**APPENDIX C. SUMMARY OF FINDINGS FROM STRUCTURED LITERATURE REVIEW**

**Signs/symptoms**

|  |  |  |  |
| --- | --- | --- | --- |
| Symptom/sign | Number of articles (N=27) | All symptom-related quotes/description | Reference |
| Pruritus/itch | 11/27 |  *“It’s like when you have an itch and scratch it but that doesn’t relieve it. It’s raw with eczema, you can’t feel the soreness just the itching, the blood runs and you still scratch”* | 28-30  |
| 1,21,31-36 |
| Soreness/pain/tenderness | 9/27 | Soreness/pain/tenderness mentioned – no quote | 1,29,31,33-38  |
| Erythema (redness) | 4/27 | *“Red lumps, they are inflamed sores, if you scratch them too much they bleed”.* | 29 |
| 1,30,34 |
| Lichenification (thickening) | 4/27 | Lichenification (thickening) mentioned – no quote | 32,35,39,40\* |
| Scaling/flaking/cracking | 3/27 | *“Skin disease that forms scales that flake off, itchy and unpleasant, makes you feel as if you have the plague”.* | 29 |
| 1,41 |
| Skin lesions | 3/27 | Skin lesions mentioned – no quote | 28,31,39\*  |
| Fissures  | 3/27 | Fissures mentioned – no quote  | 39,42,43\* |
| Skin irritation | 2/27 | *“The irritation, constant itching, like sitting in a bed of ants or spiders”* | 29 |
| 36 |
| Dryness/roughness | 2/27 | *“My appointment was of value to me indicating my dry skin type and preventative measures.”* | 41 |
| 1 |
| Papules  | 2/27 | Papules mentioned – no quote | 39,40\* |
| Skin sensitivity  | 2/27 | *“so my skin has become really sensitive and perhaps thinner than it used to be”* | 28 |
| 44\* |
| Stinging | 2/27 | Stinging mentioned – no quote | 1,30 |
| Bleeding | 1/27 | Bleeding mentioned – no quote | 1 |
| Oozing/weeping/exudation | 1/27 | Oozing/weeping/exudation mentioned – no quotes  | 1 |
| Skin tightness  | 1/27 | Skin tightness mentioned – no quote | 1 |
| Sensitivity to the sun | 1/27 | Sensitivity to the sun mentioned – no quote | 45 |
| Swelling | 1/27 | Swelling mentioned – no quote | 41 |
| Transepidermal water loss | 1/17 | Transepidermal water loss mentioned – no quote | 39\* |
| Vesicles  | 1/27 | Vesicles mentioned – no quote | 39\* |

\*Article specific to patients with hand eczema

**Proximal impacts**

|  |  |  |  |
| --- | --- | --- | --- |
| Impact | Number of articles | Quotes/description | Reference |
| Sleep disruptions | 9/27 | Sleep disruptions mentioned – no quote | 1,28,28,31,33,34,36,45,46 |
|  Bodily/physical discomfort | 9/27 | *“People don’t realise how uncomfortable it is”* | 29 |
| 30,32,34,36,42,43,45,47 |
| Excoriation (skin picking) | 3/27 | Excoriation/skin picked mentioned - no quote | 32,39,40\* |
| Tiredness/fatigue | 3/27 | Lack of energy, tiredness/fatigue mentioned – no quote | 28,36,40 |
| Scratching | 1/27 | Clothing ruined by treatments and scratching mentioned – no quotes | 28 |
| \*Article specific to patients with hand eczema |

|  |  |  |  |
| --- | --- | --- | --- |
| Impact | Number of articles | Quotes/description | Reference |
| Restricted clothing and style choice  | 11/27 | *You can’t wear the clothes you’d like to, after all only cotton is feasible”*  | 28,29 |
| 21,28,30,33,36,37,41,43,46  |
| Physically unable to complete activities  | 9/27 | Physically unable to complete activities mentioned – no quote | 21,29,31,33,35,37,42,43,46 |
| Bathing/showering issues  | 2/27 | Bathing/showering issues mentioned - no quotes | 28,33 |

**Distal impacts**

|  |  |  |  |
| --- | --- | --- | --- |
| Impact | Number of articles | Quotes/description | Reference |
| Worry/concern | 1/27 | Worry/concern mentioned – no quote | 1,28-32,36,40-42,47,48 |
| Self-consciousness  | 12/27 | *“Because I meet the public all the time I feel more self-conscious. People ask ‘What’s the matter with your face? I feel it undermines my position and makes me look younger than I am”.*  | 29,30,41,26 |

|  |  |  |  |
| --- | --- | --- | --- |
| Impact | Number of articles | Quotes/Description | Reference |
| Ceasing to partake in usual hobbies/activities  | 10/27 | *“I forced myself to go swimming - it was silly as I felt so self-conscious”.* | 29,33,41 |
| 28,35,37,42,43,45,46  |
| Disease is time consuming  | 2/27 | Disease is time consuming mentioned – no quote | 29,35  |
| Uncomfortable meeting new people/in new situations  | 2/27 | “*The girls at work lark about. I’ve got used to them. They show pity and make jokes. I know the girls now, I wouldn’t like strangers to do that”.* | 29 |
| 37\* |

