Clinical pain research

Tone Marte Ljosaa*, H. Bondevik, J.A. Halvorsen, E. Carr and A.K. Wahl **The complex experience of psoriasis related skin pain: a qualitative study**

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Abstract

Background and aims: Psoriasis is a common chronic skin condition, causing skin lesions with thickened and scaling skin, as well as erythema and inflammation that may involve painful sores, cracks, and pustules. Previously psoriasis was regarded as a painless skin condition. However, over the past decade studies show that skin pain is a frequently reported and bothersome symptom in patients with psoriasis. There is however a lack of rich narratives describing the experience of skin pain in these patients. The aims of this qualitative study were therefore to explore in depth how patients experience psoriasisrelated skin pain, and how they deal with it.

Methods: Thirteen patients with psoriasis were recruited from a dermatology ward and outpatient clinic. One of the investigators (TML) performed individual, semi-structured interviews at an undisturbed room in the hospital. Interviews were thematically analyzed using the method of Systematic Text Condensation as described by Malterud (2012). Results: Three main themes were identified from the interviews. First, the skin pain experience was complex. Patients used a variety of adjectives and metaphors to describe their pain, and their skin was sensitive to stimuli of everyday activities. Itch was a common cosymptom, and could both mask pain but also cause severe pain due to excessive scratching and damage to the skin. Second, skin pain had a negative impact on patients' life. Skin pain reduced their physical activity level, impaired their sleep, and made them irritable, depressed, unconcentrated on tasks, as well

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as withdrawn from other people and social activities. Third, patients dealt with their skin pain in various ways. Although some took action to relieve the pain and distract themselves from pain, most of the patients applied maladaptive and passive coping strategies such as put up with it, avoid painful activities, become fearful or trivialize their pain.

Conclusions: The experience of psoriasis related skin pain is complex. The pain has a major negative impact on patients' life in terms of physical, emotional, cognitive, and social functions. Patients use a variety of adaptive but most frequently maladaptive coping strategies in order to deal with their skin pain.

Implications: This study provides new and in-depth knowledge on psoriasis related skin pain. This information is valuable for further work on pain assessment tools and pain management recommendations customized for skin pain experienced by patients with psoriasis.

Keywords: skin pain; cutaneous pain; psoriasis; coping.

1 Introduction

Psoriasis is a common chronic inflammatory immune mediated disease that affects about 0.7-2.9% of the population in Europe [1]. Psoriasis involves a variety of clinical skin manifestations, but often lesions are characterized with thickened and scaling skin, as well as erythema and inflammation. Potential causes of psoriasis related skin pain are sores, cracks, inflammation, and pustules [2]. Until the 21st century, psoriasis was not regarded as a condition that caused painful skin lesions. However, over the past decade a small but increasing number of quantitative and qualitative studies show that these patients experience bothersome skin pain [3-5]. Between 16.1% and 63% of patients with psoriasis report skin pain [4, 6-9], with mean pain intensity of moderate to strong severity [4, 6, 8]. Patients describe this pain as unpleasant, itchy, aching, sensitive, hot/burning, tender, cramping, sore, and stinging [4, 6, 8, 10]. Presence of skin pain is also related to more severe psoriasis [4, 6, 11–15], psychological distress [7, 11, 16], poor sleep [6] and low quality of life [13, 15–17].

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Pain is a subjective experience, and only the person in pain knows how it feels [18, 19]. The pain experience is multidimensional in nature, with sensory, affective and cognitive-evaluative qualities. Sensory qualities include intensity, quality, location, and temporal, spatial and thermal properties of the pain experience. Affective qualities include words that describe tension, fear and autonomic properties, while cognitive-evaluative qualities encompass the overall severity of the pain experience [20, 21]. According to the biopsychosocial model of pain, bodily sensations, emotions, memories, perception, social surroundings and culture influence the pain experience [19, 22, 23].

