

**Care and treatment needs of immunosuppressive therapy patients with warts and impact on everyday life: a qualitative study**

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## **Title page**

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## **Abstract**

**Introduction:** Patients receiving immunosuppressive therapy have an increased risk of developing verrucae vulgaris (warts). They often suffer from dissemination of numerous warts, complicated by low treatment response and long-term treatment. How patients experience these challenges is not well characterized. The aim of this study was to explore how patients on immunosuppressive therapy experience everyday life with warts on the hands and feet, and their needs related to care and treatment.

**Methods:** The study took a phenomenological-hermeneutic approach. Semi-structured interviews were conducted with 10 adults. Data were analyzed using the thematic analysis described by Braun and Clark.

**Results:** Warts on the hands and feet impact everyday life and cause feelings of stigma and pain. Patients request treatment and hope to be cured although the prospects are poor. Self-treatment is experienced as a burden, because of the need for more specific information about and skills to treat the warts, and because individual patients' resources are not considered. Patients experience a lack of care continuity.

**Conclusions:** Patients request a person-centred care and treatment approach, to establish a relationship with health care professionals. Establishing care continuity might reduce patients' treatment-related insecurity.

Keywords: qualitative study, verrucae vulgaris, warts, immunosuppressive therapy

## **Introduction**

Patients on immunosuppressive therapy have an increased risk of developing warts (1, 2).

Over time, these patients may develop numerous warts, which can often be large, extensive and resistant to treatment. They often receive long-term treatment without documented cure (1, 3). Warts on the hands and feet are one of the most distressing side effects of kidney transplantation (4). These patients have an increased dermatology life quality index score compared to those without warts (3, 5).

Even for patients with a normal immune system, visible warts on the hands and feet have a negative impact on quality of life (6, 7). Embarrassment, fear of others' negative appraisal, frustrations with the persistence and recurrence of the warts and time spent on treatment are common feelings among these patients (6, 7).

In clinical practice, patients on immunosuppressive therapy receive continuous treatment at 2-3 week intervals for several years and often with various treatment protocols in combination with self-treatment. However, these long-term treatments have a limited effect and often no documented cure (1, 3). How the above factors affect patients' everyday lives and how they experience care and treatment are not well characterized. Thus, the aim of this qualitative study was to explore how patients on immunosuppressive therapy experience everyday life with warts on the hands and feet, and their care and treatment needs.

## **Materials and Methods**

The study was designed and conducted as a qualitative study, using semi-structured interviews to gain an in-depth understanding of the patients' experiences. The study was based on a phenomenological-hermeneutic approach (8).

### ***Setting***

The study took place at a Danish university hospital, at an outpatient clinic specializing in dermatology.

### ***Study participants***

Patients were invited to participate when they attended the outpatient clinic for treatment. Those who accepted were contacted by the first author, who scheduled the semi-structured interviews. All invited patients agreed to participate. Five men and five women, aged 35-68 were included. The inclusion criteria were: patients in treatment with immunosuppressive medicine over the age of 18, diagnosed with warts on the hands and/or feet for a minimum of one year and having received treatment at the outpatient clinic for at least six months. We aimed for variation in age and sex (9). See Table 1. The interviews were conducted from February to June 2019.

Insert **table 1**

### ***Data collection***

Three patient representatives who received treatment in the Department of Dermatology in Odense were involved to discuss the relevance of the study and contribute with perspectives of what is significant to investigate and to clarify the aim of the study. Their perspectives, together with a literature review and the authors' experiences gained from clinical practice,

contributed to the preparation of an interview guide. The interviews were conducted by the first (NTM) and third (KH) authors, digitally recorded and transcribed verbatim. The interviews were conducted in an undisturbed room at the outpatient clinic, either before or after the patients received treatment.

### ***Ethical considerations***

The study was registered and approved by the Danish Data Protection Agency (ID: 19/5737). Participants received oral and written information about the study, and signed a written consent form prior to the interviews. Approval by the National on health research ethics was not required, in accordance with Danish law (10).

