The journey of having scabies—A qualitative study

Bettina Trettin1,2, Jette Amstrup Lassen1, Flemming Andersen1,2, Hanne Agerskov3

1 Department of Dermatology and Allergy Centre, Odense University Hospital, Denmark
2 Research unit of Dermatovenerology and Allergy Centre, University of Southern Denmark, Denmark
3 Department of Nephrology, Odense University Hospital, Denmark

Received: June 11, 2018 Accepted: September 17, 2018 Online Published: September 25, 2018
DOI: 10.5430/jnep.v9n2p1 URL: https://doi.org/10.5430/jnep.v9n2p1

ABSTRACT

Background and objective: Scabies is considered to be a common skin infection in the field of dermatology, but it is also, by the World Health Organization referred to as a neglected disease. It can cause complications such as secondary infections linked to the development of glomerulonephritis and chronic kidney disease. Furthermore, scabies is associated with stigma, shame and social isolation. To date no qualitative study, has explored this area in depth. The aim of this study was to gain an in-depth understanding of the lived experiences of patients diagnosed with scabies.

Methods: A phenomenological-hermeneutic approach was applied and semi-structured interviews were conducted with 10 participants with scabies. Data were analyzed according to Ricoeurs’ theory of interpretation: naïve reading, structural analysis and critical interpretation and discussion.

Results: The study revealed that patients were affected by uncontrollable and unbearable itching, which caused insomnia and distress, and lead to coping strategies to bring relief. Scabies was experienced as a never-ending journey, characterized by misdiagnosis, a long period of repeated treatment, and lack of information. Not knowing whether the disease had been cured resulted in feelings of insecurity and powerlessness. Scabies had an impact on everyday life caused by social withdrawal and due to feelings of shame, guilt and fear of rejection.

Conclusions: Having scabies is a journey that consists of uncertainty and is characterized by misdiagnosis, long period of treatment and lack of knowledge. Having scabies can be stigmatized, causing loneliness and social withdrawal. Patients with scabies are in need of care, support and information regarding physical, emotional and social well-being.

Key Words: Qualitative study, Interview, Scabies, Patients’ experiences, Dermatology

1. INTRODUCTION

The aim of this qualitative study was to explore experiences and perspectives of being a patient with scabies, and to gain knowledge in order to improve health services provided to this group during diagnosis, treatment and daily life.

Scabies is considered a common dermatological disease, easily treated with topical scabicide. However, an increase in patients with scabies in an outpatient clinic drew attention to the fact that patients with scabies expressed frustration and stress upon receiving the diagnosis and because they had to undergo treatment, often repeatedly.

Scabies is a contagious skin infection caused by the mite Sarcoropes scabiei. The mite is barely visible to the naked eye. It burrows into the epidermis and lays eggs, triggering a host immune response that leads to intense itching in response to what might amount to only a few mites.11 According to the World Health Organization (WHO), it is estimated that scabies affects more than 130 million people globally at
was performed in an endemic area with a high prevalence of where there can be limited access to health care, delayed di-
agnosis and low treatment compliance. Scabies is considered a common skin infection in the field of dermatology, but is often referred to as a neglected disease and a major public health problem in many resource-poor regions of the world, where there can be limited access to health care, delayed di-
agnosis and low treatment compliance. Scabies poses a greater threat to the population in developing countries, it is also found in industrialized countries, albeit, with a lower prevalence. Incidence rates are highest among immigrants.

Scabies can cause complications such as secondary infections caused by staphylococcus aureus and streptococcus pyogenes. Furthermore, there is evidence that there is a connection between secondary infections and the development of glomerulonephritis and an increased risk of chronic kidney disease.

Scabies affects quality of life (QoL) to a greater extent among people living in industrialized countries without economic de-
privation, where a moderately impacted QoL could be demonstrated, both socially and emotionally. A similar study was performed in an endemic area with a high prevalence of scabies. It showed a negatively affected QoL related to symptoms, shame and stigma. However, the population in the area under investigation, had a lower expectation of QoL in general, and scabies therefore did not have the same perceived impact on QoL (as life was already challenging).

Studies have investigated QoL using the Dermatology Life Quality Index (DLQI) Questionnaire, and have determined that scabies is related to stigma, shame and social isolation. No study to date has investigated individual patient perspectives on having scabies and impact on daily life. Therefore, this study sought to gather new, in-depth knowledge about the lived experience of having scabies and thereby broaden our existing knowledge.

