

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 ranged from 2.40 to 3.62, that is, all quality of life scores were within 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 |

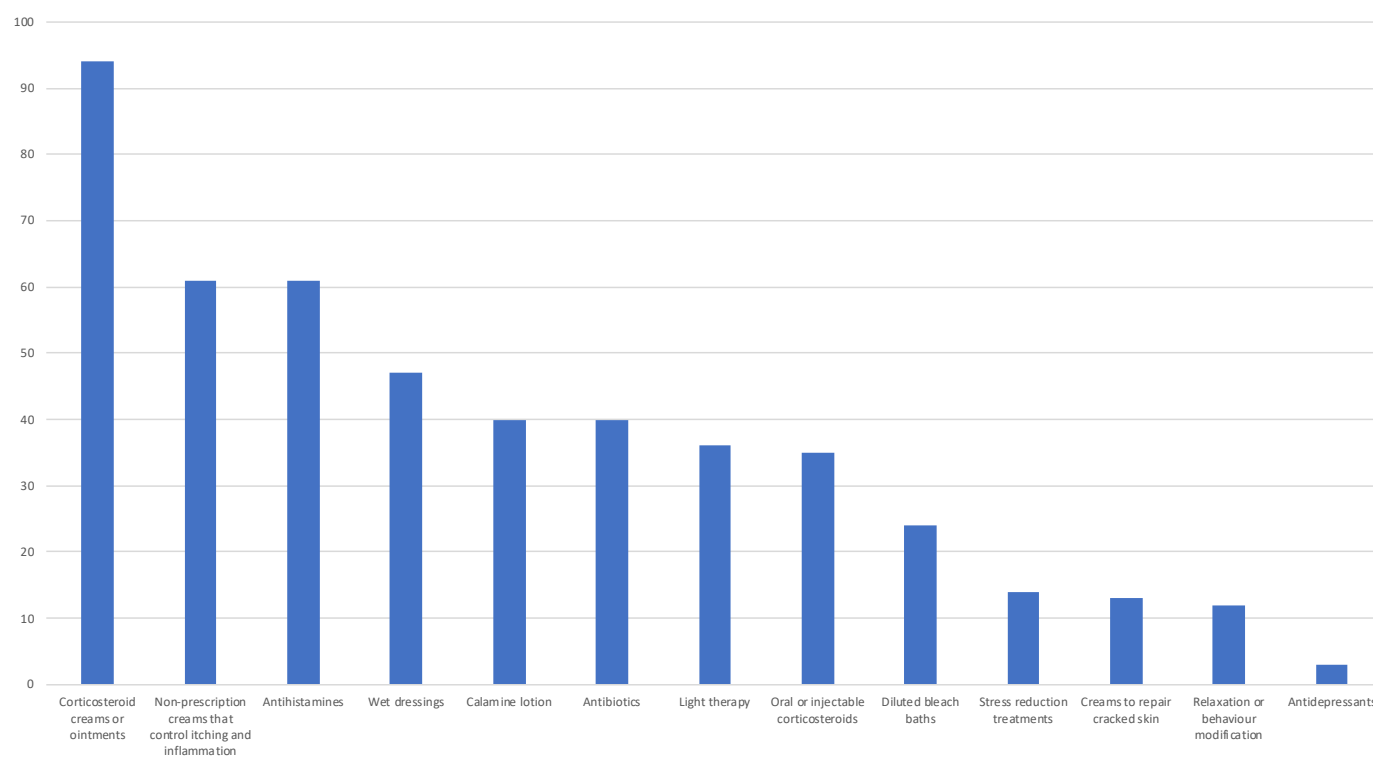


Figure 5.1: Treatments experienced (% of all participants)

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 ranged from 2.40 to 3.62, that is, all quality of life scores were within 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).