### ***Analysis***

The analysis and interpretation were inspired by Virginia Braun and Victoria Clark's thematic analysis, which consists of six phases (11). In the first phase, the entire data set was read several times to gain an overall understanding of the content of the text, and searches for meanings and patterns in the text were written down. In the second phase, the text was coded, and the software programme NVivo 11 was used. In the third and fourth phases, the consecutive codes were sorted into themes and were clarified in a coherent and meaningful way. Through discussions and the use of mind-maps, themes and subthemes were formed, in collaboration between all authors. In the fifth and sixth phases, the themes and subthemes were adjusted, and described with the inclusion of quotations to illustrate the findings. An example from the analysis process is shown in Table 2.

Insert **table 2**

## Results

Based on the analyses, four themes and two subthemes emerged (See table 3).

Insert **table 3**

### *The impact on everyday life*

The patients experience having warts on the hands and feet as stigmatizing, and live with physical and mental pain. Despite the enormous burden of the warts in everyday life, over time they learn to cope with them.

### *Dealing with the pain*

The patients live with a chronic illness and many experience that inconvenience and pain are part of everyday life. In addition to chronic pain associated with their underlying disease, they also experience pain from the warts, which affects their joy of life:

Because this one (points to the wart) really hurts every single day. I hate it ... I am already in a lot of pain, which I have had for many years. And then this gives even more pain. You can get a little depressed, it's a little hard sometimes. (ID 8)

Patients are constantly aware of the warts. If they knock the wart on something, it triggers severe pain: *“if I do something and bump it, uhhh it really hurts, it really makes me upset”* (ID 8).

Both the constant awareness of the warts and the pain the patients live with can result in depression, which has an impact on quality of life. In addition to the psychological impact, pain from the warts has a physical effect, because it limits physical activity, e.g., in terms of



walking and running. This can mean that the desire and opportunities for an active life are limited. During treatment, almost unbearable pain is experienced. However, because the treatment is of great importance, the pain is tolerated:

“I look forward to the treatment, if you can put it that way, it may be that it hurts, but I think it works”. (ID 8)

### *A feeling of stigma*

Having warts is experienced as shameful and the patients feel they deviate from “the normal”. The shame is also significant to and influences their social life, as the warts are hidden for fear of the reaction of others. The uncertainty about how others would react gives the feeling that the warts must be hidden in social contexts, and the motivation and joy in being social is thus suppressed. Allowing one’s warts to be seen can bring a sense of vulnerability and exposure, and patients have the perception that others react with nausea:

Well, I have hidden them, no-one has seen the warts, other than some of my closest friends. Then they say ‘Oh yes it is not very nice’. They might as well have said ‘It’s disgusting’, because it is. (ID 10)

The patients’ experience of having warts leads them to imagine how others look at them and react and therefore the warts are hidden.

After many years with warts and lack of treatment effect, patients experience that the warts become part of them and their everyday lives. As time goes on, patients accept them as part of their identity and try to learn to live a life with them:

Of course, it's not nice to have them, but somewhere along the line you also just get to the point where it's just, like, a part of you, so you have to live with them.

(ID 6)

### *Treatment – A high priority*

Patients struggle long-term treatment and dare not end the hospital treatment for fear of relapse or the warts spreading. Although the treatment process is long and the warts may never disappear, hospital treatment is a high priority:

I simply don't dare (to stop hospital treatment) when the healthcare professional says she can see that it's going away. I know it's still a long process I have ahead of me, but what if it just suddenly erupts in a few months, then I'll just be thrown a few years back. So I just have to fight to be finished with that rubbish. (ID 6)

Patients' uncertainty about how the warts will develop and fear of the extensive treatment going to waste if they stop the hospital treatment and become responsible for self-treatment at home lead to insecurity. The healthcare professionals (HCPs') assessment of treatment effect maintains patients' motivation for treatment and they thereby retain the hope of healing. Patients have a serious chronic disease that often presents limitations and limits their lives, and this can overshadow their experience of having warts. Although patients express the warts as "just a wart", their hopes of healing are high, and therefore hospital treatment is of great importance to them:

You could say that it's just a foot wart, YES! But as it was, I did EVERYTHING to get treatment ... so it was big (the wart). (ID 10)

The quotation illustrates how the warts are far more annoying and have a significant impact on everyday life than what they feel it is legit to express. It can be a dilemma to express the warts as a problem. On the one hand, patients have a serious chronic illness and feel a lot of gratitude to be in immunosuppressive treatment for their condition, but, on the other hand, warts have great negative impact in their daily lives:

I suffer from something worse than this (warts on hands and feet), so I think it really bounces off me a bit (how much the warts actually bother the patient). But it is annoying and tiring that I cannot get rid of them (the warts) and the trips (for hospital treatment) every 14 days ... but I am glad to do it, to get rid of it. (ID 3)

### ***The challenges of self-treatment***

Self-treatment is experienced as a significant challenge, partly because the localization of individual warts often complicates the treatment. In addition, self-treatment is experienced as an endless and demanding process:

I know you have to be on top of them (the warts) all the time to keep them in check. For me they multiply really fast, it has been really tiring. (ID 8)

The situation gives rise to concern and powerlessness because responsibility and perseverance in relation to self-treatment are necessary if the hope of healing is to be maintained. Self-treatment can therefore also be experienced as a pressure that can be difficult to manage

You get fed up with it (self-treatment) at some point. Even though I know it's for my own good, I'm still annoyed with it. (ID 3)

Self-treatment can be easier to handle when combined with hospital treatment. In that way, the course of treatment is linked with a feeling of shared responsibility, which is a relief for the patient. It provides reassurance and helps maintain motivation. It is important that the HCPs get to know, listen to and uncover the patient's life situation, because it impacts how self-treatment is planned:

It's not because I don't know how to tackle self-treatment, but when I have a period where I have no energy even to cook, then I also have no surplus energy to scrape my warts. Then you come down here and get told in almost baby words that it is important (to do the self-treatment carefully), I am fully aware that I have to scrape these warts, but they cannot put themselves into my situation. (ID 9)

When the HCPs do not take into account the patient's life situation and everyday life, the patient may experience powerlessness and feel rejected, because of an imbalance between treatment requirements set by the HCPs and the patient's resources.

Patients request more knowledge, teaching and supervision about self-treatment:

It has been a bit difficult for me (wart treatment) ... they (HCPs) could have told me a little more about how I should do it. It might not be because they didn't. (ID 1)

For the patient, the struggle to ensure sufficient self-treatment is challenging. When the dissemination of knowledge and supervision is deficient, ambiguity arises in relation to the patient's need for support and follow-up, and the patient is left feeling that they are insufficient.

### *The need for continuity in treatment and care*

Patients meet many different HCPs throughout their course of treatment, which is frustrating. This means that the patient has to mobilize energy and time to meet the HCPs' needs for an update on the warts, instead of the patient being able to choose to talk about what is important to her/him. The relationship with the HCPs is built through a series of consultations, and therefore it is particularly frustrating when there is a lack of continuity:

I think it's nice that, when you come so many times, there is a chemistry (positive relationship) ... When you have had the same (HCP) several times, then you start to have a dialogue. You have a different relationship. It just means something that you know each other ... it is on the personal level, even if the treatment is the same. (ID 2)

Continuity in meetings with the HCPs is important and allow for a dialogue. When a relationship is established with a known HCP, a basis for dialogue is created, and the patient gets to talk about what is important to her/him. In some situations, the treatment may take second place.

Conversely, there are experiences that the HCPs can better assess the effect of the treatment if there is a team of HCPs who follow the patient:

If there are several (HCPs) who have known the process for a long time and know what has happened and how it has been, they can, like, see how big the area is and how far we have come. I feel that is a good thing. (ID 5)

When several HCPs have observed the warts and the course of treatment, patients have a sense of security, and feel more certainty in relation to how an exacerbation or improvement in the condition is managed. Otherwise, if there is no agreement on how the warts are treated, it creates uncertainty and affects the relationship with the HCPs.

## **Discussion**

This study found that living with warts was a physical, social and mental burden.

Nevertheless, in time, patients accepted and learned to cope with their condition, but at the same time, they persevered in hoping to be cured. Thus, hospital treatment was important to them. The patients needed more continuity in treatment and care, together with more precise and proper information and instructions from the HCPs.