Aim
The aim of this qualitative study was to explore the experi-
ences and perspectives of patients with scabies, in order to improve health services provided to this group.

2. METHODS
The study was qualitative, using semi-structured interviews to gain an in-depth understanding of the patient experience of having scabies, and exploring the patient perspective. A phenomenological-hermeneutic approach, inspired by the French philosopher Paul Ricoeur and hermeneutic traditions are codependent and by combining the phenomenological comprehension and its descriptive character with the hermeneutic explanation a deeper understanding of a text will occur.

2.1 Setting
The study took place in a Danish University hospital, at an out-patient clinic specializing in dermatology. During the study period, standard treatment for scabies was the use of topical Permethrin 5% at day one and repeated at day seven. Oral treatment with Ivermectin was given in cases of treatment failure, or when topical treatment wasn’t feasible, due to both financial and social factors. The lack of local specific guidelines meant that the choice of treatment was based on the subjective assessment of the clinician. Patients treated for scabies are obliged to have an extensive eradication of the mites from their home done. Patients were not given the option of a follow-up visit.

2.2 Study participants
Patients diagnosed with scabies over the age of 16 years were screened from a local list by nurses and invited to participate. We aimed for maximum variation of age, sex and ethnicity. Patients excluded from the study were those who had a psychiatric diagnosis or a life-threatening disease. All participants received treatment for scabies in the out-patient clinic.

In total, 12 patients were invited to participate, from October 2017 to January 2018. One declined to participate due to multi-morbidity, and another failed to respond to the invitation. In total, 10 patients were included, four men and six women (see Table 1).

2.3 Data collection
Semi structured interviews were conducted in the location preferred by patients. Eight interviews were conducted at the out-patient clinic in an un-disturbed setting. One interview was conducted in the participants’ home and one at the participants’ workplace. All interviews were digitally recorded and fully transcribed by the first and second authors. An interview guide was used, including open questions and addressing the time before, upon and after receiving the diagnosis.

2.4 Data analysis
The process of the analysis and interpretation, inspired by Paul Ricoeur’s philosophy interpretation, was an ongoing
movement between three levels: naïve reading, structural analysis and critical interpretation and discussion. The naïve reading called for the text to be read several times to gain an initial understanding of the meaning and to grasp a sense of the text as a whole. The following structural analysis split the whole text into meaning units, by gathering quotes across the data, which expressed “what it says” in the text and “what it speaks about”. At this stage the transcripts were viewed objectively, by abstracting the units of meaning from the text as a whole creating distansiation of the text. In the dialectical process between explanation and understanding, themes and subthemes emerged (see Table 2). Findings from the structural analysis were subsequently interpreted and discussed in relation to relevant theory and other research results, with the intention of moving from an understanding of the patients’ experiences - an individual understanding - to an understanding of what the experiences referred to, i.e., a universal understanding.[18] Thus, in the critical interpretation process and discussion, there was a dialectic between explanation and understanding in order to reveal new knowledge and understanding of the lived experiences of being a patient with scabies. The aim of the critical interpretation was to gain a deeper understanding of the themes that had emerged. The findings were discussed among the entire research team.

### Table 1. Characteristics of the participants

| Sex   | Age | Number of topical treatments with Permethrin | Number of oral treatments with Ivermectin | Household infected | Time with symptoms until diagnosis in months | Treatment costs in USD | Numbers of consultations in all (N = 36) |
|-------|-----|---------------------------------------------|------------------------------------------|--------------------|--------------------------------------------|------------------------|----------------------------------------|
| Male  | 54  | 4                                           | 2                                        | Y                  | 2.5                                        | 970                    | 2                                      |
| Female| 52  | 4                                           | 2                                        | Y                  | 1                                          | 970                    | 4                                      |
| Female| 20  | 4                                           | 2                                        | Y                  | 2.5                                        | 979                    | 1                                      |
| Female| 17  | 9                                           | 4                                        | Y                  | 1                                          | 1,101                  | 8                                      |
| Male  | 17  | 8                                           | 2                                        | Y                  | 1                                          | 970                    | 4                                      |
| Female| 54  | 4                                           | 0                                        | Y                  | 0                                          | 243                    | 1                                      |
| Female| 25  | 2                                           | 0                                        | Y                  | 1                                          | 405                    | 2                                      |
| Female| 47  | 3                                           | 2                                        | Y                  | 1                                          | 566                    | 7                                      |
| Male  | 17  | 11                                          | 4                                        | Y                  | 2                                          | 1,219                  | 8                                      |
| Female| 62  | 2                                           | 0                                        | N                  | 2                                          | 161                    | 1                                      |

