



## Experiences and Perceptions of People with Chronic Skin Disease: A Qualitative Study

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### Authors' contributions

*This work was carried out in collaboration between all authors. Authors SB and EB designed the study. Author ME collected the data. Authors SB, EB, ME and MLR analyzed and interpreted the results. Authors ME and SB drafted the article. Authors EB and MLR revised it critically. All authors read and approved the final manuscript.*

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### ABSTRACT

**Aims:** Skin diseases are a common reason for consulting the general practitioner (GP). Few studies have been conducted that explore the topic of chronic skin disease from the patient's perspective. The aim of this paper was to investigate experiences and perceptions of people with chronic skin diseases and their respective pathways into the health care system.

**Study Design:** Qualitative study

**Place and Duration of Study:** GP practices and patients' homes; between July 2011 and August 2012.

**Methodology:** Interviews (20-30min) with 16 patients using a semi-structured guideline were conducted. Patients were identified by their respective GP. Adult patients suffering from a chronic skin disease were included. Interviews were taped and transcribed verbatim. Qualitative analysis was conducted by two independent raters.

**Results:** There was a broad variety of pathways into the healthcare system with about half the respondents at first contacting lay people like family members or neighbours. Nearly all participants

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reported an adverse effect on private, social or work life. Some of our respondents felt stigmatized. Most respondents applied a range of self-management strategies, mainly in the form of different dietary habits; many patients had also made use of complementary therapies. There were different patient expectations concerning GPs and dermatologists respectively.

**Conclusion:** Patients with chronic skin disease show a complex health seeking behaviour which can lead to delays in accessing the official health care system. There is a considerable impact on the quality of life. Further research should address how German GPs perceive the treatment of patients with chronic skin disease and how cooperation with dermatologists can be improved.

*Keywords: General practice/family medicine; patient perspective; skin disease; qualitative research.*

## 1. INTRODUCTION

Compared with other major disease groups, skin conditions belong to the most frequent reasons for consulting a general practitioner (GP) [1]. Chronic skin diseases such as psoriasis can affect people for the majority of their adult lives [2] and result in a significant reduction in quality of life comparable to other major medical conditions [3,4]. Psychiatric conditions such as depression frequently accompany dermatological disease [5,6]. The highly visible nature of most dermatological conditions can result in lowered self-esteem and the feeling of being stigmatized [7].

While in Germany patients also have direct access to dermatology services, in most other health care settings the GP is the first point of contact. However, other qualitative studies showed that patients were dissatisfied [8] and GPs were perceived by patients as lacking expertise in the treatment of chronic skin conditions like psoriasis as well as the necessary empathy [9]. This results in some of the patients seeking alternative sources of help [9].

In our study, we aimed to explore experiences and perceptions of people with chronic skin diseases, including pathways into the health care system, the impact on life, and resulting disease management strategies.

## 2. MATERIALS AND METHODS

We used a qualitative research approach to address our study questions, as we wished to explore access into the health care system, the personal illness concepts, and the role of GPs from the perspective of patients with a chronic skin disease in primary care. We chose single interviews as the most appropriate technique for data collection, as it created the best environment for talking to patients. The setting was private and confidential, enabling us to

explore personal issues such as fear of rejection or stigma.

### 2.1 Setting and Data Collection

We approached 16 GPs in Hessen and Rhineland-Palatinate, Germany. Every GP recruited one of their adult patients with a history of chronic skin disease.

One researcher (ME) interviewed the 16 patients between July 2011 and August 2012. We informed the participants about the study objectives and the privacy regulations. After they agreed, the interviews took place either at the GP's office, or at the patient's home. A semi-structured interview guideline was developed, pretested in two interviews and refined accordingly. We started each interview with a question on how the skin disease manifested itself in the beginning, and to whom the patient turned initially, thus reconstructing the access path into the official health system. The next major topic circled around the influence of the disease on the patient's life. We asked the participants what parts of their lives were affected the most by their disease, and which factors had positive or negative influences on disease progression. Another topic was the role of the GP in the management of the patients' chronic skin disease. This included exploring the cooperation and communication behaviour between the GPs and dermatologists in cases with specialist involvement. At the end of every interview we collected demographic data, such as gender, age and profession of every patient. Directly after the interview we collected 'milieu data' in the form of a "reflexive research journal", evaluating every interview in the light of the specific context it had been conducted in.

### 2.2 Data Analysis

The interviews were taped and transcribed verbatim. To assist data handling the material

was transcribed and analysed using MAXQDA-10 [10]. Our analysis can be categorized as a thematic survey [11], undertaken stepwise with each step informing the next [12]. The first step was to create a coding system [13]. The coding tree and coding was tested and refined within our qualitative working group. Interviews were coded mainly descriptively by two independent raters (MR and ME), and differences in coding were resolved by discussion.

