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Get a Grip on Eczema and Psoriasis on the Hands: Impact on Function, Pain, Daily Activities and Quality of Life

Moliner Passlov, Henrietta

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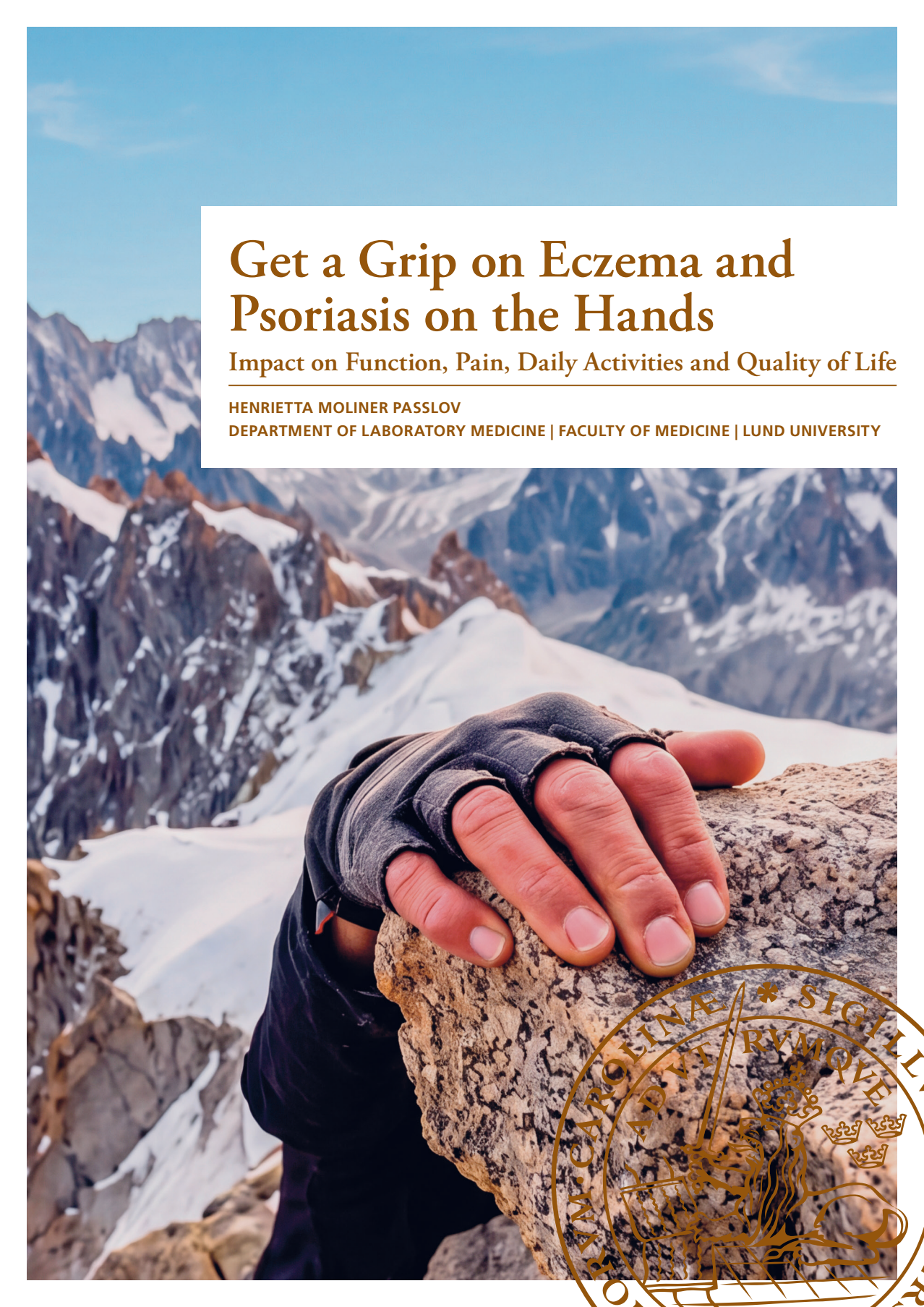
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PO Box 117
221 00 Lund
+46 46-222 00 00



Get a Grip on Eczema and Psoriasis on the Hands

Impact on Function, Pain, Daily Activities and Quality of Life

HENRIETTA MOLINER PASSLOV

DEPARTMENT OF LABORATORY MEDICINE | FACULTY OF MEDICINE | LUND UNIVERSITY





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DOCTORAL DISSERTATION

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Prof. em. Chris Anderson

Department of Biomedical and Clinical Sciences
Linköping University, Sweden

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Impact on Function, Pain, Daily Activities and Quality of Life

by Henrietta Moliner Passlov



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The soul is like the hand; for the hand is the instrument of instruments.

Aristotle

De Anima (On the Soul), III.8, 432a

Contents

Abstract	xi
List of papers	xiii
Abbreviations	xiv
Popular summary in English	xv
Populärvetenskaplig sammanfattning på svenska	xvii
1 Introduction	1
1.1 Context of the thesis	1
1.1.1 The human hand – essential for daily life	2
1.1.2 Hand function	3
1.1.3 The skin – essential for hand function	5
1.2 Hand eczema	6
1.2.1 Epidemiology	7
1.2.2 Risk factors	8
1.2.3 Prevention	9
1.3 Psoriasis on the hands	11
1.3.1 Epidemiology	12
1.3.2 Risk factors	13
1.4 Impact on daily activities, pain and quality of life	13
1.4.1 Performance of daily activities	13
1.4.2 Pain	14
1.4.3 Quality of life and health-related quality of life	15
1.4.4 The International Classification of Functioning, Disability and Health	16
2 Aim and objectives	19
3 Material and methods	21
3.1 Participants	21
3.2 Quantitative research methods	22
3.2.1 Data collection	22
3.2.2 Statistical analyses	24
3.3 Qualitative research methods	25
3.3.1 Data collection	25

3.3.2	Analysis	25
3.4	Ethics	26
4	Results and comments	27
4.1	Study I	27
4.2	Study II	29
4.3	Study III	31
4.4	Study IV	32
5	Discussion and conclusions	35
5.1	General discussion	35
5.2	Interpretation of the findings using the ICF framework	37
5.2.1	Hand function, activities and participation	38
5.2.2	Contextual factors in relation to functioning and disability	39
5.3	Novelty	41
5.4	Methodological discussion	42
5.4.1	Quantitative studies	42
5.4.2	Qualitative studies	44
5.4.3	Combining quantitative and qualitative methods	45
5.5	Conclusions	45
	Acknowledgements	47
	References	51
	Scientific Publications	67
	Paper I: Hand strength and dexterity in individuals with hand eczema	69
	Paper II: Location of hand eczema in relation to hand function, performance of daily activities and quality of life – a clinical cross-sectional study from Sweden	79
	Paper III: Perceived ability to perform daily activities among individuals with chronic hand eczema	89
	Paper IV: Experiences of challenges in daily life among individuals with cu- taneous psoriasis localised to the hands	105

Abstract

Hand eczema is an inflammatory skin disease, often with a chronic and relapsing course. Patients often report pain, clumsiness and difficulty flexing their fingers, but the consequences for hand function and for the performance of daily activities have been understudied. The overall aim of this thesis was to increase understanding of hand function and the performance of daily activities in individuals with hand eczema. Similar challenges in daily life have been reported among patients with cutaneous psoriasis localised to the hands. A further aim was to describe such challenges among individuals with cutaneous psoriasis localised to the hands.

In Study I, 21 participants with ongoing hand eczema were examined with well-established instruments for grip strength, pinch strength and manual dexterity, and 12 were re-examined when healed. At baseline the group mean did not differ significantly from normative data, but all functional tests improved significantly when the eczema had healed. Perceived difficulty in performing daily activities was associated with manual dexterity and pinch strength, but not with grip strength, and correlated strongly with pain and with quality of life measured by the Dermatology Life Quality Index.

Study II focused on whether hand eczema involving the fingertips of the thumb, index and middle fingers, which are used in most functional grips, was associated with greater impairment in hand function, daily activities, quality of life and pain than hand eczema without involvement of these sites. Forty-five participants were classified into three ordered groups according to involvement of these fingertips: hand eczema not involving the first three fingertips, eczema at these sites without fissures, and presence of fissures on any of the first three fingertips. Manual dexterity, performance of daily activities, quality of life and pain deteriorated across the three ordered groups, and palmar pinch showed the same trend, the burden being greatest when fissures were present. Grip strength, key grip and tactile discrimination showed no such relation. Pain was rated higher after the functional tests than before, in all groups.

In Study III, 11 individuals with chronic hand eczema were interviewed about the challenges they met in daily life, and the interviews were analysed with qualitative content analysis. Participants described challenges in such areas as work, household activities, leisure, personal care and socialisation. Pain from fissures, the fear of that pain and concern about the appearance of the hands were most often what made an activity difficult or impossible, and the fluctuating course of the disease made daily activities hard to plan. Which activities were difficult, and which were important, varied between individuals; work was rated the most important.

In Study IV, seven individuals with cutaneous psoriasis localised to the hands, without psoriatic arthritis or other conditions known to affect hand function, were interviewed

about how they experienced their daily activities, and the interviews were analysed with qualitative content analysis. Participants described physical consequences for the performance of daily activities, social vulnerability owing to the appearance of the hands, and uncertainty about whether their hands could be relied on from one day to the next. Most participants maintained their activities through self-initiated adaptations, and withdrew from valued activities when adaptation was no longer sufficient.

Taken together, Studies I–III indicate that hand eczema affects hand function and the performance of daily activities, and that these functions improve when the eczema heals. Manual dexterity and the grips that engage the fingertips followed both the condition of the skin and the reported difficulty in daily activities, whereas grip strength did not, and the burden was greatest when the first three fingertips were affected and fissures were present. Pain recurred across the studies, and the interviews showed that individuals often sustain their activities through adaptations they do not report spontaneously. The findings support asking patients about pain, fissures, hand function, the adaptations they have made and the activities they consider important, and suggest that hand functions, measured with tasks that resemble everyday activities, may be useful as a complementary outcome in follow-up and in treatment studies. Individuals with cutaneous psoriasis localised to the hands described difficulties and adaptations of the same kind, which suggests that this perspective is not confined to hand eczema, although the findings need to be examined in larger samples.

List of papers

This thesis is based on the following publications, referred to by their Roman numerals:

- I **Hand strength and dexterity in individuals with hand eczema**
H.M. Passlov, A. Pontén, J. Björk, B. Rosén, M. Bruze, C. Svedman, M. Isaksson
J Eur Acad Dermatol Venereol, 34(12):2856–2862, 2020.
- II **Location of hand eczema in relation to hand function, performance of daily activities and quality of life – a clinical cross-sectional study from Sweden**
H.M. Passlov, C. Håkansson, N. Hamnerius, A. Pontén, J. Björk, B. Rosén
Submitted for publication.
- III **Perceived ability to perform daily activities among individuals with chronic hand eczema**
H.M. Passlov, B. Rosén, N. Hamnerius, J. Björk, A. Pontén, C. Håkansson
Submitted for publication.
- IV **Experiences of challenges in daily life among individuals with cutaneous psoriasis localised to the hands**
H.M. Passlov, N. Hamnerius, B. Rosén, J. Björk, A. Pontén, Å. Svensson, C. Håkansson
Manuscript.

Abbreviations

ADL	Activities of Daily Living
CI	Confidence Interval
COPM	Canadian Occupational Performance Measure
COREQ	Consolidated Criteria for Reporting Qualitative Research
DASH	Disabilities of the Arm, Shoulder and Hand
DLQI	Dermatology Life Quality Index
EQ-5D	EuroQol 5-Dimension questionnaire
HRQoL	Health-Related Quality of Life
ICF	International Classification of Functioning, Disability and Health
NRS	Numeric Pain Rating Scale
QoL	Quality of Life
QOLHEQ	Quality of Life in Hand Eczema Questionnaire
SF-12	Short Form 12 Health Survey
SF-36	Short Form 36 Health Survey
STI	Shape-Texture Identification Test
WHO	World Health Organization
WHOQOL	World Health Organization Quality of Life assessment

Popular summary in English

Most of us rarely reflect on how we use our hands in daily life, as hand function is often taken for granted. We button a shirt, unlock a door, shake hands with a friend and play a few notes on an instrument without giving any of it a thought. It is only when the hands can no longer do what they have always done that we notice how much of everyday life depends on them.

Patients with hand eczema or cutaneous psoriasis on the hands describe pain, fingers that will not bend, objects slipping out of their hands, and a growing list of things they can no longer do. Hand eczema is common: about one adult in ten has active hand eczema at some point during a year, and the figure is higher in occupations such as hairdressing, healthcare, cleaning and metalwork. That hand eczema lowers quality of life has been known for a long time. Far less is known about how it affects hand function, whether the location of the eczema matters and how much fingertip fissures contribute to functional difficulties. We also know less about how people with hand eczema experience their ability to carry out daily activities and which activities matter most to them. Knowledge is limited for cutaneous psoriasis on the hands as well. Psoriasis at this site has rarely been studied in its own right, and has usually been examined together with psoriasis on the feet or with psoriasis in general. We therefore know little about how people with cutaneous psoriasis on the hands experience the impact of their symptoms on daily activities. These are the questions the four studies of this thesis set out to address.

In the first study we measured grip strength, finger strength and manual dexterity in twenty-one people with hand eczema, and asked them about their pain, their quality of life and the difficulties they had with daily activities. Twelve of the participants returned once their eczema had healed. At the first assessment the results of the group were not strikingly low, but when participants were compared with themselves after healing, hand function had improved, as had pain, quality of life and difficulties with daily activities. These findings suggest that hand eczema may be associated with measurable impairment in hand function as well as difficulties in everyday life, and that these problems may improve as the skin heals. The findings also showed that difficulty in carrying out daily activities was clearly related to poorer manual dexterity. Those who experienced greater limitations in daily life also reported more pain and lower quality of life. Every participant named at least one everyday activity that was difficult to perform. Activities involving contact with water were among the most demanding for the participants: washing up, showering, cooking and washing their hands.

The thumb, index and middle fingers are particularly important when we grip and use our hands in everyday life. In the second study we therefore asked whether the site of the eczema matters, and whether fissures on these fingertips in particular add to the burden. Forty-five people with hand eczema took part, divided into three groups: those with no eczema on

the fingertips of the thumb, index and middle fingers, those with eczema there, and those who had fissures on these fingertips as well. Manual dexterity fell step by step from the first group to the third, and the same pattern held for the ability to perform daily activities, quality of life and pain. Pinch strength followed the same trend, while grip strength of the whole hand did not differ between the groups. We also measured pain before and after the physical tests. Pain rose in all three groups after the tests, most sharply in those with fissures. Overall, the burden was heaviest for those with fissures. Eczema on a fingertip, and above all eczema with fissures, therefore seems to affect everyday life more than eczema elsewhere on the hand.