### Table 2. Units of meaning, units of significance and main theme “Being in the wrath of the itch”

| Units of meaning | Units of significance | Themes | Sub-themes |
|------------------|-----------------------|--------|------------|
| You don’t sleep. Yes, you fall asleep, but then, at 2 am, you wake up because it itches, and then you fall asleep again. You get stressed about it. Then it itches even more because you are thinking even more about it. So it’s just a vicious circle that goes at full speed. | The itching is present constantly and is so intense and unbearable that it was impossible to cope with, or think of anything else. During the night, the intensity of the itch results in lack of sleep over a long period, causing distress. | Being in the wrath of the itch -Dealing with physical, psychological and social manifestations due to itching |

#### 2.5 Ethical considerations

The study was approved by the Danish Data Protection Agency (ID: 2008-58-0035). The participants received both oral and written information prior to the interviews and were anonymized in the data analysis. They were informed that they could withdraw their consent at any time without consequences and that the participation in this study was voluntary.[22] In Denmark, qualitative studies involving interviews do not need approval by an ethics committee.

### 3. RESULTS

The naïve reading of the interviews revealed that the patients were affected by an intense itch which caused distress and insomnia. Having scabies influenced everyday life and caused isolation. In addition, the text revealed that a scabies diagnosis can leave patients untreated for a long time. Furthermore,
there seemed to be a lack of information from the health care system and a major need for thorough knowledge to deal with the disease. It seemed that the patients’ credibility was questioned by the health-care staff, through the structural analysis, three themes emerged (see Table 3).

3.1 Being in the wrath of the itch

3.1.1 Dealing with physical, psychological and social manifestations due to itching

The itching caused by scabies affected the everyday lives of the patients with negative manifestations, with regard to physical, psychological and social well-being.

“I have just scratched open so many holes...the whole way down my legs. Both my legs and then my stomach, and my hands. When I had applied creme, I nearly cried, it hurt so much. Because I wasn’t sleeping at night, I just couldn’t get up in the morning and get a whole day to function normally.”

The itching was so intense that patients scratched their skin until it bled, causing painful wounds and hypersensitivity of the skin. The itching was so intense during night that it resulted in lack of sleep, leading to distress and desperation, and therefore life as usual could not be lived.

However, during everyday life there was hope for improvement:

“So, we hope that, next year, it will be better for us. Yes, we would like to have our life back.”

Symptoms persisted for so long that it led to a state of uncertainty about whether and when the itching would disappear, and it was described that it was impossible to cope with or to think of anything else. However, there was a hope for an improvement and a return to normal life.

Table 3. Results themes and subthemes

| Results themes                | Subthemes                                                                 |
|------------------------------|---------------------------------------------------------------------------|
| Being in the wrath of the itch| Dealing with physical, psychological and social manifestations due to itching, Creating coping mechanisms |
| The journey of having scabies | The struggle during diagnosis phase, Dealing with a long period of treatment and lack of acknowledgement, The need for knowledge and information not knowing when you are cured |
| The loneliness of having scabies | Fear of rejection causing isolation, Feelings of guilt and shame |

3.1.2 Creating coping mechanisms

The itching resulted in feelings of not being at ease in either body or mind, and various strategies were applied to get rid of the itching, even for a short period of time:

“You want to take your skin off, because no matter what you do, it itches. One evening, I took plain rubbing alcohol and rubbed it in all over myself, because I couldn’t bear it...I mean, you have some foreign body or other inside you...That’s a recipe for schizophrenia.”

Strategies to cope with the itching, as recommended by healthcare staff, were considered insufficient, and the need for self-developed strategies emerged. These strategies seemed to work to a limited degree, but reflected the level of desperation experienced in trying to get rid of the itch. There was a need for a mental breathing space and relief; however, it was impossible to achieve. Furthermore, being infected with a parasite was described in detail as gross, disgusting and unhygienic, leading to feelings of being crazy, and there was a need for mental coping by dissociation from the fact that it was a parasite under the skin that was causing the itching.

