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LIVING WITH ECZEMA

A Multidisciplinary Approach

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Om vi inte hade haft hud hade själen lossnat och hoppat ut.

Julie 6 år

Från boken ”Gamla tanter lägger inte ägg” av Mark Levengood och Unni Lindell

ABSTRACT

Background: Eczema is one of the most common diseases in the population, affecting individuals of all ages. The impact on physical and psychosocial wellbeing is important. This thesis describes some aspects of this complex of problems. The overall aim was to investigate the experience of living with eczema. **Subjects:** Adult individuals with self-reported eczema. **Methods:** In Study **I**, a questionnaire was sent to 1111 adult individuals, half of whom had school medical records from childhood that suggested atopic dermatitis, and an equal number of controls. The response rate was 70.5%. The first question 'Have you had childhood eczema?' was followed by questions about eczema later in life. Study **II** used a combination of methods. A questionnaire regarding care and treatment was sent to 75 patients with atopic dermatitis or psoriasis after a completed phototherapy treatment period. The response rate was 63%. Among the responders, 19 individuals who had volunteered were interviewed in gender specific groups or pairs. In Study **III**, a purposeful sample of 19 individuals was interviewed about their everyday experiences of eczema. In Study **IV**, 34707 individuals in Stockholm County Council responded to a public health questionnaire, which included a health related quality of life instrument, EQ-5D, and a validated question about hand eczema during the past year. **Results:** Of the 403 cases that were documented by a dermatologist in Study **I**, 29% did not report childhood eczema in the questionnaire. One of the differences between those who did and did not recollect their childhood atopic dermatitis concerned who had reported the diagnostic signs in childhood. Those who remembered their childhood eczema had more often had the condition reported by parents *and* school health personnel. Those who had forgotten had more often had their eczema reported only by parents or school health personnel. More in the remembering group also had eczema after the age of 15 years, or reported having had hand eczema at some time during their life, than in the forgetful group. In Study **II** the main findings emanating from the questionnaire and interview data fell under three areas of clinical relevance: information to patients must be individually designed with a gender perspective; men and women have different attitudes toward greasing, which must be kept in mind in clinical practice; and women often appear to be underprescribed UV treatment. The analysis of the interviews in Study **III** revealed various aspects of how the body of a person with eczema 'dys-appears'. At a bodily level, the skin dys-appears with itching and burning sensations as well as a general feeling of being ill, or a bodily restlessness. At a social level, 'dys-appearance' is related to considerations about how one is different from others and one's appearance in the gaze of others, e.g. concerning personal hygiene and bleeding patches. These bodily and social 'dys-appearances' are to some degree mutually interactive, and become deeply intertwined in the daily lives of the interviewees, with respect to cultural, social and gender norms. In Study **IV**, it was found that HRQoL was lowered in individuals of both genders with hand eczema irrespective of age. EQ-5D index for hand eczema was on par with that for psoriasis and asthma, all common diseases with impact on public health. **Conclusion:** For the affected individuals, eczema has a considerable psychosocial impact. Their voices tell of a life with eczema: sharing their day-to-day experiences, as well as their experiences as patients, they give important information and a deeper understanding of this disease. Together with the quantitative HRQoL data showing the magnitude of this problem, this points to the importance of intensified preventive measures and treatment efforts.

Keywords: body, dys-appearance, eczema, EQ-5D, gender, HRQoL, illness experience, interviews, narratives, population-based study, public health, questionnaire, recall bias

SAMMANFATTNING

Bakgrund: Eksem är en sjukdom som drabbar individer i alla åldrar och är en av våra vanligaste sjukdomar i befolkningen. Eksem har en viktig inverkan på den fysiska och psykosociala hälsan. Denna avhandling beskriver några aspekter av denna problematik. Det övergripande syftet var att undersöka erfarenheten att leva med eksem.

Urval: Vuxna individer med självrapporterat eksem.

Metoder: I Studie **I** sändes ett frågeformulär till 1111 vuxna individer, varav hälften var utvalda på grund av en anteckningar som indikerade atopiskt dermatit i barndomens skolhälsovårdsjournaler och hälften kontroller. Svarsfrekvensen var 70,5 %. Den första frågan ”Har du haft eksem i barndomen?” följdes av frågor om eksem senare i livet. I Studie **II** användes en kombination av metoder. 75 personer som avslutat en behandlingsserie med ljusterapi för atopiskt eksem eller psoriasis fick sig hemsänt ett frågeformulär om vård och behandling. Svarsfrekvensen var 63 %. I ett senare skede intervjuades 19 personer som anmält ett sådant intresse, i könsspecifika grupper eller par. I Studie **III** intervjuades ett strategiskt urval om 19 personer angående deras vardagserfarenheter av eksem. I Studie **IV** analyserades svaren från personer som besvarat Stockholm läns landstings folkhälsoenkät 2006. I enkäten ingick bland annat en fråga om handeksem det senaste året, samt ett instrument för mätning av livskvalitet, EQ-5D.

Resultat: Av de 403 fallen i Studie **I**, var det 29 % som svarade nekande på frågan om de hade haft eksem i barndomen. Skillnader mellan de som mindes respektive inte mindes sitt barndoms eksem var till exempel vem som hade rapporterat de diagnostiska tecknen på atopisk dermatit i barndomen. Den minnesgoda gruppen hade oftare rapporter *både* från föräldrar *och* skolhälsovårdspersonalen. De glömska hade oftare rapporter endast från antingen – eller. Fler ur den minnesgoda gruppen hade också haft eksem efter 15 års ålder eller hade någon gång haft handeksem. I Studie **II** tematiserades huvudfynden till tre kliniskt relevanta områden: patientinformationen måste anpassas individuellt med ett könsperspektiv, män och kvinnor har olika attityder till insmörjning vilket man ska ha i åtanke i den kliniska verksamheten, samt att kvinnor tenderar att vara underbehandlade med ljusterapi. Analysen av intervjuerna i Studie **III** visar olika aspekter av hur kroppen ”dys-appears”. På en kroppslig nivå visar det sig att huden ”dys-appears” med klåda och brännande förnimmelser, liksom att kroppen ”dys-appears” med en allmän känsla av sjukdom eller en kroppslig rastlöshet. På en social nivå är ”dys-appearance” kopplat till tankar om hur man skiljer sig från andra och i tankar om hur man ser ut i andras ögon, till exempel i frågor som personlig hygien eller blodiga fläckar. Kroppslig och social ”dys-appearance” påverkar varandra ömsesidigt i olika grad och blir starkt sammanflätade i individernas vardagsliv. Upplevelsen av eksem kopplas även till kulturella och sociala normer hos omgivningen. I Studie **IV**, framkom det att den hälsorelaterade livskvaliteten var negativt påverkad hos individer av båda könen med handeksem, oavsett ålder. EQ-5D index för personer med handeksem var ungefär lika som för personer med astma eller psoriasis – vanliga sjukdomar med inverkan på folkhälsan.

Slutsatser: Eksem har en betydande psykosocial påverkan på individerna. Deras röster om ett liv med eksem, avseende vardagserfarenheter lika väl som erfarenheter i egenskap av patienter, ger viktig information och en djupare förståelse av denna sjukdom. Tillsammans med de kvantitativa data som visar omfattningen av detta problem, visar det på vikten av intensifierat förebyggande arbete och tillika behandlingsinsatser.

LIST OF PUBLICATIONS

This thesis is based on the following papers, which will be referred to in the text by their Roman numerals.

