8.47	4	6.90	2	4.76
Participant describes information about adult eczema (including that there is a lot about childhood eczema)	3	7.69	4	9.76	2	3.39	5	8.62	1	2.38
Participant describes information about the side effects of treatments	1	2.56	3	7.32	3	5.08	5	8.62	1	2.38
Participant describes information about genes, genetic causes and hereditary links to eczema	2	5.13	1	2.44	3	5.08	2	3.45	2	4.76
Participant describes information about mental health and emotional support	2	5.13	3	7.32	1	1.69	2	3.45	2	4.76

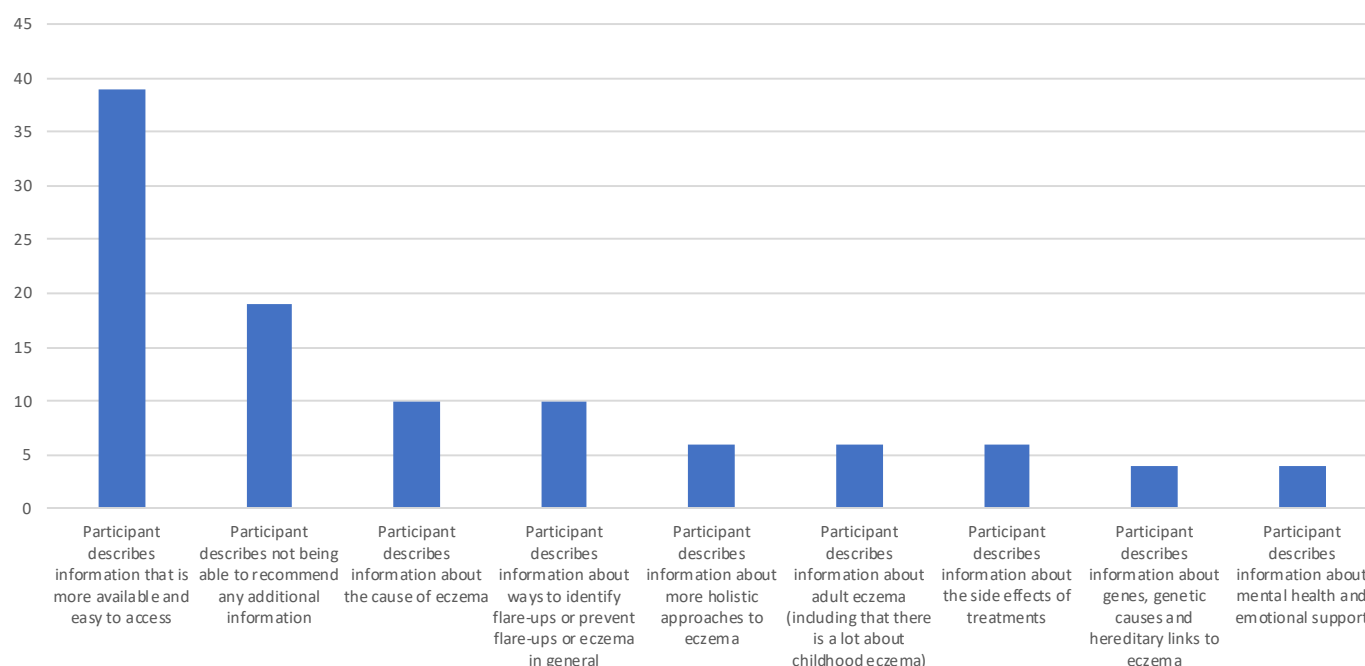


Figure 9.11: Expectations of information provision (% of all participants)

Expectation of health professional communication

Participants were asked whether there was anything they would like to see improved in the future in relation to the way that health professionals communicate with patients. The most frequent theme was the expectation that health professionals communicate with more compassion, empathy and to take their condition seriously (n=28, 28.00%). There were 20 participants (20.00%) that described the need for more accurate information and for health professionals to have more expertise in the field. An additional theme identified was that participants expect health professionals to listen to the patient, as they know their body best (n=14, 14.00%). This was followed by the expectation to have a care plan or structured follow-up (n=12, 12.00%) and finally, the expectation that health professionals should offer information about all treatments, medical and complementary (n=10, 10.00%).

Participant expects health professionals to be compassionate/empathy/take eczema seriously.

Yes. I feel like I'm just nitpicking if I say that they don't understand how life-limiting it can be. Sometimes you feel like they're just, "Oh, you're a bit itchy." They don't really understand that it's quite disabling. Yes, they don't understand how serious it can actually get. Particularly if sometimes your skin's itchy and it doesn't show up as really red. Sometimes you can get the eczema that's pretty much invisible but it's still just feels like 10 million mosquito bites. [laughs]. It feels like, "Oh,

what?" Yes. (It's definitely not nitpicking) Yes, that's it. Participant 42

I think just sort of not very condescending. So, being a little bit less condescending and appreciating that you're experiencing something that is making your life difficult and it's frustrating, and you want help. But I think, yeah, I think a bit of bedside ... I think really good interpersonal skills and some empathy would be good. And being careful not to just step into that patient/doctor role of, "I'm just gonna bully you because you're my patient and I'm the expert and you just have to do this. I'm actually not offering you any alternative." Yeah, a bit more collaborative as to how you can come up with, I don't know, a way of managing things. Participant 53

Yeah, definitely I think health professionals need to have a level of care and empathy, and support. It tends to be missing from a lot of male doctors that I've seen. That's completely lacking from their treatment. With that comes other things. If you're lacking empathy, and you already have this belief, or this knowledge that conflicts with what you're saying, then you're immediately ... Even if there's all this fantastic information, or new information presented, because of their lack of empathy and their large egos, they just ... It just goes in one ear out the other, so they don't really give you much credibility. You are in a position where you feel like you need to justify a lot of stuff, and you need to do more work to get them to actually give you the care that you're after. Yes, I think a level of support and empathy, and maybe smaller egos would be great. Participant 91

Participant expects more accurate information about eczema/education about eczema for health professionals so they are better equipped to explain eczema.

*Look, I think probably one of the things I think is sadly lacking across a lot of GP's is probably even just education around eczema, what it is and how it affects people. I think they tend to be a bit blasé and maybe I would be too if I saw 20 people a day with eczema rashes. I might be a bit more blasé about what you say or what you give people. I think it's probably GP's are not particularly well-educated sometimes around eczema and eczema conditions. **Participant 8***

*It's hard, and I haven't really necessarily been in that for a while, but I would just like to know that they're updated with all of their information, so they actually have everything on hand. Sometimes I trust myself more than I trust them and that's not right. Yeah, right so I'd love to have the confidence that they're attending to it, as it is a really serious issue. **Participant 54***

*Yes, perhaps a better recognition of what is just the standard eczema and what's getting quite an extreme eczema that's affecting people and really starting to affect them in their day-to-day lives. I really don't feel like anyone's been rude or written me off or not taking me 100% seriously. I'm sure that they have, but just perhaps failing to recognize that it's becoming a bigger issue than what it is. I don't know whether part of that might have been...I don't want to blame everybody else because part of that's probably my fault for a few years where I've just gone, "Ah, what's the point in saying it because nothing else is going to change?" But it might be nice if people didn't get to that point and feel like there's no reason to go to the doctor because they're not going to tell me anything new that I don't already suspect they're going to tell me. **Participant 63***

Participant expects health professionals to listen to the patient, as they know their body best/more time.