Almost 50% of patients feel moderate to extreme discomfort because of the warts (7). This includes embarrassment, fear of negative appraisal by others and frustration because the warts persistently affect their social well-being. This is in line with some of the findings in our study. We found that the visibility of the warts led to feelings of shame and fear of rejection by others. As a result, patients tried to hide their warts in social contexts. It is well known that patients with skin diseases often have feelings of being stigmatized (12, 13). In the case of warts, the stigma may be related to the fact that it is caused by an infection and is thus contagious (14).

One study found that a substantial proportion of the study population did not consider the pain they experienced from warts to be a burden (7). This is in contrast to our study, as we found that pain related to warts was experienced as a significant burden that affected the patients mentally, and restricted their physical ability, thereby negatively impacting their everyday lives. However, our study population were all on immunosuppressive therapy, and it could be that the burden of warts was experienced differently to those with warts but no underlying chronic disease. It is well known that living with multiple chronic conditions has a significant negative impact on everyday life, and is highly associated with physical limitations and negative mood (15, 16).

Patients with warts on the hands, feet or face are particularly frustrated about the time spent on treatment (6). In our study, this was not the case. We found that the patients persevered with treatment in the hope of being cured; therefore, receiving regular treatment was important to them. Although the patients felt that the warts were a huge burden, and they all had an underlying severe disease, they learned to live with and accept a life with warts.

Patients with multiple chronic conditions often have to adjust their lives and at the same time they report a strong desire to keep their chronic disease under control, by employing various strategies. Although long-term treatment of a chronic disease is experienced as a burden, it also regencies as an essential component in the management of their disease (17). In our study, treatment at the hospital was a high priority for patients. Given that all the patients acknowledged that a complete cure was unrealistic, their persistent hope of a sufficient treatment could be regarded as a coping strategy.

Furthermore, we found that the HCPs' observation and assessment of the treatment effect had a significant impact on the patients' hope for a cure. Guidelines for the management of cutaneous warts describe that, in patients with a reduced immune function, treatment is not likely to result in cure, but can help to reduce the size of the warts and reduce functional and cosmetic problems (1). Our findings suggest that following the treatment guidelines and informing patients about the realistic prognosis may avoid patients' building up an unrealistic hope of being cured.

This study revealed that patients experienced a discrepancy between the HCPs' expectations of, and the patients' resources in relation to, self-treatment at home. The patients expressed the need for skills and competencies to perform self-treatment that matched their individual challenges and needs. This is somewhat consistent with findings in a stud with other dermatological patients, where limited consideration of patients and their situations creates a

need for individualized health education (18). It is well known that information, communication and education are important components in patient-centred care (19, 20). Disease-specific and person-specific education are essential and necessary when patients have to learn skills in order to manage their treatment (20). Nevertheless, research in dermatology has identified unmet needs in terms of information and support for self-management of skin conditions (18, 21). Since it is recommended that patients with warts combine treatment at hospital with treatment at home (1), we suggest that the HCPs follow this recommendation and meet patients' current needs, taking in account their everyday life and emotional well-being.

Our study revealed that patients experienced a lack of continuity in care delivered by HCPs, resulting in insecurity about treatment effect. Some patients did not experience that the HCPs understood or knew about their life situation, leaving patients with their social and psychological needs unaddressed. A lack of continuity in care can have an impact on patients' sense of trust, and when patients perceive that HCPs have a limited understanding of their situation, it can affect the communication negatively impact the treatment effect (18). However, working in an outpatient clinic can be challenging in terms of organizational factors, such as limited time and that a patient may see a number of different HCPs. This can make it difficult for the HCPs to get to know the patients and adapt care to individual expectations and needs (22). Ideally, HCPs should get to know the patients and be able to gain insight into their needs, expectations and preferences, in order to make clinical assessments and decisions.

### **Strengths and limitations**

A limitation of the study is the small sample size of 10 patients. However, in qualitative research, sample size is usually determined based on informational needs, and therefore relies



more on data saturation rather than numbers of participants. (23). In our study, we reached data saturation at the 10th interviews. The qualitative approach was used to obtain in-depth insight that matched the aim and this is considered a main strength of the current study. Another limitation of this study is that two of the authors (NTM and KH) are employed at the clinical setting and thus involved in the care and treatment of patients with warts. This involves a risk that the researchers would affect the findings. Therefore, the researchers constantly reflected on their preconceptions in regard of the interpretation of the findings. Furthermore, the study was conducted systematically, and all co-authors were involved at all stages of the data analysis.