\*Article specific to patients with hand eczema

|  |  |  |  |
| --- | --- | --- | --- |
| Impact | Number of articles | Quotes/description  | Reference |
| Performance at work effected  | 8/27 | *I’m sure there are many people whose ability to work is severely impaired by pruritus. As for myself I’m worried about not being able to work for 10 hours or longer every day when it itches the whole day (male age 23: somatoform pruritus, student).* | 28  |
| 21,29,31,33,35,43,46 |
| Lack of employment opportunities  | 7/27 | *“they might be looking for somebody smart, not a handicapped person”.[in terms of job interviews]* | 29,43\* |
| 21,28,40,43,46 |
| Inability to keep job | 5/27 | Inability to keep job mentioned – no quote | 21,29,37,46,48  |
| Factors at work that effect condition (e.g., chemicals) | 3/27 | Factors at work that effect the condition mentioned – no quote | 29,39,44\* |
| Expensive treatments  | 2/27 | Expensive treatments mentioned – no quote | 28,28  |
| Bankruptcy | 1/27 | Bankruptcy mentioned – no quote | 48 |

|  |  |  |  |
| --- | --- | --- | --- |
| Impact | Number of articles | Quotes/description  | Reference |
| Family friction | 8/27 | “*It’s hard on family life, because you’re easily irritated, you have very little energy and you’re not up for much, which ranges from being with your wife to spending time with the children*” | 30 |
| 21,29,33,35,37,43,48 |
| Uncomfortable in the presence of others | 6/27 | “*I don’t go over to my workmates now; I just sit on my own”.* | 29 |
| 28,31,36,37,40  |
| Poor relationship with health professional | 6/27 | *“I don’t think the doctors have any idea of the torture that we go through . . . I just don’t think that the doctors pay enough attention to the skin problems and the effects that they have on patients.”*  | 28,36,43,48  |
| 28,30 |

|  |  |  |  |
| --- | --- | --- | --- |
| Impact | Number of articles | Quotes/description  | Reference |
| Romantic relationship problems (including sex life) | 11/27 | *“It’s been hard for my husband to adjust. I was covered from head to toe and lost some hair. It doesn’t rule us any more, it’s in the background, but we have had a lot of upsets”.* | 29,26 |
| 21,28,28,30,33,34,37,46,48  |
| \*Article specific to patients with hand eczema |

|  |  |  |  |
| --- | --- | --- | --- |
| Impact | Number of articles | Quotes/description  | Reference |
| Impact of treatment use  | 9/27 | *“I can see that it has damaged my skin [topical corticosteroid], but I can simply not do without it. I have to take the risk, because even though I know it damages my skin in the long run, as it has already done, I can simply not bear to live if I cannot take the peak off the malaise that comes with eczema.”* | 28,30,36,41,43  |
| 21,29,33,41 |
| Differences in impacts due to disease severity | 6/27 | Differences in impacts due to disease severity mentioned – no quote | 34,38,42,45-47 |
| Eczema is not referred to as serious condition | 2/27 | *“I wish they would call it a disease because then one would be taken seriously and would be entitled to proper treatment and all that it entails...”* | 28 |
| 43\* |
| Physical appearance  | 2/27 | “*The actual marks on your skin, makes you feel dirty, as if you don’t wash”* | 29 |
| 34 |
| Patients turn to alternative medicines  | 2/27 | *“I need to try different approaches because I feel I haven’t been successful solely relying on conventional medicine”*  | 28,30 |
| Variation in perceived causes/triggers of disease | 1/27 | *“It began with these small blisters, but then I know that my eczema is due to nickel.”* | 43\* |
| Too many descriptions of pruritus | 1/27 | Too many descriptions of pruritus mentioned – no quotes | 28 |
| Difficult to identify cause of pruritus | 1/27 | Difficult to identify cause of pruritus mentioned – no quotes | 28 |
| Unpredictability of disease  | 1/27 | Unpredictability of disease mentioned – no quotes  | 30 |

1. Charman CR, Venn AJ,Williams HC. The patient-oriented eczemameasure: development and initial validation of a new tool for measuring atopic eczema severity from the patients' perspective. Arch Dermatol 2004;139(12):1483–1489.