Numbers do not tell the whole story. In the third study we interviewed eleven people with chronic hand eczema about how well they felt they managed their daily activities and which of those activities mattered most to them. They spoke about work, housework, leisure, personal care, travelling and their social lives. Work mattered most, and was also among the hardest to manage. Some had changed occupation, sold their business or cut their hours, and several kept working against their doctor's advice to take sick leave, either to protect their income or to spare their colleagues the extra work. Others described struggling to cook, showers that made the symptoms worse, and phones that would not unlock because their fingerprints had worn away. All of them described difficulties in social situations and shame about how their hands looked, and the handshake came up in every interview as something to be dreaded. What usually made an activity impossible to perform was the pain from fissures, the fear of that pain, or the thought of how their hands would look to other people. The fluctuating nature of the disease made it hard to plan ahead or trust that their hands would function when needed.

Patients with psoriasis on the skin of the hands often describe much the same trouble as patients with hand eczema. In the fourth study we therefore asked whether what we had found was peculiar to hand eczema, or whether it extended to cutaneous psoriasis on the hands as well. We interviewed seven people who had psoriasis on the hands but no joint disease. Most managed to carry out their activities, but at a cost: gloves, dressings, altered grips, tasks quietly avoided and help from others. Several of the adaptations had become so much a part of ordinary life that they no longer registered as adaptations at all. When adaptation was not enough, participants withdrew from activities, sometimes from the very things they liked best. Here too there was shame about how their hands looked, and the uncertainty of not knowing what the next day would bring.

Together the four studies give a picture of what it means to live with hand eczema and with psoriasis on the hands, a picture that is needed both to give the individual patient better support and to assess how severe the disease is. Knowing where the eczema sits, and whether the fingertips have fissures, tells us something about what the disease means in everyday life. This thesis began with what patients told us in the clinic. That is also where I hope the benefit of this work will return.

Populärvetenskaplig sammanfattning på svenska

De flesta av oss tänker aldrig på hur och till vad vi använder våra händer. Vi knäpper en skjorta, låser upp en dörr, hälsar med ett handslag och spelar några toner på ett instrument utan att reflektera över hur det går till. Först när händerna inte klarar av det de brukar blir det tydligt hur mycket av vardagen som vilar på dem.

Patienter med handeksem eller handpsoriasis beskriver smärta, fingrar som inte går att böja, att de tappar saker och att vardagliga aktiviteter blir svåra att utföra. Handeksem är vanligt, ungefär en av tio vuxna har ett aktivt handeksem någon gång under ett år, och i vissa yrken, till exempel bland frisörer, vårdpersonal, städare och metallarbetare, är det betydligt vanligare. Att handeksem kan sänka livskvaliteten är väl känt. Mindre känt är vad sjukdomen gör med handens funktion, om det spelar någon roll var på handen eksemet sitter, och hur stort besvär en liten spricka på en tumme kan orsaka. Vi vet också för lite om hur den som är drabbad själv upplever sin förmåga att utföra vardagens aktiviteter, och vilka av dessa aktiviteter som det betyder mest att kunna utföra. Kunskapen är begränsad även när det gäller handpsoriasis. Handpsoriasis har sällan studerats för sig, utan har oftast undersökts tillsammans med psoriasis på fötterna eller hos personer som även har psoriasisartrit, där ledpåverkan i sig kan påverka handfunktionen. Därför vet vi endast lite om hur personer med psoriasis just på huden på händerna upplever att besvären påverkar deras förmåga att utföra vardagens aktiviteter. Det är dessa frågor som avhandlingens fyra delarbeten handlar om.

I det första delarbetet mätte vi handstyrka, fingerstyrka och finmotorik hos 21 personer med handeksem, och frågade dem samtidigt om upplevd smärta, livskvalitet och svårigheter att utföra dagliga aktiviteter. Tolv deltagare kom tillbaka när eksemet hade läkt. Vid den första mätningen var resultaten på gruppnivå inte anmärkningsvärt låga, men när deltagarna jämfördes med sig själva efter läkning hade samtliga värden tydligt förbättrats. Handeksem kan alltså påverka hand- och fingerstyrka samt finmotorik på ett mätbart sätt, och när eksemet läker förbättras funktionen igen.

I studien framkom även att svårigheter att klara vardagliga aktiviteter tydligt hängde samman med sämre finmotorik. De som upplevde större begränsningar i vardagen rapporterade också mer smärta och sämre livskvalitet. Alla deltagare hade någon aktivitet i vardagen som var svår att utföra. Mest besvärliga var aktiviteter som innebar kontakt med vatten, till exempel att diska, duscha, laga mat och tvätta händerna.

Tummen, pekfingret och långfingret är särskilt viktiga när vi greppar och använder handen i vardagen. Därför ville vi i det andra delarbetet ta reda på om det spelar någon roll var på handen eksemet sitter, och om sprickor just på dessa fingertoppar innebär en tyngre börda. Totalt deltog 45 personer med handeksem. De delades in i tre grupper: personer utan eksem på fingertopparna på tumme, pekfinger och långfinger, personer med eksem på

dessas fingertoppar och personer som dessutom hade sprickor där. Finmotoriken var stegvis sämre för varje grupp, och samma mönster fanns för förmågan att utföra dagliga aktiviteter, för livskvaliteten och för smärtan. Styrkan i fingertoppsgrepp visade samma tendens, medan greppstyrkan i handen inte skilde sig mellan grupperna. Vi mätte också smärtan före och efter de fysiska testerna. I alla tre grupperna var smärtan högre efter de fysiska testerna, och ökningen var störst hos dem med sprickor. Tyngst var bördan för dem med sprickor. Eksem på en fingertopp, och särskilt eksem med sprickor, tycks alltså påverka vardagen mer än eksem på andra delar av handen.

Mätvärden säger ändå inte allt. I det tredje delarbetet intervjuade vi elva personer med kroniskt handeksem om hur de upplevde att de klarade av att utföra sina dagliga aktiviteter och vilka aktiviteter som betydde mest för dem att kunna utföra. Svaren rörde arbete, hushållsarbete, fritid, personlig hygien, transporter och socialt umgänge. Arbetet betydde mest, och var samtidigt bland det svåraste att klara. Några hade bytt yrke, sålt sitt företag eller gått ner i arbetstid, och flera arbetade trots att läkaren hade rekommenderat sjukskrivning, för att inte förlora inkomst eller belasta sina kollegor. Andra beskrev att de hade svårt att laga mat, att duschen förvärrade besvären, och att telefonen inte gick att låsa upp eftersom fingeravtrycken var oläsbara. Alla beskrev också svårigheter i sociala sammanhang och skam över hur händerna såg ut, och handslaget återkom i varje intervju som något att bäva inför. Det som oftast gjorde en aktivitet omöjlig att utföra var smärtan från sprickor, oron för smärta och tanken på hur andra skulle se på deras händer. Sjukdomens växlingar gjorde det svårt att planera och att lita på att händerna skulle fungera när de behövdes.

Då patienter med handpsoriasis i mötet med vårdpersonal ofta beskriver liknande besvär som de med handeksem, ville vi i det fjärde delarbetet ta reda på om ovanstående resultat gäller handeksem i synnerhet eller även handpsoriasis.

Vi intervjuade sju personer med psoriasis på huden på händerna, utan ledsjukdom. De flesta klarade av att utföra sina aktiviteter, men till ett pris: handskar, förband, omlagda grepp, undvikande av vissa moment och hjälp av andra. Flera av anpassningarna hade blivit så självklara att de inte längre uppfattades som anpassningar. När anpassningen inte räckte drog de sig ur, ibland från det de tyckte allra bäst om. Också här fanns skammen över synliga händer och osäkerheten inför nästa dag.

Tillsammans ger delarbetena en bild av vad det innebär att leva med handeksem och med handpsoriasis, en bild som behövs både för att bättre kunna stötta den enskilda patienten och för att bedöma sjukdomens konsekvenser för den som är drabbad. Var eksemet sitter, och om det finns sprickor på fingertopparna, säger något om vad sjukdomen innebär i vardagen. Den här avhandlingen började med det patienterna berättade på mottagningen. Det är också dit nyttan av detta arbete ska tillbaka.

Chapter 1

Introduction

1.1 Context of the thesis

This thesis has emerged from many years of clinical practice as a healthcare counsellor in an occupational and environmental dermatology department. In this setting, I have frequently met patients whose hand eczema or cutaneous psoriasis on the hands affects not only their skin but also their everyday lives.

Their accounts describe how symptoms such as pain, together with functional limitations including difficulties gripping objects and performing fine motor tasks, can interfere with work, domestic responsibilities, leisure activities and social participation, ultimately affecting quality of life. These clinical encounters raised questions about how such consequences are understood and assessed within dermatology.

Research on hand function in other medical fields, such as hand rehabilitation and occupational medicine, has contributed substantially to the understanding of the functional consequences of hand injuries and disorders, including their effects on daily activities. In these fields, standardised measures for assessing hand function and performance of daily activities are commonly included in clinical evaluation. Such assessments provide an important foundation for understanding functional impairment, rehabilitation needs, and treatment outcomes [17, 65, 88, 120].

Despite the central role of the hands in everyday life, hand functions have been sparsely studied in dermatology. Several important questions therefore remain unanswered.

Is hand eczema associated with a measurable impairment in hand strength and manual dexterity? Is the location of hand eczema and the presence of fissures associated with pain,

impaired hand functions, limitations in the performance of daily activities, and reduced quality of life? What challenges do individuals with chronic hand eczema experience when performing their daily activities, and how important is it to them to be able to perform these activities? Does psoriasis affecting the hands, another inflammatory skin disease, influence individuals' perceived ability to perform daily activities?

A central question guiding this thesis is how the consequences of eczema and cutaneous psoriasis on the hands can be more comprehensively assessed and understood, while incorporating the patient's own perspective.

1.1.1 The human hand – essential for daily life

Behold the hands, how they promise, conjure, appeal, menace, pray, supplicate, refuse, beckon, interrogate, admire, confess, cringe, instruct, command, mock, and what not besides, with a variation and multiplication of variation which makes the tongue envious.

*Michel de Montaigne
Essays, Book III, "Of Experience" [35]*

The human hand is an organ of exceptional versatility, whose complexity has shaped, and been shaped by, the evolution of our species [81, 91, 105]. It may be regarded as an adaptive and multifaceted instrument closely integrated with the brain, through which ideas and intentions are translated into action [86, 87]. Whether in the construction of monumental structures, the expression of artistic inspiration, or the performance of routine daily activities, the hand acts as the essential intermediary between thought and practice. The close functional relationship between the hand and the brain is reflected in the extensive representation of the hand within both the motor and sensory cortices [86], and the way an individual uses the hand in everyday life is mirrored in the organisation of those cortical representations [40]. These representations are not fixed, but reorganise in response to altered use, injury or disease [86].

The movements and gestures of our hands also play a significant role in shaping body language and identity [49, 79, 94]. Throughout human history, we have recognised and celebrated this importance. Handprints and hand stencils are among the oldest known rock-art motifs, appearing on cave walls in different parts of the world tens of thousands of years ago, and reflecting the enduring importance of the hand as a marker of presence, agency, and human expression [8, 110, 118]. We continue this tradition today, preserving plaster casts of a newborn's tiny hands, tracing the outlines of a loved one's fingers, and decorating our own hands in celebration. Our daily interactions are rich with hand-mediated communication, such as handshakes that convey trust, high-fives that celebrate victory, waves

that signal departure, and handclaps that show enthusiasm [49, 79, 94]. In art, poetry, sculpture, and song, the hand remains a recurring motif of presence, commitment, and creative power. Whether the hand is used as a tool or as a sign, it depends on capacities that are easily taken for granted: it must grip, it must feel, and it must be usable without pain.

1.1.2 Hand function

The activities performed with the hands during an ordinary day differ between individuals and, for the same individual, from one day to the next. Factors such as health, occupational demands, household tasks, leisure interests and the physical and social environment all contribute to how the hands are used. Many tasks require both hands, although the two hands rarely contribute equally: one commonly manipulates while the other holds, steadies or positions the object [17].

Manual dexterity, often called fine motor skill, denotes the ability to perform coordinated movements of the hand and fingers when grasping, releasing and manipulating objects [83]. It rests on five factors: stability, mobility, strength, sensibility, and a finely tuned interplay between the sensory and motor systems of the central and peripheral nervous systems [17, 137]. None of these is sufficient alone; grip formation depends on their integration, which is why hand function should be assessed across several domains rather than through strength alone [158]. Figure 1.1 depicts this complex interaction across different domains as a tree, in which the physiological factors form the branches, environmental and personal factors the root system, and the resulting activity and participation the foliage.

In 1956, Napier distinguished two fundamental categories of prehension: the power grip, in which the whole hand secures the object against the palm, and the precision grip, in which the object is controlled between the fingertips [104]. Later, using video analyses of healthy individuals performing everyday tasks, Sollerman refined this distinction into eight main grip patterns, summarised in Table 1.1 [69, 138]. Two of them dominate: the pulp pinch and the key grip, each accounting for about a fifth of the grips observed, and both engaging the pulp of the thumb together with the radial fingers. Seven of the eight are represented in the Sollerman hand function test, in which twenty standardised everyday tasks are graded from 0 to 4 according to the grip the participant adopts and the time required [139].

Sensibility comprises several levels, of which two are relevant here: protective sensation, the ability to register touch and to withdraw from a potentially harmful stimulus, and tactile gnosis, the ability to identify objects by touch alone, on which object manipulation in everyday manual tasks depends [17, 131].

Friction between the skin and the object contributes to the stability of the grip, and the



Figure 1.1: Hand function, here depicted as a tree, is highly complex. The physiological factors in the "branches", such as stability, mobility, strength, sensibility and a well-functioning interaction between hand and brain, are not the only ones that matter. Other physiological factors such as the skin, together with environmental and personal factors in the "root system", are also of great importance for activity and participation: the "foliage and blossom". Adapted with permission from [17].

sensory nerves of the palmar skin continuously report the properties of the object and how it is held, allowing grip force to be adjusted from moment to moment [73, 74]. Grip therefore requires skin that is both adherent and adaptable. It also requires that use be painless, since pain provoked by pressure or stretch alters how an object is grasped, irrespective of the underlying strength and mobility [17, 73].