3.2 The journey of having scabies

Having scabies was described as a journey, characterized by waiting for the correct diagnosis, for proper treatment and not knowing when you are cured.

3.2.1 The struggle during diagnosis phase

Enduring symptoms until one was diagnosed correctly was characterized as a long period of frustration:

“The next time we were up there, she (the dermatologist) said that: ‘NOW it was scabies’, now we had been infected. And I became a bit annoyed about that, because the spots hadn’t changed in the previous two month. How could then be that it WASN’T scabies last time, and now, this time it IS scabies?”

The initial misdiagnosis led to negative feelings that the condition had aggravated, which had resulted in being con-
tagious and infecting others. Feelings such as anger, disappointment, irritation and frustration were directed at both healthcare staff and themselves, because the misdiagnosis prevented the condition from being treated correctly from the beginning. There was a strong trust in health professionals as authorities, and there was an attempt to join forces to solve the misdiagnosis. However, the constant itching and frustration regarding not being cured resulted in readdressing the health care system, insisting on further medical work-up.

3.2.2 Dealing with a long period of treatment and lack of acknowledgement

Patients felt exhausted because the treatment failure had extended the length of their suffering. Undergoing the same treatment several times without sufficient effect had an impact:

“I feel so powerless, because we’ve been through this three times. If we DON’T get rid of it THIS time, what the hell ARE WE GOING TO DO? We are doing everything they say…I mean, what is it that’s going wrong?”

There were feelings of powerlessness and being left with no other options than to undergo again the same treatment as recommended before, because no other alternatives were offered. Undergoing treatment and eradication of the mites from the home several times was challenging, both due to persisting symptoms and the work involved in fumigation, which disrupted their everyday lives. The expectation of receiving a systemic treatment was not met in some cases, resulting in experiences of having to justify previous treatments. There was a perception that the health-care staff was predisposed against previously correct treatment causing frustration. Furthermore, there was a perception of discrimination, since some patients’ wishes for systemic treatment were met and this was discussed between patients. During treatment, instructions provided by the health-care professionals were followed precisely, however, patients did not achieve a sufficient cure, leaving them behind with feelings of failure and of being under suspicion of not having handled scabies correctly.

3.2.3 The need for knowledge and information, not knowing when you are cured

During the treatment period, the patients felt insecure. They did not know what to expect or how to handle the diagnosis:

“How long does it take? What is it that one does to contract scabies? We have asked, but we haven’t really got any answers. We have asked if it is 5 or 10 or 15 or 100 of those mites that are sitting there and causing trouble. They think exactly this, is it something to do with household cleaning? Where does it come from? Why does it come? Is there anything we can do better?”

Feelings of uncertainty arose and there was a need for both general and very specific information. The lack of information caused self-reproach and guilt.

Experiences of being misinformed resulted in both financially and emotional consequences:

“The fact that I’ve received incorrect information, about how we should treat ourselves, I can’t do anything about that. Why should it cost me 300 (USD) extra? I can’t understand that."

Another said:

“Of course, I feel really bad that my parents have spent 800 USD on something that they actually didn’t want. It’s not nice, but I mean I haven’t done something by choice.”

Having scabies was a financial burden; the treatment was expensive and was prescribed several times without sufficient effect. This led to feelings of guilt and powerlessness, but also questions about the reasonableness of the cost.

There seemed to be an overall need to acknowledge scabies as a disease more than a condition:

“You have a PARASITE inside in your body, I mean, it is... SCABIES IS A DISEASE, and it’s something you have to have checked up until you are cured. It’s not something one can simply guess about. As far as I’M concerned, it’s been that, that has been the hardest.”

Being diagnosed with scabies created a sense of insecurity and was experienced as a disease that needed proper management and follow-up until one could be given a clean bill of health.

Furthermore, having scabies was not just an individual concern - it affected the whole family and they needed to be addressed as one unit:

“Dad and I were not invited to either the first or second consultation with the dermatologist. Though we went along the second time, because we thought it would be smart for us all to visit the doctor. I was only invited to the third consultation.”
As a family member, having symptoms and being excluded from an out-patient consultation of one’s relative caused frustration, leaving the remaining relatives with a feeling of insecurity and of not being welcome.

The journey was characterized by misdiagnosis, a long period of treatment involving personal expense and a lack of information. Not knowing when one was cured resulted in feelings of insecurity and powerlessness.