I. **C. Moberg, B. Meding, B. Stenberg, Å. Svensson, M. Lindberg** Remembering childhood atopic dermatitis as an adult: factors that influence recollection. *British Journal of Dermatology* 2006 **155** 557-560.

II. **L. Waernulf, C. Moberg, E. Welin Henriksson, B. Evengård, F. Nyberg** Patients' views on care and treatment for psoriasis and eczema including a gender perspective. *The Journal of Dermatological Treatment* 2008 **19** 233-240.

III. **C. Moberg and S. Olin Lauritzen** The dys-appearing skin – narratives of a life with eczema. Submitted.

IV. **C. Moberg, M. Alderling, B. Meding** Hand eczema and quality of life – a population based study. *British Journal of Dermatology* In press.

CONTENTS

LIST OF ABBREVIATIONS

DLQI	Dermatology Life Quality Index
EQ-5D	EuroQol – 5 Dimensions
HRQoL	Health Related Quality of Life
IgE	Immunoglobulin E
TTO	Time Trade-Off
VAS	Visual Analogue Scale

LIST OF FIGURES AND TABLES

1 INTRODUCTION

This thesis is about eczema, notably what it means to live with eczema, one of the most common illnesses in our society, affecting individuals of all ages. There is a great span in the individual suffering because of eczema, ranging from minor inconveniences to major health problems involving hospital care. For the purpose of this investigation I have delved into some aspects of this complex of problems, always with the individuals' reports forming the base for analysis. In the health care settings, the medical history is the primary story. People with an illness must tell their story in medical terms and limit the discourse to specific areas. In this context, people's experiences and their biography can be reduced to issues of body, symptom and disease. There is however no clear devide between the 'medical gaze' and the lay experience of eczema. For many people with eczema, the lay knowledge is also influenced by medical knowledge, as a result of encounters with physicians and the health services and also as they seek information about their diagnoses and symptoms in literature and on the web.

Eczema is often a chronic illness. However, people with eczema do not live most of their lives as patients. The eczema rather becomes part of an every-day life where illness is negotiated and handled on a day-to-day basis. At the same time, being a patient and having contact with professionals in the health care services is also part of the illness experience, as reflections about care and treatment can be important aspects of daily life.

2 BACKGROUND

2.1 THE SKIN

The skin is the human's largest organ; the average area in a man is 1.8 m^2. A usual description of the skin is that it consists of three layers. The *epidermis* makes the skin resistant against wear and tear and some toxic substances. The *cutis* contains blood-vessels that help regulate the temperature and supply the skin with oxygen and nutritives. The *sub-cutis* contains lipid cells that protect against cold and bumps. One of the most important functions of the skin is to act as a physical and biological barrier to the external environment, preventing penetration by irritants and allergens. At the same time it prevents the loss of water and maintains internal homeostasis. Other important tasks of the skin are to sense cold, heat, pain, touch and itch and to regulate body temperature. It is also shown that the skin plays a role in the subjective directional sensibility (Norrsell *et al.*, 2001) and thereby helps persons to keep their balance. The skin can also send signals to the environment, for example when we blush.

2.2 ECZEMA

Eczema is a condition where there is an inflammatory reaction in the skin. It is a very common disease, affecting at least 1/4 of the population in Sweden. The repercussions in terms of health care costs, lowered quality of life and subjective suffering must not be underestimated. The most common diagnoses of eczema are atopic dermatitis and contact dermatitis. Basic treatment consists of emollients and topical corticosteroids (Chang *et al.*, 2007).

Atopic dermatitis, or atopic eczema, is a chronic inflammatory skin disease that causes intense itch. Many patients with atopic dermatitis have a personal or family history of allergic rhinitis and asthma. Many, but not all, have IgE antibodies directed against inhalant allergens and common foodstuffs. Both genetic and environmental factors play a role, as they both contribute to an excessive immune response to allergens. The condition is characterized by an epidermal barrier dysfunction, which is responsible for the dry skin that plagues so many patients with atopic dermatitis, together with the described abnormal immune response and cutaneous reactivity. Atopic dermatitis often starts in infancy with dry, red cheeks and rashes on the extensor sides of arms and legs. From two years of age, the childhood phase begins, with eczema in the flexural parts on arms and legs. In adolescence the eczema is typically found in the gluteal region and on the neck. In adults, the locations of atopic dermatitis are similar to those in childhood and adolescence, but additionally the hands are more frequently involved (Burns *et al.*, 2004). Atopic dermatitis has been shown to have an impact on health-related quality of life when measured with both generic and skin-specific instruments: the impact is especially strong in the social and emotional dimensions (Holm *et al.*, 2005).

There are two types of *contact dermatitis*: allergic contact dermatitis and irritant contact dermatitis. The *allergic* contact dermatitis is a reaction to some substance in the environment that the person has been in contact with (Gober and Gaspari, 2008). Patients with contact allergy are instructed to avoid the allergens to which they are sensitive. This may not always be naturally easy for the patients, as is indicated by a Danish study from 2004 (Noiesen *et al.*, 2004). According to this study, people's ability to follow instructions and read labels was influenced by their social position. These social translations or versions of the medical instructions mean that the instructions are carried out differently depending on the patient's background. *Irritant* contact dermatitis is defined as an inflammatory response of the skin to an exogenous agent without requirement of prior sensitization. Factors such as water exposure, mechanical stress, chemical hazards and oxidative stress work together with mini-traumas such as scratching to cause a barrier dysfunction and eczema. Irritant contact dermatitis has a serious impact on the social as well as occupational lives of the sufferers (Fluhr *et al.*, 2008). It is commonly believed that women have more sensitive skin than men, and that they are more sensitive to skin irritating factors, but there is no evidence of this. The existing gender differences in the prevalence of contact dermatitis are due to differences in exposure, with more women in risk occupations such as nurses, hairdressers, institutional housekeeping, cleaning and also a higher exposure to water and other irritant substances at home (Occupational Health in Stockholm County Council 2007).

2.2.1 Itch

From an evolutionary point of view, the itch – and the subsequent scratching – may have functioned as a method to remove poisonous substances or insects from the skin. A psychosocial approach suggests that the scratching also may be a response to being in a fight or flight predicament, as the autonomic activation associated with fight or flight might cause changes in the skin which is interpreted as an itch (Adler, 2003). One well known endogenous agent that evokes itch is histamine, which is released from mast cells when tissues are inflamed or stimulated by allergens. Once released, histamine induces itch by triggering the excitation of unmyelinated C-fibres. The itching evokes a strong urge to scratch in order to suppress it, and persons with eczema may enter a vicious circle of itch – scratch – more itch and so on. The itching may also be suppressed by painful mechanical and thermal stimuli. However, the effect of such painful stimuli is weaker among individuals with atopic dermatitis, indicating that the itching in this disease has a more complex foundation (Shim and Oh, 2008). Significant cross-talk occurs among stratum corneum (the outermost layer of the epidermis), keratinocytes, immune cells, and nerve fibres, which are in close proximity to one another and induce itch. Many peripheral and central mediators have been shown to be important in itching. Mediators can act either directly on free nerve endings or keratinocytes, or indirectly by inducing the release of mast cell content or by potentiating the effect of other mediators (Yosipovitch and Papoiu, 2008).

2.3 PUBLIC HEALTH

The goal of a population-based approach to health is to understand and improve health at the population level. In a paper from 1989, Kickbusch defined public health as:

> '…the science and art of promoting health. It does so on the understanding that health is a process engaging social, mental, spiritual and physical well-being. It bases its actions on the knowledge that health is a fundamental resource to the individual, the community and to society as a whole and must be supported through sound investments into conditions of living that create, maintain and protect health' (Kickbusch, 1989).