"I think it's probably more about, being a bit open minded. You know, I've definitely found that, because they just seemed to be focused on this type of treatment is the only treatment that works. And, actually seeing that there is actually other ways of treating somebody. Because, it is diet. It is your psychological state. It is whether you're exercising or not. It is your family and friends support group and all those things. You know, when they're talking to us I think it would be more helpful to touch base on that. What else are you doing? Is there anything else that,

*you know Would you like some information? Or, you know, have you tried this? Or, this is the best that I know. Even actually putting it out there, is there a list of people in our area. You can, probably someday, you could do yourself through the eczema association. You should find out. But, this is a great get together, you know, once a week, here's their number." **Participant 18***

*Hugely. Again looking at it holistically not looking at it as skin disease. Looking at it from a whole body perspective and the whole environment perspective. From a whole body is, I'm talking about diet, habitat, stressors in the environment all of those things. I didn't know how to tell this story but it's always stuck in your mind and I'd love to have these stories told somewhere. I've had stress in eczema. **Participant 19***

*Yes, I'd like to see them do a longer consult, but I know that's not going to happen (laughs). Yeah, eczema is so complex. It's really hard, you know with six minute meetings at the GP, it's a really hard thing to deal with. I can't expect the GP to explain it properly to me in six minutes or outline all the possible treatment options. And I think that sometimes that the GPs, no, got a rash, here's the steroid cream. That's what they write the script for and you're out the door. So, I'm not too sure that even the GPs are actually highly up with how eczema should be monitored. And where to, if there steroid creams aren't actually working or you've been on them for too long, where to from here. I'm not too sure that they understand what to do with that. **Participant 65***

Participant expects to have a care plan or some type of follow-up.

*Well, it would be so good-- I don't know if they do this or whether my doctors just haven't done it, but my son has an asthma plan. Why can't they do like an Eczema plan? Like, "In the days they flare-up, do this." Something like that would be really good. A management. Yes. **Participant 12***

*I think there just needs to be a greater understanding from health professionals about eczema, because I feel like they disregard it as a serious condition. I feel like they really need to develop some action plan, a long-term action plan rather than just providing a quick fix steroid cream. Were somebody can be on steroid cream in five years or something, because that's all that's ever been given. I feel they need to really take it seriously and treat it as a serious condition, because it is. **Participant 38***

*Yeah. So a follow-up would be good. When you go in for eczema, especially with a GP, because that's what I think everybody at this point call. When you go in to prove the GP, I think they should explain how eczema works. That it is an individual experience and that you're going to go through different things of trial and error to trial, and it's not necessarily going to work. And then follow up to see if things have worked, and calling to see what the next step to take. There's a lot of... I've given up at different points, and I think a lot of people have felt the same that go to the GP who will prescribe this. It works for bit, stops working, and then you just go, "I'm not going to go because nothing's going to work." **Participant 61***

Participant expects health professionals to provide information about all treatment alternatives, including both medical and complementary treatments.

Personally, they should try and get to the root cause of eczema for the just fixing the sort fixing like the symptoms on top of it. Also asking them if they want to take alternative treatments. Obviously, the medication they're going to provide and to not going to fix it but there is other things that you can do yourself-- I don't know I suppose it depends on how keen you are to follow it up or you know even the adults, depends on how long they've had it for if it's just a one off I don't know. I say that every person with asthma has eczema. There's obviously a correlation they're always in and

*out of the doctor's to something looks like a breakdown in your immune system somewhere. **Participant 55***

*It'd be nice if they could give you more info. Yes, well lots of my doctors say, "Well okay." I mean, he does give me options and creams but that is all it is. There's never any, you know "Oh maybe try this or try that." Like I would've never thought about clinical trials or anything like that. Yes, that would be interesting to know if they can bring that other, "Okay, we've used cortisone cream for forty years, maybe we'll try something else." That would be a good conversation to have. **Participant 64***

*Maybe give a lot more options because I know for me, I've only been given one option at a time. Unless I do go to different doctors in different areas, sort of thing. The ones that I've been to in SUBURB, they've given me one and when I came to the LOCATION, they have me a different steroid cream. And I was living in LOCATION for a while. They didn't prescribe me anything. They only just gave me an option to go to a pharmacist and get this one type of cream. There wasn't anything else. So, maybe in the future, there could be a long list or different types of options to choose from or depending on how severe it is or isn't. **Participant 75***

Table 9.4: Expectations of health professional communication

Expectations of health professional communication	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 expects health professionals to be compassionate/empathy/take eczema seriously	28	28.00	5	45.45	4	15.38	12	29.27	7	31.82
Participant expects more accurate information about eczema/education about eczema for health professionals so they are better equipped to explain eczema.	20	20.00	3	27.27	8	30.77	5	12.20	4	18.18
Participant expects health professionals to listen to the patient, as they know their body best/more time	14	14.00	0	0.00	6	23.08	3	7.32	5	22.73
Participant expects to have a care plan or some type of follow-up (Including communication between health professionals)	12	12.00	1	9.09	3	11.54	5	12.20	3	13.64
Participant expects health professionals to provide information about all treatment alternatives, including both medical and complementary treatments	10	10.00	1	9.09	0	0.00	7	17.07	2	9.09

Expectations of health professional communication	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
Participant expects health professionals to be compassionate/empathy/take eczema seriously	12	30.77	10	24.39	18	30.51	13	22.41	15	35.71
Participant expects more accurate information about eczema/education about eczema for health professionals so they are better equipped to explain eczema.	8	20.51	9	21.95	11	18.64	11	18.97	9	21.43
Participant expects health professionals to listen to the patient, as they know their body best/more time	6	15.38	8	19.51	6	10.17	8	13.79	6	14.29
Participant expects to have a care plan or some type of follow-up (Including communication between health professionals)	5	12.82	4	9.76	8	13.56	8	13.79	4	9.52
Participant expects health professionals to provide information about all treatment alternatives, including both medical and complementary treatments	4	10.26	4	9.76	6	10.17	5	8.62	5	11.90

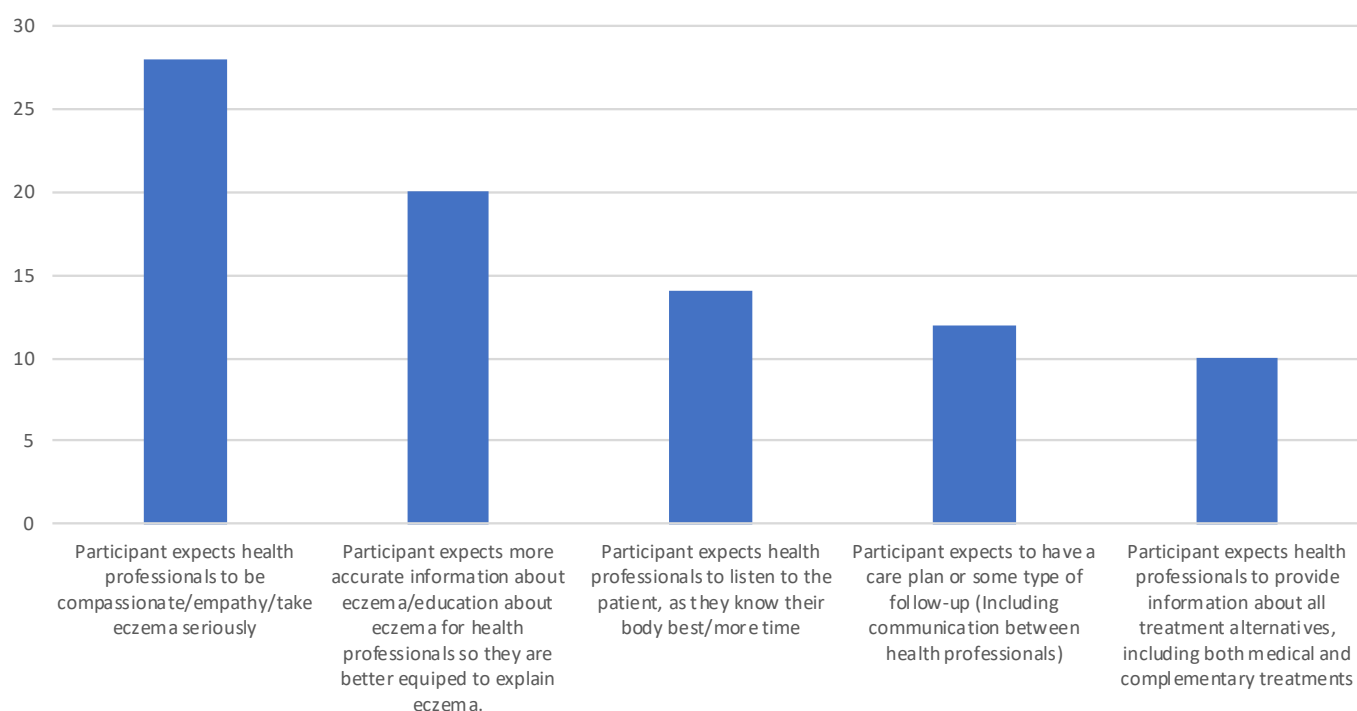


Figure 9.12: Expectations of health professional communication (% of all participants)

Expectation of care and support

Participants were asked whether there was anything they would like to see in relation to the care and support they receive. There were two main themes identified including recommendations to develop

opportunities to understand their condition, whether it is in relation to allergies, triggers or how to manage their condition (n=18, 18.00%). The second main theme was the recommendation for specialist services, either a clinic or telephone support line that is accessible to people diagnosed with AD (n=13, 13.00%).

