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A changed life: The life experiences of patients with psoriasis receiving biological treatment

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F.A., D.B.D and H.A. have no conflicts of interest to declare.

Bulleted statements:

What is already known about this topic?

- Patients with psoriasis are marked by the disease physically, psychologically and emotionally.
• The introduction of biologics has improved treatment outcomes and health-related quality of life.

What does this study add?

• This is the first qualitative study to explore the everyday life experiences of patients with psoriasis receiving biological treatment.
• The personal transition from having psoriasis to having clear skin is a major physical change, but psychological issues caused by psoriasis remain.
• Fear of treatment discontinuance is an ongoing emotion; patients are reluctant to initiate discussion about these concerns with healthcare professionals.

What are the clinical implications of this work?

• Entering the personal transition of receiving biological treatment may require assistance from healthcare professionals. A patient-centred approach is significant in order to recognize the need for individualized care of the patient.
• Health care professionals should address patients’ fear of discontinuance in order to reduce uncertainty and to ensure that patients are fully informed about their future treatment.
A changed life: The life experiences of patients with psoriasis receiving biological treatment

Summary

Background: Psoriasis has a large negative impact on quality of life and is associated with both depression and anxiety. The introduction of biologics has improved treatment outcome but the ways in which patients perceive these improvements are not well characterized.

Objectives: To investigate the everyday life experiences of patients with psoriasis receiving biological treatment in order to gain an understanding of their needs and to improve the quality of care.

Methods: A qualitative narrative methodology was utilised. A total of 48 hours of participant observations during consultations, and 15 semi-structured interviews, were conducted with patients receiving biological treatment. Data were analysed according to Ricoeur’s theory of interpretation.

Results: Receiving biological treatment was experienced as a turning point, with a significant impact on physical, psychological and emotional levels. However, psychological consequences, such as isolation and social withdrawal, seemed to be a part of the patient’s identity; the negative perceptions of psoriasis left marks behind that affected the patient’s self-image. Perceived fear of discontinuance of the biological treatment resulted in insecurity, and patients were reluctant to initiate discussion about these concerns with health care professionals.

Conclusion: Providing assistance when patients enter the transition of receiving biological treatment may be important. Patients’ fear of biological treatment being discontinued is an ongoing issue that health care professionals could address.
Introduction

Psoriasis has a large negative impact on quality of life, and is associated with depression and anxiety. When complicated by psoriatic arthritis, patients have even poorer quality of life, higher healthcare costs, lower income, higher unemployment rates, higher risk for disability, and more comorbidities. Despite improvements in treatment, the majority of even well-controlled psoriasis patients are still not satisfied with their treatment. This may be due to patients’ dissatisfaction with psoriasis management, including lack of empathy and support by health care professionals (HCP) who fail to recognize psoriasis as a complex long-term condition, not acknowledging that living with psoriasis goes beyond the skin.

Living with psoriasis can affect self-image and is associated with stigmatisation and social isolation. Patients with psoriasis suffer from pain, redness and flares and struggle with altered body image. Psoriasis may affect patients’ major life-changing decisions and shape their lives in ways that might have been different with the absence of psoriasis. These illness perceptions can be related to The Common-sense Model of Self-Regulation (CSM), which states that the ways in which patients perceive their condition is related to a certain pattern of how they structure their perceptions of illness. These illness perceptions are cognitive representations, consisting of personal experiences based on patients’ cultural and social contexts. Scharloo et al. found that patients with psoriasis with lower levels of perceived control and curability of illness, have lower health outcomes. These patients have been shown to have difficulties in controlling negative emotions; also, the illness perceptions are associated with disease severity. In contrast, disease severity is perceived differently among patients and HCP. Thus, exploring patients’ experiences may contribute towards a shared understanding of illness perceptions.

The introduction of biologics has improved treatment outcome and health-related quality of life, and offers long lasting benefits. The use of biologics leads to physical improvement and greater confidence, but some psychosocial impact may remain. While biologics may change patients’ lives and their illness perception, how patients perceive these changes is not well characterized. Therefore, the objective of this study was to investigate the everyday life experiences of patients with psoriasis receiving biological treatment.