A concern for health is one thing we share in common. The notion of public health is inherently a collective representation, where individual health goals can be framed within the concept of population health.

Prevention is a cornerstone of public health. It is about preventing disease, disability and premature death. Primary disease prevention involves the identification and removal of disease-causing risk factors (Weed, 2005). This is sometimes done using laws and regulations, and sometimes by information campaigns to the public.

Thus, in public health, the purpose is to act before people have become patients. Here epidemiologists and environmental health researchers have a joint responsibility to gather relevant scientific knowledge and to apply this knowledge in practice (Weed and McKeown, 2003). Qualitative methods are increasingly used to deepen the understanding of areas and/or phenomena which call for improvement.

2.4 HEALTH-RELATED QUALITY OF LIFE

WHO has defined ‘health’ as ‘a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity’. This definition is not intended to be a scientific one, but more of a manifesto. Still, it contains more than one dimension of health, and therefore will serve as an example here[1]. The word ‘health’ shares the same etymology with the word ‘whole’ (www.etymonline.com). Leder and Krucoff (2008) write that ‘in health the body, self and world form a dynamic whole integrated in equilibrium. This is what illness disrupts, bringing about a multifaceted dis-integration of relations’. For the understanding and explanation of health (as well as illness), it is of importance to acknowledge the repertoire of accessible conceptions within each culture.

‘Quality of life’ has also been defined by WHO, as ‘the individuals’ perceptions of their position in life, in the context of the cultural and value systems in which they live and in relation to their goals, expectations, standards and concerns’ (Both *et al.*, 2007). Positive quality of life can also be simply described as ‘the emotion of happiness and the sensation of pleasure’ (Nordenfelt, 1995), although this is not a definition.

In a medical context however, quality of life is normally described as health related quality of life (HRQoL), since the quality of life is seen in relation to different aspects of health. The measurement of HRQoL is done using various instruments, constructed for the purpose. Normally, these include questions about the physical, psychological and social consequences of impaired health. Three levels of HRQoL instruments are

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[1] For an interesting discussion on the definition of health, see articles by Nordenfelt and Brülde in Medicine, Health Care and Philosophy, Vol 3 pp 305-315.

used in dermatology. Generic instruments are designed to be used irrespective of diagnosis or condition. With these instruments it is possible to make comparisons between different states of ill-health. Skin-specific instruments have been developed to capture the complex of problems usually found in dermatology. The first and most frequently used instrument is named Dermatology Life Quality Index (DLQI) and was developed in the United Kingdom 1994 (Finlay and Khan, 1994). Even more sensitive, disease-specific instruments have been developed for different diagnoses. A pilot rosacea-specific quality of life instrument has been published, which captures topics such as avoiding certain foods or beverages and frequency of flushing (Nicholson *et al.*, 2007). Another pilot instrument measuring the effect of itch on quality of life has also recently been published (Desai *et al.*, 2008).

Although many instruments include different domains of health, there is no agreement on precise definitions, and researchers may mean very different things when they use terms such as ‘sick leave’, ‘sleep disturbances’ and ‘other inconveniencies’. Also, cultural differences may cause problems with interpretation and comparison (Both *et al.*, 2007).

EQ-5D is a generic HRQoL instrument, which implies that it is applicable to a wide range of health conditions (www.euroqol.org). It provides a simple descriptive profile and a single index value for a health status (Figure 1). The respondent is asked to indicate his/her health state by ticking (or placing an X) in the box against the most appropriate statement in each of the five dimensions. The EQ VAS records the respondent’s self-rated health on a vertical, visual analogue scale (0 – 100) where the endpoints are labelled ‘Best imaginable health state’ and ‘Worst imaginable health state’.

An EQ-5D health state may be converted to a single summary index by applying a formula that essentially attaches weights to each of the levels in each dimension. These coefficients are calculated from either Time Trade-Off or VAS studies with individuals in the general population, and are therefore slightly different in different countries. There are today value sets from 13 different countries (Oppe, 2007a;Oppe, 2007b), but unfortunately none from Sweden.

Figure 1. EQ-5D UK English version.

Mobility
I have no problems in walking about ☐
I have some problems in walking about ☐
I am confined to bed ☐
Self-Care
I have no problems with self-care ☐
I have some problems washing or dressing myself ☐
I am unable to wash or dress myself ☐
Usual Activities (*e.g. work, study, housework, family or leisure activities)*
I have no problems with performing my usual activities ☐
I have some problems with performing my usual activities ☐
I am unable to perform my usual activities ☐
Pain/Discomfort
I have no pain or discomfort ☐
I have moderate pain or discomfort ☐
I have extreme pain or discomfort ☐
Anxiety/Depression
I am not anxious or depressed ☐
I am moderately anxious or depressed ☐
I am extremely anxious or depressed ☐

There are cardinal as well as ordinal differences in the individual variations in the values for EQ-5D health states. Cardinal differences arise when people value health states differently. Ordinal differences arise when there is a disagreement as to whether the move from one state to another represents an improvement or a deterioration. It is therefore recommended that results obtained using the value sets should be treated with extreme caution at the individual patient and small group level (Roberts and Dolan, 2004).

2.5 DISEASE AND ILLNESS

The concepts of illness, disease and sickness have been useful to distinguish between different aspects of ill-health. *Disease* is the term for a physiological malfunction. It is an organic phenomenon which is measurable by objective means. *Illness* is a subjectively interpreted undesirable state of health, witch involve subjective feelings and interpretations of signs and symptoms. Illness is experienced and observed by the subject and can thus only indirectly be accessed by others, for instance through the accounts presented by the ill individual. *Sickness,* on the other hand, refers to the social identity of the ill individual as defined by others, and constitutes a set of rights and duties for the ill person in society. Sickness is thereby located in society and defined by the ways individuals can participate in the different social settings. Sickness is measured by levels of performance with reference to expected social activities when performance fails to meet social standards (Twaddle and Nordenfelt, 1993).

A chronic *disease* is defined as having one or more of the following characteristics: they are permanent, leave residual disability, are caused by nonreversible pathological alteration, require special training of the patient for rehabilitation, or may be expected to require a long period of supervision, observation, or care (Larsen, 2002). Chronic *illness* on the other hand has been described as:

> …the kind of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted. Chronic illness involves a recognition of the worlds of pain and suffering, possibly even death, which are normally only seen as distant possibilities or the plight of others (Bury, 1982).

Bury describes further how chronic illness disrupts the normal rules of reciprocity and mutual support in relations to family or wider social networks.

This characterisation does not necessarily presuppose a chronic disease. Chronic illness can be, for example, a permanent impairment *caused* by a disease, or a condition where no underlying pathology can be found. Furthermore, the suffering from chronic illness may be direct or indirect. This direct suffering may be due to the pain, fatigue or other unpleasant sensations, such as itching or restlessness. Indirect suffering is then a more general feeling, related to the impact of the illness, for instance when a person comes to think about his or her pain and reflects on the consequences of the illness (Nordenfelt, 1995).

2.6 LIVING WITH CHRONIC ILLNESS

According to Toombs (1992), there are no understood differences between the body and the self, and illness creates in this way a threat not only against the body but also against one's real self. 'Loss of self' is according to Charmaz (1983) the nature of suffering in chronic illness, when the broader significance of experiencing suffering in these conditions is acknowledged, with heightened self-concern about the person they see themselves becoming.

