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Lived Experiences, Disease Management and Expectations in a Nursing-Led Psoriasis Unit: A Qualitative Study

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Highlights

What are the main findings?

- Phototherapy in psoriasis operates as a "double-edged sword", where its clinical effectiveness is counterbalanced by a substantial logistical and psychosocial burden that may exacerbate disease activity.
- Patients experience a profound biographical disruption, driven by visible lesions, chronic symptoms, and an "adherence–stress cycle", alongside significant gaps in knowledge about systemic comorbidities

What are the implications of the main findings?

- These findings highlight the need to move beyond skin clearance toward integrated, patient-centred care models that address psychosocial, educational, and logistical dimensions of the disease.
- Establishing a specialised nursing referent within dermatology units is essential to improve patient navigation, treatment adherence, and overall quality of life.

Abstract

Background: Psoriasis is a chronic, systemic and immune-mediated disease that affects over 60 million people worldwide. Although phototherapy is a safe and effective treatment, its demanding thrice-weekly clinical regimen imposes a significant treatment burden that can disrupt the patient's life narratives. Despite its clinical importance, little is known about how patients navigate the logistical and emotional complexities of this therapy within specialised nursing-led units. **Objective**: To explore the lived experiences, disease management strategies, and healthcare expectations of patients with psoriasis undergoing phototherapy. **Methods**: A descriptive phenomenological design was adopted. Between 2019 and 2022, purposive and exhaustive sampling was used to recruit 72 participants receiving treatment at a specialised nursing-led phototherapy unit in a tertiary hospital in Spain. Data were collected through semi-structured interviews and analysed using inductive thematic content analysis supported by NVivo 12 Pro. **Results**: Eleven subtopics emerged within four main thematic areas: (1) Knowledge about the disease and treatment options: A striking dichotomy exists between a well-recognised psychological burden and a persistent lack of awareness regarding systemic physical comorbidities and biological therapies; (2) Triggers of the disease and flare-ups: Psychological stress was identified as the primary driver of disease activity, overshadowing secondary external factors; (3) Functional and logistical stressors: The rigorous frequency of sessions creates an "adherence-stress cycle," where the effort to maintain therapeutic continuity paradoxically generates the stress that exacerbates clinical flares, leading to profound biographical disruption and a perceived incapacity to fulfil professional and family roles; (4) Healthcare expectations and systemic barriers: Participants identified diagnostic delays and inequities in the financing of supportive care, manifesting as a collective demand for a permanent professional nursing referent to act as an anchor

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for integrated care. **Conclusions**: Phototherapy functions as a “double-edged sword” where clinical efficacy frequently conflicts with the logistical rigour of the treatment. Clinical skin clearance is insufficient if the biographical and systemic gaps remain unaddressed. This investigation advocates for a paradigm shift toward integrated care models where specialised dermatology nurses provide the necessary clinical navigation to support patients “beyond the surface” of the disease.

Keywords: disease management; qualitative research; nursing care; patient-centered care; phototherapy; psoriasis; treatment adherence and compliance

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1. Introduction

Psoriasis is a chronic, immune-mediated and inflammatory disease. It’s a major global health challenge that affects more than 60 million people worldwide, has prevalence rates reaching up to 11.4% in certain high-income countries [1]. Traditionally, psoriasis has been viewed as a dermatological condition but, recent evidence supports its classification as a systemic disease with associations beyond the skin [2]. This pathology is frequently linked to comorbidities such as cardiovascular disease, metabolic syndrome, non-alcoholic fatty liver, obesity [3] and other immune-mediated diseases such as Crohn’s disease [4]. The impact of the disease is not only physical, patient with psoriasis reports symptoms of anxiety and depression, often exceeding the psychological distress seen in other chronic conditions [5].

The clinical forms of psoriasis are heterogeneous and diverse. It can affect any part of the body, hairy areas and nails. There are inverted forms that particularly affect the genitals, breast folds, armpits, buttocks as well as pustular forms; while other affect only the palms and soles [6]. These skin lesions, which are usually visible, have a significant impact on self-concept and relationships with others [7]. Shame, low self-esteem, and social withdrawal are common, often affecting daily functioning and quality of life [8,9]. This experience is frequently interpreted through the lens of biographical disruption [10], where the chronic skin condition forces individuals to fundamentally redefine their identities and social roles. This biographical disruption is compounded by a high prevalence of psychiatric comorbidities; as shown in a recent 2024 systematic review, patients with psoriasis exhibit significantly elevated rates of anxiety, depression, and suicidal ideation compared to the general population [11].

Among the therapeutic options available to improve the symptoms of people with psoriasis, phototherapy is widely established as a safe and effective therapeutic treatment for the management of moderate-to-severe psoriasis [12,13]. However, from a patient-centred perspective, this treatment is associated with a high burden, primarily due to the demanding attendance protocol it requires. The need for thrice-weekly in-hospital sessions over an extended period of time asks for significant time commitment and persistent effort from the individual. In addition, adherence rates must be high in order to achieve the desired effectiveness [14]. This regimen creates significant logistical tensions, complicating work-life balance and often leading to a “vicious cycle”. The stress of maintaining adherence to such a demanding schedule can trigger emotional distress, which in turn exacerbates clinical flares [15]. Despite its known benefits, the burden it places on the patient has not been explored in depth and how approach this type of treatment requires special attention.