Materials and methods
Design

A qualitative narrative methodology was utilised, using participant observation and semi-structured interviews. The study took a phenomenological-hermeneutic approach and was inspired by Ricoeur’s thoughts on narrative and interpretation. Ricoeur argues that the phenomenological and hermeneutic traditions are co-dependent and that, by combining a phenomenological comprehension and its descriptive character with a hermeneutic explanation and interpretation, a deeper understanding of a text will arise. To ensure and improve the transparency of this study, the Standards for Reporting Qualitative Research (SRQR) guided the reporting.

Researcher characteristics and reflexivity

Phenomenology and hermeneutics both seek to uncover the life world or the lived experiences of individuals. In this study, the phenomenological approach involved the search for descriptions of patients’ experiences of receiving biologics. The hermeneutic approach was applied to create meaning and achieve an understanding of these experiences. To do so, an interpretation is required. In qualitative research, the researcher’s presence during data gathering is unavoidable. The first author was employed at the institution where the data were gathered. However, not involved in the care of patients with psoriasis, and was therefore able to attend the participant observation in an open-minded way. Having a background as a health care professional, and in qualitative research it is inevitable that one has an influence the research. Thus, reflexive practice was performed, including the assessment of subjectivity, throughout the entire study. After each session of participant observation and interview, reflexive thoughts were written down and discussed within the research group to create awareness of preconceptions.

Study setting

The study was carried out in an outpatient clinic at a university hospital in Denmark, where patients receiving biological treatment have regular follow-ups every three months. These patients receive the biologics for free, as the costs are covered by the health system. Patients were included using a purposive sampling strategy, to achieve diversity in sex, age and geographical distance. All participants were over the age of 18 and were Danish-speaking: see Table 1.

Data collection
The first author conducted 48 hours of participant observation. The overall aim of the participant observation was to gain insight into the interaction, communication and issues discussed during consultations, to grasp a sense of the lived lives of the participants. Patients received written and oral information and gave their consent before attending the consultation. Patients included in the participant observation were randomly selected, meaning that all patients scheduled for an out-patient visit on the days the researcher was present were included, if they gave their consent. No participant declined. A total of 49 patients were observed. Participants were invited to participate in semi-structured interviews during these observations, and signed an informed consent, allowing the first author to contact them to schedule the interview. Participant observations were conducted from June to September 2018. An observational guide was developed, based on Spradley’s nine dimensions. During the observations, field notes were written and included informal interviews with both patients and HCP. Field notes were subsequently transcribed verbatim.

In total, 18 patients were contacted by phone and invited to participate in the semi-structured interviews. Two patients did not respond and one declined to participate due to lack of time. Interviews (N= 15) were carried out from September to November 2018 and were conducted in the location preferred by the patients: either in the patient’s home (N=9), at the hospital in an undisturbed room (N=4) or by telephone (N=2). All interviews were conducted by the first author and transcribed verbatim. The interview guide was developed on the basis of the existing scientific knowledge on the research topic, the study aim, and the preliminary findings derived from the participant observations. Each interview started with open-ended questions about the participants everyday life experiences with psoriasis, to acknowledge their history and individual perspectives. The interview continued in a more structured manner, covering the themes in the interview guide, including the biological treatment, the treatment process and everyday life (Table S1; see Supporting Information). Both the participant observations and the interviews were conducted in Danish.

Analysis

The transcribed field notes and interviews were gathered as one overall text and the analysis was inspired by Ricoeur’s theory of narrative and interpretation. The text followed a three-step process, consisting of naïve reading, structural analysis and critical interpretation and discussion. In the naïve reading, the text was read several times to establish an initial impression of what the text was about. This step was performed by the first author. In the structural analysis, the interpretation was carried out by identifying units of meaning (what is said) and units of significance (what the text speaks about). This step was performed by the first and
last authors through reflections and discussion, to ensure saturation, agreement and the perspective of the research objective. In a dialectical process between explanation and understanding, themes and subthemes emerged. The intention in this step was to move from an understanding of the patients’ experiences – an individual understanding – to an understanding of what the experiences referred to, i.e., a universal understanding. 

Findings were subsequently interpreted and discussed in relation to theory and other research results. The aim of this critical interpretation was to gain an even deeper understanding of the themes that had emerged. Findings were discussed among the entire research team. An example of the structural analysis can be found in Table S2 (see Supporting Information). The analysis was performed in Danish and the quotes were translated into English by a professional translator.

Ethics

The study was approved by the Danish Data Protection Agency (2012-58-0018), following the principles of the Declaration of Helsinki.