Table 1.1: The eight main grip patterns identified in video analyses of healthy individuals performing activities of daily living (ADL), with their approximate relative frequency of use. Adapted from [69, 138].

Grip	Description	%
Pulp pinch	The object is held between the thumb and the pulp of the index finger, the middle finger, or both	20
Key grip	The object is held between the thumb and the radial side of the index finger, as when turning a key. Also called lateral pinch	20
Palmar pinch	The object is surrounded by the thumb, index finger and middle finger. Also called tripod pinch	10
Five-finger pinch	The object is held between the thumb and all four fingers without contact with the palm	15
Diagonal volar grip	The object rests against the palm with its axis diagonal to the hand	15
Transverse volar grip	The object rests against the palm with its axis transverse to the hand	14
Spherical volar grip	The thumb and fingers surround an object that also contacts the palm	4
Extension grip	The object is held between the thumb and the extended fingers, with palmar contact	2

1.1.3 The skin – essential for hand function

Covering the entire body, the skin is commonly regarded as the largest organ of the human body and has several functions that are essential for survival [76, 121]. One of its most important roles is to act as a protective barrier between the body and the external environment, helping to protect against physical trauma, chemical irritants, ultraviolet radiation, allergens, and pathogenic microorganisms [121].

The skin is composed of the epidermis and the dermis, resting on the underlying subcutaneous tissue [76, 153]. The outermost layer, the epidermis, forms the main interface with the external environment [121]. Beneath it, the dermis contains blood vessels, nerves, hair follicles, sweat glands, sebaceous glands, and connective tissue, thereby contributing to strength, elasticity, and sensory function [76, 153]. The subcutaneous tissue provides insulation, cushioning, and energy storage [76, 153]. Together, these structures allow the skin to regulate body temperature, limit excessive water loss, contribute to vitamin D synthesis after exposure to sunlight, and take part in immune surveillance [14, 107, 121].

In addition to its protective and regulatory functions, the skin is also an important sensory organ [74, 93]. A fine network of sensory nerve endings and receptors enables the perception of touch, pressure, vibration, pain, and temperature [10, 36, 74, 75, 93]. These sensory functions help the individual to detect harmful stimuli and interact with the environment, and they provide the feedback needed for object manipulation, grip-force adjustment, and fine motor control [73, 74].

On the hands, these general functions take on a particular importance. The skin of the palm and the fingers is thick and hard-wearing, and it holds firmly against the underlying tissue

so that it does not slide when an object is grasped [76, 153]. It is also densely innervated, which is what makes it possible to feel the shape, texture and weight of what is held and to adjust the grip accordingly [73, 74]. On the back of the hand, the skin is instead thin and loose, allowing the fingers to be bent and the hand to be closed. Optimal hand function thus requires skin that is intact, supple and painless to use [17].

At the same time, the skin of the hands is continuously exposed, since it meets everything the hands are used for. Water, soap, disinfectants, cleaning agents, foodstuffs, plants, metals and protective gloves act on the skin during work and household tasks, along with friction, pressure, cold and dryness [13, 59, 144]. The hands are also difficult to protect and to rest, as sparing them means refraining from ordinary daily activities. Demands on the skin are therefore high on the hands, while protection is limited, which is one reason why the hands are a common site for skin complaints and skin disease [144].

Skin diseases may interfere with these functions at several levels. Inflammatory conditions such as eczema and psoriasis can affect both the epidermis and the dermis, causing erythema, scaling, fissuring, pain, itching, and impaired barrier integrity [6, 101, 144]. On the hands, such changes may affect both the skin and hand function: fissuring and hyperkeratosis alter the pliability and friction on which grip depends, pain discourages the firm contact that many grips require, and impaired sensibility degrades the feedback described above. Because the hands take part in almost every daily activity, from touching and grasping to greeting, expressing and working, these limitations may extend into work, domestic life and social participation [30, 31, 96].

The consequences of skin disease are not limited to physical symptoms, but are also part of how individuals are perceived by others and how they perceive themselves [34, 128]. This is particularly relevant for areas that are difficult to conceal, such as the hands and face [128]. Changes in skin appearance may lead to embarrassment, social withdrawal, reduced self-esteem, and psychological distress [34, 128]. Chronic skin diseases have therefore been associated with considerable reductions in quality of life and, in some individuals, with symptoms of anxiety or depression [34, 115]. The burden may be especially pronounced when the disease affects the hands, since they are constantly visible and essential for communication, work, self-care, and social interaction.

1.2 Hand eczema

Hand eczema is a common inflammatory skin disease affecting the hands and wrists. It is clinically heterogeneous and may present with erythema, oedema, vesicles, papules, scaling, hyperkeratosis, fissures, pain and pruritus [60, 144, 151, 159]. The aetiology is often multifactorial, involving both endogenous susceptibility, particularly previous or ongoing atopic



Figure 1.2: Hand eczema. Close-up of a patient's hand with eczema and eczema with fissures on a thumb. Images from [42, 43].

dermatitis, and exogenous exposures such as irritants and contact allergens [144, 151]. Hand eczema is commonly classified by aetiology, including irritant contact dermatitis, allergic contact dermatitis and endogenous forms, although overlap between subtypes is frequent [12, 144].

Hand eczema often follows a recurrent or chronic course. Chronic hand eczema is usually defined as hand eczema persisting for more than three months or recurring at least twice within one year [12, 144]. The course is often prolonged and relapsing, particularly when diagnosis and appropriate intervention are delayed [55]. Hand eczema is of particular relevance in occupational dermatology, since work-related exposures may contribute to disease onset, aggravation and chronicity [12, 144]. The cause of hand eczema cannot be determined reliably by clinical appearance alone, since different aetiological subtypes may present with similar morphology [12, 144]. Patch testing is therefore an important diagnostic tool when allergic contact dermatitis is suspected, as it can identify relevant contact allergens from occupational, domestic or environmental exposures [72].

Active hand eczema may be associated with difficulties in performing daily activities [116]. Visible disease may also lead to embarrassment, avoidance behaviour, sleep disturbance and reduced health-related quality of life [1, 46].

1.2.1 Epidemiology

The occurrence of eczema is generally measured as period prevalence (e.g. “past 12 months”) rather than point prevalence (“on the day of measurement”), because period prevalence captures more cases and more of the relevant disease burden, and because it gives more stable estimates in a fluctuating condition such as eczema. The estimated 1-year prevalence of hand eczema in the general population is approximately 9–10%, while the lifetime prevalence is approximately 14–15% [123]. Population-based studies have reported incidence rates

of first-time hand eczema onset ranging from 5.5 to 8.8 cases per 1,000 person-years [85, 95], while a recent meta-analysis estimated a pooled incidence rate of 7.3 cases per 1,000 person-years [123]. Reported prevalence and incidence estimates vary between populations owing to differences in study design, case definitions, demographic characteristics, and geographical setting [123, 145]. The occurrence of hand eczema is highest among young adults and gradually declines with increasing age [145]. The average age at disease onset is in the early to mid-twenties, although approximately one-third of affected individuals report disease onset before the age of 20 years [145]. These findings indicate that hand eczema frequently develops early in life and remains prevalent throughout adulthood.

1.2.2 Risk factors

As already indicated, the aetiology of hand eczema is generally multifactorial. There are several well-documented risk factors, including both endogenous susceptibility and exogenous exposures [133, 144]. Past or present atopic dermatitis is a strong endogenous risk factor, reflecting impaired skin barrier function and increased vulnerability to irritants and allergens [133, 144]; a genetic contribution to this susceptibility is well established [85, 151]. The risk of developing hand eczema has been reported to be approximately three to four times higher among individuals with a history of atopic dermatitis in childhood [54, 71, 141]. Susceptibility and exposure generally act together rather than independently, and the same work carries a higher risk for individuals with atopic dermatitis than for others [3, 133]. Exogenous risk factors include wet work, frequent handwashing, repeated exposure to detergents or solvents, and prolonged glove use, all of which are particularly relevant in occupational hand eczema [13, 68, 144]. Allergic contact sensitisation may also play a role, with commonly reported contact allergens including nickel, cobalt, fragrances, preservatives such as methylisothiazolinone and methylchloroisothiazolinone, and rubber accelerators [58, 142, 144]. Hand eczema is more common in women than in men, but this difference is largely confined to younger age groups and has been attributed mainly to differences in exposure rather than to greater inherent susceptibility [85, 95, 100, 145]. Exposure outside paid work may also contribute to hand eczema, particularly through dishwashing, cleaning, laundry and the care of small children, although the independent contribution of these exposures has proved more difficult to demonstrate; among Swedish healthcare workers, handwashing outside work was not associated with hand eczema once occupational exposure and other factors had been accounted for [59].

Occupational risk factors can be divided into irritant and allergenic exposures. Irritant exposures, such as water, soaps, detergents, disinfectants and solvents, damage the skin barrier and are the most common cause of occupational hand eczema [24, 134]. Allergic hand eczema develops after sensitisation to specific workplace allergens, including rubber chemicals, preservatives, hair dyes, acrylates, epoxy resins, and metals such as nickel and

chromium [58, 134]. Wet work and irritant exposures are particularly relevant in certain occupations, and the risk is correspondingly high in healthcare, cleaning, hairdressing, food handling, childcare, and construction [24, 59, 66]. The risk of occupational hand eczema increases with the frequency and duration of wet work and cumulative exposure to irritants [59].

Occupational skin diseases are among the most frequently reported occupational diseases in Europe, but the systems through which they are notified and registered differ considerably between countries, and so does the knowledge that can be drawn from them [37]. Although Sweden has continuous national registration of notified occupational diseases through the Information System on Occupational Injuries (ISA) administered by the Swedish Work Environment Authority [4], occupational skin diseases are likely to be underreported. The responsibility for notifying the authorities rests primarily with the employer, while the employee is expected to inform the employer about the suspected occupational injury or disease. Potential barriers to reporting include limited knowledge among both employers and employees about what constitutes an occupational disease and the perceived limited prospect of obtaining compensation, which may reduce the incentive to report a suspected occupational disease. The criteria for recognising occupational injuries were substantially tightened in 1993, although the evidentiary requirements were subsequently relaxed in 2002 [140]. Notifications fell steeply over the same period, and the preparatory work preceding the 2002 amendment attributed part of that decline to the stricter evidentiary rules, noting that workers often saw little purpose in pursuing a claim they were unlikely to win [126]. Our neighbouring country, Denmark, offers an instructive comparison. Cases assessed by the national authority responsible for occupational injuries are entered into a register that has repeatedly been used for research, and these data identify skin diseases as the most frequently recognised occupational diseases in the country, with contact dermatitis accounting for the large majority of them [23, 134]. Irritant exposure underlies approximately 70% of the recognised cases of hand eczema and wet work about two thirds of these, while health-care workers, cleaners and kitchen staff together account for almost half of all cases [23, 68].

Risk factors may influence both the onset of hand eczema and its clinical course. A history of atopic dermatitis, greater age, severe disease at the time of diagnosis and low socioeconomic status have been associated with a poorer prognosis and with prolonged sick leave and loss of employment [31, 32], and Swedish follow-up data show that hand eczema frequently persists over many years [97].

1.2.3 Prevention

As hand eczema affects multiple aspects of an individual's life and is associated with substantial societal costs, particularly due to sick leave and reduced work ability, it is essential to identify effective preventive strategies [31, 119, 144]. As described in Section 1.2.2, the

disease may both develop and worsen as a result of occupational exposures and other environmental factors. Prevention should therefore not only aim to avoid disease onset, but also include measures implemented after disease development in order to prevent progression, relapse, and chronicity [11, 108, 144, 149]. Preventive measures are conventionally divided into primary, secondary, and tertiary prevention, a useful division given the chronic and relapsing nature of hand eczema [108, 144].

Primary prevention aims to reduce the incidence of hand eczema by minimising exposure to irritants and allergens [11, 108, 144]. This is particularly important in high-risk occupations, where substitution of hazardous substances, protective measures, and educational programmes focusing on skin protection have demonstrated preventive value [11, 108, 149]. Regular use of emollients to support the skin barrier can also be an important protective factor at this stage [11, 144]. In a systematic review, van Gils et al. concluded that there was moderate evidence for the effectiveness of prevention programmes for hand dermatitis compared with usual care or no intervention, particularly in reducing disease occurrence and improving adherence to preventive measures [149].

Secondary prevention focuses on early detection and prompt intervention, so that exposure can be reduced, skin protection optimised, and treatment initiated before the disease progresses to a more persistent form [28, 108, 144]. Contact allergy investigation through patch testing is important at this stage, as it allows identification of relevant allergens and facilitates targeted avoidance strategies, which are important for improving prognosis [72, 144].

Tertiary prevention aims to reduce the long-term impact of established disease, prevent relapses, and support continued work ability [2, 135, 144]. Multidisciplinary interventions, including dermatological treatment, patient education, and occupational adjustments, are often required [2, 28, 135, 144]. In patients with persistent or recurrent disease, renewed evaluation of occupational and non-occupational exposures, including possible contact allergy, remains important, as unrecognised allergen exposure may otherwise hinder successful management [72, 144]. Structured tertiary individual prevention programmes have shown effectiveness in improving disease control and supporting continued employment [2, 135].

In summary, prevention of hand eczema requires coordinated efforts across all levels of prevention. Both general and individualised measures, including systematic evaluation of contact allergy when indicated, are essential to reduce the disease burden at both individual and societal levels [2, 28, 31, 72, 119, 135, 144].

1.3 Psoriasis on the hands

Psoriasis is a common, chronic, immune-mediated inflammatory disease with systemic manifestations. Chronic plaque psoriasis (psoriasis vulgaris) is the most common clinical subtype, accounting for approximately 80–90% of all cases. It is characterised by well-demarcated erythematous plaques covered with silvery-white scales and commonly affects the extensor surfaces of the elbows and knees, the scalp, and the lumbosacral region. Pruritus is one of the most common symptoms, although pain and discomfort may also occur depending on the anatomical location and severity of disease [6, 53].

Psoriasis is increasingly recognised as a systemic inflammatory disease and is associated with several important comorbidities, including psoriatic arthritis, obesity, metabolic syndrome, type 2 diabetes, cardiovascular disease, and metabolic dysfunction-associated steatotic liver disease. These comorbidities contribute substantially to the overall disease burden and should be considered in the comprehensive management of affected individuals [6, 53].



Figure 1.3: Psoriasis on a hand. Image from [44].