| 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 |

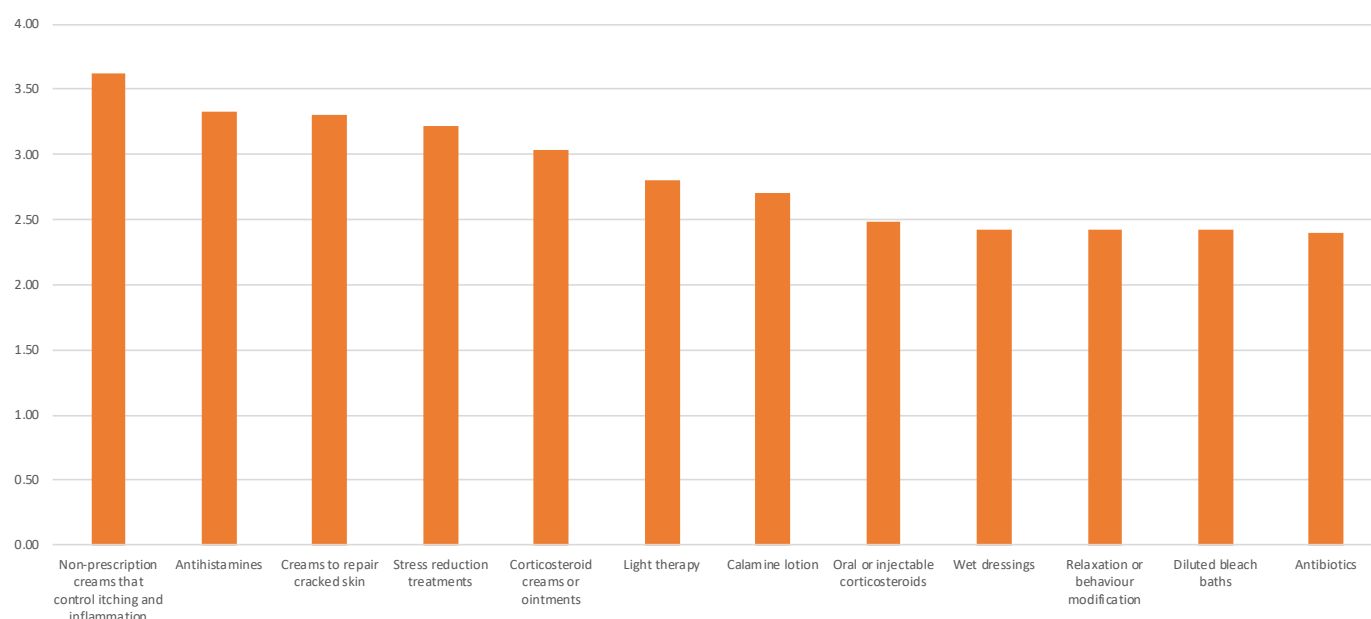


Figure 5.2: Treatments experienced and mean quality of life

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 |

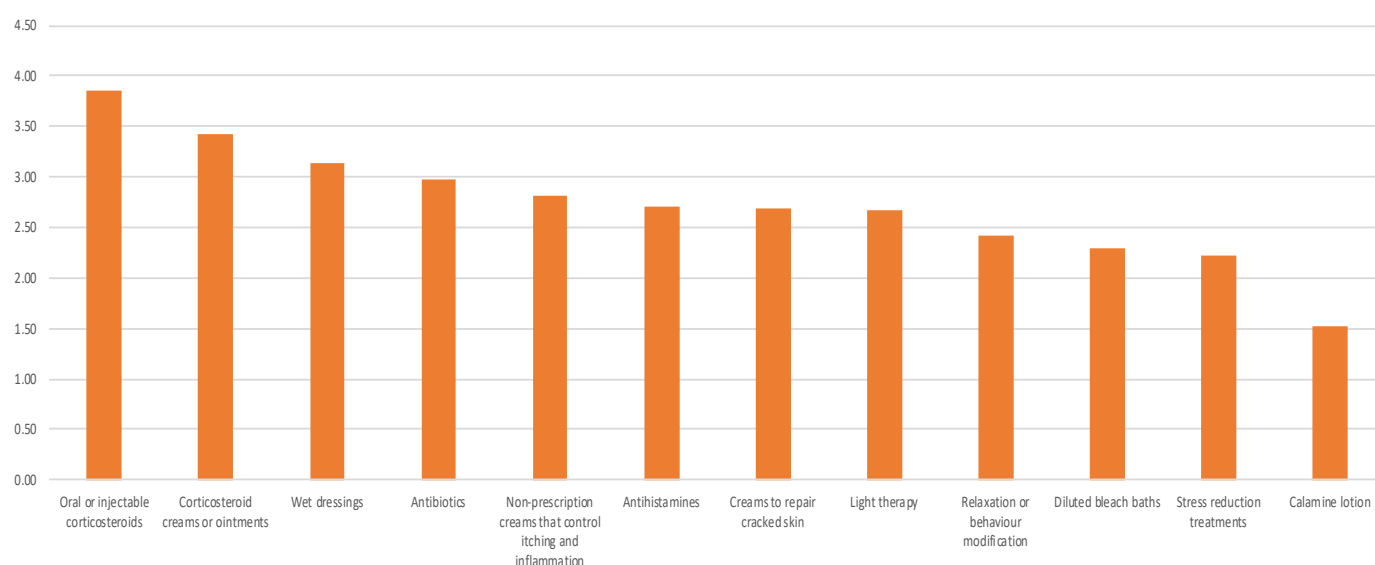