3.3 The loneliness of having scabies

Being diagnosed with scabies could elicit feelings such as guilt and shame. There also seemed to be a tendency to isolate oneself, caused by fear of rejection.

3.3.1 Feelings of guilt and shame

Having scabies was described as an embarrassment and self-inflicted:

“Having scabies is linked to the old days. When you get scabies, it’s because you have poor hygiene … because it’s one of the worst things you can get. Such shame, like if you had syphilis.”

Scabies was a taboo subject, associated with a rare disease contracted due to lack of hygiene, or with sexually transmitted diseases, which elicited a sense of shame. Guilt arose even more strongly when the illness persisted for a long period. Questioning what was done wrong and feelings of not being sanitary enough led to a negative impact on the self-image.

3.3.2 Fear of rejection causing isolation

Feelings of stigma and fear of rejection by those in their circle were avoided by hiding the visible signs of scabies:

“I didn’t tell anyone that I had scabies. And no-one asked I noticed that I preferred to have long sleeves so that people couldn’t really see it.”

The visible signs were hidden because of shame and due to the presumption that people would dissociate themselves from a person with scabies. Telling others about scabies was considered carefully and brought up a dilemma. On one hand being responsible and obligated to inform people, to avoid contagion and on the other hand not wanting to let people know about their condition. Informing others about the diagnosis could bring relief; however, it could also confirm one’s fear of rejection:

“It has really affected my everyday life, that people shield themselves because they don’t want it (risk of being infected), that has been the hardest for me.”

Another said:

“It’s generally disgusting. I had a colleague, she thought it was REALLY disgusting and could hardly bear to be near me. It was more the THOUGHGT that there was something that WAS LIVING on my body. She thought that was really disgusting.”

Telling others about the diagnosis led to experiences of being stigmatized and created feelings such as hurt, anguish and shame when rejection occurred. This experience confirmed the fear of prejudgment and caused social withdrawal.

However, not informing people of the diagnosis caused an even greater tendency towards isolation:

“At the moment I spend more time a bit to myself. I don’t go to school or anything. None of them know that I have scabies.”

Being silent about the disease resulted in lengthy periods of reduced communication and social interaction. Thus, scabies was a barrier to forming and maintaining social networks and led to both loneliness and isolation - with feelings of being alone in the world.

4. DISCUSSION

This study explored patients’ experiences of and perspectives about having scabies. The study revealed that patients were affected by an uncontrollable and unbearable itch, causing insomnia and distress, and leading to the creation of coping strategies in the search for a breathing space. Scabies was experienced as a never-ending journey, characterized by misdiagnosis, a long period of repeated treatment, including outgoings and a lack of information. Not knowing when one was cured resulted in feelings of insecurity and powerlessness. Furthermore, scabies had an impact on everyday life, caused by social withdrawal and due to feelings of shame, guilt and fear of rejection.

Jin-gang et al. found that scabies symptoms were one of the domains that caused a great impact on QoL in patients with scabies, and it is well known that the pruritus is particularly severe at night and that sleep disturbances are common. However, to the best of our knowledge no qualitative study has explored the phenomenon of pruritus in patients who did not have a chronic disease. A study about chronic pruritus have shown that it imposes a substantial psychological burden and that it has a negative impact on...
daily life, causing sleep disturbances, affecting one’s ability to work and experiences of not being taken seriously by healthcare professionals. This is consistent with the findings in our current study, which indicates the importance of appreciation and acknowledgement of the impact of pruritus, even in a non-chronic or non-life-threatening condition, such as scabies, in order to develop more sufficient strategies to relieve symptoms. Additionally, this acknowledgement could reduce feelings of being disgusting and unhygienic and the need for self-developed coping strategies caused by desperation, as shown in our current study. The implementation of a nursing programme “Coping with itch” has shown to be a promising intervention for pruritus; however, its focus is in patients with chronic pruritic skin diseases. A study investigating the effectiveness of the programme showed a significant decrease in catastrophizing and helpless coping in the intervention group. Although scabies is not a chronic condition, our findings showed that coping strategies suggested by the healthcare professionals were considered insufficient. This seems to highlight the relevance of supporting these patients by the provision of a structured programme, in order to acknowledge their intense itch and help them to cope with it.