This thesis addresses one particular type of chronic illness, namely eczema. Research on people's experiences of living with a chronic illness indicates that, without being life-threatening, such illness has a strong influence on the life of the sufferer. Studies of chronic illness can tell us what this means in the daily life, about when the illness causes difficulties or makes it impossible to act as usual in different everyday situations.

Chronic illness can also isolate the sufferer in different ways in social life. He or she may be unable to participate in work or family life, or they may themselves choose to withdraw due to weakness or disfigurement. Moreover, others may withdraw from the ill person for various reasons. Furthermore, the experience of illness is dependent on, and varies with, culturally shared ideas on e.g. the causes of illness, conceptions of body and mind and also the ways one draws on medical knowledge (Conrad, 1987).

2.6.1 The lived body

In studies of the meaning of chronic illness, social science researchers have through the last decades payed more attention to the subjective, experiencing body. The body can, on the one hand, be seen as situated within and formed by social relationships and processes, that is, the body as the source, location and medium of society (Shilling, 1993). The body is also seen as something meaningful and intentional, as 'lived' (Merleau-Ponty, 1989). The lived body is not an experienced object amongst other objects. The lived body is the *prerequisite* for the ability to understand the world. From this perspective, the focus is how something 'shows itself'. Merleau-Ponty (ibid) argues that we experience the world in terms of the 'I can' that is, we are oriented towards certain activities based on our capacity and habituality.

According to Merleau-Ponty (ibid) our experience of the world emerges from our bodies as well as our minds, both at the same time. The place where the communication between body and mind can be understood is the existence, our repeated and changeable way to act, feel and think, that is, in our lived experiences. The lived experience has been discussed as the way human beings give meaning to their situation (Moi, 1999). The concept of the 'life-world' is central to this phenomenological tradition and refers to the human world of lived experience. The life-world is thus what the individuals give meaning to, and act in, with their whole bodies (ibid). Further, the lived body is enculturated in the sense that it is a specific body, in a specific environment, and it is marked by the habits, behaviours and evaluations, as well as the language and arts, that have surrounded it from the very beginning.

Typically, the individual is unreflective about his or her body prior to the onset of illness. As a consequence, most people act in the world with little consideration of the body per se. 'Hälsan tiger still'[2]. Researchers in the phenomenological tradition have developed a set of concepts to explore the body in health and illness. Leder (1990) discusses the ways the body 'disappears' when it is not at the focus of attention. In normal functioning, the senses through which we experience the world disappears – becomes a nullpoint. In times of pain or ill health, there is a breakdown from normal functioning and the body calls for attention and thematization. This is in Leder's words a 'dys-appearance' – where the prefix 'dys' stands for bad or ill. When the body dys-appears, it calls for self-reflection, and 'we are no longer dispersed out *there* in the world, but suddenly congeal right *here'* (ibid, p.75). When the body dys-appears, as in pain, it also pulls us back to the now, instead of being in the past-present-future condition of normal functioning. In such situations we experience *to* the body, and not *from* it.

In disease, the abilities to engage in the world is constricted and the intentionality, the 'I can', is dis-abled. Leder elaborates on the body as ground for expression, and communication operates according to a 'from-to'-logic. 'No matter wherever I physically move, and even in the midst of motion, my body retains the status of an absolute 'here' around which all 'theres' are arrayed' (ibid, p.13).

Furthermore, Leder argues, the awareness of one's body is a social phenomenon, where the self-understanding involves the 'seeing of what other see in me' (ibid, p.92). The perspective of the individual is in this sense extended through the perspective of another person. For instance, when a person feels stared at, he or she becomes aware of his or her body as the other person sees 'my body' as an object and thus blocks the

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[2] Untranslatable proverb about the silent nature of health, meaning roughly something like 'No news is good news', or 'if it ain't broke it don't need fixing'.

possibility to extend her seeing through mine. This means that the mutual incorporation of the world is transformed to refusal and disruption, a social 'dys-appearance'.

Eczema affects the body in its visual appearance as well as the general well-being. The sometimes chronic course of this condition implicates that eczema accompany the sufferer through life. Since the skin is a location for tactile experiences and a source of aesthetic considerations, it is a complex illness for the bearer. According to Leder (1992), 'When the body falls sick, we are left not simply with a broken machine, but with a world transformed; a disease undermines our sense of self and autonomy, our relations with others, our habitual experience of space and time' (p.5). The concept of a lived body thus extends the biomedical body with all aspects of being a *someone* who has all these experiences. Eczema is also an illness which is mostly managed by the sufferer herself. It is the person herself who make most of the day-to-day decisions about how to handle the situations in life concerning her skin.

2.6.2 Health and gender

Traditionally, medical science has assumed the definition of a biological sex in research and education. Another approach is the division into biological sex and social gender. Seen in this perspective, differences between men's and women's experiences are manifestations of both the biologically based variable sex and the socioculturally based construct of gender. For women, whose reproductive capacities often have been construed as biological correlates of their ability to become mothers and wives, femininity is a procreative, care-giving role. Bendelow (2000) discusses in her work how the experience of pain is linked to cultural and social norms about women being more in the 'natural' world in terms of bodily functions and the domestic sphere. For men, masculinity is frequently defined in terms of physical strength and independence (Connell, 1995). Also body image is gendered in the sense that men and women are socialized to view their bodies differently and to value different physical qualities and ideals (Clarke *et al.*, 2008). The concept of gender has the possibility of illustrating the meaning of such differences for men and women. In this sense, health related ideas and behaviours may be seen as the individuals' ways of constructing and demonstrating masculinity and femininity. A gender perspective in studies of health and illness, can contribute to the reduction of gender differences in care and treatment and to increase our knowledge about mechanisms behind such differences (Enns, 1997).

3 AIM

The aim of this thesis is to investigate the experiences of living with eczema. To do this, four questions have been posed:

- How well do people remember their childhood eczema, and which factors influence their recollection?

- How do patients with atopic dermatitis and psoriasis experience their care and treatment?

- How do people experience their eczema outside the medical context, in their everyday life?

- How is the HRQoL for individuals with hand eczema in the general population?

4 METHODS

To explore experiences of health and illness, qualitative and quantitative methods can supplement each other, depending on the specific research question. By drawing on quantitative as well as qualitative data, researchers may further their understandings about illness experiences as simultaneously somatic and social processes. For this reason, a few different methods have been applied to investigate what it is like to live with eczema (Table 1).

Table 1. Brief description of number of participants and methods used in Study I – IV

	Study I	Study II	Study III	Study IV
Participants	783	47 + 19	19	25471
Methods	Questionnaire Statistical analysis	Questionnaire and interviews Statistical analysis and inductive thematic analysis	Interviews Narrative analysis	Questionnaire Statistical analysis

4.1 STUDY I

School medical records for children born 1960 – 1969 were reviewed by a trained dermatologist. School healthcare is compulsory and at that time all children in Sweden underwent a physical examination by a doctor at the ages of 7, 10 and 13 years. At these examinations notes were made in medical records. At school start, when the children were 7 years old, the parents also filled in a health declaration in which questions about eczema and allergic diseases/symptoms were given the answers ‘yes’ or ‘no’. After an overall assessment of the available data, 600 cases of children with signs or symptoms of atopic dermatitis (e.g. itchy eczema in the flexural parts of arms and legs) and 600 controls were selected. At the time of the study it was possible to retrieve current postal addresses for 1111 of the cases and controls. A questionnaire consisting of 22 items was sent out, and after two reminders 783 individuals (70.5%) had returned it. The first question in the questionnaire 'Have you had childhood eczema?' was followed by questions concerning eczema later in life, occurrence of hand eczema, contacts with health care and common environmental risk factors for hand eczema. At the time when they answered the questionnaire, the cases and controls were in the age range of 31 to 42 years. Differences between proportions were calculated with X^2 tests. Analysis was performed with SPSS version 12 (Inc., Chicago, IL, USA).