While several factors influence the pain experience, pain also affects physical, psychological and social functions [24]. Additionally, pain evokes attempts to deal with it. Pain related coping strategies may be helpful or not, such as adaptive (e.g. problem-focused, distractive) vs. maladaptive (e.g. emotional-focused, avoidance-based) [25, 26]. Successful assessment and treatment of pain should address factors that influence pain [22], pain impact on function [24] and coping [25].

Whilst there is a growing body of evidence on the disease and symptoms of psoriasis, there is a lack of an in depth understanding about the patients' experience of skin pain. Therefore, the aims of the study were to explore (1) how psoriasis related skin pain unfolds, and (2) how patients deal with skin pain. Knowledge about the patients' own experience is important for future work on recommendations on how to manage psoriasis related skin pain.

2 Methods

2.1 Design

This qualitative study is part of a larger study with individual patient interviews (n=13) and four clinician focus groups (n=38) investigating views on psoriasis related skin pain. In the present study, the in-depth individual semi-structured interviews, with a purposeful sample of patients with psoriasis, were used to explore the patients' experience with skin pain and the context in which these experiences are situated. The study is framed in a qualitative and interpretive paradigm.

2.2 Setting

The interviews took place in a dermatology ward and an outpatient clinic in a university hospital in Oslo. We conducted the interviews during the patients' hospital stay or after the outpatient clinic consultation.

2.3 Recruitment

Thirteen patients provided rich and relevant data. The sample size was based on estimates and recommendations in literature on qualitative research methodology [27, 28]. Thirteen patients were in this study sufficient to provide new knowledge about psoriasis related skin pain. The sample size is also justified by the strong internal validity of the study (i.e. information power): The aims were narrow, the respondents had highly specific characteristics for the study aims, there was a sound theoretical background for the planning and analyses, the quality of the interviews was high, and an in-depth analysis strategy was used.

Inclusion criteria were psoriasis diagnosis, recent experience of psoriasis related skin pain (past week), age over 18 years, and fluency in Norwegian. Exclusion criteria were psychological and cognitive restrictions that prohibit patients from participating in interviews. A clinician at the ward and author of this article (JAH) contacted patients for recruitment either in a consultation at the hospital or by phone. Demographic and clinical information was collected (see Table 1). Severity of psoriasis was evaluated using the Psoriasis Area and Severity Index (PASI) and scored by the first author (TML).

2.4 Data collection

The interviews were conducted from March 2014 to May 2015 by one of the authors (TML), who is an experienced researcher and clinical nurse with expertise in pain and pain management. The interviews took place in a private room (quiet and undisturbed) in the hospital, and lasted between 28 and 59 min (mean 40 min). The interviewer used a topic guide (Table 2) based on discussions within the research team and literature reviews. All interviews were recorded. Data collection was continued up to the point where the interviewer (TML) evaluated that rich data was obtained, and little new information was gained when adding more patients into the study.

2.5 Analysis

Data were analyzed when all interviews were completed. The audiotaped material was transcribed verbatim
 Table 1: Demographic and clinical characteristics of the study sample.

Characteristics	n (%)	Median (range)
Age (years)		59 (22–86)
Psoriasis duration (years)		14 (0.5–58)
PASI score (0–72)		8,4 (3-14.2)
Mean skin pain intensity last		5 (2–7)
week (0–10 NRS)		
Worst skin pain intensity last		7 (3–10)
week (0–10 NRS)		
Gender		
Male	5 (62)	
Female	8 (38)	
Education		
Primary school	4 (31)	
High school	3 (23)	
University <4 years	3 (23)	
University >4 years	3 (23)	
Work situation		
Currently working	9 (69)	
Retired or on social benefits	4 (31)	
Living arrangement		
Alone	8 (62)	
Together with spouse/children	5 (38)	
Psoriasis type		
Plaque	3 (23)	
Guttate	11 (85)	
Inverse	8 (62)	
Palmoplantar	5 (39)	
Scalp	10 (77)	
Nail	9 (69)	
Pustulosis	1 (8)	
Primary provider of dermatology care		
General practitioner	4 (31)	
Private dermatologist	2 (15)	
Dermatological outpatient clinic	4 (31)	
Dermatology ward	6 (46)	

n = number; PASI = psoriasis area and severity index; NRS = numeric rating scale.