Nursing professionals in dermatology units play a vital role in bridging the gap between clinical severity and patient well-being. Beyond the technical administration of ultraviolet radiation, nurses carry out complex interventions focused on patient education and psychosocial support, addressing the health determinants that are often overlooked in brief medical consultations. These nurse-led interventions are now recognized not only as complementary, but as fundamental components of comprehensive psoriasis care [16]. Despite the importance of nursing role on patient education, many patients harbour misconceptions about the disease. For exemple, some may share the belief that psoriasis is contagious or that it can be completely cured, which can hinder proper treatment [17]. Zhang et al., analyzing the knowledge and attitudes of people with psoriasis, highlight that patients continue to show an insufficient understanding of disease triggers, genetic factors, and the potential long-term side effects of systemic treatments [18]. Conversely it has been shown that increased knowledge is positively correlated with more favorable attitudes and effective self-management practices among individuals with psoriasis [19].

While quantitative research has extensively mapped adherence rates and clinical outcomes [20,21], there is a scarcity of in-depth, qualitative evidence exploring the lived experience of this treatment burden, particularly within nursing-led units. Understanding how patients cope with the emotional, professional, and social impact of phototherapy is essential for developing nurse-led models of care that go beyond the disappearance of skin symptoms towards more holistic support for the person. Therefore, this study aims to explore the lived experiences and disease management strategies of people with psoriasis undergoing phototherapy, providing useful information to improve patient-centred nursing practice.

2. Materials and Methods

2.1. Design

A qualitative study was conducted using a phenomenological approach. This design allowed for an in-depth exploration of the first-person experience of the phenomenon under study, in this case, the treatment burden and disease management among people with psoriasis undergoing phototherapy. The study was situated within Husserl's interpretative paradigm, recognizing that the health-illness process is a subjective reality constructed through the personal and social contexts of the participants [22]. Although this study represents the qualitative strand of a larger mixed-methods research project, it is presented here as a robust, independent analysis of the patients' subjective narratives to provide a comprehensive understanding of the psychosocial impact of phototherapy.

2.2. Setting and Participants

The study was conducted in a phototherapy unit managed by a nurse within a university hospital in Spain. An intentional and exhaustive sampling strategy was used, inviting all patients who were included in the initial, more extensive project from which this qualitative study derives. Four inclusion criteria were included: (1) age ≥18 years; (2) confirmed diagnosis of psoriasis; (3) currently receiving phototherapy; and (4) ability to provide informed consent and participate in an in-depth interview. Patients with other dermatological conditions or cognitive impairments were excluded.

The final sample consisted of 72 participants recruited between 2019 and 2022. There were no participants who declined to participate. Although the sample size exceeds the usual range in descriptive phenomenological studies, it was justified by the objective of achieving high 'informative power'. This concept, proposed by Malterud et al., replaces Glaser and Strauss's concept of data saturation [24] as the sole criterion for establishing sample size in qualitative studies [25]. In this case, the sample was considered adequate for the phenomenon under study, as it was influenced by a wide variety of highly heterogeneous life circumstances. By including a considerable number of participants, it was possible to take into account a wide spectrum of existential contexts: from people in the early stages of adulthood with a recent diagnosis of psoriasis to those with a longer history of the disease, as well as different family structures, family responsibilities and workloads. This broad selection ensured that not only was data saturation achieved, but that it was thoroughly verified across different patient profiles, allowing for robust identification of the patterns found.

2.3. Data Collection

Data were collected between December 2019 and July 2024 through individual, semi-structured face to face interviews. The interviewer was the nurse (PhD) responsible for the phototherapy service, therefore, the participants already knew her but, they didn't know of her personal goals and motivations. She also served as the principal investigator the project. Interviews followed four pre-defined guiding themes: (1) understanding of psoriasis and treatment options; (2) perceived triggers of flare-ups; (3) disease-related stressors; and (4) suggestions for improvement in healthcare services. Interviews lasted 30–40 minutes, were conducted in a private room in the same hospital and were audio recorded with the verbal and written consent for subsequent analysis. The interviewer kept a field notes journal at all times. In it, she recorded reflections and important aspects of the participants' nonverbal language. In addition, sociodemographic data were collected, such as age, gender, marital status, employment status, mental illness, difficulty of going to therapy.