Psoriasis also has psychosocial consequences. Individuals with psoriasis report experiences of stigma, shame, embarrassment, and concerns about negative social evaluation because of the visible nature of the disease. Such experiences may contribute to reduced self-esteem,

social withdrawal, impaired interpersonal relationships, restrictions in work and leisure activities, and diminished health-related quality of life [47, 80, 125, 132]. Rapp et al. reported that patients with psoriasis described impairments in several domains of health-related quality of life, measured using the Short Form 36 Health Survey (SF-36), that were comparable to those reported by patients with conditions such as cancer, congestive heart failure, diabetes, depression, chronic lung disease, and arthritis [125].

Involvement of the hands is of particular clinical importance due to their essential role in everyday functioning and social interaction [30, 61]. The hands account for only a small proportion, less than 5%, of the total body surface area, yet their central role in everyday life means that psoriasis affecting this site may have consequences that are disproportionate to the extent of skin involvement. Hand function is fundamental for self-care, domestic activities, employment, communication, and social participation, domains that in the International Classification of Functioning, Disability and Health (ICF) are described as activities and participation [156]. Limitations affecting the hands may therefore influence many aspects of daily living [150]. Because the hands are continuously visible during social interaction, psoriasis affecting this area may contribute to physical discomfort and to the stigma described above [47, 61]. Involvement of the hands has been identified as an important determinant of impaired health-related quality of life [18, 30, 117]. Assessment of disease severity should therefore consider not only the extent of skin involvement but also the anatomical localisation of the lesions when treatment decisions are made [48, 143].

Common symptoms reported by individuals with cutaneous psoriasis affecting the hands include dryness, scaling, fissuring, pain, and discomfort, all of which may interfere with everyday activities [77, 117]. Nevertheless, the specific consequences of cutaneous psoriasis localised to the hands have received limited attention. Previous research has often evaluated hand involvement together with foot involvement under the broader concept of palmoplantar psoriasis [30, 117], grouped the hands with other difficult-to-treat sites such as the scalp, face, genitalia, feet, or nails [18], or included participants with psoriatic arthritis, making it difficult to distinguish the impact of cutaneous disease from limitations attributable to joint disease [21]. As a result, knowledge of how cutaneous psoriasis affecting the hands influences everyday life remains incomplete.

1.3.1 Epidemiology

Psoriasis affects an estimated 125 million people worldwide, and in Western Europe the prevalence is around 2% [6, 53, 114], with marked geographical variation; northern European populations tend to report higher figures than those in southern Europe or outside Europe. In Sweden the condition affects roughly 2–3% of the population, corresponding to some 200,000–300,000 people. Men and women are affected in about equal numbers [53]. A family history is common, with 30–40% of patients in clinical cohorts reporting an af-

affected first-degree relative [9]. Although psoriasis can begin at any age, two subtypes are conventionally distinguished: an early-onset form, presenting at or before 40 years of age and frequently accompanied by a positive family history, and a late-onset form, presenting after 40 years, in which a positive family history is less common [29, 62].

Hand involvement is common in psoriasis, although it has traditionally been described within the broader category of palmoplantar psoriasis. Palmoplantar involvement has been reported in approximately 12–16% of individuals with psoriasis [39, 98]. More recent studies indicate that psoriasis affecting the dorsal aspects of the hands may be even more prevalent than palmar involvement [9]; in one study, dorsal hand lesions were observed in 85% of patients with hand psoriasis, whereas palmar involvement was present in 47% [77].

1.3.2 Risk factors

Psoriasis has a strong genetic component and results from a complex interaction between genetic susceptibility and environmental factors. Several factors have been associated with the onset or exacerbation of psoriasis, including skin trauma (Koebner phenomenon), infections, common medications, cigarette smoking, excessive alcohol consumption, and psychological stress [6, 53].

Obesity has also been associated with an increased risk of psoriasis, greater disease severity and poorer treatment outcomes, as have smoking and alcohol consumption [7, 103, 127].

1.4 Impact on daily activities, pain and quality of life

1.4.1 Performance of daily activities

Few activities in an ordinary day are performed without the hands, and a disease located on them might therefore affect daily activities directly. Hand eczema has long been recognised as interfering with work, household tasks, leisure activities and social interaction [46, 96]. However, the meaning and scope of the term “daily activities” may vary between studies and disciplines. In this thesis, the term *daily activities* encompasses all activities in which an individual engages as part of everyday life, including self-care, domestic tasks, work, leisure and social participation.

In dermatology, the impact of disease on daily activities is commonly assessed as a component of health-related quality of life. Such effects are captured, for example, by the Dermatology Life Quality Index (DLQI) [45] and by the functioning domain of the Quality of Life in Hand Eczema Questionnaire (QOLHEQ) [109, 111]. Population-based research using the QOLHEQ has demonstrated impairment within the functioning domain among indi-

viduals with ongoing hand eczema [122]. These instruments primarily assess self-reported consequences. Qualitative studies further illustrate these consequences, with patients describing adaptations to everyday routines and limitations in household, leisure and social activities [52, 129]. Within the World Health Organization's International Classification of Functioning, Disability and Health (see section 1.4.4), the consequences of hand eczema for everyday life may be understood mainly as activity limitations and participation restrictions, rather than solely in terms of disease pathology or impairments in body functions and structures [156].

1.4.2 Pain

Pain is a complex and multidimensional experience involving sensory, emotional, cognitive, and social components. The International Association for the Study of Pain defines pain as “an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage” [124]. This definition emphasises that pain is a personal experience influenced by biological, psychological, and social factors, and that it cannot be inferred solely from observable tissue damage. The notes accompanying the definition add that a person's report of pain should be respected, and that verbal description is only one of several ways in which pain is expressed.

Pain may be acute and protective, but when it persists or recurs for more than three months it is generally classified as chronic pain. Chronic pain may become a clinical problem in its own right and can affect emotional well-being, physical functioning, work ability, and quality of life [148]. Despite its clinical importance, pain is difficult to describe and measure. It cannot be measured directly in the same way as physiological variables such as blood pressure or body temperature. Instead, assessment relies primarily on patient self-report. Instruments such as the Numeric Pain Rating Scale and Visual Analogue Scale are widely used and provide important information about pain intensity, but they do not fully capture the sensory quality, emotional meaning, or functional consequences of pain [70]. This difficulty was described by Virginia Woolf in *On Being Ill*, where she observed that when a sufferer tries to describe pain to a doctor, “language at once runs dry” [154]. Her observation remains relevant in clinical research, where a highly subjective and context-dependent experience must often be translated into standardised measures. These measures also record pain at a single moment, commonly while the person is at rest, which is a limitation in conditions where pain is provoked by using the affected body part. It is also one reason why numerical ratings benefit from being complemented by accounts in which individuals describe their pain in their own words.

The hand is central to interaction with the environment and is involved in almost all activities of daily living. In hand rehabilitation, absence of pain has been described as an important prerequisite for optimal hand function [17]. Pain affecting the hand can interfere

with grip, pinch, and fine motor control, and its consequences therefore reach well beyond the symptom itself, into self-care, work, leisure, and social participation.

Hand eczema affects a body site that is in constant use and repeatedly exposed to mechanical and chemical stress. Although itch has traditionally been regarded as a hallmark symptom of eczema, pain is increasingly recognised as an important and distinct part of the disease burden in hand eczema. In adults with chronic hand eczema, itch and pain have been reported as two of the most common and burdensome symptoms [159]. Patients commonly describe pain using sensory terms such as burning, soreness, stinging, and tenderness, and these symptoms may interfere with sleep, hand use, and emotional well-being. Pain in hand eczema is therefore a matter of context and consequences as much as of intensity.

Several clinical features of hand eczema may contribute to pain, such as erythema, oedema or infiltration, vesicles, papules, fissures, desquamation, lichenification, and hyperkeratosis [15]. Fissures and inflamed skin may be repeatedly stressed during daily activities, whether these involve gripping and pinching, contact with water and irritants, or manual work.

Recent epidemiological research further supports the clinical relevance of pain in chronic hand eczema. In the Danish Skin Cohort, individuals with chronic hand eczema had a higher use of analgesics than the general population, and analgesic use was higher among those with moderate-to-very-severe disease than among those with mild disease [60]. Analgesic use is an indirect indicator of pain, and other explanations cannot be excluded. Nevertheless, these findings provide further support for a clinically relevant burden of pain in chronic hand eczema.

1.4.3 Quality of life and health-related quality of life

The concept of quality of life (QoL) has long historical and philosophical roots. Reflections on what constitutes a good life can be traced back to ancient Greek philosophy, where Aristotle's concept of *eudaimonia* is commonly understood as living well, human flourishing, or the realisation of a good and meaningful life [5, 82]. Although Aristotle did not define quality of life in the modern medical sense, his work illustrates that questions concerning well-being, human flourishing and what makes life good have a long intellectual history [82].

Despite these historical roots, QoL remains a complex and multidimensional concept, and there is no single universally accepted definition. The term has been used in different ways across philosophy, sociology, psychology, medicine and public health [155]. In medical and health-related research, QoL is generally understood in a broader sense than health status alone, including subjective evaluations of physical health, psychological well-being, level of independence, social relationships, personal beliefs and the surrounding environment [155].

A distinction is commonly made between overall QoL and health-related quality of life (HRQoL). While overall QoL concerns a person's broader life situation, HRQoL focuses more specifically on how health, illness, symptoms, treatment and functional limitations affect everyday life and well-being [78, 152]. The terms *health*, *quality of life* and *health-related quality of life* are sometimes used interchangeably, although they refer to distinct but overlapping constructs [78].

Quality of life is an important outcome to examine in individuals with hand eczema, as the condition can impose a substantial physical, psychological, social and occupational burden [1, 33, 144]. Although clinical assessments capture visible disease severity, they may not fully reflect patients' individual experience of symptoms such as pain, pruritus, and impaired hand function, or their effects on the performance of daily activities and work participation [1, 56]. Evaluating QoL or HRQoL therefore provides essential insight into patients' lived experiences and supports a more comprehensive, patient-centred understanding of the burden of hand eczema [33, 90].

Several instruments have been used to assess HRQoL in individuals with hand eczema. The Dermatology Life Quality Index (DLQI) is one of the most widely used dermatology-specific instruments [45], while the Skindex questionnaires provide a broader assessment of the effects of skin disease on symptoms, emotions and functioning [26]. In hand eczema, the Quality of Life in Hand Eczema Questionnaire (QOLHEQ) is particularly relevant because it is disease-specific and assesses symptoms, emotions and functioning, as well as treatment and prevention [109]. Although generic instruments, such as the SF-36, SF-12, EQ-5D and WHOQOL measures, may be less sensitive to the specific burden associated with dermatological conditions, they allow comparisons across diseases or populations.

These instruments capture the consequences of hand eczema as the individual reports them, but they do not measure hand function itself. Grip strength, manual dexterity, sensibility, and pain caused by use, which are assessed routinely in hand rehabilitation [17], have rarely been examined in individuals with hand eczema or with psoriasis on the hands, and their relation to the performance of daily activities in these conditions is largely unknown.

1.4.4 The International Classification of Functioning, Disability and Health

The present thesis uses the International Classification of Functioning, Disability and Health (ICF) [156], developed by the World Health Organization (WHO), as a conceptual framework to support the interpretation of the findings. The ICF provides a biopsychosocial framework for describing and understanding health, functioning, and disability by considering the interaction between a person's health condition, functioning, and contextual factors. In Chapter 5, the framework will be used as an aid in interpreting how the results relate to different aspects of functioning and to place the findings within a broader health

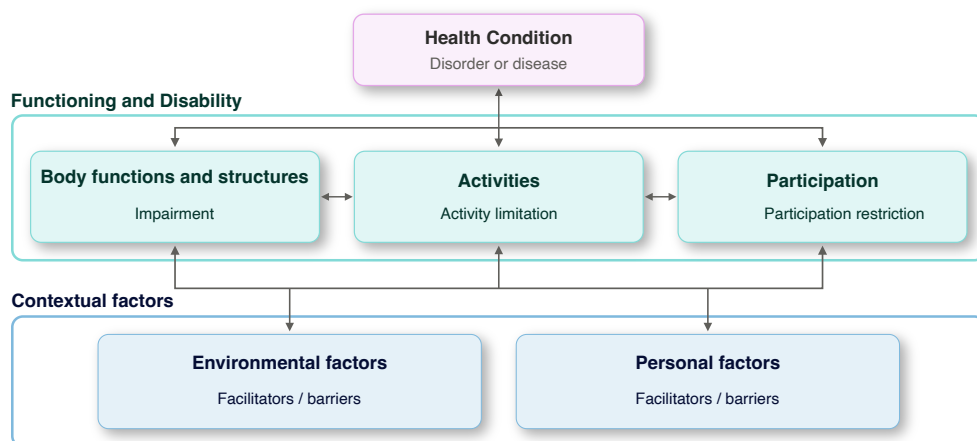


Figure 1.4: The ICF framework: Interactions between the components of the International Classification of Functioning, Disability and Health (ICF). Reproduced from the World Health Organization (2001).

perspective.

The ICF, illustrated in Figure 1.4, consists of two main parts. The first, Functioning and Disability, includes Body Functions and Structures and Activities and Participation. Body functions refer to the physiological and psychological functions of the body, while body structures refer to anatomical parts. Activities refer to what individuals do, while participation concerns their engagement in everyday life situations.

The second part, Contextual Factors, includes Environmental Factors and Personal Factors. Environmental factors refer to the physical, social, and attitudinal environment in which a person lives. Personal factors concern individual characteristics, such as age, previous experiences, and coping strategies. Although personal factors are included in the conceptual framework, they are not classified using specific ICF categories.

Chapter 2

Aim and objectives

The overarching aim of this project was to investigate the consequences of ongoing hand eczema or psoriasis for hand function, its impact on health-related quality of life, and the perceived ability to perform daily activities.

The specific objectives were to:

- Investigate whether hand eczema is associated with a measurable impairment of hand strength and manual dexterity and to study the relationship between hand function and the ability to perform activities of daily living (ADL), pain level and quality of life measured with the Dermatology Life Quality Index (DLQI). (Study I)
- Investigate whether the location of hand eczema, in particular involvement of the fingertips of the first three digits and the presence of fissures, is associated with hand function, performance of daily activities, health-related quality of life and pain. (Study II)
- Explore the challenges that individuals with chronic hand eczema experience when performing their daily activities, and the importance they place on being able to carry out those activities. (Study III)
- Describe the challenges in daily life experienced by individuals with cutaneous psoriasis localised to the hands. (Study IV)

Chapter 3

Material and methods

This thesis is based on four studies: Studies I–III involve individuals with hand eczema, whereas Study IV involves individuals with psoriasis affecting the hands. Studies I and II are quantitative, while Studies III and IV are qualitative.