including all words, audible sounds, pauses and expressions of feelings. The four-stage method of Systematic Text Condensation (STC) [29, 30] was used to analyze the text: (1) get a total impression, (2) identify and sort meaning units, (3) condensation, and (4) synthesizing. Firstly, three researchers (HB, AKW, TML) read the interviews to get a total impression and identify preliminary themes (i.e. starting points for organizing the data). The authors discussed the content and themes that evolved. Secondly, the interviews were read again, and themes, meaning units (i.e. text containing information about the research questions), and codes (labels connecting related meaning units into code groups) were identified and discussed in an iterative manner between the two first steps. Thirdly, condensates (i.e. text that combines the content from the meaning units of each code group) were created. Finally, one researcher (TML) summarized the content of the condensates to generalized descriptions and concepts concerning the skin pain experience.

2.6 Ethical approval

The study is approved by the Regional Ethics Committee (2013/1602 REK sør-øst), and the Data Inspectorate (2013/15046) at the hospital where the data collection took place. Informed consent was obtained from all patients included in this study. The study was performed in accordance with the tenets of the Helsinki Declaration.

3 Results

We identified three main themes from the interviews: (1) the complexity of experienced skin pain, (2) skin pain impact on life, and (3) dealing with skin pain. The presented quotes from the interviews are translated (Norwe-gian to English) and illustrate the themes.

3.1 The complex skin pain experience

Patients used several words to express skin pain, such as hurt, ache, strong discomfort and sore in addition to pain. Words that described the sensory pain experience were searing, sore, stinging, burning, hurtful and tight feeling. Common affective and evaluative words were unpleasant, bothersome, terrible, nasty, and irritating (Table 3). As one of the patients put it: "It's stinging and it's searing and it's sore and it's sensitive and it itches and yes – it's that simple – yes, and it's that difficult and bad" (P7).

Patients often used metaphors to describe skin pain, such as: "Your skin feels like rolling around in stinging nettles" (P3), and "It feels like walking on burning coal with needles" (P5). Some metaphors expressed very sever skin pain: "It feels like being scourged" (P1) (P3), "It feels like an inferno" (P3), and "The skin feels like an open wound" (P7)(P1). Several patients claimed that the skin pain felt differently in various body parts and with various types of psoriasis. The tightening and pressing pain sensation was often described with presence of thick plaques, while "bursting pain" was often related to pustules. However, there was no clear pattern

Number	Main questions	Follow up questions	
1	Tell me about the skin pain you experience in	a. How does it feel?	
	relation to your psoriasis	b. Can you describe it?	
2	How do you feel when you have skin pain?		
3	How does the skin pain influence you?	How does the skin pain influence you? In your daily life?	
4	Do you have other symptoms in your skin except	a. How does it feel? Can you describe it?	
	pain, such as burning sensation, itch, and	b. Is this or these symptoms similar to	
	stinging?	or different from pain?	
5	What do you do when you have skin pain?		
6	Is there anything that relieves your skin pain (e.g.		
	creams, ointments, baths, medication, alcohol)?		
7	Is there anything that worsen your skin pain?		
8	Do you take any medication in order to relieve	a. If yes, does it help?	
	your skin pain?	b. If no, why not?	
9	How do you feel about talking about and focusing	a. Is it ok for you, or do you find it	
	on your skin pain?	difficult or problematic?	
		b. If so, what is difficult or problematic?	
10	Is there anything you would like to add or say –		
	something I have not asked you about already?		

of specific painwords used for specific psoriasis locations and types.