Figure 5.3: Treatments experienced and effectiveness

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 |

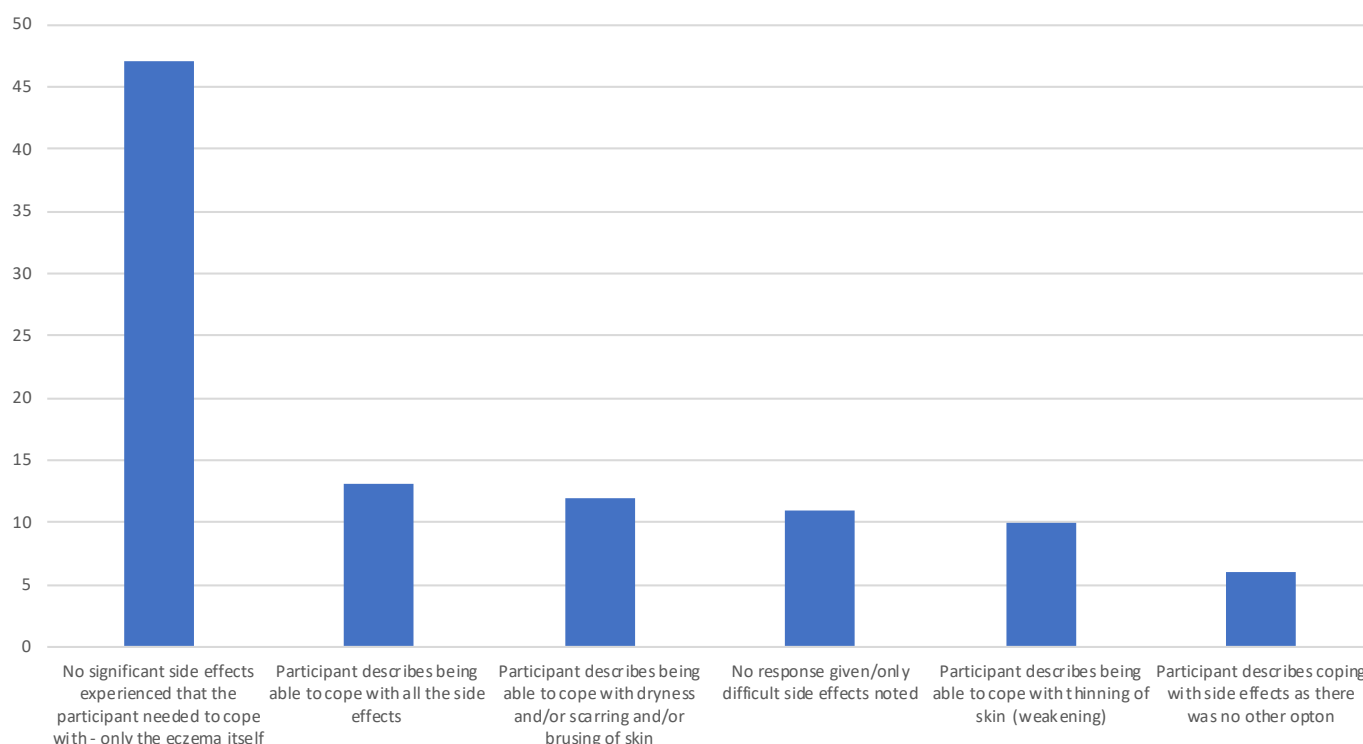


Figure 5.4: Side effects that participants could cope with (% of all participants)