Results

The naïve reading revealed that biological treatment seemed to represent a turning point in patients’ lives; however, being accepted for biological treatment could be a struggle. Treatment with biologics seemed to create an awareness of the impact psoriasis had in one’s former everyday life, and threw light on how significant the biological treatment was. The structural analysis revealed three main themes and three subthemes. The findings are presented in chronological order – following the life experiences of patients with psoriasis before and during biological treatment, meaning that no theme was more common than any other.

The struggle to get biologics

Living with psoriasis and having to fight to become a candidate for biological treatment was stressful, and had physical, psychological and emotional consequences for the patients.

Not living life to the full

The physical pain, wounds, flares and itching prevented attendance at social activities, while maintaining a job required so much strength that there was no energy left for a social life:
‘I went to work, went home to lie down on the couch, and then I went back to work the next day.’ (Participant 13)

The social withdrawal entailed a psychological element as well:

“If, on rare occasions, I went out, there was always an empty seat next to me, and that empty seat followed me everywhere. I felt like as if I was carrying a big badge that said: I have plague.’ (Participant 14)

The prejudices from the outside world caused by bullying and dissociation from the person with psoriasis resulted in feelings such as being gross and contagious. Those feelings occurred in social settings, which resulted in avoidance and feelings of being cut off from the outside world.

Prior to the biological treatment, they had undergone the same topical treatment for many years without sufficient effect, and this had affected their everyday lives in negative ways:

‘Then I tried Methotrexate. But after about four to five months, it happened that every Wednesday, when I took it, I felt sick on Wednesday, Thursday and Friday, like nauseous and a headache.’ (Participant 5)

The experience of severe side effects of Methotrexate (MTX), such as nausea and fatigue, made it impossible to live everyday life as they wanted. However, it was considered the price that had to be paid to achieve even small improvements in the condition. There were experiences of having to discontinue the systemic treatment, which caused frustration, because the small improvements achieved were not permanent.

Biologics as an unobtainable goal

Being considered for biological treatment was experienced as a struggle and felt like “passing through the eye of a needle”. It was often refused by HCP due to high treatment costs, despite the fact that the patient was an eligible candidate for treatment:

‘I had asked, because I’d heard that something new had come on the market, something about injections, but he (the doctor) said no, that was too expensive.’ (Participant 1)
The sense of being a financial burden to society resulted in frustrations and the experiences of being dependent on the health care system. A feeling of self-reproach also arose, and patients questioned whether they had fought hard enough or they were to blame for not receiving the biological treatment sooner. This may seem to be a paradox, since patients’ requests were dismissed due to financial circumstances. Despite feeling that they were financial burden because of high treatment costs, patients pointed out the human consequences treatment delay had on extending their suffering.

In spite of the struggle and the patient-perceived restricted access to biological treatment, scepticism towards the treatment was also expressed:

‘I didn’t really have any (expectations), because I thought, oh well, maybe I can’t tolerate that either?’ (Participant 12)

Scepticism around initiating biological treatment originated in previous failed treatments, which meant that some participants had low expectations; however the hope of a better quality of life was a driving force. Having lived with the physical, psychological and emotional burden of psoriasis for years, it was difficult to imagine how life could be different. In contrast, having high expectations, such as total clearance of the skin, resulted in disappointment:

‘I probably expected it (the psoriasis) to disappear completely, but afterwards I found out that you can only expect 75% of it to disappear.’ (Participant 3)

Not achieving full skin clearance when expected resulted in uncertainty as to whether the right biologic was being used. There were reflections on how to adjust one’s expectations in relation to the biologic used and how to discuss this with the HCP.

The struggle included not only dealing with being considered as a candidate for the treatment, but also tackling everyday struggles involving insufficient topical treatment, severe side effects, and the prospect of biological treatment as an unobtainable goal.

The patient looks directly at me and says: ‘Today you are with me and I would like to tell you something. When I came here the first time the doctor told me: “You can’t get help.” I had to wait 2 years before I got the medicine. I know it is an expensive medicine. Back then I had to have plastic bags on my feet in my shoes or else my feet cracked, it was horrible.’ (Field note)
Adapting to everyday life

Receiving biological treatment was experienced as a turning point, with a significant impact on physical, psychological and emotional well-being.