The study was approved by the Ethics Committee of the Faculty of Medicine, University of Marburg (AZ 130 /11). The study complies with the declaration of Helsinki.

### **3. RESULTS**

#### **3.1 Sample Characteristics**

Table 1 details the characteristics of the 16 participants. Half the participants were female and participant age ranged from 18 to 76 years. Duration of disease ranged from one to 40 years and most respondents reported suffering from psoriasis vulgaris.

#### **3.2 The Themes**

A number of different issues (see Table 2) were identified, a lot of these being inter-related and partly overlapping. Three main themes emerged: 'pathways into the health care system', 'impact of chronic skin disease on life', and 'management in primary care'.

##### **3.2.1 Pathways into the health care system**

Table 3 summarizes the quotes relating to this topic. Participants reported different pathways into the official health care system, with a broad time range from the first symptom until seeking professional help.

###### *3.2.1.1 Preliminary and lay information*

Some participants had already formed an opinion about their respective skin disease. About half of the participants received first information on chronic skin diseases from familiar people such as family members, friends or neighbours. Some received information from family members who were affected by the same or a similar skin disease. In some instances this 'medically

unfiltered' lay information caused uncertainties for the person concerned.

###### *3.2.1.2 Triggers for visiting a GP as first source of information*

The other half of interviewed patients said that they approached their GP directly in order to get further information about their skin disease. Hereby the extent of symptoms such as itching or visible cosmetic lesions triggered the visit.

###### *3.2.1.3 Period of time between first symptoms and initial GP contact*

Most of the participants told us that they had waited for about a month before visiting their GP. Some regarded their disease as something temporary which would end without any specific therapy, others initially denied their disease. Consequently, some patients waited longer than a year until they contacted a GP.

##### **3.2.2 Impact on life**

Nearly all participants reported that different aspects of their lives had been adversely affected by their chronic skin disease, including private, social and also work life. Some of our respondents felt stigmatized and all had developed a range of coping strategies to address the above mentioned problems. Table 4 summarizes the quotes relating to this topic.

###### *3.2.2.1 Private and social environment*

Participants mentioned several restrictions with a negative impact on their social environment. These mainly affected leisure activities such as swimming or sauna visits, where the skin is exposed towards others.

###### *3.2.2.2 Professional environment*

Impact on professional activity differed between respondents and was clearly dependent on the severity of the disease and type of employment. People who had to work with high hygiene standards, such as in the medical sector or the food industry mentioned significant limitations. While some respondents who had to cope with considerable absenteeism from work were forced to change their career, others (e.g. teachers) reported good compatibility with their respective jobs.

**Table 1. Characteristics of participants (n=16)**

<b>Patient ID no.</b>	<b>Sex</b>	<b>Age</b>	<b>Marital status</b>	<b>Professional/social status</b>	<b>Disease*</b>	<b>Duration of disease (years)</b>	<b>Dermatologist involved in therapy</b>
1	F	64	married	Retired	Psoriasis vulgaris/Atopic eczema	5	X
2	F	50	married	No qualification	Psoriasis vulgaris	17	X
3	F	48	married	Vocational training	Psoriasis vulgaris	22	X
4	M	72	married	Retired	Psoriasis vulgaris	41	Ø
5	M	52	married	Vocational training	Psoriasis vulgaris	42	X
6	M	48	married	Vocational training	Psoriasis vulgaris	26	X
7	M	62	married	Vocational training	Secondary dermatological disease due to vascular problem	4	Ø
8	M	68	married	Retired	Psoriasis vulgaris	13	X
9	F	76	married	Retired	No specific diagnosis	1	Ø
10	M	55	married	Self-employed	Atopic eczema	38	X
11	M	18	single	Trainee	Atopic eczema	12	X
12	F	49	married	University degree	Psoriasis vulgaris/Rosacea	5	X
13	F	52	married	Vocational training	Psoriasis vulgaris	34	X
14	M	61	single	Vocational training	Psoriasis vulgaris	40	X
15	F	41	married	University degree	Psoriasis vulgaris	4	X
<b>16</b>	<b>F</b>	<b>52</b>	<b>married</b>	<b>Vocational training</b>	<b>Psoriasis vulgaris</b>	<b>6</b>	<b>X</b>

*\*Most participants suffered from psoriasis representing different stages of this disease ranging from mild to severe symptoms*

**Table 2. Themes and sub-themes**

<b>Pathways into the health care system</b>
- Preliminary and lay information
- Triggers for visiting a GP as first source of information
- Time period between first symptoms and initial GP contact
<b>Impact on life</b>
- Private and social environment
- Professional environment
- Mental stress and fear of stigma
<b>Management in primary care</b>
- Self-management
- GP management
- Specialist (Dermatologist) management