The journey of having scabies included experiences of misdiagnosis, leading to feelings such as anger, disappointment, irritation and frustration when an incorrect diagnosis was received, leaving them to live with itching for several months and not being given the opportunity to prevent contamination. Misdiagnosis of scabies is common, leading to treatment delay and increase of health costs. However, the impact this has on patients’ experiences has not been investigated. Fitzsimons et al. investigated patients at home, waiting for coronary artery bypass surgery, and found; that uncertainty, anxiety, loss of control, disappointment with treatment, rage, frustration and changes in family and social relationships occurred during the unknown duration of the waiting time. Fogarty et al. found in a concept analysis describing the wait for healthcare that waiting was identified as an unspecified yet unmeasurable period of time between identification of a healthcare problem and its diagnosis and treatment, during which patients experience uncertainty and powerlessness. There are similarities between Fogarty and Cronin’s finding and those from the present study, revealing how waiting for a diagnosis of scabies had an impact on daily life. Furthermore, being diagnosed with scabies included a long period of treatment that created uncertainty, since patients did not get rid of symptoms as expected. According to Mishel’s Theory of Uncertainty in Illness, uncertainty is defined as “the inability to determine the meaning of illness-related events when a patient cannot structure or categorize an event because of insufficient cues”. Three components, symptom pattern, event familiarity and event congruence, provide stimuli and are structured by the patient into a cognitive schema, thereby creating less uncertainty. The three components are influenced by two variables: cognitive capacity and structure providers. Although the symptom pattern in scabies can be consistent, predictable, salient and distinguishable, representing classic symptoms, scabies can also represent non-classical symptoms, causing patients trouble in identifying the symptom pattern, thus increasing uncertainty. Although scabies is not a chronic disease, not being familiar with symptoms causes uncertainty itself for patients and this challenges the ability to determine meaning of illness related events. Event congruence refers to consistency between the expected and experienced in illness-related events, facilitating interpretation and understanding. Findings in our study revealed that expectations of a certain treatment and of cure by a predetermined time were unmet and this caused insecurity. There was an overall need for scabies to be recognized and communicated as a disease instead of a condition and there was also a need for follow-up. The patients in our study had certain expectations of a certain treatment, these expectations were not met which created uncertainty, consistent with Mishel’s theory. Furthermore, our findings determined that insecurity also arose due to lack of knowledge, and more general and specific information about scabies was needed. According to Mishel, structure providers, such as healthcare professionals, can strengthen the stimuli framework by providing information on the causes and consequences of symptoms and can thereby expand a patient’s knowledge in order help them form a cognitive schema and reduce uncertainty.

The journey of having scabies was characterized as a long period, which caused insecurity; however, during our further interpretation of the findings, it seemed that the journey consisted of insecurity. Scabies was a subject of taboo, connected to feelings of guilt and not being sanitary enough, thus leading to a negative impact on self-image. The emotional burden of skin diseases is enormous, and has a negative impact on QoL. Ghorbanibirgani et al. found that patients with psoriasis experienced feelings of stigma that led to a weakening of the self-concept, which is consistent with our findings. Ghorbanibirgani et al. further revealed that patients with psoriasis were rejected by others, causing them a painful experience and leading to the decision not to disclose their disease. This is also consistent with our findings, where telling others about the diagnosis revealed feelings of stigma, hurt and anguish causing social withdrawal.
Feelings of stigma and fear of rejection by those in one’s circle were avoided by hiding the visible signs of scabies. Studies have investigated QoL using the Dermatology Life Quality index (DLQI) Questionnaire, and determined that scabies is related to stigma, shame and social isolation.[14,15] Stigma is described by Goffman as: “the situation of the individual who is disqualified from full social acceptance”, outlined by three distinct types of stigma: abominations of the body, blemishes of individual character and tribal. Furthermore, Goffman categorizes stigma by four criteria that can affect the perceived level of deviance: Visibility, publicity, obstructiveness (affecting social interaction), and relevance.[33] The criteria often overlap, depending on perceived depravity, an individual’s choice, and external factors. Since our study showed that patients hid their visible signs due to shame, it could point to the fact that having scabies is the subject of body stigma. Hiding your visible sign and not knowing if others may find out or what they think adds tension to the situation. According to Goffman, the management becomes about tension management, in order to reduce the tension which he refers to as “covering”. However, some patients succeeded in their attempt to “cover” and in this case, the object of management was the tension that arose within a social interaction between the patients and their circle of people, avoiding stigmatization by social networks, by reducing the number of people who could find out. These strategies led to a sense of disconnectedness, isolation, brief time exposure and relationship distance management. Our findings showed that being silent about the diagnosis was a barrier to forming and maintaining social networks, leading to loneliness and isolation. With Goffman’s theory in mind, our findings show that stigma is the reason for social withdrawal and feelings of being alone in the world.