3.1 Participants

Participants in all four studies were patients recruited from dermatology or occupational and environmental dermatology clinics in southern Sweden.

Study I included 21 adults with ongoing hand eczema (14 women and 7 men; mean age 47 years, range 22 to 62). Eczema had to be present on the volar aspect of at least one hand, regardless of duration, and the participant had to be in need of further treatment. Twelve of the 21 participants were re-examined once their eczema had healed, or had improved as far as the participant considered possible; for practical reasons, follow-up was capped at 21 months.

Study II included 45 patients with ongoing hand eczema (29 women and 16 men). Eczema had to be present on at least one hand, irrespective of severity or duration. All had had hand eczema for longer than three months and 23 for more than five years.

Study III included 11 adults with ongoing chronic hand eczema. Eczema was regarded as chronic when it persisted for more than three months or recurred at least twice within a year, following the ESCD definition [144], and participants had to be candidates for systemic therapy. The group comprised five men and six women (mean age 46, range 22 to 63).

Study IV included seven adults with cutaneous psoriasis localised to the hands. Here, psori-

asis on the hands meant psoriasis vulgaris of the hands confined to the skin and explicitly excluded cases co-occurring with arthritis, so that any effect on hand function could be attributed to the skin rather than the joints. The group comprised five men and two women (mean age 47, range 32 to 60).

Three participants took part in both Study II and Study III, and one participant took part in Studies I-III.

3.2 Quantitative research methods

Studies I and II assessed hand function with a battery of instruments established in hand surgery and occupational medicine [17, 88], described in detail in section 3.2.1 below. Study I compared participants with ongoing hand eczema both with published normative values and with themselves once the eczema had healed. Study II tested the hypothesis that hand function, pain, performance of daily activities and quality of life are more affected when the eczema involves the fingertips of digits I to III, and more affected still when fissures are present at those sites.

3.2.1 Data collection

Table 3.1: Overview of the outcome measures used in Studies I-II.

Instrument	Measured outcome	Study I	Study II
Jamar dynamometer	Grip strength	●	●
Pinch gauge	Palmar pinch	●	●
	Key grip	●	●
Purdue pegboard	Manual dexterity	●	
Mini Sollerman test	Manual dexterity		●
Shape-Texture Identification (STI) test	Tactile discrimination		●
Numeric Pain Rating Scale (NRS)	Pain	●	●
Custom questionnaire	Performance of daily activities	●	
DASH	Performance of daily activities		●
DLQI	Health-related quality of life	●	●
QOLHEQ	Health-related quality of life		●

Assessment of hand function

Grip strength (volar grip) was measured in both Study I and Study II with a Jamar dynamometer, the handle set to the second, standard position, following the procedure described by Mathiowetz [92].

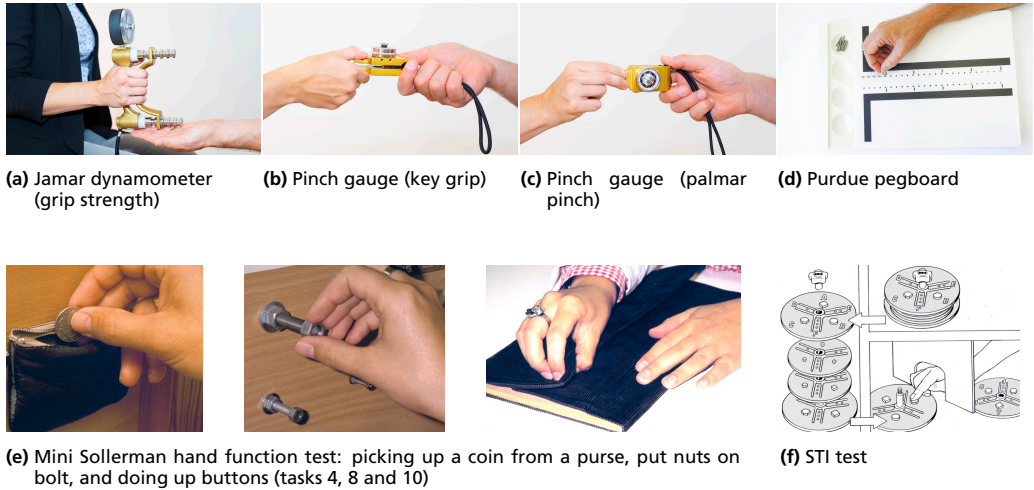


Figure 3.1: Instruments used to assess hand function. Grip and pinch strength were measured in both studies with (a) the Jamar dynamometer, (b) the pinch gauge in key grip and (c) the pinch gauge in palmar pinch. Manual dexterity was assessed with (d) the Purdue pegboard in Study I and (e) the Mini Sollerman hand function test in Study II, and tactile discrimination with (f) the Shape-Texture-Identification test in Study II. Figures (a)-(d) from Study I [116], (e) by Birgitta Rosén, (f) by Fredrik Johansson.

Finger grip was assessed in both studies with a pinch gauge (0 to 27 kg, B & L Engineering) in two grips: the palmar pinch and the key grip, the two grips most frequently used in daily activities and the ones that engage the fingertips of digits I to III [69, 138].

Manual dexterity was captured differently in the two studies. Study I used the Purdue pegboard, on which the participant placed as many pins as possible in 30 seconds, one hand at a time [146]. Study II used the Mini Sollerman test, an abbreviated form of the Sollerman hand function test comprising three of its twenty standardised tasks (do up four buttons of different sizes, pick up four coins of different sizes from a purse and put four nuts of different sizes on bolts), selected since they have been shown to correlate well with the full test [41, 130, 139], scored according to the grip the participant adopted and the time taken to complete each task. The score therefore registers a change of grip, which a count of pins does not.

Tactile discrimination was assessed in Study II with the Shape-Texture Identification (STI) test [131], in which participants identified shapes and raised-dot textures by touch behind a screen. The standard procedure examines the index finger for median nerve function and the little finger for ulnar nerve function. Since the concern here was the skin of the three radial digits rather than a nerve lesion, the procedure was adapted so that the thumb, index and middle finger were each tested and the three scores averaged, to a maximum of 6. Protective sensation, which is a prerequisite for the test, was first confirmed with a Semmes–Weinstein monofilament [17].

In both studies the tests were administered by the same researcher, always starting with the dominant hand. Standardised encouragement was given before each test.

Patient-reported measures

Pain was rated on the Numeric Pain Rating Scale (NRS) in both studies, from 0, no pain, to 10, the worst imaginable pain [70]. In Study I it was recorded once, immediately before the functional tests; in Study II it was recorded both before and after the tests, to capture whether it changed when participants used their hands to perform tasks involving common functional grips representative of everyday activities.

Performance of daily activities was measured differently in the two studies. No hand-eczema-specific instrument such as the QOLHEQ was available when Study I was carried out. A 26-item questionnaire covering common hand-intensive daily activities, including those patients describe in the clinic, was therefore constructed; each item scored from 0, no difficulty, to 3, impossible to perform. Since hand eczema might vary from one day to the next, participants graded their ability as it was on the day of testing rather than over the preceding week, and gave their most likely response where a task had not arisen that day. The final score was the mean of the scores of completed items, those marked not applicable being excluded. Study II instead used the validated Disabilities of the Arm, Shoulder and Hand questionnaire (DASH) [65], 30 items rated from 1 (no difficulty) to 5 (unable), averaged and rescaled to a score from 0 to 100, with the preceding week as the reference period.

Health-related quality of life was measured in both studies with the Dermatology Life Quality Index (DLQI) [45], ten items scored 0 to 3 and summed to a total score of 0 to 30. Study II additionally assessed health-related quality of life with the Quality of Life in Hand Eczema Questionnaire (QOLHEQ) [109], 30 items across four domains, symptoms, emotions, functioning, and treatment and prevention, giving a total score from 0 to 120. For all of these measures, a higher score indicates greater impairment.

3.2.2 Statistical analyses

In Study I, functional scores from all four tests were standardised to z-scores using published normative data [57, 92], so that each score expressed the number of standard deviations by which a participant's score differed from the reference value for their sex and age. A z-score beyond ± 1.96 was taken as a significant difference from the norm. Changes between baseline and after healing were analysed using the Wilcoxon signed-rank test, while associations between the functional tests, performance of daily activities, DLQI, and pain were assessed using Spearman's rank correlation. Analyses were performed in R version 3.2.2.

In Study II, the grip and pinch measurements were standardised to z-scores. The Mini Sollerman and STI tests were compared against fixed scores of 12 and 6, respectively, rather than age- and sex-specific normative data. The participants were classified into three ordered groups according to fingertip involvement and the presence of fissures. Trends across the ordered groups were tested using the non-parametric Jonckheere–Terpstra test. Analyses were performed in SPSS Statistics version 30.0. In both studies, P values below 0.05 were considered statistically significant.

3.3 Qualitative research methods

3.3.1 Data collection

Data for Studies III and IV were collected through semi-structured, face-to-face interviews, conducted in Swedish by the first author. In both studies the interview guide was developed using similar structure and type of questions as the Canadian Occupational Performance Measure (COPM) [84], a client-centred occupational therapy instrument in which people identify the activities they find difficult to perform. The guide was structured around the course of an ordinary day, so that participants named the hand-related difficulties they met during it. In Study III the participants also rated on the COPM scales, from 1 to 10, both their perceived performance of daily activities and how much they valued these activities. The interview guide for each study was evaluated in a pilot interview. Both pilot interviews led only to minor linguistic refinements and were therefore included in the final datasets. The interviews lasted about an hour, between 35 and 80 minutes, and were conducted in a quiet room, audio-recorded and transcribed verbatim. Both studies were reported in accordance with the COREQ checklist [147].

3.3.2 Analysis

Studies III and IV were analysed by qualitative content analysis [50]. The transcripts were first read through several times to give an impression of the whole. Passages related to the aim of the study, whether a single word, a sentence or a longer phrase, were then lifted out as meaning units, shortened without losing their sense, and given codes; the codes were compared with one another and gathered into categories, and into subcategories where the material warranted them. In Study IV the analysis also addressed the latent content of the interviews, that is, the underlying meaning of what participants described rather than only what they stated outright. In both studies the first and last authors coded the transcripts independently and then compared their readings, returning to the original text wherever these diverged and continuing until they agreed. Quotations were used to let the

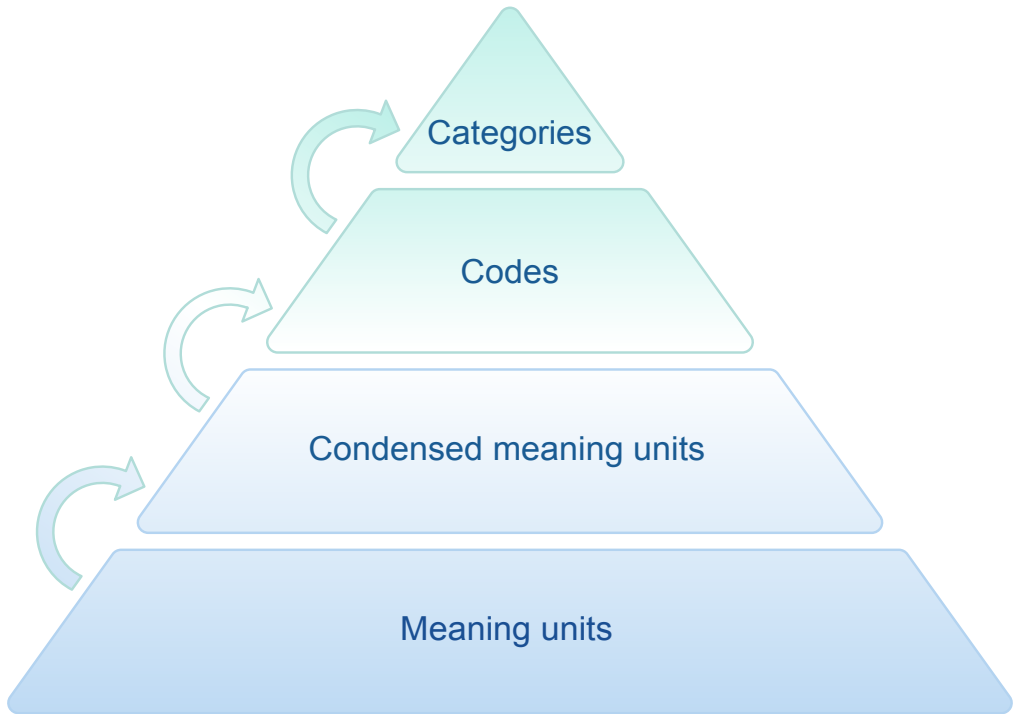


Figure 3.2: The qualitative research process leading from meaning units to categories.

participants speak in their own words; all quotations were translated into English and the translations checked by a native speaker.

3.4 Ethics

All four studies were conducted in accordance with the Declaration of Helsinki [157]. Written informed consent was obtained from the participants. Study I was approved by the regional ethical review board in Lund, the body responsible at the time it was carried out, while Studies II, III and IV were approved by the Swedish Ethical Review Authority (Dnr 2021-01871, Dnr 2021-05682-02).

Chapter 4

Results and comments

4.1 Study I

In Study I, hand function was evaluated in 21 participants with hand eczema. The assessment included tests of volar grip strength, palmar pinch/key grip, and manual dexterity, together with patient-reported measures of pain, health-related quality of life, and ability to perform daily activities. A subgroup of 12 participants underwent repeat assessment after healing, enabling within-participant comparison of hand function during hand eczema and after healing.

At baseline the group mean was within the normative range on every functional test, though the spread between participants was wide. Finger strength measured by palmar pinch deviated most, with a mean z-score of -1.07 on the left hand (95% CI -1.84 to -0.30) and -1.19 on the right (95% CI -1.84 to -0.54), intervals that lie wholly below the reference mean.

Among the twelve participants re-examined after their hand eczema had healed, every functional measure improved to a statistically significant degree in both hands: hand grip strength ($P = 0.011$ on the left and 0.0092 on the right), palmar pinch ($P = 0.013$ for both hands), key grip ($P = 0.0087$ on the left and 0.0085 on the right) and manual dexterity ($P = 0.024$ on the left and 0.0087 on the right). Their perceived ability to perform daily activities, their DLQI score and their reported pain improved in the same way ($P = 0.0024$, 0.0038 and 0.0036 respectively).