**Table 3. Quotes relating to pathways into the health care system**

<b>Preliminary and lay information</b>
"Because I also knew about my brother and at some point my brother said to me, 'M., you have to accept this'...'Look at me!'. Well, and then I thought 'this isn't possible, you have to do something'" (Patient 9, female, 2)
<b>Triggers for visiting a GP as first source of information</b>
"Well, primarily I would say, it was the itching" (Patient 10, male, 15)"Because the summer was near and I thought 'no, you can't run around like this, this isn't possible!'" (Patient 2, female, 9)
<b>Time period between first symptoms and initial GP contact</b>
"Because I actually always think it will disappear on its own" (Patient 9, female, 25) "At that time I did not want to accept that I was also affected by this disease (psoriasis). I refused to believe it and fought against it. Accordingly, I hesitated for quite a long time until I made an appointment with my GP."(Patient 16, female, 5-7)

### 3.2.2.3 Mental stress and fear of stigma

Participants mentioned mental stress both as trigger and as consequence of their skin disease. Some respondents felt ashamed and expressed their fears of being stigmatized.

### 3.2.3 Management in primary care

Table 5 summarizes the quotes relating to this topic. Most respondents applied a range of self-

management strategies, mainly in the form of different dietary habits; many patients had also made use of complementary therapies. There were different patient expectations concerning GPs and dermatologists respectively.

**Table 4. Quotes relating to impact on life**

<b>Private and social environment</b>
"And then I thought 'O God, no! It's summer and I can't wear any skirts and can't go to the swimming pool' "(Patient 2, female, 21) "I loved going to the sauna.[...] that's currently impossible for me..." (Patient 3, female, 29)
<b>Professional environment</b>
"You have a good job interview and then the final sentence is 'What do you have on your hands?' And then I explain ..." (Patient 5, male, 50) "I worked as a butcher and in a grocery store [...] then I got these scales and I couldn't work at all" (Patient 11, male, 31)
<b>Mental stress and fear of stigma</b>
"Well, I really was not fond of going to school because my face looked like a small Freddy Krüger. Everything was open and it did not look good ...and when you then went to school and everyone was whispering and so on...." (Patient 11, male, 47) "It's no secret that from time to time people stare at you [...]wondering: 'What does she have there? Hopefully nothing contagious!'" (Patient 16, female, 17)

### 3.2.3.1 Self-management

Most patients tried to make dietary changes; the majority seemed to benefit from different dietary habits. Other strategies included different homemade remedies to alleviate pruritus. Several patients mentioned bioresonance therapy as a complementary treatment approach that they had tried out.

### 3.2.3.2 GP management

Patients had different expectations concerning their GP. Half of the participants expected either a clear diagnosis or an immediate cure. Others stated that the GP should recognize acute issues in the course of chronic disease. In cases of milder disease GPs were mainly expected to

perform standard procedures like issuing prescriptions, coordinating referrals or performing routine checks. Some of the patients also expected the GP to coordinate and carry out further treatment.

Most patients mentioned the importance of a well-functioning doctor-patient relationship which included mutual trust as a cornerstone in the management of chronic skin disease. The GP was regarded the primary contact person.

**Table 5. Quotes relating to management in primary care**

<b>Self-management</b>
“Everything histamine-rich, avoid it!” (Patient 1, female, 40)
“Little meat, no coffee, no sugar, no chocolate, no alcohol, no acids, no wine.” (Patient 12, female, 65)
“And then I also tried milking grease and somebody said an old home e remedy against pruritus would be to bath in vinegar water [...]” (Patient 5, male, 22-23)
“I was at (a doctor practicing) homeopathy where doctor A had sent me for bio resonance therapy.” (Patient 3, female, 39)
<b>GP management</b>
“My GP especially says when something is acute [...]. In this respect I trust him fully [...]” (Patient 4, male, 49)
“I’ve had this for 40 years, I know it all. In the end [...] I only go when my pills are used up [...]” (Patient 5, male, 41)
“Well, principally the first contact person for me is the GP, because of our good relationship.” (Patient 16, female, 40)
<b>Dermatologist management</b>
“The dermatologist? [...]not good, because the office is quite crowded.” (Patient 5, male, 45)
“Doctor C (the patient’s GP) called (the dermatologist) and asked if I could pop in [...], 2 hours later, I was there. [...] So I guess if I had waited until I could get an appointment at the dermatologist, it would have taken about three weeks [...]” (Patient 2, female, 44-46).
“They (the GP and dermatologist) know each other quite well. [...] And therefore the relationship is OK. She gave him (the GP) a short report” (Patient 10, male, 59)

### 3.2.3.3 Specialist management

Cooperation between GPs and dermatologists were judged very differently, ranging from good

joined patient care to lack of coordination. Most patients complained of the lack of quick access to dermatology services. Generally, specialists played a more important role in severe disease and complex treatment decisions. Some GPs had their own ways of helping their patients to get a timely dermatology appointment.