Patients described that their skin could be painful and sensitive to stimuli that are normally non-painful, such as touch from clothes, and pressure when putting on creams or bumping into things: "And when it is at its worst on the elbow, then it's painful to put the elbow on the table or just a brush of a sweater. Because then it is so thick and it is so sore and it has cracked. It bleeds, so ... so just a touch is unpleasant". (P4). The painful sensation could be out of proportion to both the stimuli and the size of the psoriasis plaque: "Yes, if clothes touches there, then it is painful. It stings, it is sore. It is searing. All kinds of pain in a way, in that little spot – it is not even big!" (P13).

The patients also talked about itch in relation to skin pain. Most thought itch was different from pain, while some experienced itch and pain as co-existing symptoms. However, all patients described that itch was bothersome and irritating. Fiercely scratching the skin would eventually lead to an ulcer, bleeding, and pain. "Itch is not pain. No. Itch is - after the sweet itch comes the sour sting [Norwegian saying] ... and it is true, you know, scratching makes you blissful - and then it becomes damn painful afterwards. Because often what happens after you scratch, you scratch a hole and an ulcer, and ulcers are usually painful" (P7). Another patient stated: "Often it goes together, but sometimes it is more painful than itchy for example, because then it is so painful that I don't notice the itch - or the other way around: It itches so much that I don't notice that I'm in pain" (P5).

3.2 Skin pain impact on life

Skin pain had a negative impact on the patients' physical function. The skin cracked and caused pain with activities, and made it difficult to move around, walk, lie and turn in bed at night, get up from- and down into a chair or sofa, get in and out of a car, brush the hair, open bottles and cans, and pass stools.

Patients also described problems falling asleep and waking up several times at night, and being fatigued due to lack of sleep. One described how pain and poor sleep got her into a viscous cycle: "So, you're uncomfortable, you're in pain – and then I sleep poorly. Yes. And that always leads to a viscous cycle ... so the poorer you sleep the more pain you get and because you get more pain, then you sleep even poorer – and then you become even more sulky, even more grumpy". (P7).

Skin pain also had a negative effect on the patients' psychological and cognitive function, such as mood, mental state, and ability to concentrate. One patient said: "I slept until 6 in the afternoon. I was so depressed, and I had no quality of life what so ever ... it was so bad ... the skin pain, how it looked, self-esteem and painful and all ... it wasn't cool" (P5). Some patients said that skin pain made them feel hopeless: "You cannot run from your self – you just have to sit there and accept it. That's what is so hard to accept, really, but you have to accept it. I see no other way (P3)". Another patient explained: "It doesn't help to think that there is light at the end of the tunnel, when you know you're going to lie there in

Table 3:	Descriptors of skin	n pain experience in patients with psoriasis.	
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Type of descriptors	English descriptors	Norwegian descriptors
Physical sensory	Searing/smarting	Svie
descriptors	Sore	Sår
	Stinging	Stikkende
	Burning	Brennende
	Tight feeling	Klemmende/pressende
	Sore	Øm
	Pin-prick	Nålestikk
	Sensitive	Ømfintlig
	Bursting	Sprengende
	Hot	Varm
	Tender	Sart
	Tearing	Rivefølelse
	Pounding	Dunkende
	Aching	Verkende
	Cutting	Skjærende
Affective	Terrible	Forferdelig
lescriptors	Horrible/cruel	Grusom
	Sad	Leit
	Enervating	Enerverende
	Devilish	Djevelsk
	Awful	Fælt
	Paralyzing	Lammende
valuative	Unpleasant	Ubehagelig
lescriptors	Bothersome	Plagsom
	Nasty	Ekkel
	Irritating	Irriterende
Pain words	Pain	Smerte
	Painful	Smertefull
	Hurt	Vondt
	Ache	Verkende
	Strong discomfort	Sterkt ubehag
	Sore	Sårt
Metaphors for	Like a fire on the inside	Som en innvendig brann
		Være hudflettet
oainful skin	Like being scourged	Som å bli flådd
	Like the skin is ripped off of you	Som å være hudløs
	Like being skinless	
	Your skin feels like a raw mass	Huden føles som en rålig masse
	Like walking on burning needles	Som å gå på brennende nåler
	Like walking on burning coal with needles	Som å gå på brennende kull med nåler
	The nails feel like they are bent upwards	Neglene kjennes som om de blir bøyd opp
	Feels like being trapped in a body which is not yours	Kjenner deg som fanget i en kropp som ikke er din
	It's like an inferno	Det er som et flammehav
	It's painful when the skin feels too small	Det er vondt når huden kjennes for liten ut
	It feels like rolling around in stinging nettles	Det er som å rulle seg i brennesle
	The skin feels like an open wound	Huden føles som et åpent sår
	It feels like a belt which is tightened and tightened	Det føles som et belte som strammer og strammer
	and tightened	og strammer
	It's like a shield on your head that tightens and	Det er som et skjold over hodet som strammer og
	irritates	irriterer
	It feels like being cleaned with a steel brush	Det føles som å bli vasket med stålbørste