Difficulty with daily activities was related most closely to manual dexterity and to the two grips that engage the fingertips. On the right hand the strongest association was with manual dexterity ($\rho = -0.63$, $P = 0.0021$) and on the left with palmar pinch ($\rho = -0.64$, $P = 0.0019$). Key grip ranked second on both hands ($\rho = -0.62$, $P = 0.0029$ on the left and $\rho =$

-0.48, $P = 0.028$ on the right). The relation to hand grip strength was weaker and reached significance in neither hand ($\rho = -0.33$, $P = 0.15$ on the right; $\rho = -0.40$, $P = 0.073$ on the left). Difficulty with daily activities correlated strongly with both quality of life and pain, at $\rho = 0.72$ in each case ($P = 0.00022$ and 0.00027). All twenty-one participants reported some restriction in daily life, most often in tasks involving water and in opening jars and cartons, and a small number of participants reported being unable to perform these tasks at all (Figure 4.1).

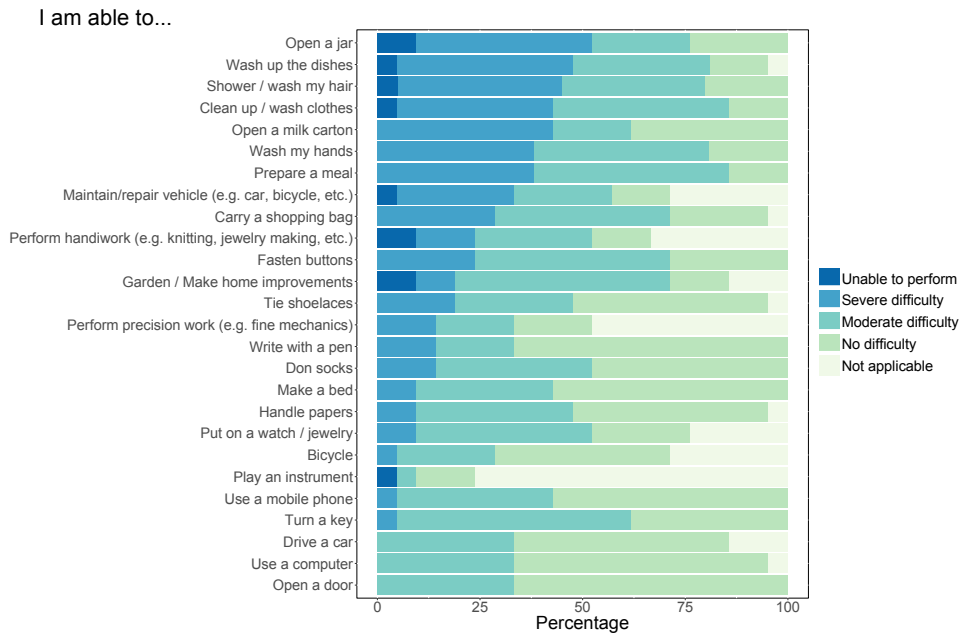


Figure 4.1: Ability to perform activities of daily living (ADL) in 21 participants. The participants rated their ability to perform activities of daily living, ranked by severity, at baseline, when they had hand eczema. Figure from Study I [116].

The comparison with normative data should be interpreted with some caution. At follow-up the participants performed better not only than at baseline but also than the reference values, possibly because most of them had physically demanding occupations. If so, the level of performance to be expected of them lies above the population mean, and their impairment at baseline was greater than the comparison with normative data indicates. The actual impairment of each participant is therefore best established by comparing their own performance before and after healing.

The functional tests measure a maximal effort performed on a single occasion under standardised conditions, which does not correspond to the way the hands are used in the course of a day. A participant may make a temporary effort to complete a test in spite of pain; one participant did so although a fissure on her fingertip had begun to bleed. A result within the normative range does not, therefore, exclude difficulties in daily life. The strong cor-

relation between pain and perceived difficulty in performing daily activities suggests that patients who report pain associated with their hand eczema may also have a reduced ability to perform daily activities, and that this deserves attention when treatment is planned. That the perceived ability to perform daily activities was most closely related to dexterity and to palmar pinch might be explained by the content of the questionnaire, in which the majority of the items concern activities involving manual dexterity and finger strength.

4.2 Study II

Study II examined 45 patients with ongoing hand eczema, classified into three ordered groups according to involvement of the fingertips of digits I to III: no involvement of these sites (control), eczema at these sites without fissures, and fissures at these sites. Across the three groups the mean values for grip and pinch strength, expressed as z-scores, lay close to the normative reference values, with palmar pinch running somewhat lower. Neither volar grip ($P = 0.297$ on the left, 0.776 on the right) nor key grip ($P = 0.418$ on the left, 0.157 on the right) showed any relation to the location of the eczema, and individual scores varied widely, particularly for the key grip. Palmar pinch showed a trend across the ordered groups on the left hand ($P = 0.044$); on the right hand the trend did not reach the conventional significance level ($P = 0.062$).

Manual dexterity declined monotonically from the control group through the eczema tips group to the fissures tips group in both hands ($P = 0.014$ on the left, 0.022 on the right), as seen in Figure 4.2. Most participants in the control group scored at or close to the maximum of 12, whereas the scores of the fissures tips group were spread across the lower half of the scale. Tactile discrimination, assessed with the Shape–Texture–Identification (STI) test, was reduced in 28 of the 45 participants. The reduction did not, however, follow a clear trend ($P = 0.060$ on the left, 0.204 on the right).

As seen in Table 4.1, the patient-reported outcomes worsened progressively across the three groups. Performance of daily activities, health-related quality of life (DLQI and QOLHEQ) and pain, assessed both before and after the functional tests, all deteriorated as fingertip involvement increased, with quality of life and pain separating the groups most sharply ($P = 0.004$ for DLQI, 0.008 for QOLHEQ, 0.040 for DASH, and 0.003 for pain both before and after testing). The median DLQI rose from 8 in the control group to 10 where the fingertips were affected and 20 where fissures were present, that is from a moderate to a very large effect on the patient's life [64], and the median QOLHEQ from 36.5 to 46.5 and 73, corresponding to a slight, a moderate and a strong impairment of health-related quality of life [113]. The median DASH score rose from 9.2 to 20.4 and 36.2. Pain before testing rose from a median of 1.0 to 1.5 and 4.0, and in every group the rating taken after the tests exceeded the one taken before, by one point in the control and eczema tips

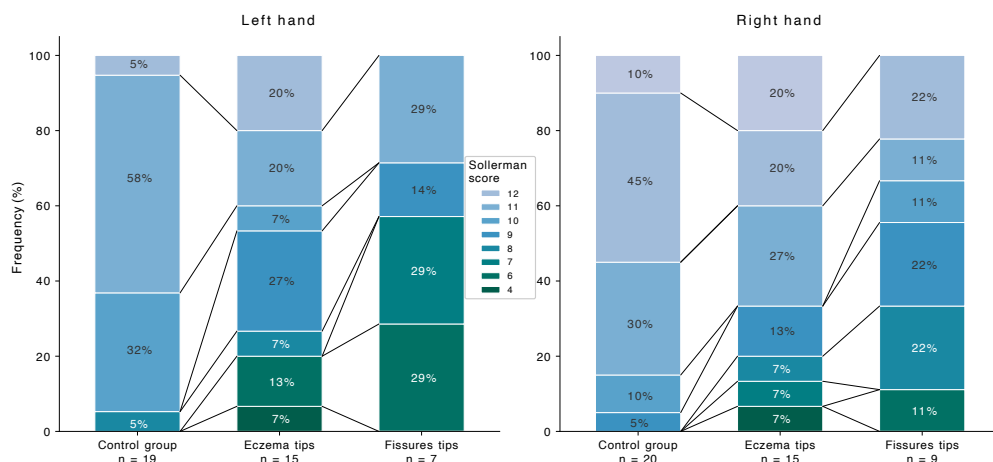


Figure 4.2: Manual dexterity. Stacked bar chart comparing the distribution of Mini Sollerman test scores across the three groups for the left hand (n=41) and right hand (n=44). *Control*: Hand eczema without involvement of any of the three fingertips of digits I–III. *Eczema tips*: Hand eczema with involvement of any of the three fingertips of digits I–III, without fissures on the fingertips of digits I–III. *Fissures tips*: Hand eczema with fissures specifically on any of the three fingertips of digits I–III. A lower score indicates poorer manual dexterity. Figure from Study II.

groups and by two where there were fissures.

Manual dexterity, measured with the Mini Sollerman test, decreased across the ordered groups, whereas volar grip and key grip showed no such trend. The Mini Sollerman test consists of tasks that closely resemble everyday activities and, in contrast to the Jamar dynamometer and the pinch gauge, where the grip is predefined, it reflects not only whether the task is completed but also which grip the participant selects and the time required, which may explain why it distinguished between the groups. During testing, several participants with fissures appeared to adopt compensatory strategies in order to spare the affected finger, which is not possible to capture with instruments where the grip is predefined.

Reduced tactile discrimination was found in a majority of the participants, but no clear trend was seen across the ordered groups, and the small sample size may have limited the power to detect one. Protective sensation was preserved. Eczema is a peripheral condition, and inflammation and altered skin structure may affect the function of the mechanoreceptors of the fingertips, but, unlike after a nerve injury, the signal pattern reaching the somatosensory cortex appears to remain unchanged, which may partly explain the relatively good performance on the STI test. Since the test is not timed, the longer time that several participants with affected fingertips appeared to require did not influence their scores, although a delay in the processing of tactile information could have consequences in activities such as handling small objects or fastening buttons. The impairments observed here thus appear to be related to the location of the eczema and to the presence of painful fissures

Table 4.1: Health-Related Quality of Life, Performance of Daily Activities and Pain. The Jonckheere–Terpstra test was used to compare trends across ordered groups. A higher score indicates a greater negative impact. Table adapted from Study II.

		Control (n = 18)			Eczema tips (n = 16)			Fissures tips (n = 11)			P-value
		Median	Min	Max	Median	Min	Max	Median	Min	Max	
Questionnaires	DLQI	8.0	0.0	25.0	10.0	2.0	22.0	20.0	5.0	28.0	0.004
	QOLHEQ	36.5	7.0	92.0	46.5	12.0	101.0	73.0	0.0	105.0	0.008
	DASH	9.2	0.0	75.8	20.4	1.7	65.0	36.2	15.0	75.8	0.040
NRS Pain											
	Pain before test	1.0	0.0	8.0	1.5	0.0	7.0	4.0	2.0	8.0	0.003
	Pain after test	2.0	0.0	9.0	2.5	0.0	9.0	6.0	3.0	9.0	0.003

Control: Hand eczema without involvement of any of the three fingertips of digits I–III. *Eczema tips:* Hand eczema with involvement of any of the three fingertips of digits I–III, without fissures on the fingertips of digits I–III. *Fissures tips:* Hand eczema with fissures specifically on any of the three fingertips of digits I–III.

rather than to reduced sensibility.

The patient-reported outcomes deteriorated in the same order as the measured ones, and the group with fissures was the most affected on all of them. Eczema at this location therefore deserves particular attention in clinical practice, and treatment should not be tapered until the fissures have healed, even when erythema and oedema have resolved.

4.3 Study III

Study III was based on semi-structured interviews with 11 adults with chronic hand eczema, all of them candidates for systemic treatment. Six categories were identified during qualitative content analysis of the interviews: work, household management, leisure, personal care, socialisation and transportation, with acquaintances, family and intimacy forming subcategories within socialisation. The fluctuating course of the disease emerged as a central difficulty, since participants could not know from one day to the next what their hands would allow, and were therefore unable to plan reliably or to keep commitments.

Which activities were difficult, and which mattered, varied considerably between participants. Work was rated the most important activity in the group and among the hardest to sustain, with several participants changing careers, reducing their hours or working against medical advice to avoid loss of income. Cooking and intimacy followed in importance. Pain from fissures and concern over the appearance of the hands were the factors most often described as making an activity impossible.

Participants managed their daily activities through a range of strategies, including favouring the less affected hand, adopting new grip patterns, relying on gloves, bandages and other aids, and lowering their expectations. Where a participant had a partner, that partner’s

share of certain activities tended to increase as the eczema worsened.

All participants described difficulty in social situations, shame connected to the appearance of the hands, and distress around shaking hands.

All participants described difficulties in performing their daily activities, and the severity of these difficulties varied with the fluctuating course of the disease, which made it difficult for them to plan their lives and frequently resulted in broken commitments and cancelled activities.

Most participants reported substantial difficulties with work-related activities, which is in line with previous studies showing that hand eczema may affect work ability, particularly in occupations involving hand-intensive tasks, wet work or exposure to irritants and allergens. Most of the participants held positions of this kind, but difficulties were also described with dry and clean tasks such as writing with a pen, handling papers and using a mobile telephone, and it is therefore worth noting that even such activities are not free from discomfort. The consequences of chronic hand eczema for society are well documented, but the present findings also point to a personal financial burden, since the loss of income associated with sick leave could prevent participants from following medical advice, as could a reluctance to add to the workload of their colleagues.

Concern about the appearance of the hands was described as a common disabling factor, and several participants described their eczema as a stigma and avoided social activities for that reason. This is in line with the finding that visible skin diseases place a considerable burden on social interaction, and that individuals with dermatoses located on the hands are more likely to perceive their condition as a disability than those whose disease is located in less visible areas [128]. Pain, in particular from fissures, affected the performance of daily activities within all categories, which corresponds to the association measured in Study I.

Since chronic hand eczema affects several areas of life, rehabilitation needs to take the circumstances of the individual patient into account, preferably within a multidisciplinary team in which physical, psychological and social aspects can all be addressed.