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 |

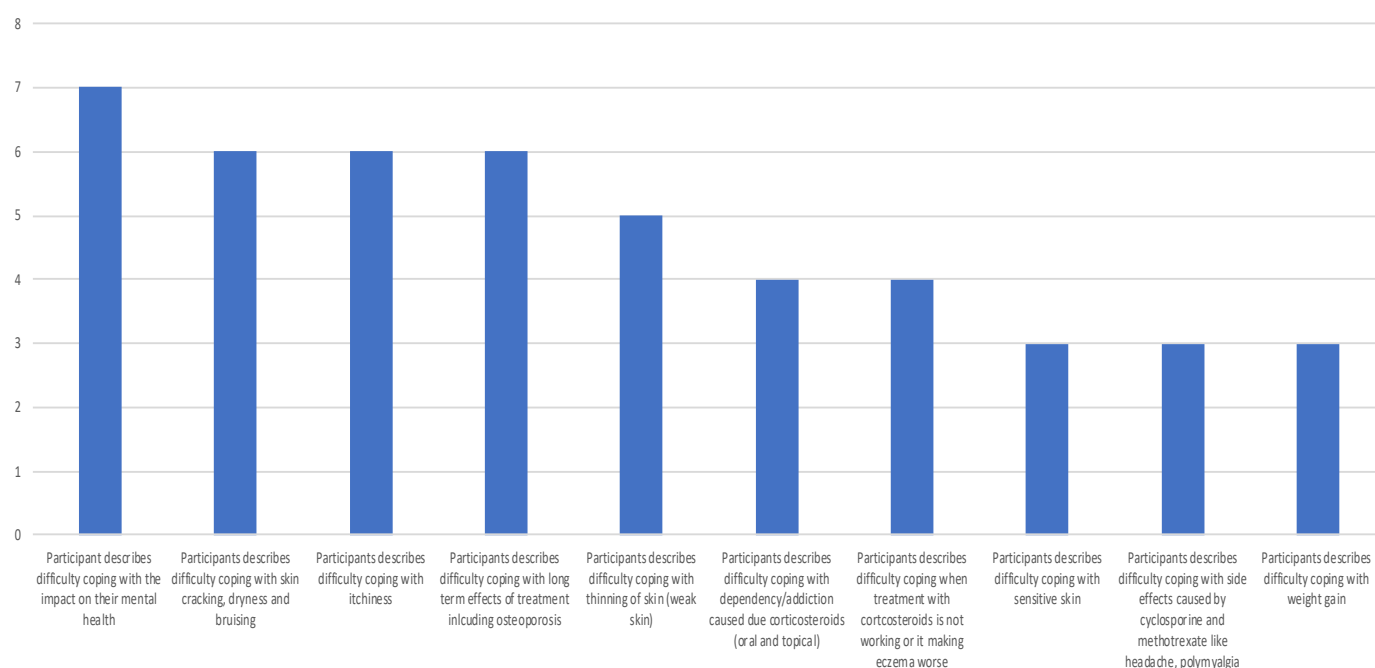


Figure 5.5: Side effects that participants found difficult to cope with (% of all participants)