Table 9.5: Expectations of care and support

Expectations of care and support	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 recommends more opportunities to understanding eczema (more information regarding allergies, triggers and how to manage eczema)	18	18.00	2	18.18	5	19.23	4	9.76	7	31.82
Participant recommends specialist clinics or services where they can talk to professionals (phone, online)	13	13.00	1	9.09	2	7.69	8	19.51	2	9.09
Participant recommends need of mental health/emotional support	8	8.00	0	0.00	0	0.00	2	4.88	6	27.27
Participant recommends being able to connect with other patients (support groups, online forums)	7	7.00	0	0.00	4	15.38	3	7.32	0	0.00
Participant recommends need for more information/awareness about available services	7	7.00	0	0.00	3	11.54	2	4.88	2	9.09

Expectations of care and support	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/ Trade educated (n=42)	
Participant recommends more opportunities to understanding eczema (more information regarding allergies, triggers and how to manage eczema)	6	15.38	9	21.95	9	15.25	8	13.79	10	23.81
Participant recommends specialist clinics or services where they can talk to professionals (phone, online)	4	10.26	6	14.63	7	11.86	9	15.52	4	9.52
Participant recommends need of mental health/emotional support	6	15.38	6	14.63	2	3.39	4	6.90	4	9.52
Participant recommends being able to connect with other patients (support groups, online forums)	1	2.56	3	7.32	4	6.78	5	8.62	2	4.76
Participant recommends need for more information/awareness about available services	3	7.69	1	2.44	6	10.17	3	5.17	4	9.52

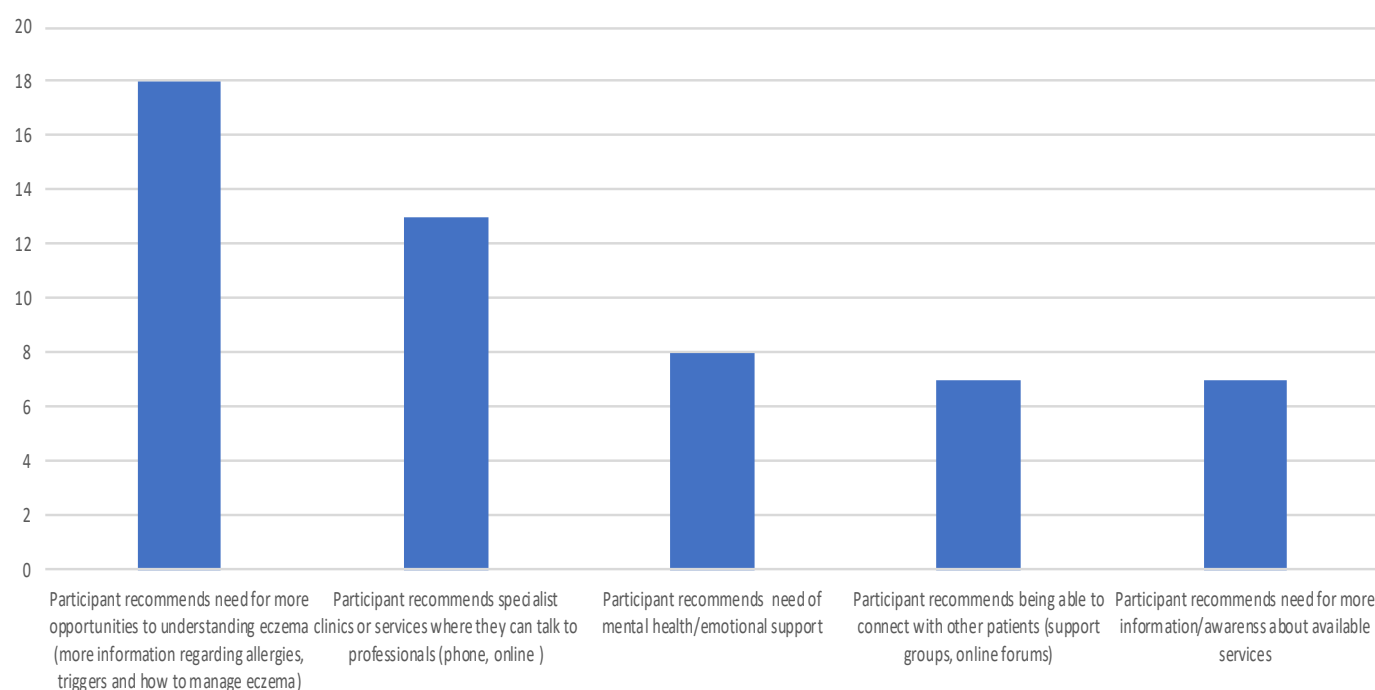


Figure 9.13: Expectations of care and support (% of all participants)

Messages to decision-makers about the treatment and care that people affected by AD

Participants were asked what their message to people who make decisions about their condition would be. There was one main theme noted by over half of the cohort (n=56, 56.00%) where participants had the message that their condition should be taken seriously and that there is a need for compassion and to actively listen to patients. This included that their condition can be debilitating and that it is life-long:

I definitely think that referrals to specialist being more easily obtained would be good. And there's a lot of things around my eczema of recent times ... And, look, I remember things as a child being very similar around my eczema, instead of being more really as a child, I was treated by the health system in those days. Which had sanitised nurses and support unavailable back then. Maybe my eczema might have been better across a number of years than what it has been. Yeah, so I think it's probably sort of a mixed bag of things that need to happen. And I think probably for a lot of people with eczema and stuff it probably starts, it's lifelong. It probably starts for most people in their childhood. It's not something you develop, often, out of the blue as an adult. It's something you probably grow up with, and live with, and by the time you get to be an adult, you're sort of almost like, "This is part of day to day life."

Participant 8

Yes, I think it would be that actually eczema is very debilitating and it's much more debilitating than they give it credit for. Even as a kid, you are ashamed of what you have, you are uncomfortable. You're always itching and it just doesn't look-- It's unsightly and you know that, you know within yourself that actually people are judging you for itching. It's actually much more debilitating than they would suggest it is. If I was talking to the Government, I would suggest that they pay more attention to their care system, so what care system they offer. I don't think dermatologists should be practicing in the area of eczema. They're other areas, they give more empathy into the business or it was for my dermatologist to seem to be his business. He didn't really care about it. He wasn't usually vested in knowing more. I think it would be better to have a support network that deals with eczema rather than dermatologists. **Participant 80**

That in almost every aspect of the life of someone with chronic eczema is affected negatively. We're unable to ... Okay, so I'm speaking from my point of view that it's harder to progress financially. There's a lot more mental and emotional strain on the person, so there

needs to be more support in these areas. I tried to get support when I went to a doctor a long time ago, one or two doctors, and neither of them were write a letter to say that I was unable to work, even though, it was almost impossible for me to work because I was just covered in eczema; I was covered in it, and it was emotionally really really difficult to work, and physically as well, it was painful, and I was bleeding over the clothes I was trying to sell, but there was no support because I wasn't using the medication that they said that I had to use, which would cause me more problems. I think there needs to be a bit more understand and a bit more support around that. Also that eczema is not just ... Eczema is a symptom of something. Eczema isn't the cause. It's not the issue, it's a result of something happening in the body, and it's not always going to be the same thing for everybody, so there needs to be more funding, I guess, in this research. I shouldn't say more, because I don't know how much funding there already is, but I would like to think that they would start to take into consideration the aspect of the issue being more than just a skin-related issue, and that it comes from somewhere.