Breaking out of isolation

Receiving biological treatment was experienced as being given a new lease of life and a personal transformation. This included new feelings of being attractive as well as a sense of achievement in getting rid of the physical symptoms:

‘It was like being 18 again and free as a bird. I could do anything I wanted without that damn disease controlling my life, and you can create friendships without having the feeling that you are someone who is contagious.’ (Participant 14)

‘It (biologics) is the reason that today I have a wife.’ (Field note)

Receiving biological treatment meant that they regained control of everyday life and feelings of freedom and self-determination arose. Furthermore, the workload involved in managing the condition was reduced, along with the distress this had caused. A physical transformation was expressed in terms of how the skin gradually improved over hours, to days, to weeks until finally the psoriasis became invisible. Being given this new and changed life was considered as an opportunity to break out of isolation and back into society. Nevertheless, for some, this was challenging:

‘It is like, you’re totally speechless, and you don’t know what to do. You have all these opportunities, and you don’t know how to deal with them. It’s like you’re completely reset, released, you know? And you can’t control anything, it is overwhelming.’ (Participant 9)

There were feelings of being overwhelmed by opportunities. After having lived most of their lives in isolation or being used to social withdrawal, there was an awareness of how this had now changed. Despite the transformation, social participation did not come naturally, and feelings of loss of control occurred, leading to a need to seek professional help to cope in social settings. Having clear skin did not necessarily lead to feelings of having clear skin:
‘I do hope that, at some point, I will be able to do the same as everybody else. Go swimming, going to the beach without you know, trying to understand that I don’t have all these spots anymore, so that I can live with being a new version of myself.’ (Participant 4)

The health care professional asks the patient about his psoriasis. The patient answers: ‘I don’t have much of that anymore.’ Nurse: ‘But some of it can still be in there from when you had it’. Patient: ‘Yes that is certainly true, I have developed some unfortunate patterns from when I had it, like disappearing into the wallpaper.’ (Field note)

Becoming a new version of oneself could be hard, because feelings and perceptions of being gross and contagious did not disappear immediately on a mental level, in pace with the disappearance of the visible signs of the condition. The psychological consequences and social withdrawal seemed for some to have become part of their identities, and the perceptions of psoriasis had left marks behind that had a significant and lasting impact on self-image.

Facing an uncertain future

The turning point of receiving biological treatment involved a fear of the treatment being discontinued by the HCP:

‘My blood pressure goes up like crazy, when I have to go there (follow-up consultations), because I’m scared to death and really afraid, that I won’t get the biological medication, because it’s so very important in my life.’ (Participant 13)

The potential risk of not continuing the biological treatment involved two major interrelated concerns: tolerance of the treatment and the financial aspects of treatment. The potential risk that they could not tolerate the treatment or that it would suddenly stop being effective was constant, and emerged from previous experiences of treatment. Costs were a concern, and patients worried they would not be allowed to continue treatment once their disease improved. Patients were reluctant to initiate a discussion about these concerns with HCP, and when concerns were expressed, HCP did not always respond:

The doctor looks at the skin and in between she types something on the computer. Then she asks the patient: ‘Are you satisfied?’ The patient: ‘Yes, very much, I fear that I might not be allowed to continue (the biological treatment) and that would be awful’. The doctor looks at her computer...
screen while calculating a PASI score. Then she turns towards the patient: ‘Should we continue with the 15 weeks?’ ‘Yes let’s do that’, the patient answers. (Field note)

While patients acknowledge that a potential treatment withdrawal created both psychological and physical stress, they did not seek to address these concerns because they considered that mentioning it would give the HCP an opportunity to consider discontinuing the treatment. Unexpressed concerns affected patients:

‘Sometimes, when I’m there, they (HCP) say: “Well then, we will continue the treatment”. Then I think, hopefully they won’t take it away from me now.’ (Participant 1)

Concerns about biological treatment discontinuation created uncertainty and insecurity and resulted in fear and negative beliefs about the future. Switching back to topical treatment would mean going backwards and not being able to live life to one’s full potential; it represented a return to a life of pain and isolation.