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 |

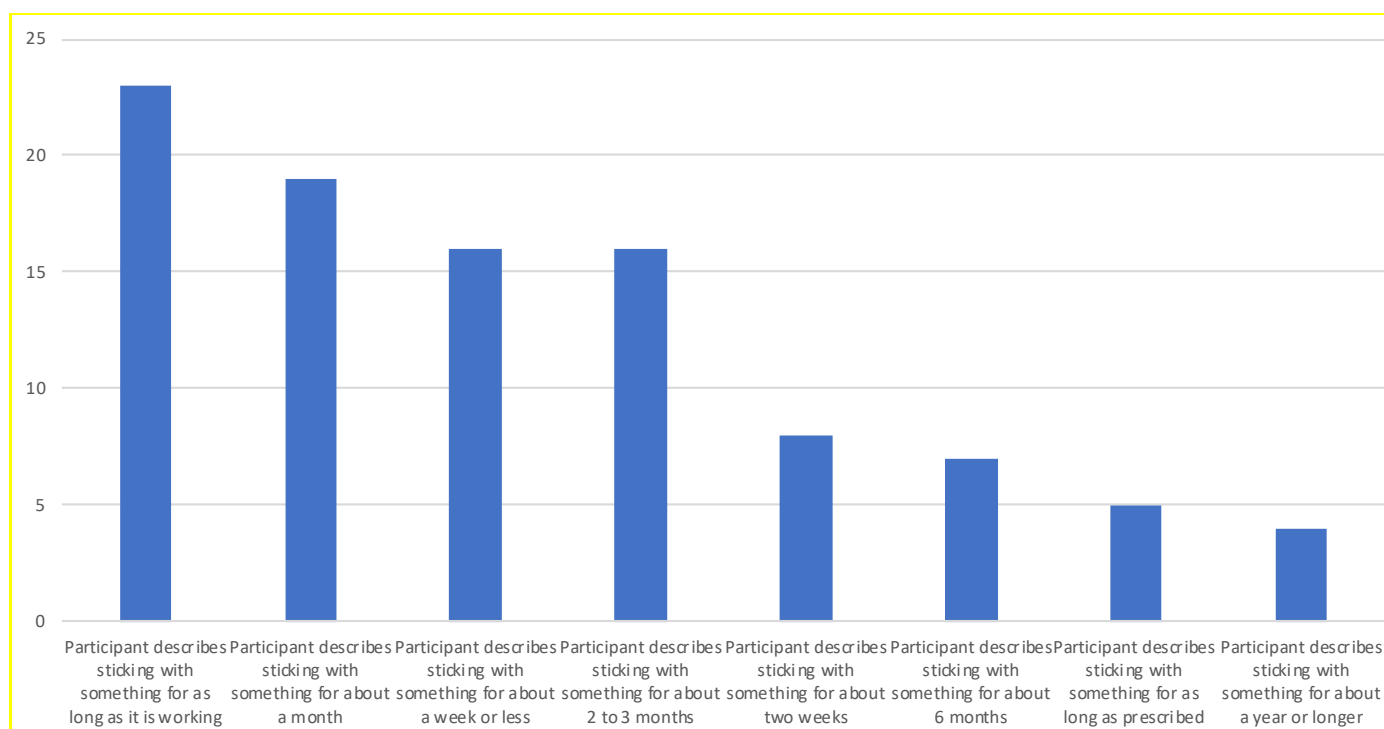


Figure 5.6: How long patients stick to a therapy (% of all participants)