Participant 91

There were 34 participants that whose message was to treat the condition holistically, including emotional support, having a care plan and being told about treatment options:

Just to take that holistic approach, that it's not just about fixing what you can see. Also, really and especially in our society now, eczema does have a big impact on your mental health and your relationships, and the worse that it is, the more of an impact it does have. Yes, so it's not just a thing that happens to your skin. It affects all of you and the people around you.

Participant 6

My message would be to look at them from a holistic perspective, so don't just give them access to a GP who just gives them steroids, and wet dressing treatments, but to give them a really well rounded service. So, for example, giving them a dietician, giving them the GP, the specialist, any other kind of ...all that they have. Yeah, so just looking at a whole person, giving them psychological help if they need that as well. Yeah.

Participant 34

I'd say that it's really important to take a look at statistics, and at its baseline, eczema is a condition, it's an autoimmune condition that is perpetuated by stress. I'd like, just as aside, I'd be curious to see the increase of the diagnosis of things like eczema, psoriasis, stress, and anxiety. I would love to see what the stats are now,

compared to fifty years ago. I think that would be a really interesting indicator. Then, of us needing to, again, take a holistic approach to, not so much combating, but supporting health, as a whole. It's things like, we need to be aware of the ridiculous workload that most people have. We need to be aware of the high incidence of stress and anxiety, and then, having an awareness of health and nutrition, and how that affects skin health, too. I guess, it's a bit of a tangent, but I'd say, what I would want to say is, we need to re-evaluate how our current health system can support well-being. I think we're missing the mark, particularly in mental health, and skin health. I guess, again, it comes back to that question you asked before, in terms of not booking our GP so that they have to see - work ten hour shifts, and miss those signs and signals, but just, supporting public health more, that's it. So that we have the resources that we need to live life. It's a dream, definitely. **Participant 46**

An additional 15 participants (15.00%) had the message that there needs to be more funding, not only for research but to develop health professionals to have more understanding and knowledge of the condition:

*I see. I would say that there needs to be easier access for acute situations that need advice urgently. Whether that's more...how do you get more doctors to become dermatologists, I don't know. I guess that or more funding for clinical nurse specialists that can take the dermatologist's advice, a common dermatologist's advice and implement that across a bigger population. Or a clinic you go to see, whether it's nurse practitioners or something that do dermatology. I would say the cost of creams and moisturizers and stuff on the PBS. It can get really expensive, whether or not you can get the wrong prescription because that hardens the, not cure, but treatment. **Participant 13***

*Yes. Definitely. I know that there is certain drugs and treatment available in the rest of the world, like in the US, that's unavailable here yet. I feel I don't think they're doing enough research or putting enough money towards these treatments or these drugs that could really help some people over here in Australia, who don't have the access to this treatments overseas. **Participant 38***

*I think....obviously putting money into research would be fantastic. I know that these things take a lot of time and a lot of money but it does affect so many people. Having a bit more dedication to it...I know there are a lot of people just get as a kid and get out of it. There's been so many more adults and older people with it that we're spending so much money and time on this throughout our lives and having a bit more money there for research and development would be fantastic. It's not just an itchy rash for a kid it can be somewhat debilitating disease throughout our lives like I can't be going, it's never going to go away. **Participant 72***

The final theme was a message to consider the cost of treatments and financial burden patients often face (n=11, 11.00%):

*Help us out with money. That would be nice. Making treats for us. Listen to us because I know there are some things out there, and I know that it's hard, you've got subsidies for pretty much a lot of things. My dad's got diabetes, so he gets subsidized, which frustrates me with that, but I think- (frustrating) It's just more so that, why does that get subsidized, and not this? I work right next to the Priceline Pharmacy, so when they've got 50% off stuff that I use, I will spend hundreds of dollars on it, because it's going to save me a lot of money. Anytime I have to pay full price on it I hate it, because I know I'm going to use it very quickly, and if I can get it on sale it will all add up for me. The biggest one is the financial side of things. It's a very expensive problem to have, or condition to have. I spent \$45 on creams alone, recently. That was on top of the sixty-something dollars I spent the day before on my medication. Within 24 hours, I spent over \$100, just on stuff to help me get through. **Participant 83***

*This actually cost them a lot of money. It's \$80 for a tube of cream that lasts two weeks. This is expensive. We should actually help fund some of this, because it's lifelong....just like they would consider a disease like diabetes. **Participant 85***

*Making it available financially, making it available in terms of getting the product. That's a long message, sorry...and my husband. He's had to take time off work to care for me quite a lot. **Participant 90***

Table 9.6: Messages to decision-makers

Messages to decision-makers	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's message is to be take eczema seriously: be compassionate, empathetic and try to understand that it can be debilitating and that it is life-long (listen to the patient)	56	56.00	8	72.73	14	53.85	23	56.10	11	50.00
Participant's message is treat eczema holistically, including supporting mental health, having care plans, choice of treatments and information in relation to all available options.	34	34.00	2	18.18	8	30.77	16	39.02	8	36.36
Participant's message is to invest in eczema including research, professional development of and access to eczema specialists and treatments	15	15.00	2	18.18	4	15.38	7	17.07	2	9.09
Participant's message is to provide understand the financial implications of eczema and provide financial support.	11	11.00	0	0.00	3	11.54	2	4.88	6	27.27

Messages to decision-makers	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/ Trade educated (n=42)	
Participant's message is to be take eczema seriously: be compassionate, empathetic and try to understand that it can be debilitating and that it is life-long (listen to the patient)	23	58.97	19	46.34	37	62.71	30	51.72	26	61.90
Participant's message is treat eczema holistically, including supporting mental health, having care plans, choice of treatments and information in relation to all available options.	11	28.21	15	36.59	19	32.20	19	32.76	15	35.71
Participant's message is to invest in eczema including research, professional development of and access to eczema specialists and treatments	4	10.26	9	21.95	6	10.17	10	17.24	5	11.90
Participant's message is to provide understand the financial implications of eczema and provide financial support.	5	12.82	5	12.20	6	10.17	5	8.62	6	14.29

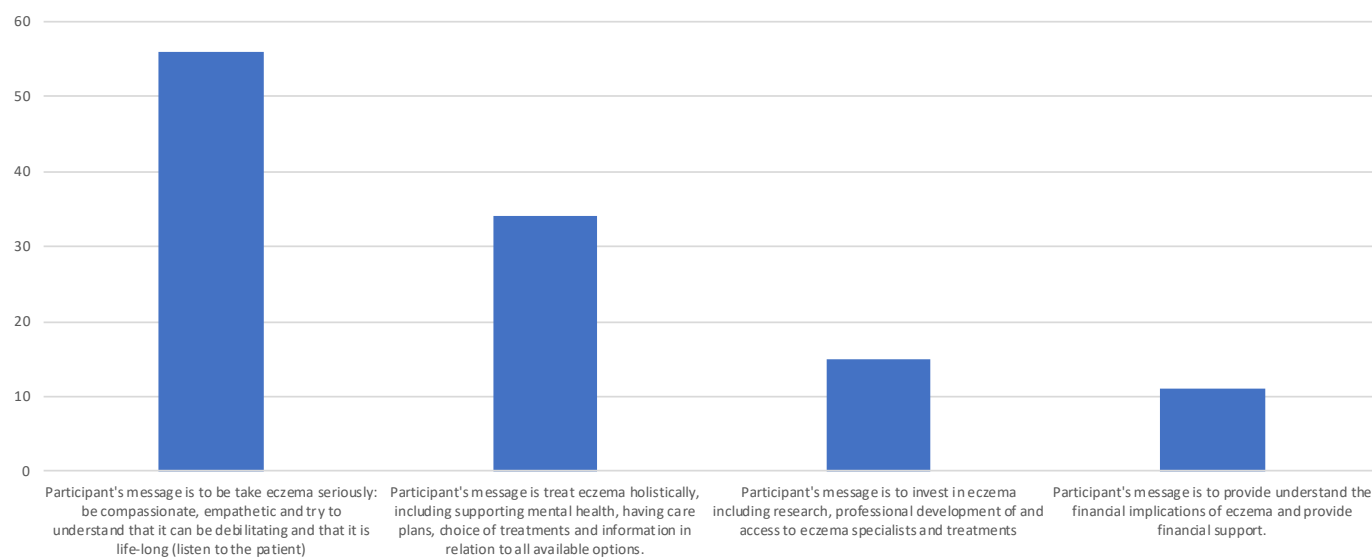


Figure 9.14: Messages to decision-makers (% of all participants)