2.4. Data Analysis

All audio-recorded interviews were transcribed verbatim manually by the primary investigator to ensure total immersion in the data, avoiding the use of automated transcription software. The transcripts were then imported into "Nvivo 12 Pro" to facilitate a systematic and transparent coding process [26]. Data were analysed using conventional qualitative content analysis, an inductive approach where categories and themes are derived directly from the participants' narratives without the imposition of preconceived theoretical frameworks [27]. This approach is ideal for studies where existing knowledge about a phenomenon is limited, as it captures the richness of participant perspectives in a structured and transparent manner, providing a solid foundation for understanding their needs and challenges. The initial analysis, conducted by the main researcher, was subject to investigator triangulation, an experienced dermatology nurse independently reviewed the coding structure, leading to final consensus.

2.5. Rigor and Trustworthiness

Several strategies were employed to ensure credibility, confirmability, transferability and dependability of the findings [28]: Credibility was enhanced through two key methods. Firstly, the findings were validated in a peer debriefing process with a second, senior dermatology nurse, who reviewed the coding framework and transcripts to ensure the emergent themes were well-grounded in the data. Secondly, a form of member checking was conducted, where participants were provided with feedback on the interview findings to ensure the interpretations accurately reflected their intended meanings. To ensure confirmability and actively manage potential researcher bias, a robust reflexive process was maintained throughout the study. We acknowledge that the principal investigator's dual role as both interviewer and analyst could introduce bias. To mitigate this, the researcher engaged in reflective journaling to critically examine personal assumptions and preconceptions. This internal reflection, combined with the external check provided by the peer debriefing, ensured the findings remained neutral and true to the participants' narratives. Transferability was addressed through detailed descriptions of the study's context and participants, while dependability was supported by a consistent research process, including verbatim transcription, the use of duplicate recordings, and the maintenance of field notes to capture contextual nuances.

2.6. Ethical Considerations

The study received approval from the Ethics Committee of the University General Hospital of Valencia (Approval number 7/2019). Participants provided informed consent. Identifiable data were anonymised, and audio files were deleted after transcription. When exploring a topic related to anxiety and stress caused by attempting to balance treatment, disease management, and social, family, and work life, it is important to be aware that participants may become emotionally overwhelmed during the interview. The researcher was prepared to postpone the interview if necessary for this reason. However, participants who became emotionally overwhelmed preferred to continue, stating that the interview itself was therapeutic for them. To ensure psychological well-being, dermatologists from the unit were available to refer participants to mental health services if required.

3. Results

To present the findings, all participant responses have been anonymised to ensure confidentiality. Direct quotes are included to illustrate key findings and are identified by a participant code (e.g., P41, female, 22), which reflects an anonymous identification, gender, and age. Also, demographic characteristics of the participants are presented in Table 1 to provide context for the sample. However, in line with a qualitative methodology, numerical quantifiers are intentionally avoided in the reporting of the thematic findings to ensure that the focus remains on the rich, detailed nature of the participants' experiences rather than on frequency.

Inductive analysis of the interviews revealed a complex interaction between psoriasis treatment and the patient's experience. The results were structured into four general thematic areas, which align directly with the central themes of the interview script. From those areas, eleven subtopics emerged derived from data. Figure 1 provides a summary outline of each thematic area and subtopics.

Table 1. Characteristics of the participants.

Averege Age	46.5 years old
Variables	**Frenquencies**
Gender:	
- Male	43% (31)
- Female	57% (41)
Marital Status:	
- Married/stable relationship	71% (52)
- Divorced, widowed or single,	29% (21)
Employment status:	
- Active	58% (42)
- Without job	13% (9)
- Student	4% (3)
- Retired	25% (18)
Mental illness	
- Yes	24% (17)
- No	76% (55)
Difficulty of going therapy	
- No	79% (57)
- Yes	21% (15)