Relevance to practice
In clinical practice, the findings of this study draw attention to the need for healthcare professionals to emphasize and communicate scabies as a disease that needs proper equal treatment and follow-up, in accordance with a guideline. The common misdiagnosis of scabies calls for a more thorough medical work-up. Previously, treatment failures and persisting pruritus up to several weeks after treatment indicate the relevance of supporting these patients by a structured programme, in order to acknowledge their itch and helping them to cope. Healthcare professionals should be aware that uncertainty can be reduced by providing equal, specific and general information about scabies; specifying what patients can do and what is uncontrollable. Healthcare professionals should provide emotional support through a holistic therapeutic approach, including anti-stigma strategies.

5. Conclusion
This study identifies that having scabies is a journey that consists of uncertainty and is characterized by misdiagnosis, a long period of treatment and lack of knowledge. Dealing with physical, psychological and social manifestations due to itching affects everyday life in a negative way. Having scabies is stigmatized, causing loneliness and social withdrawal. Patients with scabies are in need of care, support and information regarding physical, emotional and social well-being.

Acknowledgements
The authors would like to thank all the participants in this study for sharing their experiences.

Conflicts of Interest Disclosure
The authors declare that there is no conflict of interest.

References
[1] Panahi Y, Poursaleh Z, Goldust M. The efficacy of topical and oral ivermectin in the treatment of human scabies. Annals of Parasitology, 2015; 61(1): 11-6.
[2] WHO. Neglected tropical diseases, Scabies. 2015. Available from: http://www.who.int/neglected_diseases/disease_s/scabies/en/
[3] Christophersen J. The epidemiology of scabies in Denmark, 1900 to 1975. Arch Dermatol. 1978; 114(5): 747-50. https://doi.org/10.1001/archderm.1978.01640170047009
[4] Heukelbach J, Feldmeier H. Scabies. The Lancet. 2006; 367(9524): 1767-74. https://doi.org/10.1016/S0140-6736(06)68772-2
[5] Feldmeier H, Heukelbach J. Epidermal parasitic skin diseases: a neglected category of poverty-associated plagues. Bulletin of the World Health Organization, 2009; 87(2): 152-9. https://doi.org/10.2471/BLT.07.047308
[6] Hay RJ, Johns NE, Williams HC, et al. The global burden of skin disease in 2010: an analysis of the prevalence and impact of skin conditions. J Invest Dermatol. 2014; 134(6): 1527-34. PMID:24166134 https://doi.org/10.1038/jid.2013.446
[7] Hay RJ, Steer AC, Engelman D, et al. Scabies in the developing world–its prevalence, complications, and management. Clin Microbiol Infect. 2012; 18(4): 313-23. PMID:22429456 https://doi.org/10.1111/j.1469-0691.2012.03798.x
[8] Lapeere H, Naeyaert JM, De WEERT J, et al. Incidence of scabies in Belgium. Epidemiology and Infection. 2008; 136(03): 395-8.
[9] World Health Organization. The current evidence for the burden of group: A streptococcal diseases. 2005.
[10] Thomas J, Peterson GM, Walton SF, et al. Scabies: an ancient global disease with a need for new therapies. BMC Infect Dis. 2015; 15:
250. PMid:26123073 https://doi.org/10.1186/s12879-015-0983-z

[11] Svartman M, Finklea JF, Earle DP, et al. Epidemic scabies and acute glomerulonephritis in Trinidad. Lancet. 1972; 1(7744): 249-51. https://doi.org/10.1016/S0140-6736(72)90634-4

[12] Hersch C. Acute glomerulonephritis due to skin disease, with special reference to scabies. S Afr Med J. 1967; 41(2): 29-34. PMid:6016945

[13] Chung SD, Wang KH, Huang CC, et al. Scabies increased the risk of chronic kidney disease: a 5-year follow-up study. J Eur Acad Dermatol Venereol. 2014; 28(3): 286-92. PMid:23374101 https://doi.org/10.1111/jdv.12099

[14] Jin-gang A, Sheng-xiang X, Sheng-bin X, et al. Quality of life of patients with scabies. Journal of the European Academy of Dermatology and Venereology. 2010; 24(10): 1187-91. PMid:20236379 https://doi.org/10.1111/j.1468-3083.2010.03618.x

[15] Worth C, Heukelbach J, Fengler G, et al. Impaired quality of life in adults and children with scabies from an impoverished community in Brazil. Int J Dermatol. 2012; 51(3): 275-82. PMid:22348561 https://doi.org/10.1111/j.1365-4632.2011.05017.x

[16] Kvale S, Brinkmann S. Interview: introduktion til et håndværk. Kbh.: Hans Reitzel; 2009.