## 4. DISCUSSION

### 4.1 Main Findings

People with chronic skin disease showed different pathways into the healthcare system, with many respondents at first contacting lay people like family members or neighbours. Nearly all participants reported an adverse effect on private, social or work life, including perceived stigma. Most respondents applied a range of self-management strategies such as different dietary habits. There were different patient expectations towards GPs and dermatologists.

### 4.2 Strengths and limitations

This study interviewed men and women from the general population who suffered from different chronic skin diseases. It is one of the first qualitative studies that especially addresses the question how these patients gain access to the official health care system. While several former qualitative studies only addressed psoriasis patients, we did not limit our sample to this disease. However, due to underlying epidemiology, most patients in our sample also suffered from psoriasis.

Our study also has several limitations. The semi-structured interview method has limitations in internal validity. We tried to triangulate this with other tools for qualitative research like the use of a reflexive research journal and obtaining milieu data. We tried to minimize interpretation bias by evaluating our data with several members of the research group and discussing our results constantly during the entire analysis process. Our sample is not big enough to reflect all chronic skin disease; most of the cases are psoriasis patients who may have lower quality of life which might affect the result of the study. Results might also be influenced by the fact that patients were selected by their physician and that part of the interviews took place in the physician’s office. Another point to consider is the fact that our study was conducted in German. The transcript translation into English may have

resulted in some distortion of the original meaning. In an attempt to minimise this effect, the manuscript was corrected by a native English speaker with a medical background. Since patients were selected by their respective GP, there could be a bias towards a favourable relationship between both. Finally, our findings relate to the specific context of the German health care system. However, our findings should also be applicable to other primary health care settings.

### 4.3 Comparison with Existing Literature

Our findings show the importance of the GP as a first point of contact for patients with chronic skin diseases. The German health care system has so far only partly established a classical gate keeper model. Where this approach is established, with the GP also being the first contact point for patients with skin disease, it has been shown that the number of uncoordinated specialist visits could be reduced substantially [14]. Research on patients suffering from chronic psychiatric illness showed that for these patients an appointment with a GP (in contrast to a specialist) was perceived as less embarrassing and stigmatising [15], a finding that is also supported by our data. We also showed the importance of lay information in the early process of patients' information search. By nature the quality of information provided by this system is very heterogeneous and can lead to distorted perceptions [16].

Nearly all participants reported that different aspects of their lives had been adversely affected, including private, social but also work life. Part of our respondents felt stigmatized, and all had developed a range of coping strategies to address the above mentioned problems. Other qualitative studies conducted with psoriasis patients support our findings. Nelson and colleagues could show that patients experienced psoriasis as a complex condition involving physical, psychological and social challenges [9]. Magin et al. [8] also conducted semi-structured interviews with 29 psoriasis patients and reported considerable psychological morbidity including mood and anxiety symptoms, embarrassment, shame, impaired self-image, low self-esteem and stigmatisation. In addition, a variety of other quantitative studies concerning patients with severe chronic skin disease show considerable co-morbidity [17], increased overall-mortality [18] and association with psychiatric morbidity [19]. However, a study that investigated cognitive

appraisals held by patients about their psoriasis could show that such beliefs are not strongly associated with the objective clinical disease severity. While the majority of respondents agreed that psoriasis had a major consequence on their lives and their self-perception, nearly half of the patients also showed indicators of adjustment to their disease [7].

Patients had different expectations towards their GP, ranging from making a clear diagnosis or applying an immediate cure to recognition of acute problems in the course of chronic disease. GPs were mainly expected to perform standard procedures like issuing prescriptions, coordinating referrals or performing routine checks. Nelson et al. [9,20] could show that GPs were perceived as lacking knowledge and expertise in the management of psoriasis, failing to recognize this disease as a complex long-term condition. This stands in a certain contrast to our findings, where most patients did not criticise the GPs' management. A possible explanation could be the fact that in Germany, specialist care including dermatology services is offered in the ambulatory sector, and can be directly approached by patients. As a consequence, most patients with chronic skin disease visit a dermatology practice parallel to consulting their GP, and would then rather blame their dermatologist for a lack of expertise, or no longer present dermatological problems to their GP.

Many of our patients had also made use of complementary therapies, a fact that is also found in other studies where patients partly disengaged from the official health care system seeking alternative sources of treatment [9].

## 5. CONCLUSION

Patients with chronic skin disease show a complex health seeking behaviour which can lead to delays in accessing the official health care system. There is a considerable impact on the quality of life. Further research should address how German GPs perceive the treatment of patients with chronic skin disease and how cooperation with dermatologists can be improved.

## CONSENT

All authors declare that written informed consent was obtained from the patients which includes publication of anonymized patient quotes.

## COMPETING INTERESTS

Authors have declared that no competing interests exist.

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