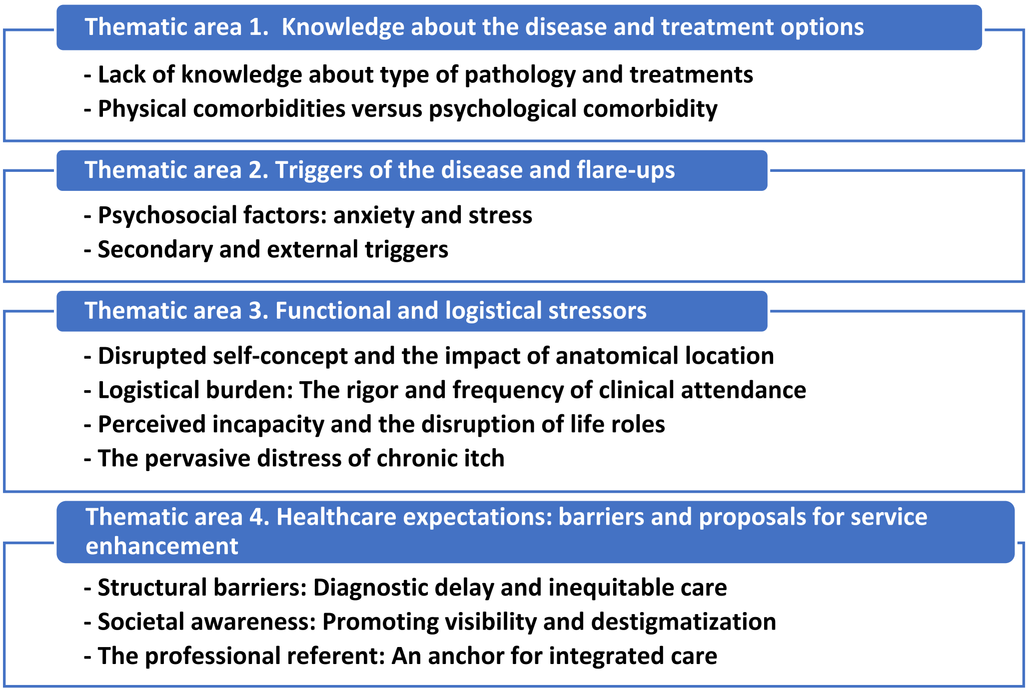

Figure 1. Thematic Areas and Subtopics.

The results are presented below, structured according to the four main thematic areas.

3.1. Thematic area 1: Knowledge About the Disease and Treatment Options

This thematic area explores the participants' understanding of psoriasis and their familiarity with the available therapeutic pathways. The findings highlight a significant disparity between a well-recognised psychological burden and a persistent lack of awareness regarding systemic physical comorbidities.

3.1.1. Lack of Knowledge About Type of Pathology and Treatments

The knowledge displayed across these categories was generally not sufficient to ensure satisfactory empowerment. With regard to the chronicity of the disease, it is evident that not all individuals were aware that psoriasis is not curable, and, in some cases, they even doubted this fact.

"Well, I know that what I have is chronic; right?" (P41, female, 22).

The lack of knowledge about the pathology is such that another patient confessed her belief that she could infect her relatives.

"I was really ashamed... My brother had a daughter, and I didn't even pick her up. Because I thought - what if she catches it?... I didn't even know what it was. I didn't even know it was psoriasis until I came here in August, I always thought it was eczema." (P55, female, 41).

Concerning treatment options, there was also a significant gap in knowledge. For instance, the next comment is a relevant example of this.

"He [doctor] gave me acytetrine, which was the best thing at the time, but then it stopped working and I don't know what other options there are for psoriasis". (P4 female, 71).

Even though a segment of the patient cohort exhibited a higher level of knowledge about the subject, they expressed worries about biological and immunosuppressive treatments, with cancer being identified as the main concern.

"I know that there are vaccines. The doctor wanted to prescribe it to me, but I refused because it is based on lowering the immune system and being more able to develop cancers". (P45 male, 51).

3.1.2. Physical Comorbidities Versus Psychological Comorbidity

A striking disparity was observed between the participants' awareness of the psychological and physical impacts of psoriasis. While the potential for psychological burden—specifically anxiety and depression—was universally acknowledged and often perceived as an inherent part of their daily struggle, awareness of systemic physical comorbidities was notably deficient.

There was a tendency toward scepticism and a lack of awareness regarding the potential for other physical pathologies. Some patients stated that it was only after commencing phototherapy and receiving information from the nurse in charge that they became aware of their increased risk of suffering from certain pathologies.

"You read a lot, and everyone says different things. I heard something from the heart, but I'm not sure. I don't know." (P78, female, 41).

"You were the one who told me that psoriasis has a tendency for people to put on weight, I had no idea, you were the one who told me. And I had no idea about fatty liver either, no one had told me about it." (P11, female, 62).

In contrast, participants demonstrated an intimate understanding of the skin-mind connection, they identified anxiety and stress as a mental consequence of their illness. As an example, the next patient indicated that he lacked knowledge regarding the presence of physical comorbidities, however reported experiencing significant psychological distress associated with the disease.

"No, I have no information on whether psoriasis can affect me physically with other diseases, but psychologically it certainly does affect you". (P66, male 34).

Also, several patients shared that they experienced their situation as "like a snake biting its own tail … if I have anxiety, it makes me itch, then I scratch and I have more anxiety." (P55, female, 41).

3.2. Thematic Area 2: Triggers of the Disease and Flare-Ups

Participants identified a wide range of factors that triggered clinical outbreaks. However, the discourse revealed a clear hierarchy in terms of frequency and perceived impact. Consequently, this thematic area was divided into two topics: Psychosocial factors: anxiety and stress, which emerged as the main and most widespread trigger; and Secondary and external triggers, including factors such as weather, infections, and physical trauma.

3.2.1. Psychosocial Factors: Anxiety and Stress

The most significant causal factor was having suffered stressful life events, which were perceived to both precipitate the disease and exacerbate its outbreaks. Examples of such events included the death of a family member, the suffering of some type of serious illness, financial problems, or even legal issues.

"I was diagnosed with colon cancer when I was 34 years old, [then] after 6 months I had another CAT scan, and they told me … I had a tumour on my ovary. They took it all out. I started to experience a lot of changes in which there is no one to inform you of anything. And all this hand stuff [eczemas] has come about because of what I've been through ". (P64, female 42).