4.2 STUDY II

In this study of patients' views on care and treatment for psoriasis and atopic dermatitis, a combination of methods was used. A questionnaire consisting of 15 questions was distributed to patients diagnosed with psoriasis or atopic eczema who had been prescribed phototherapy and topical treatment. All participants in the study were recruited in a treatment ward at one hospital-based outpatient dermatology department in the Stockholm County. The questionnaire was designed in order to elicit information which could form a basis to improve care. The questions covered patients' views about their disease and its care and treatment, solicited their ideas for improvement at the clinic, and asked whether they would consent to be interviewed. Apart from demographical data, the five questions relevant for this investigation were answered on a 0 – 10 scale. In all, 75 questionnaires were distributed and 47 (63%) were returned. Non-parametric Mann-Whitney and Spearman rank order tests were used to analyse questionnaire data. Analyses were carried out using Statistica version 7.1 (SAS Institute Inc., Cary, NC, USA).

As mentioned above, in the questionnaire the respondents also had the opportunity to volunteer to be interviewed. Altogether 19 patients (11 women, 8 men) were interviewed in groups, pairs and one individual interview. Interviews were conducted with men and women separately, to enable exploration of possible gender differences. The interview followed a guide with open-ended questions to ensure that the same questions were systematically covered. Examples from the interview guide were e.g. ‘What were your expectations on your first visit to a physician at this clinic?’ and ‘How do you experience the follow-up of your treatment by a nurse or physician?’ The interviews were audio-taped and transcribed verbatim. Inductive thematic analysis according to Hayes (2000) was performed:

1. Interviews were audio taped and transcribed verbatim. All transcriptions were compared with the audiotapes to ensure accuracy of transcription. Potentially identifying information was removed during transcription.
2. In order to get at good view of the material, the text was read and reviewed independently by two investigators.
3. The text was once again reviewed independently and passages considered relevant were marked and later compared between two investigators.
4. Preliminary themes were explored.
5. Key sentences in the text were sorted on the basis of the preliminary themes.
6. Taking one theme at a time, the text was again reviewed and the relevant facts connected with the theme were collected. For each theme the text was read specifically within the context of the theme.
7. The themes were established.
8. Relevant data belonging to each theme were summarized and refined by two investigators at several meetings. Typical quotes for each theme were also found.

4.3 STUDY III

In the questionnaire used in Study I, it was possible for the respondents to give their telephone number if they agreed to be contacted again. In this way, 15 persons were recruited. An additional four persons were recruited by a notice in dermatology clinics at three university hospitals. The altogether 19 persons (10 women, 9 men) who agreed to participate had long experience of eczema since childhood and still suffered from eczema.

Table 2. Names[3], age and occupation of the 19 interviewees in Study III.

Name	**Age (years)**	**Occupation**
Adrian	35	Computer work
Beatrice	36	Full time sick-leave
Celia	41	Owner of a business
Daniella	41	Office work
Eric	36	Computer work, former construction worker
Fanny	34	Preschool teacher
Gabriella	39	Office work
Helen	33	Gardening work
Ingrid	39	Office work/part time sick leave
Jennifer	27	Cook
Kevin	41	Caretaker
Leo	34	Unemployed, former cook
Malte	33	Car mechanic
Nike	39	Gardening work
Olivia	34	Theatre manager
Peter	41	Computer work
Rafael	27	Medical engineer
Sune	34	Industry worker
Thomas	24	Student

The participants were interviewed individually to explore their experiences of a life with eczema. The interviews were conducted according to a narrative approach (Kleinman, 1988), starting with a broad open-ended question: ‘Can you tell me about your eczema?’ The

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[3] Pseudonyms, which were used during the entire analysis.

interviews lasted between 35 and 90 minutes and were transcribed verbatim by the interviewer. After reading and re-reading, relevant passages of the transcripts were structured as ‘lines’ and ‘stanzas’ according to Gee’s model (1991), where some paralinguistic signals were retained in the transcript, such as laughter, inhalations and sighs. The purpose was to preserve some of the original characteristics of how the experiences were presented in the interviews, to allow for a detailed process of analysis that would capture not only the story told by the interviewee but also details in how they ascribe meaning to what they told. This structure functioned to organize the transcriptions in order to better understand how the narrative is constructed.

4.4 STUDY IV

The questionnaire for the *Public Health Survey of Stockholm County Council 2006* was distributed to 57009 randomly selected individuals aged 18 – 84 years, during the second half of 2006. It consisted of 90 questions covering different aspects of public health and risk factors. Response rate among persons of working age (18-64 years) was 58%. The questionnaire included a validated question concerning hand eczema: ‘Have you had hand eczema on any occasion during the past 12 months?’(Meding and Barregård, 2001). Also EQ-5D, an instrument for the measurement of health related quality of life, was included in the survey (www.euroqol.org). This is a generic instrument, which means that it is applicable to a wide range of health conditions. EQ-5D is designed for self-completion by respondents, and is completed by choosing one of three severity levels on five dimensions (see fig. 1). The responses to the dimensions create a profile. It is then possible to calculate an index out of this profile by subtracting a coefficient.

In this study, indices were calculated using UK coefficients, since unfortunately there are no Swedish value sets yet. From full health (index =1.0), there is a value to subtract if the respondent has stated moderate (level 2) or severe (level 3) problems in some, or all, of the dimensions (Szende *et al.*, 2007). A constant is subtracted once if the index is not 1.0, and if there are one or more level 3 answers, the N3 factor is subtracted once (Figure 2).

The coefficients are based on TTO studies, where 2 997 persons representative of the non-institutionalised adult population of England, Scotland and Wales were asked to value the health profiles. TTO involves asking the respondents to imagine giving up some life-span to have perfect health (Dolan *et al.*, 1996;Dolan, 1997).

Figure 2. Coefficients for the estimation of the EQ-5D index value based on UK TTO valuation studies.

EQ-5D-dimension	**Coefficient**
Full health (11111)	1.0
Mobility	
Level 2	-0.069
Level 3	-0.314
Self-care	
Level 2	-0.104
Level 3	-0.214
Usual activities	
Level 2	-0.036
Level 3	-0.094
Pain/discomfort	
Level 2	-0.123
Level 3	-0.386
Anxiety/depression	
Level 2	-0.071
Level 3	-0.236
Constant (at least one 2 or 3)	**-0.081**
N3 (at least one 3)	**-0.269**

The questionnaire is concluded with a question concerning an estimation of the individuals’ general health status and is answered on a visual analogue scale 0 – 100 (Burström *et al.*, 2001).

X^2 tests were performed to test for differences in proportions reporting problems in the five dimensions of the EQ-5D. Mann-Whitney tests were performed to test differences between EQ-5D indices. Spearman correlation was used to measure the correlation between index and VAS values. For the above analyses SPSS version 16.0 (SPSS Inc. Chicago IL USA) was used. In order to adjust for confounding variables when estimating the difference of EQ-5D index between those with and those without hand eczema, a beta regression, a type of generalized linear model, was performed (Smithson and Verkuilen, 2006). The beta-regression was performed using the procedure NLMIXED in SAS 9.1 (SAS Institute Inc. Cary, NC, USA).