4.4 Study IV

Study IV concerned a different patient group: seven adults with psoriasis vulgaris of the hands confined to the skin, joint involvement being an exclusion criterion, so that the difficulties described could be attributed to the skin itself. The interviews were analysed with qualitative content analysis addressing both manifest and latent content. As seen in Figure 4.3, three categories were identified: physical consequences for daily activity performance, social vulnerability, and living with uncertainty and altered capability. Most

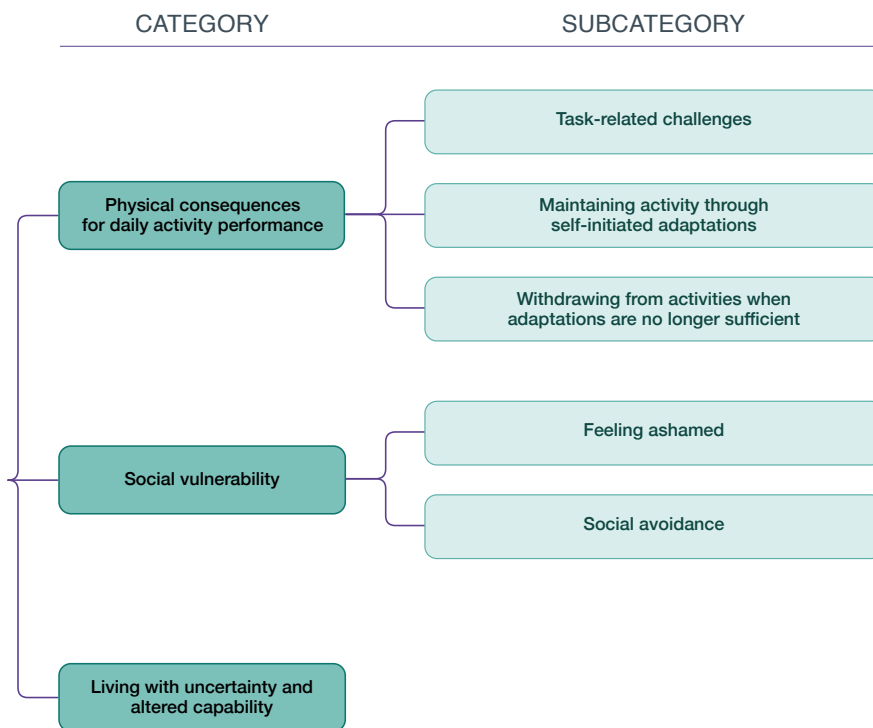


Figure 4.3: Results from the qualitative content analysis. The categories and subcategories found during content analysis are presented as a flowchart. Figure from Study IV.

participants continued to work, run a household, travel and pursue leisure interests, though this was often possible only through self-initiated adaptations such as gloves, plasters and bandages, altered grips, the avoidance of particular tasks and reliance on others. When adaptation was no longer sufficient, participants withdrew from activities, some abandoning valued pursuits during flares and others continuing despite the pain or the risk of aggravating the condition.

Difficulty at work followed the physical demands of the job, and participants in hand-intensive or wet occupations described a greater burden, yet administrative work was not free from difficulty.

The visibility of the hands gave rise to shame and a sense of stigmatisation, leading to concealment of the hands and avoidance of social and intimate contact, with handshaking reported as a frequent source of unease.

Participants also described a reduced trust in their hands and an uncertainty, from day to day and across the seasons, about what those hands would manage, which made activities

hard to plan and was a particular source of stress at work. Some adaptations had become so integrated into daily life that participants no longer recognised them as adaptations.

The impact of cutaneous hand psoriasis on daily life may not always be readily apparent. Participants often maintained their usual activities by relying on strategies that had gradually become part of their normal routines. Although these adaptations enabled continued participation, they could require substantial additional effort and planning and were frequently accompanied by pain or discomfort. The fluctuating nature of symptoms adds further complexity, as functional difficulties may be limited at the time of a clinical encounter but become considerably more pronounced during subsequent flares. Exploring not only whether patients are able to perform daily activities, but also how they manage to do so, may therefore help clinicians recognise unmet needs.

When adaptation was no longer sufficient, participants withdrew from activities, some from highly valued ones during flares, whereas others considered it worthwhile to continue despite pain or the risk of aggravating the skin condition. Activity limitation in cutaneous psoriasis on the hands is thus not solely a matter of physical capacity. The participants also described a reduced trust in their hands and an uncertainty as to whether grip, precision or sustained effort would be available on a given day. Such fluctuation is not readily captured by a single clinical assessment, since a patient may function adequately during the consultation and still expect daily activities to become painful or impossible during the next flare.

Chapter 5

Discussion and conclusions

5.1 General discussion

Taken together, Studies I–III contribute to a more detailed understanding of how hand eczema may affect hand function and the performance of daily activities. Study I demonstrated that ongoing hand eczema may be associated with measurable impairment in strength and manual dexterity and that these functions improved as the eczema healed, providing a basis for considering hand function as a relevant outcome in hand eczema. Study II extended these findings by showing that the functional consequences also appear to depend on lesion location: involvement of the first three fingertips was associated with greater impairment in manual dexterity and palmar pinch strength, particularly when fissures were present. Study III adds an everyday-life perspective, showing how pain, fluctuating symptoms and altered hand use affect work, household activities, leisure and social participation, and how individuals use adaptations to manage these difficulties. Thus, the quantitative and qualitative findings support each other while capturing different dimensions of functioning. Study IV provides a cautious extension of this perspective to cutaneous psoriasis affecting the hands, where similar adaptations and activity-related difficulties were described; however, given that the study has a small sample size and focuses on a different diagnosis, these findings should primarily be considered hypothesis-generating.

The findings of Studies I and II suggest that objective measurements of hand function could play a useful role in the assessment and follow-up of patients attending dermatology clinics with hand eczema, and serve as complementary outcomes in treatment studies. Among the instruments used in the present studies, the Mini Sollerman hand function test appears particularly well suited to this purpose. The test includes tasks resembling activities in daily life and takes into account the grip selected, the time required to complete the task and

whether the task was performed with difficulty, so that the score registers a change of grip. The full Sollerman Hand Function Test was developed on the basis of commonly used grips in daily activities, including precision grips involving the thumb, index and middle fingers [69, 139]. In Study II, participants with painful fissures sometimes avoided the affected finger and used alternative grips. Such compensatory strategies could be observed during the Mini Sollerman test but would not be captured by measurements in which the grip is predefined, such as the dynamometer and the pinch gauge. The test is quick to administer and requires little equipment, which makes it feasible in a dermatology clinic and suitable as a complementary outcome measure in treatment studies.

Repeated assessments during treatment may show whether improvement of the hand eczema is accompanied by improvement in hand function and in the ability to use the hands, and may identify the patients for whom this is not the case. Such patients may need interventions in addition to dermatological treatment, such as rehabilitation, ergonomic measures or adaptations at work or in daily activities, and an assessment of hand function offers a means of identifying them. Multidisciplinary interventions of this kind are already established within secondary and tertiary prevention in Germany, where dermatological treatment is combined with patient education and occupational adjustments, and where structured individual prevention programmes have improved disease control and supported continued employment [2, 135]. Objective measurements may contribute both to identifying individuals who could benefit from such interventions and to evaluating their effect.

The findings from Study IV raise the question of whether objective assessment of hand function may also be relevant in patients with cutaneous psoriasis affecting the hands, as participants described difficulties with grip and manual dexterity and frequently adapted how they used their hands in daily activities. However, as the study was qualitative and included only seven participants, it cannot be assumed that patients with hand psoriasis would demonstrate the same objective functional impairments as those observed in hand eczema. Future studies could therefore investigate hand function in this patient group, particularly using an activity-based measure such as the Mini Sollerman hand function test.

In the clinical encounter, these findings argue for asking patients directly about pain, fissures, hand function, the performance of daily activities and the adaptations they have had to make, and about which of their activities are of particular importance to them. Such questions are necessary because the difficulties are not otherwise disclosed. In Study IV, several adaptations had become so habitual that the participants no longer recognised them as adaptations, and in Study III the activity rated as most important, work, was also among the hardest to sustain. For some patients, treatment of the skin may need to be combined with further support, such as occupational therapy, ergonomic measures, or psychosocial support.

5.2 Interpretation of the findings using the ICF framework

The ICF provides a useful framework for interpreting the findings of this thesis since it considers functioning in terms of body functions and structures, activities and participation, in interaction with the health condition and contextual factors. Functioning is therefore not understood solely as a consequence of the health condition, but also in relation to the activities a person needs or wants to perform and the circumstances in which these activities take place. This is particularly relevant to the present thesis, in which different methods capture different aspects of functioning: performance-based measures of hand functions, patient-reported difficulties in daily activities, and interviews describing how these difficulties are experienced and managed in everyday life. Figure 5.1 places the findings from Studies I–IV within the components of the framework.

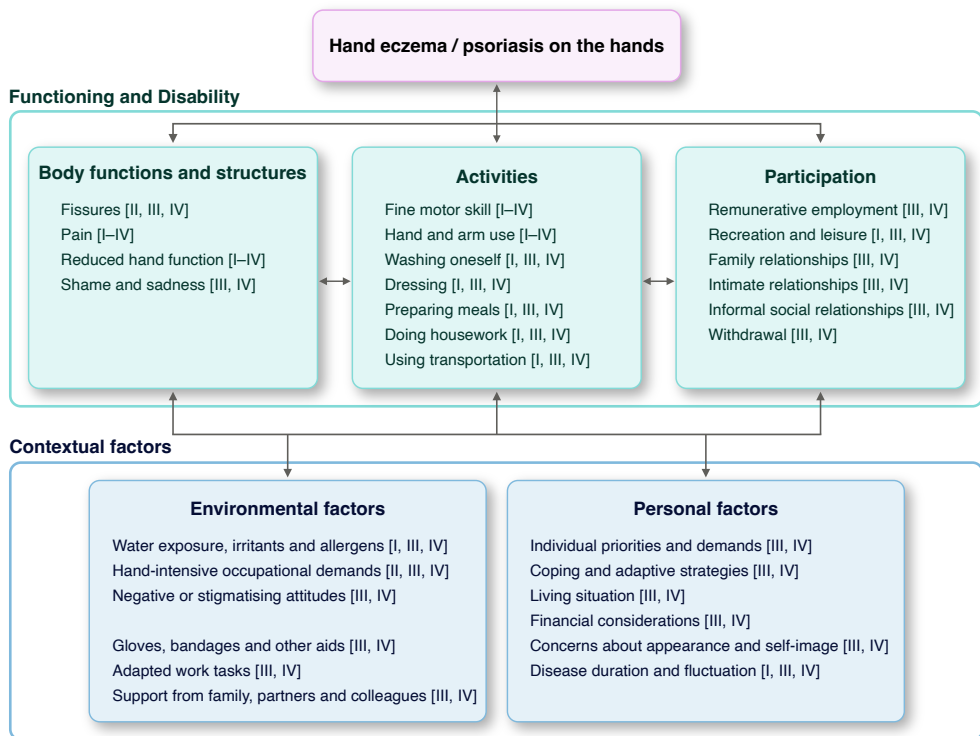


Figure 5.1: Findings from Studies I–IV placed within the components of the ICF [156]. Roman numerals indicate the study in which the finding was reported.

5.2.1 Hand function, activities and participation

The findings from Studies I–III indicate that hand eczema may affect several aspects of functioning, although the problems differed between individuals and varied with the condition of the hands. Pain was a recurring problem across all three studies and is also recognised as an important symptom of chronic hand eczema in previous research and clinical guidelines [144, 159]. Study I also found changes in hand strength and manual dexterity during ongoing hand eczema, with improvement in these functions when the eczema had healed. In Study II, involvement of the first three fingertips was associated with greater impairment in manual dexterity and palmar pinch strength and with more pain, particularly when fissures were present. However, no clear associations were found for volar grip strength, key grip strength or tactile discrimination. Study III adds to this picture, as participants described painful fingertip fissures, reduced grip ability, altered fingertip sensation and difficulties controlling finger movements, particularly when the eczema was worse. Thus, pain, grip-related problems and difficulties with manual dexterity were identified in several studies, whereas the findings concerning sensory function were less consistent.

Study III also described sadness and shame, particularly in relation to social situations. These findings are consistent with previous research showing that visible skin disease may have substantial social consequences and that people with hand-localised dermatoses may experience stigma and restrictions in social interaction [128, 129]. Participants in Study IV likewise described shame concerning the appearance of their hands. Although based on a small qualitative sample, these findings suggest that some of the challenges identified in chronic hand eczema may also be relevant for individuals with cutaneous psoriasis localised to the hands. Stigmatisation related to visible hand lesions has also been reported in psoriasis [47, 61].

Difficulties in performing daily activities were found across Studies I–III. In Study I, all participants reported some difficulty with activities of daily living, and these difficulties were related to manual dexterity, grip strength and pain. In Study II, limitations in daily activities were assessed using the DASH, with greater limitations among participants with involvement of the first three fingertips, particularly when fissures were present. Study III provided a more detailed description of which activities were difficult and how they were affected. Participants described problems with work-related tasks, preparing meals, personal care, housework, leisure activities and transportation. Fine motor skill and gripping were recurrent difficulties in activities such as handling objects, opening doors, exercising, driving and cycling.

The consequences also concerned participation in important areas of life. Work was highly valued but difficult for many participants in Study III. Previous studies have similarly shown substantial effects of hand eczema on work ability, sick leave and continued employment [31, 38, 112]. Recreation and leisure could be restricted, and some participants stopped activ-

ities when the hand eczema was worse. Family relationships, informal social relationships and intimacy were also affected. Social participation was sometimes restricted because participants felt ashamed or embarrassed about their hands, which is consistent with previous qualitative and survey-based research on the social burden of chronic hand eczema and visible skin disease [128, 129]. In Study IV, participation was similarly restricted by both the physical demands of an activity and the visibility of the hands, and participants withdrew from valued activities when adaptation was no longer sufficient.

Individual results in Study II also varied considerably. During the Mini Sollerman test, some participants, particularly those with fissures, completed the tasks by using alternative grips or avoiding an affected finger. This shows that the ability to complete a task may be maintained even when the way the hand is used is affected. Study III adds another aspect, as the activities that participants found difficult varied considerably between individuals and as the hand eczema fluctuated. Participation could also be affected for reasons other than difficulties in physical hand use. For example, shame and embarrassment about the appearance of the hands led some participants to avoid social activities.

5.2.2 Contextual factors in relation to functioning and disability

The findings from Studies I–III suggest that the consequences of hand eczema in everyday life are influenced by the context in which activities are performed. The demands placed on the hands, available adaptations and support from others may either increase or reduce the difficulties associated with symptoms and impaired hand function.

The demands of work and other daily activities appear particularly relevant. In Study I, activities involving water and opening containers were among those causing the greatest difficulty. In Studies I–III, many participants had occupations involving intensive hand use or frequent wet work. Wet work and exposure to irritants are well-established factors in hand eczema, and the occupational consequences of the condition may include reduced work ability, sick leave and occupational change [38, 144]. Study II noted that this occupational profile may have contributed to the reported work-related limitations, while Study III described difficulties in hand-intensive work, wet work and activities involving irritants. However, participants in Study III also reported problems with less physically demanding tasks, such as writing, handling paper and using a mobile phone; some could not unlock their telephones because their fingerprints were no longer readable. Taken together, these findings suggest that functional difficulties are related not only to exposure to water or irritants, but also to the specific demands an activity places on the hands. Pain, reduced grip ability or impaired manual dexterity may therefore have greater consequences when the person's work or daily activities require frequent, precise or sustained hand use. Study IV points in the same direction, as difficulties were related to occupational demands, although administrative work was not free from problems.