21. Finlay AY. Measures of the effect of adult severe atopic eczema on quality of life. J Eur Acad Dermatol Venereol 1996;7(2):148–154.

28. Bathe A, Weisshaar E, Matterne U. Chronic pruritus—more than a symptom: a qualitative investigation into patients' subjective illness perceptions. J Adv Nurs 201;69(2):306–316.

28. Jowett S, RyanT. Skin disease and handicap: an analysis of the impact of skin conditions. Soc Sci Med 1985;20(4):415–418.

29. Nørreslet M, Bissell P, Traulsen JM. From consumerism to active dependence: patterns of medicines use and treatment decisions among patients with atopic dermatitis. Health 2010;14(1):91–106.

30. Boehm D, Schmid-Ott G, Finkeldey F, et al. Anxiety, depression and impaired health-related quality of life in patients with occupational hand eczema. Contact Dermatitis 2012;67(4):184–192.

31. Ginsburg IH, Prystowsky JH, Kornfeld DS, et al. Role of emotional factors in adults with atopic dermatitis. Int J Dermatol 1993;31(9):656–660.

32. Herd R, Tidman M, Ruta D, et al. Measurement of quality of life in atopic dermatitis: correlation and validation of two differentmethods. Br J Dermatol 1997;16(4):262–267.

33. Misery L, Finlay AY,Martin N, et al. Atopic dermatitis: impact on the quality of life of patients and their partners. Dermatology 2007;215(2):123–128.

34. Mühleisen B, Büchi S, Schmidhauser S, et al. Pictorial Representation of Illness and Self Measure (PRISM): a novel visual instrument to measure quality of life in dermatological inpatients. Arch Dermatol 2009;144(7): 774–780.

35. Noerreslet M, Jemec GB, Traulsen JM. Involuntary autonomy: patients' perceptions of physicians, conventional medicines and risks in the management of atopic dermatitis. Soc Sci Med 2009;69(9):1399–1405.

36. Ahmed A, Shah R, Papadopoulos L, et al. An ethnographic study into the psychological impact and adaptive mechanisms of living with hand eczema. Clin Exp Dermatol 2015;39(5):485–261.

37. Kiebert G, Sorensen SV, Revicki D, et al. Atopic dermatitis is associated with a decrement in health-related quality of life. Int J Dermatol 2002;40(3): 148–158.

38. Weistenhöfer W, Baumeister T, Drexler H, et al. How to quantify skin impairment in primary and secondary prevention? HEROS: a proposal of a hand eczema score for occupational screenings. Br J Dermatol 2011;164(4): 807–81.

39. Whalley D, McKenna S, Dewar A, et al. A new instrument for assessing quality of life in atopic dermatitis: international development of the Quality of Life Index for Atopic Dermatitis (QoLIAD). Br J Dermatol 2004;126(2): 274–283.

40. KernickD, CoxA, Powell R, et al. Acost consequence study of the impact of a dermatology-trained practice nurse on the quality of life of primary care patients with eczema and psoriasis. Br J Gen Pract 2000;26(445):555–558.

41. Moberg C, Alderling M, Meding B. Hand eczema and quality of life: a population-based study. Br J Dermatol 2009;161(2):387–393.

42. Mollerup A, Johansen J, Thing LF. Knowledge, attitudes and behaviour in everyday life with chronic hand eczema: a qualitative study. Br J Dermatol 201; 169(5):1056–1065.

43. Cvetkovski RS, Zachariae R, Jensen H, et al. Prognosis of occupational hand eczema: a follow-up study. Arch Dermatol 2006;141(3):295–301.

44. Grob J, Revuz J, Ortonne J, et al. Comparative study of the impact of chronic urticaria, psoriasis and atopic dermatitis on the quality of life. Br J Dermatol 2005;152(2):289–285.

45. Long CC, Funnell C, Collard R, et al. What do members of the National Eczema Society really want? Clin Exp Dermatol 1993;18(6):

486–521.

46. Wittkowski A, Richards HL, Griffiths CE, et al. The impact of psychological and clinical factors on quality of life in individuals with atopic dermatitis. J Psychosom Res 2004;57(2):195–200.

47. Poot F, Antoine E, Gravellier M, et al. A case-control study on family dysfunction in patients with alopecia areata, psoriasis and atopic dermatitis. Acta Derm Venereol 2011;91(4):405–411.

48. Magin PJ, Adams J, Heading GS, et al. Patients with skin disease and their relationships with their doctors: a qualitative study of patients with acne, psoriasis and eczema. Med J Aust 2009;190(2):62–64.