5 RESULTS

Summary of main findings

5.1 STUDY I

In this study about factors that influence recollection of childhood eczema the first question gave the basis for subsequent analysis. Of all cases (individuals whose school health medical record suggested eczema), 29% (n=118) responded 'no' to the question of whether they had had childhood eczema. In the following text they will be referred to as the 'forgetful group'. Those who recalled their childhood eczema (71%, n=285), will be called the 'remembering group' (see Table 3).

Table 3. Response to the questionnaire question: 'Have you had childhood eczema?' by persons with and without atopic dermatitis in childhood according to school health medical records.

Group	Yes (I have had childhood eczema)	No (I have not had childhood eczema)	Total number
Cases (atopic dermatitis in childhood)	285 (71%)	118 (29%)	403
Controls (no atopic dermatitis in childhood)	38 (10%)	338 (90%)	376

There was a difference between the remembering and the forgetful group concerning who had reported the eczema in childhood. In the remembering group, diagnostic signs of atopic dermatitis were noted *both* by parents *and* by school health care in 51% of the cases, compared to 16% in the forgetful group.

The remembering group differed from the forgetful group in some other aspects as well, see Table 4.

Table 4. Results of the questions concerning eczema, hand eczema and consequences of eczema.

	Remembering group (n=285) %	**Forgetful group** (n=118) %
Eczema after the age of 15	73***	31
Eczema the past 12 months	50***	27
Hand eczema ever	51***	18
Visits to a physician due to eczema after the age of 15	50***	26
Sick leave > 1 week due to eczema	12**	3

**=p<0.01
***=p<0.001

5.2 STUDY II

The answers to four of the five – for the purpose of this study – relevant questions in the questionnaire are shown in Table 5. The self-reported discomfort score was significantly lower (p<0.001) after a phototherapy treatment period, regardless of the individual pre-treatment score (data not shown).

Table 5. Gender differences regarding information, self-reported adherence to greasing, and disease-related discomfort after phototherapy treatment.

	Men m (range)	Women m (range)	p-value
Have you received sufficient information about your disease from the staff at the clinic? *0 = low extent, 10 = high extent*	5.5 (1 – 10)	6.5 (0 – 10)	NS
To what extent do you grease your skin according to the instructions received from the staff at the clinic? *0 = low extent, 10 = high extent*	7.0 (3 – 10)	9.0 (6 – 10)	p<0.001
How much discomfort do you feel when your skin is at its worst? *0 = no discomfort, 10 = extreme discomfort*	7.0 (5 – 10)	9.0 (2 – 10)	p<0.01
How much discomfort do you feel after a phototherapy treatment period? *0 = no discomfort, 10 = extreme discomfort*	3.0 (0 – 7)	5.0 (0 – 10)	NS

Analysis of data from interviews revealed three main areas of clinical relevance, presented in Table 6.

Table 6. Main areas of clinical relevance for the caring of patients with atopic dermatitis and psoriasis as they emerged in the interviews.

Areas of clinical relevance	Categories
Information and knowledge	• The importance of information • The medical encounter • Patients' own experience about the disease
Attitudes about topical treatment	• The never-ending greasing • Trial and error • Uncertainty
Phototherapy	• Aspects on effects of phototherapy treatment • Risks, responsibility and feedback • Phototherapy accessibility

From the questionnaire we learned that the patients were not entirely satisfied with the information they received about their disease from clinical staff, and no gender differences were seen. In the interviews, however, men and women emphasized partly different aspects of this topic. Women in our study tended to be more information-seeking about their disease and what could affect the disease course. They were also more inclined to share their own knowledge, in the medical encounter as well as in encounters outside the medical context. Men on the other hand were more hesitant to ask questions they suspected were self-evident.

Both women and men regarded the women as more conscientious than men in following instructions given to them about creams and ointments. While men placed more emphasis on the importance of treatment feedback and assistance from the medical staff, the women revealed a more proactive attitude towards the creams, both in searching for the best alternative and in developing strategies for their daily treatment.

The women reported significantly higher discomfort scores than the men when asked to grade their discomfort when the disease was at its worst. There was no significant difference in discomfort scores between men and women after phototherapy treatment. In the interviews women reported greater difficulty in getting access to phototherapy, and they were also more explicit about the positive side-effects of phototherapy for themselves as well as benefits for society. Both men and women were anxious about the risk of burning their skin. Nevertheless, in the phototherapy treatment situation more women were prepared to assume some of the responsibility for the therapy, while more men stressed the importance of staff continuity and treatment feedback.

5.3 STUDY III

The result shows that living with eczema means being constantly aware of one's body – particularly during periods of flare-up. First, at a bodily level, eczema causes the surface of the body to 'dys-appear' in Leder's words (1990). When the hands or any other part of the body are burning and itching, the normal focal 'disappearance' is destroyed. Instead of disappearing from attention, meaning for instance that the focus of attention is on the work that the hands perform, the focus shifts back to the body, to the hands, and the ideas about what one is going to *do* with the hands are disturbed. Second, the eczema can also cause 'deep' symptoms, an 'internal' feeling of illness. Normally, minor changes in the body's condition do not raise any questions, but are seen as part of the experience of being human (ibid). But when the eczema causes extreme tiredness or a physical unrest that makes it difficult to sit still for extended periods of time, these changes can destroy one's ongoing involvement in the world. The 'dys-appearing' body becomes a hindrance in daily life. Third, at a social level, individuals suffering from eczema interpret and evaluate the everyday social situations that they encounter along with the eczema. The eczema becomes an important component in valuing one's self-esteem and possibilities to participate in social life – including how this pertains to gender norms. If the eczema is visible, or causes the sufferer to behave in deviant manners, the person's involvement in the world changes from just *being* someone, to seeing themselves from the outside. The bodily dys-appearance may in this sense be a prerequisite for the social dys-appearance, for instance when the eczema makes other people to withdraw from contact with the sufferer because of a fear that it might be contagious. But it can also be the other way around, as when reactions from others makes the sufferer behave in ways that are bad for the eczema, e.g. washing the hair too often. Treatment of eczema on the scalp makes the hair look greasy and dirty, but washing the hair with shampoo and water to often is not recommended medically.

5.4 STUDY IV

Hand eczema was associated with a lowered HRQoL. Mean indices were lower for the hand eczema group compared to the no hand eczema group, in all the three age groups (18-34, 35-49, 50-64) and in both genders ($p<0.001$). In Table 7, mean index, mean VAS and a correlation between the two values are shown.

Table 7. Mean EQ-5D index, mean EQ-5D VAS and correlation between the two values for individuals with and without hand eczema in total and subgrouped by age and gender.

Hand eczema					
Gender	**Age (years)**	**n**	**Index**	**VAS**	**Corr coeff. Index vs. VAS**
Men	18-34	257	0.852	79.813	0.379
Men	35-49	324	0.777	75.133	0.603
Men	50-64	286	0.739	72.206	0.691
Women	18-34	574	0.831	78.930	0.528
Women	35-49	565	0.786	75.671	0.671
Women	50-64	451	0.705	71.760	0.745
All	18-64	2457	0.782	75.674	0.555
No hand eczema					
Gender	**Age (years)**	**n**	**Index**	**VAS**	**Corr coeff. Index vs. VAS**
Men	18-34	2969	0.898	83.218	0.446
Men	35-49	3728	0.874	81.540	0.524
Men	50-64	3714	0.836	79.646	0.606
Women	18-34	3937	0.861	80.920	0.496
Women	35-49	4406	0.839	80.142	0.565
Women	50-64	4036	0.793	78.546	0.664
All	18-64	22790	0.848	80.542	0.626

A lowered HRQoL for individuals with hand eczema was also apparent from the examination of the five different dimensions of the EQ-5D

(Table 8). The only exceptions where hand eczema did not cause higher proportions of reported problems were young men and women (18 – 34 years) in the dimensions 'mobility', 'self-care' and 'usual activities'.