pain for hours (P3)". In terms of cognitive function, one is ... I love to read, but I haven't managed that, 'cause patient revealed that: "When it is insanely painful all the I can't concentrate ... so it affects my ability to concentime, I cannot focus on anything else but how painful it

trate, actually." (P6).

In terms of social function, patients explained that skin pain interfered with spending time with friends, work, and sexual life. The pain would drain energy, and get them in a bad mood. Some did not want to bother others with their complaints. One patient explained that: "I'm a very social person … um, it hurts and you don't feel like being with others and you withdraw. It's natural, because you're grumpy and bitchy – so you can't manage, because it takes so damn much having pain" (P7).

3.3 Dealing with skin pain

Some patients used problem-focused and distractive approaches to deal with skin pain. They used moisturizing or steroid creams, bandages, sports tape, warm baths or cool showers, or if it was really bad occasionally took analgesics to ease their skin pain. Some patients ignored the pain: "I try to escape. I try to pretend it's not there. I think I start to think about other things ... and sometimes I manage" (P10). They also engaged in activities that took their mind off the pain, such as watch TV, read, write, work or bake.

More often patients engaged in passive and avoidance-based coping such as clenching their teeth and just putting up with it, because they thought there was nothing they could do: "No, I just have to put up with it – short and sweet – put up with it. That's it!" (P1). Some patients said they avoided activities that caused skin pain: "If there is a crack or something under your foot, then you walk in the best possible way or so it doesn't hurt. Yes. You rather sit still" (P10).

Several patients were emotion-focused in dealing with skin pain. They became sad, frustrated or fearful. "I have cried a lot – because it's so painful. Yes, and swear and scream, but that doesn't help either" (P6). "It's an inferno … I feel like I'm scourged … it's like the skin is flogged off. I'm scared to death … oh, now I'm a raw mass, I think. I'm scared to death several times" (P3).

A number of patients used "comforting thinking" in dealing with pain. They trivialized their skin pain in parts of the interview, although they explained that their pain was quite bothersome and had a negative impact on their lives. "I handle the pain pretty well. At least I think so myself. So – I'm pretty used to it in a way. I don't think much about it" (P5). This patient described in the same interview that the skin pain was intensely strong, made him depressed and was a major obstacle in the relationship with his girlfriend.

4 Discussion

The patients described a complex symptom picture with a rich narrative of skin pain, and how this pain affected their life as well as how they dealt with their pain. Thus, the present qualitative study provides a more comprehensive understanding of the experience and consequences of psoriasis related skin pain than previous reports.

The rich descriptions of pain and metaphors used in the present study have not previously been described, although sensory pain qualities have been [4, 6, 8]. The vivid images of skin pain experienced as horrible, devilish, an inferno, an open wound, walking on burning coal, and being scourged are testimonies of a severe symptom load that can cause considerable suffering and impairment. The patients explained that the pain was severe and bothersome especially in periods with severe psoriasis, and this finding is also supported by other studies [4, 6]. Assessing pain qualities can enhance the clinician-patient communication, and help clinicians to better understand the pain and suffering that patients experience [20]. Note that pain qualities cannot determine the type of pain (i.e. nociceptive vs. neuropathic), but are valuable for symptom management.