Section 10 Advice to other patients and families

Section 10: Advice to other patients and families**Summary**

- Participants were asked what advice they would give to other people who are newly diagnosed with AD and their families. There were two key themes including to find what works best for you and this was noted by 26 participants (26.00%). The next most common theme was in a similar vein where participants spoke about various individual products that had worked for them, demonstrating the individual nature of the condition (n=24, 24.00%). Other themes included to pay attention to your diet, as many people found this to be helpful (n=18, 18.00%), do as much of your own research as possible (n=11, 11.00%) and to use gentle body washes and moisturizers - be diligent with moisturizing (n=11, 11.00%).

Advice to others diagnosed with AD

Participants were asked what advice they would give to other people who are newly diagnosed with AD and their families. There were two key themes including to find what works best for you and this was noted by 26 participants (26.00%). The next most common theme was in a similar vein where participants spoke about various individual products that had worked for them, demonstrating the individual nature of the condition (n=24, 24.00%). Other themes included to pay attention to your diet, as many people found this to be helpful (n=18, 18.00%), do as much of your own research as possible (n=11, 11.00%) and to use gentle body washes and moisturizers - be diligent with moisturizing (n=11, 11.00%).

Participant's advice is to find what works for you

*Never stop looking for the right treatment for you, because treatments work for some people and don't work for other people. I've been recommended things that-- a miracle cure for some people, but have no effect on me. I feel the best thing somebody could do is just to continue looking for an answer. **Participant 38***

*Just see a doctor and get on to it if things are getting bad. And keep trying moisturisers and those kinds of things and find out what works for you, but what works for someone is not going to work for someone else. You kind of ... It's a bit of a trial and error sometimes. But yeah just kind of make sure you get on to it before it gets too bad. **Participant 56***

My general advice would be do what works for you. Sometimes they're going to tell you not to have a hot shower, but sometimes that's what you want. Your skin's a mess, you just want to dry it out. You want a hot shower that's steaming hot. I know it's the worst thing you can do for it, and you regret it the next day probably, when you have a scratch, but in the moment, the temporary relief is everything. I don't know, it's just, I think, do what works for you as well. Some things, it's generalized to do this, and sometimes that just doesn't work for someone. There's no point doing a general plan for someone that's not going to work for. I think, as well, talk about it. Actually, say how much it's having a problem, an impact on you, because I've gotten very complacent with it, and have just been-- I've gotten very complacent with it and been like, "It's fine, it's all right." When actually, it's quite bad. I think the more people that let people know how horrible it is, the

*more people are going to be able to understand. **Participant 83***

Participant's advice is to concentrate on their diet

*The other thing I would tell them, too, would be to sort their diet out. Yeah. I would say to them to minimise your sugar ... I'm not saying avoid it, I'm just saying minimise it, and eat well. Yes, just get good nutrition. But if you actually minimise your flour and sugar intake, you actually minimise a lot of rubbishy foods, processed foods. And then that all gets worked out. But yes, if you eat rubbish, your skin will be a lot worse. **Participant 32***

*I would definitely say, just that three-pronged approach, almost like a stool. Like stool legs. I'd say, good quality, nourishing, simple whole foods. Eating less from packets, and more just preparing food from scratch. Then, I would say, gut health, gut support, and then, stress levels and sleep. I think those three things are really imperative to just good health, and good, happy skin, and happy energy levels. Then, if possible, and if someone's in a position to afford it, like, just seeking help of a professional, like a naturopath or a herbalist. Just to help them make those lifestyle tweaks, because I think it can be quite overwhelming. You look at our general lifestyle, and our general diet, which is from packets. To make that change over to cooking your own food, I think, can be a bit of a jump for a lot of people, but I think just simplifying diet and lifestyle, that's the main thing. **Participant 46***

*Number one, I would say look internally. Look for good, healthy fruits and vegetables. Find any food allergies that may trigger the eczema and yeah, just look internally. I think that's the best advice I can suggest. **Participant 67***

Participant's advice is to do your research and find as much information as possible - ask for help

*Well, seek out as much information as you can about it. Talk about it to your GP and just take the advice that you're given. **Participant 7***

For an eczema sufferer I'd tell them what I wish I could tell them, that it's okay, it's all good and that what you're going through is actually going to make you a better person, but from a family perspective I suppose I would tell them to really try connect with the right sources to ensure they were up to date with everything that was happening within any eczema discussions etc, etc. I try to think if it, if I had a kid

right now I would be actively searching for a reputable source that could give me advice on what I could do to ensure the quality of life that my kid or whatever. Definitely, as I said there needs to be a forum for that, and I'm not sure if there is one, or if I have missed that. **Participant 54**

Do your research. Especially if you feel like you're not getting anywhere with the medical system, definitely. Do a lot of reading. Educate yourself, rather than finding out knowledge, things from other people. But also, taking things from other people on board, but definitely do your own research. **Participant 58**

Participant's advice is to use gentle body washes and moisturizers - be diligent with moisturizing.

Look, I have to say, that I think for me, probably, making sure that I'm moisturise regularly. I tend to have dry skin at the best of times and I think that weighs as a precursor to eczema, sort of, increasing or becoming more of a problem. So, I do think keeping moisturising up all over probably has actually helped with some of the outbreaks. For me, anyway. And I think that's probably why my back is the worst because that's probably the area that is the hardest to put moisturiser and stuff on. Because it's the area you

often forget. The area you often, probably you don't attend to as much and then you get a little flare up and you go, "Oh, bugger." And then you start paying attention to it for a while, it settles down, and it goes away and then you sort of get back into that habit and forget about it again, and then, bang. It comes up again. **Participant 8**

I think the thing that has really helped me was committing to regular moisturising, and that's something that the dermatologist really drummed into me. And I probably was a bit slack on that for quite a while, it doesn't necessary help but it does help a bit. **Participant 44**

Okay, I think the advice that I would give them, is keep tabs on how long you've used the steroid cream for, if the doctor gives you steroid cream. And if you've used it for more than two weeks and it's not working or each time you try and get off it, the eczema comes back even worse than it's time to go to the GP and actually tell them that and say and actually ask where to from here because this is actually not working. Don't give me more of this because it's not working. **Participant 65**