Environmental factors could also act as facilitators. In Study III, adapted work tasks, gloves, bandages and practical support from family members, friends, neighbours and colleagues helped participants manage activities that were otherwise difficult, and some paid for cleaning or shopping services. Thus, the ability to complete an activity did not necessarily mean that it was unaffected by hand eczema; continued performance could require adaptation, assistance or a different way of using the hands.

The social environment was also important. Support from family, partners and colleagues could make daily activities easier to manage, whereas negative reactions from others could restrict participation. In Study III, comments, staring and concerns that others might perceive the hand eczema as unpleasant or contagious contributed to shame and avoidance of social situations. Previous research on visible skin disease similarly indicates that actual or anticipated reactions from others may contribute to social burden and perceived stigma [128]. The consequences of visible hand eczema were therefore related not only to the individual's own concerns about appearance, but also to the reactions, or anticipated reactions, of other people. Handshaking recurred in Studies III and IV as a situation in which the hands became a social problem, recalling the role of the hands in communication and social interaction described in Section 1.1.1 [49, 79]. This is consistent with other work in which difficulties related to social interactions such as handshaking have also been reported in patients with hand eczema and psoriasis [27, 61].

Personal factors further contributed to the variation between individuals. Study III showed that participants differed in which activities they found important and difficult. Work was highly valued by most participants, followed by cooking and intimacy, but priorities varied. Living situation also influenced the possibilities for managing daily activities, as participants sharing a household could redistribute some tasks. Financial circumstances could limit choices; some participants continued working despite recommendations for sick leave because of concerns about loss of income.

Participants also differed in how they managed their difficulties, using strategies such as altering their hand use, seeking assistance or lowering their expectations. During the Mini Sollerman test in Study II, some participants with fissures avoided an affected finger and used alternative grips to complete the task, and comparable strategies were described in Study III, where participants used the healthier hand or changed their grip patterns. Performance-based assessment under standardised conditions and information about performance in everyday life may therefore provide complementary information about functioning. This distinction corresponds to the ICF distinction between capacity, which refers to what an individual can do in a standardised environment, and performance, which refers to what an individual actually does in their habitual environment [156]. In Studies III and IV, participants who maintained their activities often did so through gloves, dressings, altered grips and help from others, with some adaptations becoming so habitual that they were no longer recognised as such. Successful completion of an activity therefore does not

necessarily mean that it is performed without difficulty, additional effort or adaptation.

Some participants with long-standing hand eczema described well-established ways of managing household activities, which may reflect experience gained over time, although this was not specifically examined in Study III. The balance between demands, adaptations and support also changed as the hand eczema fluctuated. Study I showed improvement in hand function and daily activities when the eczema had healed, while Study III described how changes in symptoms affected the ability to plan and perform activities. The need for adaptations and support may therefore vary over time. In addition, some activities could themselves aggravate symptoms or reopen fissures, illustrating that the relationship between the health condition, activity and contextual factors may operate in both directions. Overall, the interaction between the condition of the hands, the demands of everyday life, available support and adaptations, and the individual's priorities and ways of managing difficulties may help explain why the consequences of hand eczema differ between individuals and within the same individual over time.

5.3 Novelty

Hand eczema severity is commonly scored from the extent and intensity of the clinical signs, while burden has been examined using quality-of-life instruments; the two have been shown to correlate [1, 22, 33, 90]. In Study I we assessed hand strength and manual dexterity in individuals with ongoing hand eczema using well-established instruments (Jamar dynamometer, pinch gauge, Purdue pegboard). These instruments were already in use in other fields such as hand surgery and occupational medicine [17, 25, 88, 120], but they had not been applied to hand eczema. Repeating assessment at baseline and after healing, each participant serving as their own control, allowed changes in hand function to be attributed to the hand eczema rather than to differences between individuals. Standardising the results to z-scores against validated normative data for sex and age made it possible to compare the participants to the general population [57, 92].

Study II focused on the location of hand eczema, in particular the fingertips of digits I–III, which are involved in most functional grips when performing daily activities [138, 139]. This study combined measured hand functions (grip and pinch strength, manual dexterity, tactile discrimination) with validated patient-reported outcomes (DASH, DLQI, QOLHEQ). Classifying the participants into three ordered groups (Control, Eczema tips, Fissures tips) by fingertip involvement and the presence of fissures permitted us to investigate associations between a potentially more relevant classification of hand eczema severity and its impact on functioning and daily activities. Pain in chronic hand eczema is common and frequently undertreated [60, 159], but it is ordinarily recorded once, with the hands at rest. In Study II, we recorded pain both before and after the functional tests, giving some indication of what using the hands in daily activities costs.

Qualitative research on chronic hand eczema is not new. Rönisch et al. described the emotional and social weight of the disease across several European countries [129], Møllerup et al. showed how demanding it is to sustain preventive routines in everyday life [99], Buse et al. examined illness perceptions in occupational hand eczema [20], Sloot et al. asked patients how they experienced the care they received [136], and Grant et al. assembled a conceptual model of the disease from interviews with patients and dermatologists [52]. In all of these, daily activities appear as one consequence among several and are described in general terms. Study III took the activities themselves as its subject. An interview guide inspired by the Canadian Occupational Performance Measure (COPM) kept the account at the level of an ordinary day and asked participants to name the activities they struggled with, so that the material consists of concrete tasks rather than of an abstract impact. It also recorded how much being able to perform each activity mattered to the participant, which earlier qualitative work in hand eczema has not done, and which matters because a modest limitation in something a person values highly is not the same as a severe limitation in something they can readily relinquish.

Study IV is, to our knowledge, the first qualitative study to describe challenges in daily life among individuals with cutaneous psoriasis confined to the hands. Previous studies have shown that psoriasis can substantially affect daily life, including when the hands are involved. However, hand involvement has often been studied together with the feet as palmoplantar psoriasis [30, 117], grouped with other sites [21], or examined in populations including individuals with psoriatic arthritis, where functional limitations may partly result from joint disease [21, 150]. Existing qualitative research also addresses psoriasis more broadly, including its psychosocial impact, patient experiences, treatment burden, and interactions with healthcare [67, 102, 106]. By excluding psoriatic arthritis and other conditions affecting hand function, we could attribute the difficulties participants described to the skin itself.

5.4 Methodological discussion

5.4.1 Quantitative studies

The instruments used in Studies I and II were selected because they are standardised, widely used in hand surgery, hand rehabilitation and occupational medicine [17, 25, 88, 120], and, for grip strength, pinch strength and manual dexterity, supported by published normative values [57, 92]. Although primarily validated for use in other medical populations, they assess grip patterns and hand functions that are commonly required in everyday activities [69, 104, 138]. We therefore considered them potentially relevant and applicable also to individuals with hand eczema, whose symptoms may affect the ability to perform these frequently used grips.

The instruments are quick to administer, require little equipment, and are repeatable [41, 88]. These characteristics also made the design of Study I possible, as each participant was assessed before and after healing and could therefore serve as their own control. Under these conditions, an observed change is less likely to be attributable to factors other than the eczema.

Their principal limitation is that none of the instruments has been specifically validated in a dermatological population. Reference values derived from healthy adults [57, 92], and instruments originally developed for musculoskeletal [65] and nerve conditions [130, 131], were applied to a population whose functional limitations arise primarily from the skin.

Grip and pinch measurements capture a brief and strongly encouraged effort [92], and someone who can override pain for the few seconds a trial lasts will produce a value that says little about a working day. Study II offers an indication of what that effort costs, since pain ratings rose after a battery of tests that makes no great mechanical demand on the hand, and pain is both common and undertreated in chronic hand eczema [60, 159]. Endurance, and the accumulation of pain across repeated use, went unmeasured.

In Study I, the participants performed better at follow-up, not only compared with the baseline but also but also compared with the normative data. A likely explanation is that most of them had hand-intensive occupations, and that their normal capacity is therefore higher than that of the general population. If so, comparison with normative data for the general population will underestimate the impairment caused by the eczema in this group. This supports the use of these instruments for within-patient follow-up, where each participant serves as his or her own control, and suggests that they could be used as outcome measures during rehabilitation in clinical trials, for instance to assess the effect of systemic treatment on hand function [16].

Of the functional measures, the Mini Sollerman test appears the most promising for this patient group, because it does not confine itself to one grip and because its scoring registers which grip the participant selects [41, 138, 139]; as seen in our studies, the participants often adapted their grip depending on the dermatosis location. It has not, to our knowledge, been used in hand eczema before, and its use here should be regarded as exploratory until it has been evaluated in a larger sample and validated for this population. Although we did not perform any physical tests on the individuals with cutaneous psoriasis in Study IV, they described the same kind of grip adaptation that we observed in Study II, which indicates that the Mini Sollerman test might also be useful for measuring manual dexterity in this patient group.

Quality of life was assessed in both quantitative studies with the DLQI [45], which is quick to complete, well-validated and firmly established in dermatology [19]. Following its developers, we have described it as a measure of quality of life, but it is more accurately a measure of health-related quality of life [78, 152], and that is how it should be read here.

When Study I was carried out no instrument existed for the performance of daily activities in hand eczema, and the questionnaire constructed for the study, though grounded in the difficulties patients describe in the clinic, was necessarily unvalidated. The QOLHEQ [109] appeared afterwards and would have been the natural choice had it been available; it was used in Study II alongside the DASH, and its Swedish use rests on validation and interpretability work carried out in other language versions [111, 113].

Using the DASH [65] makes it possible to compare different conditions affecting the upper limbs. However, it has seldom been used in patients with hand eczema [63] and has not been validated for this patient group.

Since patients were recruited from dermatology clinics, predominantly from an occupational and environmental dermatology department in a limited area of Sweden, those who were invited and agreed to participate may not be representative of all individuals with hand eczema [96]. This may be particularly relevant for questionnaires that include questions about work-related difficulties.

5.4.2 Qualitative studies

Trustworthiness in qualitative research is commonly discussed in terms of credibility, dependability, confirmability and transferability [50, 51]. Each of these was considered when designing and conducting Studies III and IV.

Credibility concerns how well the findings represent the participants' experiences. The interview guide was inspired by the COPM [84], an established client-centred assessment of the individual's own perception of difficulties in performing daily activities, and kept the interviews close to an ordinary day, so that participants named concrete activities rather than describing the disease in general terms. The transcripts were read repeatedly during the analysis, and quotations were used to show how the categories were grounded in the data. The guide also has a bias, since it asks for the activities that were difficult and gives less room to those that participants managed without effort. All interviews were conducted by the first author, which gave a consistent approach but also means that the whole dataset bears the mark of one interviewer. The first author is a healthcare counsellor at the department from which the participants were recruited, though not involved in the care of any of them at the time of the interviews. The interviews were conducted and analysed in Swedish, and only the quotations were translated, with the translations checked by a native English speaker. Dependability was supported by the use of an interview guide in both studies, evaluated in a pilot interview, by a systematic analytical procedure, and by reporting in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) [147]. Confirmability was strengthened by independent coding. The first and last authors coded the transcripts separately and then compared their readings, returning to the original

text where these diverged and discussing it until they agreed. The authors differed in profession and workplace, the first author being a healthcare counsellor at an occupational and environmental dermatology department and the last author an occupational therapist and researcher at an occupational and environmental medicine department. This reduced the risk that the analysis rested on a single perspective. Both were nevertheless familiar with patients with disorders affecting the hands. Preunderstanding was described in both studies, so that possible influences on the interpretation were made transparent. Transferability depends on the participants and the setting, and sample adequacy in qualitative studies rests on the information power of the material rather than on the number of participants [89]. Both groups were narrowly defined and gave detailed accounts relevant to the aim. In Study III, no new information relevant to the aim emerged after the seventh interview, and the remaining interviews added detail to patterns already identified. In Study IV, few patients met the inclusion criteria, so purposive sampling was not possible and all eligible patients were invited. Those who agreed to participate may have had more troublesome disease, or a greater wish to describe it, than those who declined. Participants in Study III had disease severe enough to warrant systemic treatment. The findings are therefore most relevant to individuals treated in specialist care in Sweden, and less so to individuals with mild hand eczema or psoriasis managed in primary care or without medical contact.

5.4.3 Combining quantitative and qualitative methods

Combining quantitative and qualitative approaches provided complementary perspectives on how hand eczema and psoriasis affecting the hands influence functioning and daily life. The quantitative studies made it possible to measure changes and differences across groups with different disease severity in hand function, pain, performance of daily activities and health-related quality of life, whereas the qualitative studies provided a more detailed understanding of how such difficulties were experienced and managed in everyday situations. The qualitative findings also helped to place the measured impairments in context by showing the importance of activity demands, individual priorities, adaptations and support from others. The two approaches provided a broader understanding than either could have achieved alone, linking measurable functional consequences with their practical significance in daily life.

5.5 Conclusions

- Hand eczema was associated with impaired hand strength and manual dexterity. Although the group mean values were already within the normative range at baseline, grip strength, palmar pinch, key grip and manual dexterity all improved significantly once the eczema had healed, each participant serving as their own control (Study I).

- Difficulties in performing daily activities were related to manual dexterity and to the grips that engage the fingertips, and they correlated strongly with pain and with health-related quality of life measured by the DLQI (Study I).
- The location of the hand eczema matters for hand functions and the performance of daily activities. Manual dexterity declined stepwise from participants whose fingertips of digits I–III were not affected, through those with eczema at these sites, to those with fissures there, and performance of daily activities, health-related quality of life and pain deteriorated in the same order, whereas volar grip and key grip showed no relation to location (Study II).
- Individuals with chronic hand eczema described challenges in work, household management, leisure, personal care, socialisation and transportation. Work was rated the most important activity and was among the hardest to sustain. The fluctuating course of the disease, pain (and the fear of pain) from fissures and concern over the appearance of the hands were most often what made activities difficult or impossible to perform (Study III).
- Cutaneous psoriasis localised to the hands entailed physical consequences for daily activity performance, social vulnerability and uncertainty about future capability. Most participants sustained their daily activities, albeit through self-initiated adaptations, some so integrated into everyday life that they were no longer recognised as adaptations, and withdrew from valued activities when adaptation was no longer sufficient (Study IV).

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