## **Conclusion**

In conclusion, this study identified that patients with warts who receive long-term treatment need continuity in care and treatment. Findings suggest that a person-centred approach to establishing a relationship between patients and HCPs is important. Establishing continuity in care might reduce insecurity related to treatment. The patients experienced a negative impact on everyday life due to feelings of stigma and pain, which affected their physical, social and mental well-being. It is significant to patients that the treatment and care they receive is based on a person-centred approach, so that individual patients' experiences of coping with warts are understood. A person-centred approach may help to clarify and address patients' needs and resources, especially in relation to self-treatment.

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## Disclosure statement

The authors declare that there is no conflict of interest.

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**Table 1. Characteristics of the participants**

ID	Sex	Age 35-55	Age 56-75	Location of warts	Years with warts	Number of years in treatment at Dermatology Department	Current treatment	Chronic disease
ID 1	Female		X	1 foot	2	2	Pulsed dye laser	Liver transplantation
ID 2	Male		X	1 hand	>10	2	Pulsed dye laser	Heart transplantation
ID 3	Female	X		1 hand and 1 foot	>10	5	Pulsed dye laser	Systemic lupus erythematosus
ID 4	Male	X		1 foot	1-2	1	Pulsed dye laser	Kidney transplantation
ID 5	Male		X	1 hand and 1 foot	8	5	Cantharidin	Rheumatic diseases
ID 6	Female	X		1 hand and 2 foot	>10	2	Cryotherapy	Multiple sklerose
ID 7	Female	X		1 hand and 2 foot	8	2	Pulsed dye laser	Systemic lupus erythematosus
ID 8	Male	X		1 hand	9	½	Pulsed dye laser	Rheumatic diseases
ID 9	Male	X		2 hands and 2 foot	9	2	Imiquimod creme	Sarcoidosis
ID 10	Female		X	1 foot	7	6	Pulsed dye laser	Rheumatic diseases

**Table 2. An overview of the thematic analysis, illustrating three main themes and four subthemes**

<b>Quotation</b>	<b>Meaning extraction</b>	<b>Subthemes</b>	<b>Themes</b>
<i>Partly it hurts because the wart splits and when I am active, the warts are painful</i>	The patient experiences that the warts can crack and it is experienced as painful. In addition, the patient experiences that physical activity triggers pain.	Dealing with the pain	The impact on everyday life
<i>in my childhood, warts were quite ugly and something ugly to look at, especially if they were visible. I had something like that on my cornea, “oh no it’s going to be quite ugly”, it’s good they (the warts) are not in a place where they are visible.</i>	It is experienced as being exposed if the warts are visible to others and therefore it means something that the warts can be hidden.	A feeling of stigma	The impact on everyday life
<i>you could say that it’s just a foot wart, YES! But as it was, I did EVERYTHING to get treatment ... so it was big</i>	Although the warts are banal in comparison to the patients' chronic disease, hospital treatment is given high priority by patients, because the warts have a significant impact on everyday life and the patients live in the hope of healing.		Treatment – A high priority
<i>I can’t reach all the warts, I’m not that flexible.</i>	Localization can make it difficult to treat the warts at home.		The challenges of self-treatment
<i>I think self-treatment is hard. There are so many things that I have to remember every single day, and it is hard when you have such a heavy head.</i>	Self-treatment can feel like a big challenge in everyday life, especially when patients already suffer from other chronic illnesses that give them challenges in everyday life.		
<i>especially in the beginning, it was honestly a little frustrating that there was a new one (HCP) every single time. Then they had to count them and write up, probably in the health record. Each time it was a new one (HCP) who talked and talked and enquired about what and how ... now I’m telling the story again for the 10th time.</i>	It is frustrating to see many different HCPs. Having to repeat the same story is experienced as starting from scratch every time.		The need for continuity in treatment and care

**Table 3. Overview of the themes and subthemes**

<i>Themes</i>	<i>Subthemes</i>
<i>The impact on everyday life</i>	<i>Dealing with the pain</i>

<i>A feeling of stigma</i>
<i>Treatment – A high priority</i>
<i>Battling with self-treatment</i>
<i>The need for continuity in treatment and care</i>