Table 10.1: Advice from patients

Advice from patients	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's advice is to find what works for you	26	26.00	0	0.00	6	23.08	16	39.02	4	18.18
Participant's advice is varied/Things that have worked for others....use oatmeal baths, cool and hydrated, coconut oil, ointments, bleach baths, don't scratch, go in the sun/don't go in the sun, get lots of sleep, be aware of triggers, wear certain fabrics.	24	24.00	1	9.09	8	30.77	3	7.32	12	54.55
Participant's advice is to concentrate on their diet	18	18.00	3	27.27	3	11.54	9	21.95	3	13.64
Participant's advice is to do your research and find as much information as possible - ask for help	11	11.00	1	9.09	2	7.69	5	12.20	3	13.64
Participant's advice is to use gentle body washes and moisturizers - be diligent with moisturising and careful with steroid cream	11	11.00	3	27.27	4	15.38	4	9.76	0	0.00
Participant's advice is 'don't give up, it will be ok'	8	8.00	1	9.09	2	7.69	2	4.88	3	13.64
Participant's advice is to be aware of stress as a trigger and the importance of mental health	7	7.00	0	0.00	2	7.69	3	7.32	2	9.09
Participant's advice is to seek medical advice and find a GP or dermatologist that you can have a good relationship with	6	6.00	2	18.18	1	3.85	2	4.88	1	4.55

Advice from patients	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/ Trade educated (n=42)	
Participant's advice is to find what works for you	12	30.77	11	26.83	15	25.42	17	29.31	9	21.43
Participant's advice is varied/Things that have worked for others....use oatmeal baths, cool and hydrated, coconut oil, ointments, bleach baths, don't scratch, go in the sun/don't go in the sun, get lots of sleep, be aware of triggers, wear certain fabrics.	11	28.21	12	29.27	12	20.34	12	20.69	12	28.57
Participant's advice is to concentrate on their diet	5	12.82	8	19.51	10	16.95	13	22.41	5	11.90
Participant's advice is to do your research and find as much information as possible - ask for help	5	12.82	4	9.76	7	11.86	2	3.45	9	21.43
Participant's advice is to use gentle body washes and moisturizers - be diligent with moisturising and careful with steroid cream	2	5.13	5	12.20	6	10.17	10	17.24	1	2.38
Participant's advice is 'don't give up, it will be ok'	2	5.13	2	4.88	6	10.17	2	3.45	6	14.29
Participant's advice is to be aware of stress as a trigger and the importance of mental health	2	5.13	3	7.32	4	6.78	5	8.62	2	4.76
Participant's advice is to seek medical advice and find a GP or dermatologist that you can have a good relationship with	3	7.69	3	7.32	3	5.08	5	8.62	1	2.38

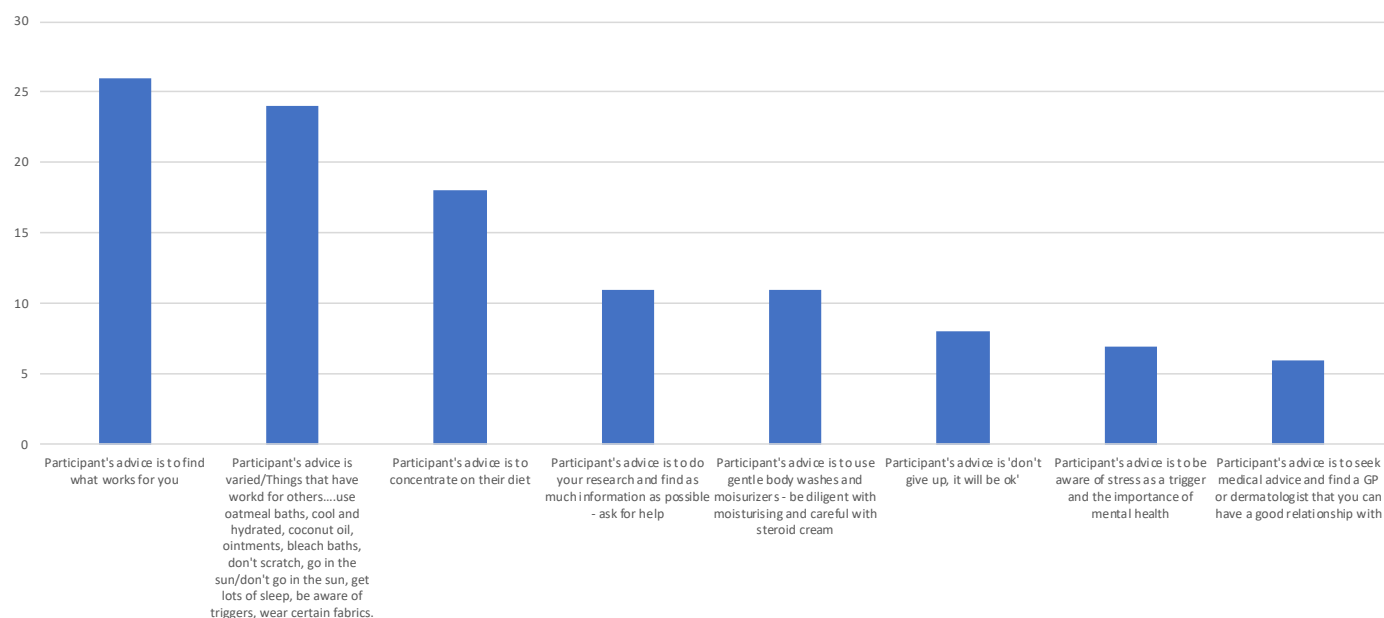


Figure 10.1: Advice from patients (% of all participants)

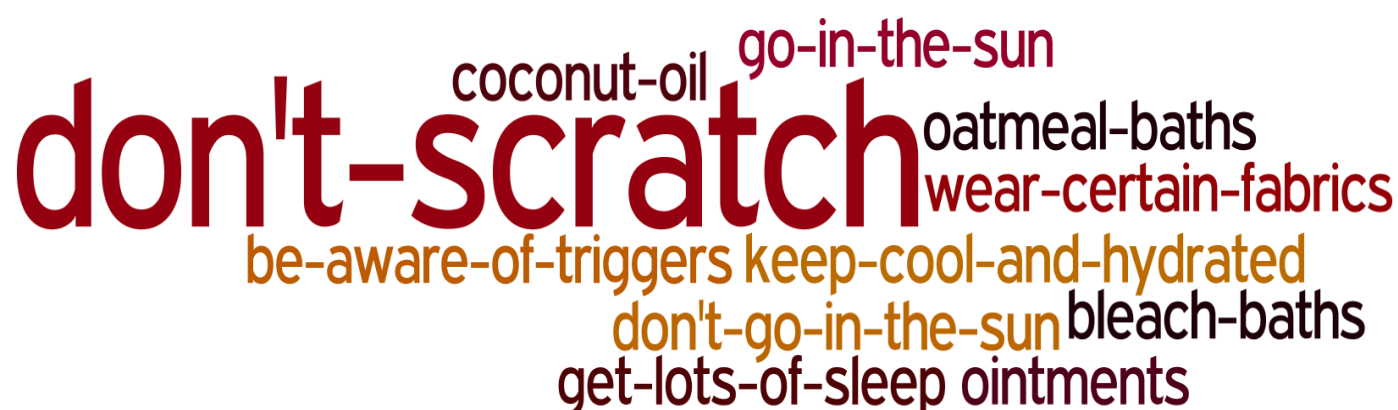


Figure 10.2: Various things that participants have found helpful in relation to their AD. Some participants mentioned 'don't scratch' however this was done with humour.

Section 11 Discussion

Symptoms, risk and diagnosis

Atopic dermatitis (AD) is a chronic, inflammatory skin condition with clinical features varying based on age of the patient.¹ It is associated with other atopic manifestations such as asthma, rhinitis and food allergy.²⁻⁴ It presents in varying degrees of severity from a mild disease treated with over-the-counter products to severe disease requiring treatment with systemic immunosuppressive agents.⁵ AD can be classified into either intrinsic or extrinsic AD with the classification of disease depending on co-existence with allergic features.⁶ Common symptoms of AD include itchiness, red to brownish-grey patches on the skin, small, raised bumps, which may leak fluid and crust over when scratched, and/or thickened, cracked, dry, scaly skin.⁷ Onset of AD occurs most commonly in infants and children, however it can occur at any age with clinical features varying with age of onset.⁸

In this PEEK study, the most common symptoms leading to diagnosis were rash-like symptoms and thickened, cracked, dry, scaly skin, which is consistent with the literature. An additional condition that led to the diagnosis of AD was allergies. This is an important observation as it demonstrates a common pathway in which eczema is diagnosed.