"I associate the onset of the disease with stress. I am absolutely certain of this, because there was a particularly critical moment in my life when my father died of very advanced Alzheimer's. I mean, he died young, and my mother was diagnosed with Hodgkin's lymphoma at the same time." (P82, female, 57).

Other patients attributed it to stress sustained over time and to situations that are not so striking. such as stress sustained at work or family responsibilities.

"I think it's when I'm very stressed, when I'm very anxious, or when I'm too busy and I don't stop thinking about taking a break". P53, female 41).

3.2.2. Secondary and External Triggers

These factors were reported only by a small subset of the sample and were often tied to specific, isolated events. While patients acknowledged their influence, these external triggers were perceived as less determinant in the long-term management of the disease compared to the inescapable burden of anxiety.

"Well, I notice that the skin lesions appear when I get a sore throat, a severe throat infection". (P27, female, 37).

"What I do remember is that while playing football, I got a very large wound, and when it was almost healed, psoriasis appeared on the scab and then it started to appear in other places". (P 62, male 43).

3.3. Thematic Area 3: Functional and Logistical Stressors

The third theme explores the main sources of distress inherent in the lived experience of psoriasis and its treatment. The analysis highlights how the role of being a patient, characterized by chronic symptoms such as itching and the logistical commitment of frequent sessions, combines to produce feelings of incapacity and a disrupted self-concept.

3.3.1. Disrupted Self-Concept and the Impact of Anatomical Location

This topic included statements about self-perception and the extent to which individuals believed they were perceived by others. The excessive concern about their aspect resulted in individuals changing their habits, such as ceasing participation in sports, or affecting the way their dress.

"Psychologically, it's the way it looks, seeing myself like this, seeing my legs as I have them. I really like to exercise, but when you wear shorts, they immediately look at your legs, and it affects me. For example, the other day in the gym a girl who was working out next to me was looking at them [legs]". (P45, male, 45).

Also, concerns regarding self-concept were highlighted in comments that revealed discomfort when working with children.

"I'm a high school teacher and my students often ask me what's wrong with my hands. Many times, when teaching, I see how the students are looking at my hands, or when they see a crack in my hand that is bleeding. I don't know, but I guess it's normal that they notice." (P61, male, 30).

"I work with blind children. All the time we use our hands to communicate and when I take them by the hands, they say to me; "Oh, you have wounds in your hands". My hands are rough for them, and emotionally, it shakes me a little." (P70, female, 57).

Patients verbalised being very upset when psoriasis appeared in certain areas (location of the disease) such as on their palms or their genital region.

"When it appears in your private parts, well, look, it gets bad, it itches, and it hurts" (P1, male, 74).

For example, the anxiety caused by the appearance of psoriasis on this patient's hands and feet was compared to that of a person who wears a colostomy bag.

"I have a colostomy bag, [but] it is not comparable. I can hide the bag; I go to the beach, to the pool; But I can't hide the psoriasis thing, and I'm fed up with my hands." (P64, female, 42).

3.3.2. Logistical Burden: The Rigor and Frequency of Clinical Attendance

Phototherapy was identified as a significant stressor, particularly the frequency of the sessions needed for the treatment to be effective.

"Coming three times a week is too much, it's a mess. I put off my study time to come, but I don't see any effects". (P6, female, 25).

A common pattern emerged, whereby patients expressed feelings of guilt for placing additional work burdens on their work colleagues and verbalised fear of potential repercussions from their bosses.

"It's annoying, you feel an added burden, especially when you have to juggle it with work. Not all bosses are going to be kind or give you permission; even though we have legal rights, you still feel pressured". (P52, female, 54).

Furthermore, some patients did not comply with the treatment and blamed it on their work commitments.

"This is a disaster [pointing to the phototherapy machines]. Between work and things at home, I haven't been able to attend all the sessions I was supposed to attend". (P 76, female 56).

3.3.3. Perceived Incapacity and the Disruption of Life Roles

Another significant stressor was the inability to perform activities previously done with ease. In the workplace, stress was exacerbated by feelings of worthlessness, as illustrated by a patient with palmo-plantar psoriasis.

"It's so hard when you have wounds on your feet that just won't heal. I feel disabled when that happens, and I must work my whole turn with these wounds. Also, I'm grateful that for the last 8 years I haven't had to use my hands so much at work. But now I got fired and I must find a new job. I don't know what I'm going to find when every four days I'm full of cuts." (P63, male, 49).

Moreover, the disease placed a significant burden in the family context, as evidenced by the following participant's account.

"It has affected me a lot. For example, I wasn't able to hold my daughter's hand while walking her to school... she was five years old when I was worse… I couldn't help her with her hygiene or comb her hair… I have to delegate tasks that are usually simple for me, but sometimes I can't." (P56, female 43).

In general, there was noticeable distress due to the deterioration that patients were experiencing in their daily activities.