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 |

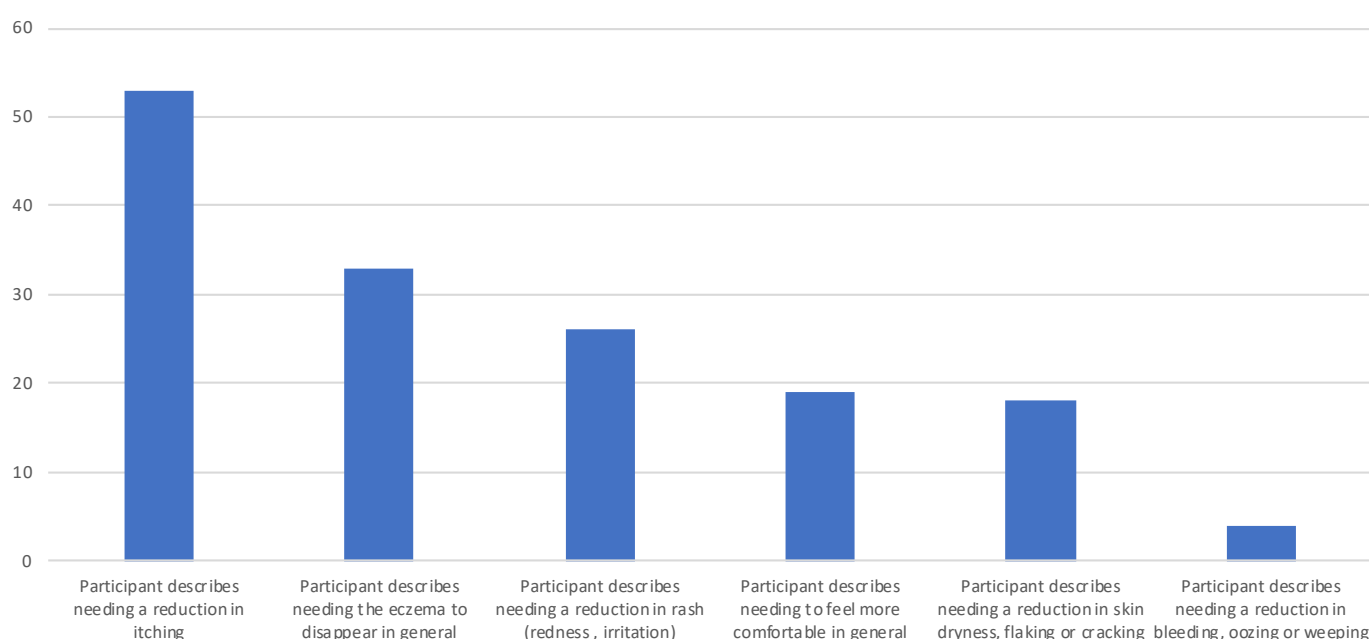


Figure 5.7: What needs to change to know a treatment has worked

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 |

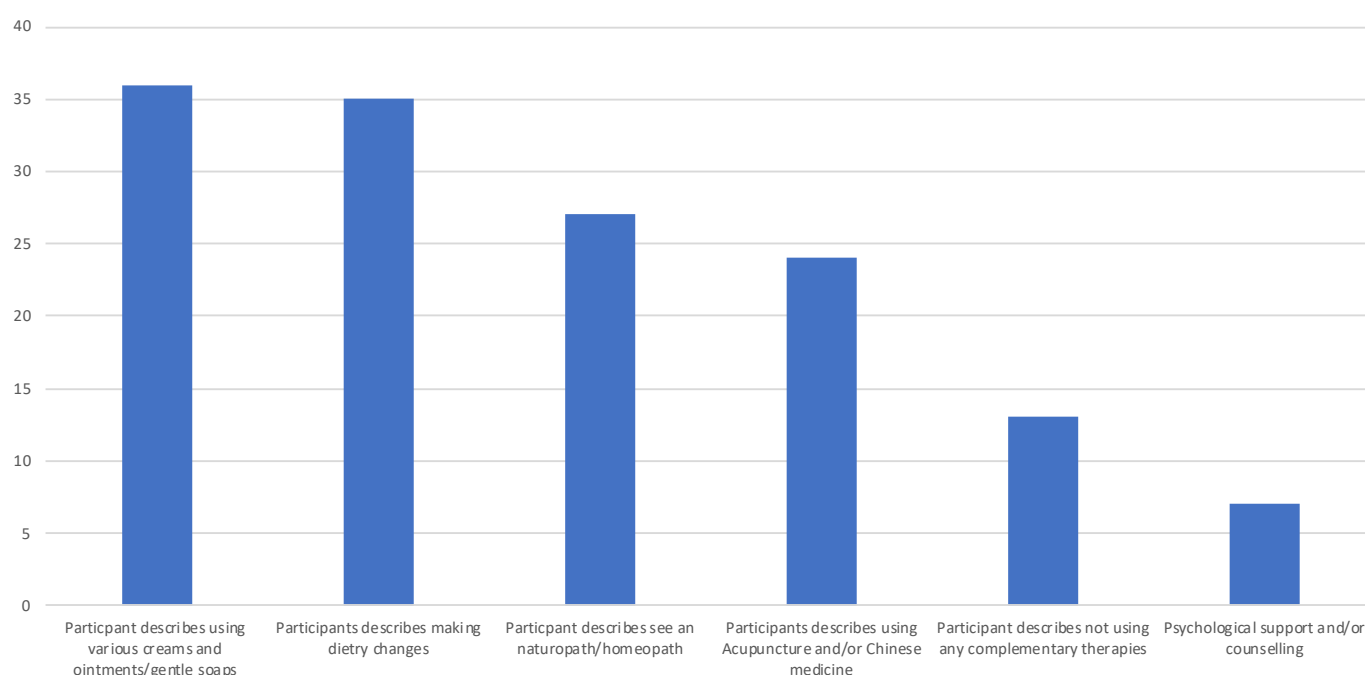


Figure 5.9: Use of complementary therapies (% of all participants)

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) | | |

Section 5

| | | |
|---|----|---------|
| 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 |