People with AD are at risk of infectious, systemic, and psychosocial comorbidities.⁹ Infectious complications in AD have been reported with majority of secondary infections being bacterial.¹⁰ AD patients are at higher risk of developing disseminated viral infections such as herpes virus and coxsackie virus¹¹ and they are also at a higher risk of developing other atopic diseases such as asthma, food allergy and allergic rhinitis, which is sometimes referred to as “atopic march”¹² People affected by AD and their caregivers often experience sleep disturbances¹³ and patients may be self-conscious about their appearance and may avoid public appearances which leads to an increased emotional burden.¹⁴ Stress is known to trigger itch and general flares in AD patients thereby exacerbating their condition.¹⁴

The main diagnostic features of AD are chronic relapsing dermatitis with pruritus (itch), xerosis (dry skin) and eczematous lesions along with specific clinical criteria.¹⁵ Diagnosis can be aided by presence of dermatographism (raised welts), keratosis pilaris (small, hard bumps), hyperlinear palms (increased marking on the palms), periorbital (area around the eye) changes, perifollicular (area around hair follicle) accentuation, and pityriasis alba (pale pigmentation of the skin).¹⁰ It is crucial to exclude these skin conditions to confirm AD diagnosis.¹⁶

In this PEEK study, the most common tests recalled were skin examination only followed by skin examination, blood test, patch test and review of medical history. There were very few instances where there was a misdiagnosis suggesting that the diagnostic pathway for this cohort of patients was relatively linear.

Treatment

The main goal of AD management is restoring the disrupted epithelial barrier, with topical therapy the most common method of current treatment.¹⁷ These include emollients, topical corticosteroids, antihistamines, topical calcineurin inhibitors and antimicrobial and antiseptic measures with some patients requiring additional oral immunosuppression therapy.¹⁷

A systematic review conducted by Nankervis et al. in 2016 assessed a total of 541 randomised control trials including 92 interventions for AD treatment.¹⁸ The results of this review indicated that very few treatments were of significant benefit. The review showed that widely used treatments such as emollients, impregnated bandages and topical corticosteroids did not result in any significant benefit, however, the authors note that ceasing treatment would not benefit patients as more research is still needed on the potential drawbacks and harms of each treatment.¹⁸

Therapies including Atopiclair® emollient,¹⁹⁻²³ ultraviolet light therapy,^{24,25} ciclosporin²⁶⁻²⁹ for severe AD and azathioprine for moderate to severe AD^{30,31} have been observed through clinical trials to offer benefit, while oral prednisolone, methotrexate, mycophenolate mofetil, biological therapies (omalizumab; mepolizumab), intravenous immunoglobulin and montelukast have potential of benefit but require more research.³²⁻⁵¹

Targeted immune therapy is an emerging area and offers a new form of treatment for patients with AD. There are a number of target biologics being investigated for the treatment of moderate to severe AD⁵²⁻⁵⁷, however dupilumab is the most advanced in relation to studies conducted and proven efficacy.¹⁷

While new therapies are emerging, the most common treatment experienced by participants in this PEEK study was corticosteroid cream. In relation to quality of life while using treatments, all treatments score relatively poorly with mean quality of life scores ranging from 'life was distressing' to 'Life was a little distressing'. In addition, participants found current treatments to be between ineffective to moderately effective only. It is therefore not surprising that there was a clear and reasonable call from participants in this study for new treatments to offer a more holistic approach and the expectation that treatments would be safe and not be detrimental to their long-term health.

Biomarkers

The current classification of AD inadequately reflects the pathophysiology and diversity of the disease.⁵⁸ The current treatment for patients not responding to topical therapy is systemic immunosuppressive therapy¹⁷ and biomarkers have the potential to aid in predicting treatment outcomes of immunosuppressive therapy by monitoring the pharmacogenetics and therapeutic effect of drugs been given.⁵⁸ Biomarker-based stratification can also help in predicting the response of the new targeted therapies.⁵⁸

Filaggrin gene mutations, which have the potential to be used as a prognostic biomarker, are frequently found in patients with severe AD and in patients who have an early onset AD.⁵⁹ The use of biomarkers is scarce in AD treatment but has the potential to optimise and personalise treatment,⁵⁸ for example, monitoring isoenzymes CYP3A4 and CYP3A5 which control bioavailability and systemic clearance of ciclosporin, can be used as biomarkers to guide AD treatment.⁶⁰ There are currently no predictive biomarkers available and the adequacy of these measures requires additional research.⁵⁸

The results of this PEEK study are consistent with the availability and progress made in the area of biomarker research. The majority of participants had not had a discussion about biomarker, however it is important to note that if and when a test does become readily available, the majority of patients are likely to be interested in accessing it.

Complementary therapies

The interplay between genetic predisposition, skin barrier defects, environmental factors and immune dysfunction, contribute to the complexity of AD.⁶¹ Due to the recurrent nature of AD throughout life, it is often managed with complementary therapies in conjunction with conventional therapies.⁶¹

Some common complementary therapies include vitamins and probiotics, however the research to support their use in alleviating AD remains limited.^{62,63} Herbal therapies in the form of tea or tinctures, creams and lotions have been used to reduce inflammation in AD.⁶¹ Acupuncture and acupressure which stimulate certain points in the body have also been used to reduce symptoms of AD.^{61,64}

Stress and anxiety, which are known as triggering factors of AD, may be reduced by massage therapy.^{65,66} Some studies also show that hypnotherapy can aid in healing of eczema by influencing the subconscious.^{64,67} Essential oils like German chamomile and yarrow can

possibly help in reducing inflammation when used in aroma therapy ^{61,64} However, it is important to note that with these complementary therapies, further research is needed to confirm their effectiveness in relation to AD symptom alleviation.⁶¹

The main treatments that participants in this PEEK study considered as complementary therapies was using various creams and gentle soaps as complementary therapies and dietary changes. Food exposure has been associated with triggering AD⁶³ and patients are often recommended to avoid foods such as dairy, gluten and sugar.⁶¹ There are however no specific overall diet that have been demonstrated to control the symptoms of AD beyond avoiding foods that individuals are allergic to.⁶⁴

Quality of life

As AD is known to have both a physiological and psychological impact and it is important to have tools which can measure QOL and disease severity.⁶⁸⁻⁷¹ A systematic review conducted in 2016 indicated that there is an absence of a single, standard measurement for QoL in AD, rather there is a large number varied instruments measuring QOL and disease severity.⁶⁹ AD is also known to have a significant, negative on quality of life (QoL) and is also associated with poor health related quality of life (HRQoL).^{70,72} Patients with moderate to severe AD have been observed to have a more significant impact on their QoL in contrast to those with mild AD^{70,72} which can include significant financial losses due to inability to go to work.⁷² AD treatment also adds a financial burden to the patient and their families including specialist consultations, medications and over the counter treatments.⁷³

Individuals suffering from AD often experience sleep deprivation and tiredness, with sleep and mood disorders reported more frequently in people affected by AD affected patients compared to the general population.⁷⁴ The theme of impact on sleep was explored in this PEEK study where close to half of all participants

described AD having an impact on sleep and this primarily referred to itchiness.

The psychological impact of AD has also been recorded, with patients experiencing embarrassment due to their appearance thereby reducing their social interaction and often leading them to alienate themselves from society.⁷⁵⁻⁷⁷ This may in turn results in psychological problems due to isolation.⁷⁸ The impact on relationships in relation to self-esteem and confidence/being embarrassed was certainly a theme within this PEEK study and an area where interventions to ameliorate this are greatly needed.

AD is known to be a time-consuming condition as patients and their care givers often need to spend more than an hour in management of it.^{69,75} Participants in this PEEK study spoke about the time required to shower and get ready, 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. The descriptions provided by participants of this process in itself gives us insights into what people with AD go through each and every day and we would encourage decision-makers to read through these descriptions and indeed this report so that they have a better understanding of the impact that AD has on individuals.