[17] Ricoeur P. Fortolkningsteori. Kbh.: Vinten; 1979.

[18] Pedersen BD. Sygeplejepraksis: sprog & erkendelse: Ph. D.-afhandling: Danmarks Sygeplejerskehøjskole; 1999.

[19] Ricoeur P, Hermansen M, Rendtorff JD. En hermeneutisk brobygger. Århus: Klim; 2002.

[20] Ricoeur P. Interpretation theory: Discourse and the surplus of meaning: TCU Press; 1976.

[21] Dreyer PS, Pedersen BD. Distanciation in Ricoeur’s theory of interpretation: Narrations in a study of life experiences of living with chronic illness and home mechanical ventilation. Nurs Inq. 2009; 16(1): 64-73. PMid:19228305 https://doi.org/10.1111/j.1440-1800.2009.00433.x

[22] World Medical Association. World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects. JAMA. 2013; 310(20): 2191-4. PMid:24141714 https://doi.org/10.1001/jama.2013.281053

[23] McCarthy J, Kemp DJ, Walton SF, et al. Scabies: more than just an irritation. Postgraduate Medical Journal. 2004; 80(945): 382-7. PMid:15254301 https://doi.org/10.1136/pgmj.2003.014563

[24] Bathe A, Weisshaar E, Mutterne U. Chronic pruritus–more than a symptom: a qualitative investigation into patients’ subjective illness perceptions. J Adv Nurs. 2013; 69(2): 316-26. PMid:22571475 https://doi.org/10.1111/j.1365-2648.2012.06009.x

[25] Os-Medendorp V, Eland-de Kok P, Ros WJ, et al. The nursing programme ‘Coping with itch’: a promising intervention for patients with chronic pruritic skin diseases. J Clin Nurs. 2007; 16(7): 1238-46. PMid:17584341 https://doi.org/10.1111/j.1365-2702.2007.07150.x

[26] Os-Medendorp V, Ros W, Eland-de Kok P, et al. Effectiveness of the nursing programme ‘Coping with itch’: a randomized controlled study in adults with chronic pruritic skin disease. Br J Dermatol. 2007; 156(4): 960-64. PMid:17535222 https://doi.org/10.1111/j.1365-2133.2007.07919.x

[27] Hong MY, Lee CC, Chaang MC, et al. Factors related to missed diagnosis of incidental scabies infestations in patients admitted through the emergency department to inpatient services. Acad Emerg Med. 2010; 17(9): 958-64. PMid:20836776 https://doi.org/10.1111/j.1365-2133.2010.08594.x

[28] Fitzsimons D, Parahoo K, Stringer M. Waiting for coronary artery bypass surgery: a qualitative analysis. J Adv Nurs. 2000; 32(5): 1235-42. PMid:1115010 https://doi.org/10.1046/j.1365-2648.2000.01595.x

[29] Fogarty C, Cronin P. Waiting for healthcare: a concept analysis. J Adv Nurs. 2008; 61(4): 463-71. PMid:18234043 https://doi.org/10.1111/j.1365-2648.2007.04507.x

[30] Mishel MH. Uncertainty in illness. Image: Journal of Nursing Scholarship. 1988; 20(4): 225-32. PMid:320947

[31] Dimitrov D, Szepeitowski JC. Stigmatization in dermatology with a special focus on psoriatic patients. Postepy Higieny Medycyny Doswiadczalnej. 2017; 71(10): 1115-22.

[32] Ghorbanibargani A, Fallahi-Khoshkhah M, Zarea K, et al. The Lived Experience of Psoriasis Patients from Social Stigma and Rejection: A Qualitative Study. Iranian Red Crescent Medical Journal. 2016; 18(7): e27893.

[33] Goffman E. Stigma. Notes on the Management of Spoiled Identity. New York: Simon and Shuster; Inc; 1963.