Table 8 The proportion of individuals reporting problems[4] in any of the five dimensions of EQ-5D in relation to hand eczema and gender

		Hand eczema	**No hand eczema**
	Age (years) n (men/women)	18-64 2457 (867/1590)	18-64 22790 (10411/12379)
EQ-5D dimension		%	%
Mobility	men	11.6***	**6.6**
	women	10.9***	**7.9**
	all	11.2***	7.3
Self-care	men	2.9***	1.4
	women	2.3**	1.4
	all	2.5***	1.4
Usual activities	men	**12.1*****	**7.2**
	women	**15.7*****	**9.9**
	all	14.4***	8.7
Pain/discomfort	men	50.4***	**36.5**
	women	51.1***	**43.5**
	all	50.8***	40.3
Anxiety/depression	men	**40.7*****	**26.7**
	women	**48.2*****	**37.2**
	all	45.5***	32.4

Comparison hand eczema vs. no hand eczema within subgroups: ** ≤ 0.01; *** ≤ 0.001
Bold = statistically significant differences ($p<0.05$) between genders within cells

There were some gender differences in the subgroups based on age, mainly in the no hand eczema group, but also in the hand eczema group. In the hand eczema group, the gender differences for the youngest age group were restricted to the dimensions 'pain/discomfort' and 'anxiety/depression'. For the oldest age group with hand eczema, gender differences were found in the dimensions 'usual activities' and 'anxiety/depression'. All gender differences were in men's favour, i.e. men had lower proportions of reported problems than the women had. In the middle age group of persons with hand eczema, there were no gender differences.

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[4] Second or third response alternative in the EQ-5D questionnaire

Mean indices for different self-reported diagnoses in the survey are presented in Table 9.

Table 9. Mean EQ-5D index for various self-reported diagnoses in the Public Health Survey Stockholm County Council 2006.

Diagnosis	**n**	**Index**
All 18 – 64 years	26336	0.839
Hay fever and/or asthma	9378	0.814
Hay fever	8759	0.814
Asthma	2175	0.796
Psoriasis	879	0.791
Hand eczema	2571	0.779
Diabetes	799	0.710
Depression	3620	0.659
Low back pain[5]	3868	0.634
Rheumatoid arthritis	515	0.561
Chronic obstructive lung disorder	209	0.559

When a beta regression analysis was performed, it was found that the strongest confounding variables were low back pain, asthma/hay fever and depression.

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[5] Two or more times during the past week.

6 DISCUSSION

6.1 ECZEMA IN EVERY-DAY LIFE

To people who suffer from illness, being a patient may be an important part of their experience, but not the only one. This makes it of interest to study the ways people handle their illness in everyday life, particularly as everyday illness experiences do not necessarily have a self-evident relation to the role as patients. People suffering from a chronic illness such as eczema will have to come to terms with the changes in life brought about by the illness. They also have to struggle to maintain a sense of self and to present themselves as the person they perceive themselves to be. To regain the control of self, individuals try to make their illness experience comprehensible, preserve their self image and to set up new goals (Frank, 1995).

When the interviewees in this thesis talk about their eczema and their itching, their experiences can not be seen as separate from social and cultural meanings. The different adaptations that they make in everyday life, in response to their eczema, are ways to bridge the gap between self and the demands of the life that they live. The participants in Study II and III all had long experience of eczema, and some of them long experience of psoriasis. Although they spoke of their eczema as something that to some extent was a part of them, and manageable in most cases, all the interviewees were affected by and had to adjust their lives to the eczema.

Bodily changes are not necessarily understood as symptoms. Some changes pass without calling our attention: they are experienced as part of being human (Leder, 1992). But when bodily changes are called a sensation, or a feeing a ‘symptom’, it is being interpreted as ‘something’. The most prominent symptom for many of the eczema sufferers is the itching. The itching can change the way the sufferer sees the situation she is in, for example the sweater that would keep you warm is – because of its texture – nothing but an instrument of torture. We found that itching disturbs the being-in-the world for a person (Study III) When the hands (or any other part of the body) are burning and itching, instead of disappearing from attention with a focus on the work that the hands perform, the focus shifts back to the hands. All the fantasies and ideas of what one is going to achieve with one's hands are disturbed.

Most chronic illnesses are potentially stigmatizing, even though they must not necessarily be so. If an individual has a feature or an attribute which attracts negative attention, others may turn away from that individual and deny fellowship. This is a stigma (Goffman, 1968), a deviation from the expectations. Having eczema, especially on visible parts of the body, obviously entails a risk of stigmatization. Others' gaze might be experienced as an infringement on one's personal integrity, for example when someone in our study (Study III) is described to others as 'the one with the red face' or when people turn away from them with a suspicion of contagiousness. A study from 1985 on the impact of skin conditions describes 'an uncomfortable feeling' if not direct unpleasantness in the presence of others and the powerful impact of anticipated responses of those around them (Jowett and Ryan, 1985). But the stigma may also be connected to invisible components of the illness, such as general feelings of sickness and tiredness that accompany the eczema. In the light of the stigma framework, we can anticipate a possible explanation to the correlation between the index value (which is based on healthy individuals assessment of different health states) and the general health status on a visual analogue scale graded 0 – 100 (Study IV). All individuals scored somewhat lower on the VAS, than their index value. Younger individuals scored proportionally even lower on the VAS scale, with only a moderate correlation as a result. The lacking information might be attributed to, among other causes, a feeling of stigmatization. Direct suffering is captured by the five dimensions of EQ-5D, but the instrument does not cover all the related indirect suffering, which would be better mirrored by the VAS-scale.

6.2 PUBLIC HEALTH ASPECTS

When research uses a biomedically derived definition of health to explore people's attitudes and behaviours, individuals are separated from the complex social physical and economic environments in which they live (Milburn 1996). The definition by Kickbusch (1989), instead emphasizes that health is a process engaging social, mental, spiritual and physical well-being. The Kickbusch approach bases its actions on the knowledge that health is a fundamental resource to the individual, the community and to society as a whole.

Today, fairly little is known about how memories of eczema in childhood influence the experience of living with eczema as an adult. Autobiographical memory is interpretations of the past, based on a combination of memory and beliefs, rather than a precise testimony. Therefore, recollections of medical ailments are probably influenced by the patients' understandings of and attitudes to their health (Cohen and Java, 1995). Those who remember their childhood atopic dermatitis are often those who still have eczema (Study I). From a public health perspective, it is important to find out more about those who gave a negative answer to the question 'Have you had childhood eczema?' We need to know how many of them there are, how much impact the childhood eczema has had on them, and how they are now.

One aspect emerging from the interviews in Study II was the possible societal benefits that might be achieved by offering phototherapy more generously. The long-lasting positive side-effects, such as improving mood and inclination to exercise etc, would perhaps outweigh the cost and risks of phototherapy treatment.