Comorbidities associated with AD such as allergic rhinitis, asthma and food allergy also negatively impact quality of life.⁷⁵ An overall assessment of the patient's condition by enquiring about physical symptoms and its impact on their work/school life and sleep may help in better assessment of QOL of the patient.⁷⁹ It is also important to educate patients and their families about the chronic relapsing nature of AD to help them have a better understanding of the disease and reduce their subsequent frustration during treatment.⁷⁹

This concept was noted by a number of participants in this PEEK study that called for more follow-up and care planning to manage their AD and also, more information and support to both identify triggers leading to flares, and how to manage them.

Health professional communication and multidisciplinary approaches

It has been suggested that it is important to have standard nomenclature for AD to avoid unnecessary confusion and so that patients can easily recall the disease they might be suffering from and have better understanding of the skin disorder.⁸⁰ Standard nomenclature is also important for entering the disease in clinical trials,⁸⁰ and a systemic review conducted in 2016, showed that AD was the most common term used overall.⁸¹ It was also recommended to use only AD across all publications, health care clinician training and in patient education to avoid confusion.⁸¹

Management of AD requires a multidisciplinary approach due to the complex nature of the disease. Patients and their families require a wide range of information, skills and support to be able to cope with the condition.⁸² This is particularly important as there is often a lack of knowledge and skills needed to follow treatment plans which hinders disease management.⁸³

As noted previously, there was a call for more follow-up and care planning from AD patients in this PEEK study, suggesting an active interest in maintaining control over their condition. A multi-disciplinary approach includes an AD specialist to medically evaluate and manage the patient, provision of psychological and behavioural support, education and nursing care and nutritional assessment and guidance.⁸⁴ A multidisciplinary approach has been observed to be beneficial in decreasing the severity of disease and improving QoL, however more research is needed to identify those patients with AD that will benefit most from a multidisciplinary approach and to evaluate its cost-effectiveness.⁸³

Information and education

Technology can play an important role in informing and educating patients about any disease. Social media platforms are also being used exchange information and engage in online discussions on different health topics.⁸⁵ Scientific journals and professional organisations are also using these platforms to disseminate information about treatments and support and patient decision making is increasingly influenced by the information available online.⁸⁵ It follows that with the growing use of internet it essential for the information available to be correct and consistent. A study by Corcimaru (2017) revealed that, recent google media trends in relation to AD have shown that the term eczema is more popular than AD.⁸⁶ The study recommends using word eczema in online education materials to improve communication.

This is in contrast to the study by Kantor (2016) that was previously discussed where the recommendation was to use only AD across all publications, health care clinician training and in patient education,⁸¹ and while the rationale for this was to avoid any more confusion, there was no evidence presented to demonstrate that confusion existing from a patient perspective.

The participants in this PEEK study consistently used the term eczema to describe their condition, and there were no themes that emerged to suggest that the use of various terms was problematic. However, this was not a specific area of investigation within the study. It is also important to note that while participants in this PEEK study primarily accessed information online, their preference was to talk to someone about their condition.

Support/Psycho-social care

The overall, negative impact on QoL of AD affected patients and care givers needs to be managed in an effective manner.⁸⁷ Patients have identified challenges in having short appointments with their dermatologist causing them to have limited information about their treatment and reducing adherence to AD treatment.⁸⁷ The chronic nature of AD also

causes negative psychological impact and patients may experience depression, anxiety and frustration.⁸⁸

In order to improve QoL, treatment of AD requires a multidisciplinary approach that includes behavioural therapy and psychotherapy in addition to dermatological therapy.⁸⁹ Therapeutic patient education (TPE) is an approach which includes patient centred care and can help in improving adherence, health outcome and QOL of life of AD affected patients and their families.⁸⁸ This approach helps healthcare providers to transfer information and skills needed by to cope and self-manage the disease and is a multidisciplinary including physicians, nurses, dieticians and psychologists.⁸⁸ An integral part of TPE is shared decision making where the patient and caregivers get to share their experience, concern and preferences regarding the treatment.⁸⁸ This information sharing process helps in identifying barriers faced by patient and can help in finding the solutions tailored to the needs of the patient and caregiver. There is also evidence that managing patient's expectations and discussing realistic outcomes of the treatment can increase adherence to treatment and lower psychological impact on the patient.⁸⁹

A key feature of AD within this PEEK study was the impact of the condition on QoL where close to half of all participants described a significant impact in relation to self-esteem and confidence, often leading to social isolation. This is a significant observation and one that warrants intervention so that the impact of the physiological presentation of AD does not result in psychological disturbance.

Conclusion and characterisation of this patient population

People with AD are commonly diagnosed after observing rash-like symptoms and thickened, cracked, dry, scaly skin, with the presence of allergies also leading to the diagnosis of AD. To reach a diagnosis, common tests include skin examination, blood test, patch test and review of medical history and there is a relatively linear diagnostic pathway for this patient population. While new therapies are emerging, corticosteroid creams remain the most common form of treatment, however most treatments score relatively poorly in relation to how they impact the QoL of a patient. In addition, most treatments are considered to be ineffective to moderately effective only. As a result, this population of patients are reasonably calling for new treatments that offer a more holistic approach and are safe and not detrimental to their long-term health.

This is also a patient population that is significantly affected by the psychological impact of their condition, including patients experiencing embarrassment due to their appearance, reduction in social interaction and increased alienation from society. This is an area where interventions to ameliorate this are greatly needed so that the impact of the physiological presentation of AD does not result in psychological disturbance.

An area of future development in the care for patients with AD is coordinated and multidisciplinary care, and this was identified by the patient population who called for more follow-up and care planning.

AD is also known to be a time-consuming condition and this patient population is required to conduct a regular and diligent routine in order to maintain their health. This is sometimes a difficult concept for people who do not have AD to understand, and we encourage people to take the time to read through this report so that more empathy and compassion can be shown to those suffering with AD.

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Section 12 Next steps

Next steps

At the end of each PEEK study, CCDD identifies three key areas that, if improved, would significantly increase the quality of life and/or the ability for individuals to better manage their own health.

In relation to the AD community, these three areas are:

- Treatments that offer a more holistic approach, that are safe and are not detrimental to long-term health.
- Interventions to address the psychological impact of AD, including patients experiencing embarrassment due to their appearance, reduction in social interaction and increased alienation from society.
- Initiatives that encourage coordinated and multidisciplinary care, including more follow-up and care planning to empower patients to proactively manage their condition.

2017 CHF Metrics

Data collected in this PEEK study also provides a basis on which future interventions and public health initiatives can be based. Some of the 2018 AD metrics that the sector can work together to improve upon are provided in Table 12.1

Table 12.1: AD 2018 Metrics

Area of evaluation	2018 data	
Baseline health	Mean	Median
Physical functioning	83.70	95.00
Role limitations due to physical health	64.00	100.00
Role limitations due to emotional problems	62.00	66.70
Energy/fatigue	42.00*	40.00
Emotional well-being	65.36	68.00
Social functioning	65.38	62.50
Pain	64.18	67.50
General health	64.18	60.00
Health change	58.40	50.00
Percentage of participants that have accessed My Health Record	16.00%	
Percentage of participants that have heard of AD at diagnosis	55.00%	
Percentage of participants that have a discussion about biomarkers/genetic tests	4.00%	
Percentage of participants where a clinical trial is discussed	5.00%	
Knowledge of condition and treatments (Partners in Health)	Mean	Median
Knowledge	24.42	25.00
Adherence to treatment	12.62*	14.00
Management of symptoms	19.49*	20.00
Coping	16.96	17.00
Total score	73.49	76.00
Care Coordination and care received	Mean	Median
Care coordination (sub-score)	64.06*	65.50
Communication	38.06*	39.00
Navigation	26.00	26.00
Care received	5.21	5.00
Total score	5.89	6.00
Fear of progression	Mean	Median
Total Score		28.00

*Normal distribution, use mean as measure of central tendency