Discussion

To the best of our knowledge, this is the first qualitative study to investigate the experiences of patients with psoriasis who are receiving biological treatment. This patient group is marked by the disease, not only physically, but also psychologically and emotionally, which is consistent with previous research. The findings of our study constitute important knowledge, improving our understanding of the nuances of the personal transition that occurs when moving from topical to biological treatment. We found that this treatment provides an opportunity to break out of isolation and adapt to everyday life. The patients felt more in control of their condition, in contrast to feeling that the condition was in control of them. Patients with rheumatic arthritis receiving biological treatment experienced a dramatic improvement in symptoms and normalisation of everyday life, which is consistent with the findings in our study. However, we found that, in some cases, the chronic psychosocial impact of psoriasis could affect a patient’s identity, resulting in difficulties in fully reversing the impact of disease, even when the skin lesions had cleared. Although the transition from having psoriasis to having clear skin was a major physical change, some psychological issues caused by psoriasis remained untreated. This could indicate that the cognitive representations of psoriasis – how patients have perceived themselves for many years – has a major impact on their illness perception, and may be difficult to change. Although clinical characteristics associated with illness perception in psoriasis have shown several negative outcomes (e.g., illness perceptions being the most consistent predictor of distress and
disability\textsuperscript{34}), few interventions have been developed to change illness perception\textsuperscript{35}. However, the use of illness perception assessment in psoriasis may assist in identifying those patients who struggle with psychological issues in their transition. According to Meleis, changes between health and illness create a transition in which patients are vulnerable.\textsuperscript{36} One aspect of a transition is that a person creates new meaning, perceptions and the development of confidence. Patients need to master skills and behaviour to manage new situations in order to achieve a healthy transition outcome.\textsuperscript{36} Each transition is unique, complex and multidimensional, and patients may need knowledge and guidance from HCP to assist them during their transition. In the present study, transitions among patients with psoriasis on biologics were prominent on a physical and mental level. Even the resolution of skin lesions can leave patients with psychological and social challenges after having lived with psoriasis for a number of years. Patients commonly feel that the challenges of living with psoriasis are not acknowledged by HCP.\textsuperscript{9} From a patient perspective, addressing these issues are important for patients to achieve their full potential.

Another important finding was the fear of discontinuance of biological treatment and the reluctance to discuss this fear directly with the HCP. The fear that treatment would stop having an effect or would lead to side-effects made patients anxious about the future. There was also anxiety about losing control and going back to a life with the disease, as well as anxiety about having to fight once more, to once again become a candidate for biological treatment. This is somewhat consistent with findings among patients with rheumatoid arthritis on biological treatment.\textsuperscript{37, 38} The experiences of struggle may be a result of the current step-edit approach that is required in Denmark before initiating biological treatment.\textsuperscript{39} Patients have to undergo and fail topicals, oral systemic treatment, and phototherapy, besides having a documented severe disease. Because the health system has limited resources, patients in our study were not approved for biological treatment despite being appropriate candidates. This is consistent with international research, which emphasizes the under-treatment of psoriasis patients.\textsuperscript{40, 41} In our study, fear of treatment discontinuation had a huge impact on everyday life, and should be taken into consideration in the care and management of psoriasis.

Recognizing and addressing the psychosocial scars of chronic psoriasis that remain even after lesions have cleared up may be an important aspect of the management of patients on biological treatment. The 2012 NICE guidance recommends offering support and information that is tailored to the individual needs of
patients in the assessment and management of psoriasis. Informing patients about their future treatment, when possible, may help reduce their anxiety.

A limitation of this study was that data were collected at the same out-patient clinic. This could have an impact on the transferability of the findings. However, the clinic treats patients with psoriasis on biological treatment from all over the Region of Southern Denmark. Another limitation of the study is that, during the participant observations, the presence of the first author may have influenced the behaviour of the participants. Nevertheless, recruiting participants after consultations ensured that the participants knew the person conducting the following interview. This allowed for the relationship to be built up and for a certain amount of trust to be developed.

The objective was to investigate the everyday life experiences of patients with psoriasis receiving biological treatment based on rich descriptions to create a theoretical understanding of the phenomenon. Ricoeur argues, that narration allows for a process of reflection in the narrator, and this provides new perspectives into their lives; therefore validation among the participants would be inappropriate. The findings must be read with this in mind. However, the study was conducted systematically and co-authors were involved at all stages of the data analysis in order to eliminate misinterpretation or over interpretation.

In conclusion, our findings demonstrate the complexity of receiving transformative treatment and highlight psychological issues not addressed or solved simply by receiving biologics. Furthermore, it may help for HCP to be aware that even well treated patients are reluctant to discuss their concerns about treatment and that patients should be given time and opportunities to discuss them.

References


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### Table 1 Participants’ characteristics

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