"I barely go out, just to walk my dog, but many mornings I can't even get up, my feet have cuts, bleed, itch, it's horrible... I definitely don't how to manage what is happening to me." (P28, female, 50).

3.3.4. The Pervasive Distress of Chronic Itch

One of the factors affecting those interviewed was the itching caused by the condition. This increased the stress levels of those who suffered from it to the point of requiring regular medication.

"Having to take pills at night so the itching would allow me to sleep, and then, in the morning, having to take another pill with the opposite effect to wake me up" (P11, woman, 62 years old).

The itching not only caused distress due to the discomfort associated with the symptoms, but also generated social discomfort when patients were seen scratching.

"If you're talking to someone, I'm afraid it will look like I have lice" (P43, man, 60 years old).

3.4. Thematic Area 4. Healthcare Expectations: Barriers and Proposals for Service Enhancement

The final thematic area delineates the participants' expectations and proposals for systemic reform, identifying critical structural gaps in the current care pathway. These insights reflect an urgent need to transition toward a more integrated healthcare model that prioritizes diagnostic efficiency, holistic support, and the formalization of specialized nursing roles.

3.4.1. Structural Barriers: Diagnostic Delay and Inequitable Care

Patients indicated a preference for earlier referrals to specialists, with the aim of facilitating a more precise diagnosis.

"When going to the heath care centre, the general practitioner doesn't know much about psoriasis, I think it's something unknown to them. I was sent there [to the dermatologist] because I started crying in the consultation room" (P61, male, 30).

Furthermore, it was determined that there was a necessity to provide a more equitable range of services. The primary concern related to the non-financing of contemporary products. The following patient conveyed a sense of banality regarding her illness; perceiving being treated as a simple aesthetic problem:

"The system today continues to consider psoriasis as a cosmetic disease. That is my perception because I have had to pay for everything I have needed, apart from the creams that contain corticosteroids, but then they cover things that are truly aesthetic such as…." (P11, female, 62).

3.4.2. Societal Awareness: Promoting Visibility and Destigmatization

The importance of raising awareness in society about this type of dermatosis was also present in the discussion. The participants felt that the general population was unaware that they were suffering. They commented that it was necessary for people to know the full extent of the consequences of these diseases simply to normalize what they were experiencing. They believed that this would help them stop feeling the burden of constantly having to explain that their condition was not contagious and would make them feel more understood.

"Unless someone suffers from psoriasis or has a family member affected by it, they do not know what it is. Raising awareness could "help us not to feel so ashamed and not to have to constantly explain what is happening to us." (P59, female, 27).

"I think the disease is still poorly understood and there's still a stigma surrounding it, with people thinking it might be contagious… I have to say it, "Don't worry, this isn't contagious," or when I see someone looking at me, I tell them it's psoriasis and that it's not contagious. I say it myself to raise awareness." (P82, female, 57).

3.4.3. The Professional Referent: An Anchor for Integrated Care

Patients indicated the need for a dedicated healthcare professional to guide them throughout the treatment process. In this case, the nurse was an example of a reliable healthcare professional. However, patients emphasized the need for nurses to have their own consultation room so they could receive patients with the privacy required for their treatment.

"It would be ideal to have a nursing consultation room just for psoriasis patients; that would be wonderful. Here, we end up sharing the consultation room with other patients and we don't have the same privacy". (P11, female, 62).

Similarly, other patients valued phototherapy, not only for its dermatological benefits, but also because they found in the nurse the professional guidance they needed.

"Coming to phototherapy and having some time to ask questions to the nurse has helped me improve the psychological aspect of my disease. She helps you; she is someone you have as a support point, and it is something that I do value a lot". (P 56, female, 43).

4. Discussion

This study revealed the multifaceted burden and logistical tensions inherent in psoriasis management, highlighting the conflict between clinical efficacy and the daily disruption caused by phototherapy. While the general psychosocial impact of psoriasis is well-documented, these findings illuminate the specific and under-researched logistical challenges of the phototherapy regimen, revealing how its demanding frequency can paradoxically exacerbate the patient's stress and perceived incapacity.

4.1. Health Literacy and Therapeutic Perceptions: Addressing the Systemic Knowledge Gap

The participants demonstrated a lack of awareness regarding the fundamental aspects of the disease and its treatment although a clear dichotomy was observed. Patients exhibited a high level of understanding regarding the psychological repercussions of the disease, viewing anxiety and depression as inherent to their experience, while remaining largely unaware of physical comorbidities. This finding coincides with the study by Cingöz et al. concluded that while patients in their sample had adequate knowledge of the potential for depression, they were unaware of other aspects, such as increased cardiovascular risk [29]. Zhang et al., in recent study on knowledge, attitudes, and practices in people with psoriasis, also confirms that despite clinical advances, patient continue to show insufficient knowledge about disease triggers, genetic factors, and the side effects of systemic treatments [18]. Nonetheless, although findings align regarding the prevailing knowledge deficit, these previous studies approach the phenomenon from a quantitative standpoint, which offers a limited understanding of the patient's subjective experience. In contrast, centering on qualitative inquiry and with similar findings as in current study, González et al. identified a lack of comprehension regarding pathophysiology and disease manifestation, with many participants harbouring misconceptions about disease contagion. It is particularly striking that, despite these gaps of knowledge, Gonzalez et al. study participants maintained a favourable perception of biological therapies [17]. This contrasts with the current study, where perceptions of such treatments were predominantly negative, driven by profound concerns regarding the potential development of oncological conditions.