Women in general score lower on the various dimensions of the EQ-5D (Burström *et al.*, 2007). As a group, individuals with hand eczema have a HRQoL that is so low as to be comparable to that of individuals with asthma and psoriasis (Study IV). Hand eczema also seems to erase some of the gender differences in HRQoL in the general population. Among the individuals in our study aged 35-49, no gender differences were found in HRQoL. The largest confounding factor in our study on HRQoL and hand eczema was low back pain (Study IV). This seems reasonable in light of the kinds of occupations that involve risk factors for hand eczema, eg. hairdressing, the health care sector, institutional housekeeping and construction work. These jobs often require uncomfortable working postures and heavy lifting. Another confounder, apart from the obvious asthma/hay fever variable, was depression. Taking these into consideration also widens the perspective from just looking at the hands of a person, to regarding more of the whole life-situation. Instead of wondering ‘what are the risk factors for hand eczema’, one might ask ‘what risk factors do this occupation or life situation involve’ and thus orient toward a more public health perspective.

6.3 CLINICAL IMPLICATIONS

When adults are asked about childhood atopic dermatitis there are several factors that influence recollection (Study I). These factors include disease severity, disease activity in adult life and who noticed the eczema in childhood. This may have clinical implications, since the doctor relies on the patient’s memory for the anamnesis. The understanding of personal experiences that illness narratives can provide also have implications for clinical practice (Study III). One aspect has to do with the doctor’s understanding of the person who enters the examining room. Kleinman (1988) describes the patient’s feelings as key ingredients of the illness experience, which are likely to affect the patient’s life experiences in general, the illness per se, and the response to care. To limit the practical and social consequences of chronic illness, individuals try to manage their symptoms on their own, and both short- and long-term management strategies may be used (Radley, 1994;Bury, 1997). Following treatment regimens is sometimes called compliance, and the opposite noncompliance. Seen from a patient perspective however, the individuals evaluate both doctors' actions and the prescribed drug in comparison to what they themselves know about their illness and medication (Conrad, 1987). This medication practice is thus something that people develop in the context of their everyday life (Conrad, 1985). In eczema, the basic treatment consists of creams and ointments, sometimes with cortisone, but always as emollients. In a Swedish study, women were less likely to receive phototherapy than men, but were prescribed self-care more often (Nyberg *et al.*, 2008). The tendency that women are more inclined to follow treatment regimens with daily greasing, is often explained in terms of women's socio-cultural legacy to care about their looks, but we consider this a simplification. Our research (Study II) showed that both men and women thought that women followed topical treatment regimens better, but also showed that they handled treatment differently, with the women developing a more proactive attitude towards the greasing routine, and the men relying more on help and feedback from the staff. The findings in study II that men were more hesitant than women to ask questions they themselves suspected were self-evident, correspond to the findings in a study by Kaplan et al.(1995). In this study of 8316 patients' visits to the practices of 344 physicians, it was found that men are less likely than women to directly ask physicians about their health problems. Women on the other hand had learned to persist in asking direct questions about their health conditions and possible treatments. A better understanding of gender differences in doctor-patient interactions might lead to greater understanding of both male and female 'compliance' and health outcomes.

Another aspect has to do with what most authors in the area of dermatology agree on, namely that the 'objective severity' of the disease in a biomedical sense is not necessarily related to the amount of subjective suffering. 'The sufferer's response to his or her cutaneous disease is determined by their unique experiences and worldview' (Watson and de Bruin, 2007). When the body dys-appears, to use Leder's (1990) term, either bodily or socially, it may start a feedback loop of negative associations and discourse, analogous to the itch-scratch circle. Dealing with these negative feedback loops can be an important task in medical practice.

6.4 METHODOLOGICAL ASPECTS

In qualitative research the purpose is to explore rather than to prove. The research that is conducted using qualitative methods aims towards discovery, insight and understanding. Qualitative methods are therefore useful in studies of how people perceive the world (Guba and Lincoln, 2008).

In this thesis, two different qualitative methods have been used. In Study II an inductive thematic analysis was used to allow topics not covered by the interview guide to emerge. The narrative interview used in Study III has proved to be productive in other studies of chronic illness (Kleinman, 1988) and also more specifically in studies of allergic conditions (Olin Lauritzen, 2007). Narrative is a pervasive and important way of organizing or reporting experience and it is an important genre of representation in everyday life. Narratives can therefore provide the researcher with in-depth material on people's understandings of the world, not only the experiences of the individual but also the set of culturally shared ideas that the individual is embedded in. Even the most personal stories display some properties that reflect collective shared cultural conventions (Riessman, 2008). The purpose of narrative interviews is to encourage the interviewees to tell freely about their experiences. Questions are asked when the interviewer wants the interviewees to elaborate their story, e.g. what did you do, think or feel then? (Mishler, 1986). Still, stories are told to someone, and are formed by other's expectations. The social context will therefore influence what stories will be told and one must not disregard the impact of the information that was given to the interviewees concerning the aim of the study.

Measuring quality of life must be done with some caution. The instruments usually measure ability and capacity. Reduced capacity is, however, not necessarily related to reduced quality of life (Brülde and Malmgren, 1998). In EQ-5D, the questions are restricted to five items, covering an equal number of dimensions. Obviously, not all variables for a precise and in-depth investigation of the HRQoL in relation to hand eczema are present. The EQ-5D has never been validated for use in dermatology, which is a disadvantage (McCombs and Chen, 2007). Another important question to ask is ‘What does it mean for the individual?’ In a survey with bounded answers, the participants do not have the possibility to tell their own story, or to identify areas of personal significance. These limitations are troublesome when one is studying complex phenomena out of context. The individuals’ perspectives will be hard to perceive. Therefore the open inductive interview study, with its accounts of a lived experience, will enrich the quantitative data. By adding qualitative to quantitative data, a deeper understanding can be reached about chronic illness as an embodied phenomenon, at the same time somatic and social. But it is of importance, if a mixed method is used in a study, that the data are collected in its own right, whether quantitative or qualitative. Qualitative data is best gathered when a qualitative methodology is applied from the beginning and vice versa.

7 CONCLUSIONS

The experience of living with eczema was in this thesis investigated using a multidisciplinary approach. For the individuals, eczema has a considerable psychosocial impact. Their voices of a life with eczema regarding their day-to-day experiences, as well as their experiences as patients, give important information and a deeper understanding of this disease. Together with the quantitative HRQoL data showing the magnitude of this problem, this points to the importance of intensified preventive measures and treatment efforts.

- It is not self-evident that people remember their childhood eczema when they reach adulthood. Those who do have usually had a more recent experience of eczema, and have had to seek some medical care for it after the age of 15 years. They also more often report having had hand eczema at some point, indicating that the visibility of the eczema is of importance.

- Men and women as patients with atopic dermatitis and psoriasis perceive somewhat different aspects of care and treatment as positive or negative. Although there are large differences within gender, there is a tendency that women are more inclined to share their lived knowledge with the medical staff and to assume responsibility for their treatment. Men in this study, on the other hand, benefit more from encouragement and feedback. If a gender perspective is acknowledged, therapeutic strategies can be customized which will counteract gender inequities in dermatological treatment.

- Living with eczema in everyday life means being constantly aware of one's body. The skin 'dys-appears', i.e. instead of disappearing from focus, as it does under normal circumstances, it calls for attention. The individual, instead of being filled with what is possible to do and how to act in the world, his or her attention is drawn back to skin. This happens on a bodily level at the surface, for example when the itching and burning for example cause a disturbing awareness of the normally ignored sensation of cloth on the skin. It also happens socially, when the gaze of others cause a shift from *being* someone, to constantly being aware of the condition of one's skin.

- On a group level, health related quality of life is lower for individuals with hand eczema than for individuals without. The EQ-5D index was on the same level as for asthma and psoriasis, both common diseases in the population with impact on public health. Since hand eczema is often a chronic disease, it is of importance to acknowledge the burden for the individual, but also for society, in order to act for the best possible prevention and treatment of this troublesome condition.

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