Patients told that non-painful tactile stimuli could cause skin pain (i.e. allodynia). This finding is partly supported by Patruno and colleagues [4] who found a lower pain threshold to pressure algometry, but less sensitivity for touch and heat. Sensory changes of hyper- and hyposensitivity are often associated with neuropathic pain conditions, but also commonly found in nociceptive and inflammatory pain conditions. Therefore, caution must be shown in drawing conclusions on type of pain solely based on sensory descriptions and tests [31]. One explanation for the discrepancy in sensory features found in Patruno's study and the present study, might be that testing sensation thresholds on skin with desquamation may not resemble the symptom experience of clothes causing friction, creams being applied in a firm manner, and bumping into things when the skin is sore, as described in the present study. Therefore, we suggest that experimental laboratory findings should be explored further in a clinical setting.

Patients revealed that skin pain considerably impacts their life, and is related to impaired physical, psychological, cognitive and social function. Similar results were found in studies on other factors of psoriasis disease that can impact function, such as appearance of skin, treatment, cleaning the home [32], various psoriasis symptoms and signs [7, 15, 32], and itch [15, 33]. Some may argue that it is difficult to distinguish the specific reason for impaired function. However, we believe that skin pain can be one of several factors that impair function in these patients. With the fluctuating nature of psoriasis, these factors may be significant with different types of psoriasis and at different stages of the disease course. Therefore, in the management of psoriasis, various symptoms and factors should be assessed and addressed according to the patient's individual experience and needs.

Interestingly, in previous studies regarding social life in patients with psoriasis [32], the appearance of the skin is the major obstacle causing the patient to feel unclean, ugly, stigmatized and therefore withdraw from social settings. However, in the present study, patients emphasized that the pain would drain their energy and impact their mood to a degree that made it difficult to socialize. In addition, they did not want to bother others with their pain. Similar findings are found in people with chronic pain conditions [34]. This study provides a more comprehensive understanding of the impaired social function of patients with psoriasis than previously described.

The present study shows that patients cope with skin pain in various ways. Some used adaptive coping strategies, and took action to relieve their skin pain. Interestingly, patients expressed that ignoring and distraction helped them deal with pain, yet the literature reports that these strategies often prevent patients adjusting to their situation. Whether coping strategies are adaptive or maladaptive, is highly individual and context specific [26], and strategies can be adaptive if they promote problem solving or alleviate psychological distress [25, 35]. Ignoring and distraction may therefore be helpful for patients with periodic psoriasis related skin pain. Note that a majority of the patients engaged in maladaptive coping, which is associated with functional disability and psychological distress [25, 35]. Therefore, we need more specific studies on pain coping, usefulness of coping strategies, and impact of maladaptive coping in relation to psoriasis related skin pain.

A limitation of this study is the lack of questions about the time-aspect of skin pain (i.e. acute, persistent, episodic) which is important information for outlining pain management strategies. In addition, the patients were recruited from one specialist health care setting. However, a variety of health care providers was responsible for the patients' psoriasis management, and this resembles the "real life" healthcare situations for these patients. Major strengths of this study are the methodological rigor, and the rich qualitative material obtained which elicits important aspects of skin pain experience. In conclusion, this study provides a comprehensive description of the skin pain experience in patients with psoriasis. Skin pain has a negative impact on physical, psychological and social function, and several patients use maladaptive coping strategies to deal with it. This study provides useful information for further work on pain assessment tools and pain management recommendations for patients with psoriasis.

Authors' statements

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Informed consent: Informed consent was obtained from all patients included in this study.

Ethical approval: The study is approved by the Regional Ethics Committee (2013/1602 REK sør-øst), and the Data Inspectorate (2013/15046) at the hospital where the data collection took place. The study was performed in accordance with the tenets of the Helsinki Declaration.

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