The clinical relevance of addressing these knowledge gaps is further underscored by Tian et al., who established a significant positive correlation between higher levels of disease knowledge and more positive attitudes and proactive management behaviours [19]. This relationship suggests that bridging the existing information deficit is a requisite for fostering patient empowerment and self-efficacy. In this regard, evidence from a recent systematic review confirms that targeted nursing interventions—specifically those focusing on structured patient education and self-management support—are fundamental for improving health-related quality of life and therapeutic adherence in the psoriasis population [16].

4.2. The Adherence-Stress Paradox: Phototherapy as a Double-Edged Sword

The results highlight a critical paradox in the management of psoriasis with phototherapy, where the treatment itself can act as a double-edged sword: while it improves the patient's clinical skin outcomes it also functions as an additional stressor by increasing anxiety levels. This aligns with international literature that conceptualizes phototherapy as an inherent inconvenient therapeutic modality [30,31]. A previous quantitative study demonstrated that the success of phototherapy was contingent upon compliance with a highly strict therapeutic regimen; furthermore, it showed that factors such as the mode of transport used, logistical difficulties in attending sessions, and the presence of anxiety negatively impacted therapeutic adherence [14]. These quantitative results are now reinforced and expanded by the first person narratives. The current paper illustrates in depth the treatment burden, identifying it as a critical factor that can reduce the patient's overall quality of life.

4.3. Biographical Disruption and the Social Stigma of Visibility

The narratives of the participants in this study provide an illustration of biographical disruption [10], where the anatomical location of lesions, especially when they are visible, forces a fundamental renegotiation of the self. In this qualitative study negative feelings or the fear of disgusting others, are closely mirrored in the work of Moschogianis et al., who also found social interactions often serve as unwelcome reminders the condicion [32}. These authors also explored a concept of "threat of self" [32]. Similarly, the current study reveals that this disruption affects the most intimate family roles by creating a profound threat to identity. For example, the inability to perform simple affectionate

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gestures, such as holding a child's han or assisting with hygiene, represents a fracture in the patient's identity as a caregiver. In this context, the skin is not only a visible symptom but also a physical barrier that prevents the fulfillment of daily roles.

On the other hand, the feelings of uselessness and disability at work, as reported by participants with palmoplantar involvement in this study, are consistent with the findings of González et al. [17], who identified psoriasis as a critical barrier to professional continuity and stability. The fear of not being able to secure future employment due to recurrent skin fractures illustrates how the disease fundamentally destabilizes a person's life trajectory.

4.4. Implications for Nursing: The Demand for a Specialized Care Model

The findings of this research reveal a profound sense of abandonment among patients interacting with the healthcare system, manifested in a collective demand for designated professional nurses to act as their primary care provider throughout the health-illness process. Although patient care dynamics are currently shifting towards a multidisciplinary approach, the need for a nurse as a point of reference collides with the medical-centric model of care, which frequently prioritizes clinical factors over the psychosocial complexities described in this analysis. As Al-Hayti et al. state, the inclusion of dermatology nurses in multidisciplinary teams is not merely an auxiliary measure, but a fundamental component that significantly improves quality of life and therapeutic outcomes [16].

In the context of phototherapy units, the nurse's role must evolve from technical administration to comprehensive patient support. The results indicate that patients require ongoing support to mitigate the burden of treatment and manage the "adherence-stress paradox" identified in this research. This specialized nursing support is crucial for deconstructing deeply ingrained myths that act as significant barriers to therapeutic success. Furthermore, as suggested by the participants' narratives, nurse-led models that include structured education and psychosocial support could address the unmet needs of those facing functional disability and social isolation, potentially reducing the burden of treatment and the overall experience of illness.

4.5. Implications for Policy and Practice

The findings of this study reveal a clear need to evolve towards a more comprehensive, patient-centred model of care, an aspiration that is in line with the guidelines of leading dermatological organisations. First, the persistent knowledge gaps we have identified underscore the urgency of implementing standardised educational programmes. As promoted by organisations such as the Spanish Association of Dermatology and Venereology (Spain) and leading patient associations such as the National Psoriasis Foundation (USA) and "Acción Psoriasis" (Acción Psoriasis) (Spain), informed patient participation is essential in the management of chronic diseases. For this education to be effective, it is essential that healthcare professionals improve their skills; we therefore recommend incorporating specific training in health communication and digital literacy, enabling them to guide patients through the complex ecosystem of online information.

At the same time, strong demand from patients for ongoing support validates the need to strengthen the role of the dermatology nurse as a key professional. This role is essential to patient's well-being and to providing them educational and emotional support. It is also actively promoted professional organisations such as the National Association of Dermatological Nursing and Research on Skin Integrity Impairment (Spain) and the "Enfermería y Psoriasis" (Nursing and Psoriasis) initiative.

Finally, these improvements at the individual and professional levels must be complemented by structural changes. It is necessary to review phototherapy administration models to lighten the logistical burden on patients as well as launching public awareness campaigns that actively combat stigma. For example, leveraging existing initiatives such as World Psoriasis Day, might have the potential of fostering a more understanding environment for people living with psoriasis.

4.6. Strengths and Limitations

A key strength of this study is its large sample size for a qualitative inquiry, allowed for a robust identification of recurring patterns across a wide range of heterogeneous life circumstances, ensuring that the findings regarding the "treatment burden" are grounded in a vast array of personal narratives. Nevertheless, it is acknowledged that the breadth of such a large sample may, in some instances, limit the possibility of achieving the granular, idiosyncratic depth typical of smaller-scale phenomenological studies.

The findings of this study must be interpreted within their specific cultural context. Conducted entirely in Spain, the participants' experiences with the healthcare system, social stigma, and disease management are inevitably shaped by the Spanish public health model and local sociocultural norms. For instance, the perception of access to care or the nature of the patient-professional relationship may differ significantly from experiences in countries with different healthcare systems. Similarly, cultural attitudes towards skin appearance and social interaction could influence the degree of stigma reported. Therefore, while these findings offer valuable insights, their direct transferability to other cultural settings should be considered with caution.

To address these limitations, future research should incorporate longitudinal designs to explore how the perceived treatment burden and disease management strategies evolve throughout the entire course of therapy. Furthermore, multicentre studies across different international healthcare frameworks are needed to identify universal systemic barriers and to compare the effectiveness of various nursing-led care models. Ultimately, further inquiry should focus on evaluating the impact of specific nursing interventions designed to deconstruct clinical myths and facilitate work-life reconciliation, ensuring that psoriasis management becomes a truly integrated and patient-centred process.

5. Conclusions

This investigation identifies a critical tension between clinical efficacy and treatment burden in the management of psoriasis via phototherapy. While this therapeutic modality is safe and effective, its rigorous administration protocol often functions as a "double-edged sword", where the logistical struggle for work-life reconciliation generates a state of chronic stress that can paradoxically exacerbate the pathology.

Furthermore, the results reveal that a significant knowledge gap persists regarding systemic comorbidities, leaving patients vulnerable to clinical myths and hindering their self-efficacy. Beyond the physical symptoms, the anatomical location of lesions triggers a profound biographical disruption, impacting the individual's identity and their capacity to fulfill professional and intimate life roles.

Ultimately, these findings demonstrate that clinical skin clearance is an insufficient goal if the patient's psychosocial needs remain unaddressed. This study advocates for a paradigm shift toward an integrated care model within dermatology units. The implementation of a specialised nursing referent is essential to serve as an anchor for the patient, providing the comprehensive clinical navigation and emotional support necessary to manage the health-illness process "beyond the surface" of the skin.

Supplementary Materials: The following supporting information can be downloaded at: https://www.mdpi.com/article/doi/s1, Figure 1: Thematic Areas and Subtopics; Table 1. Characteristics of the participants.

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References

1. Global Psoriasis Atlas 2024 -04.
2. Korman NJ. Management of psoriasis as a systemic disease: what is the evidence? Br J Dermatol 2020 -04;182(4):840–848.
3. Yamazaki F. Psoriasis: Comorbidities. J Dermatol 2021 -06;48(6):732–740.
4. De Francesco MA, Caruso A. The Gut Microbiome in Psoriasis and Crohn’s Disease: Is Its Perturbation a Common Denominator for Their Pathogenesis? Vaccines (Basel) 2022 -02-05;10(2):244.
5. Silva JBd, Wright AK, Carvalho AVE, Griffiths CEM, Ashcroft DM. Experience of living with psoriasis in Brazil: a Global Psoriasis Atlas online survey. Int J Dermatol 2025 -02;64(2):325–332.
6. Dhabale A, Nagpure S. Types of Psoriasis and Their Effects on the Immune System. Cureus 2022 -09;14(9):e29536.
7. Hassani F, Koraei A, Yaghoobi R, Zarea K. An evaluating of the relationship between body image, body satisfaction, depression, marital quality, and self-esteem in patients with psoriasis. Psychol Health Med 2021 -04;26(4):467–477.
8. Gossec L, Walsh JA, Michaud K, Holdsworth E, Peterson S, Meakin S, et al. Effect of Fatigue on Health-Related Quality of Life and Work Productivity in Psoriatic Arthritis: Findings From a Real-World Survey. J Rheumatol 2022 -11;49(11):1221–1228.
9. Nabieva K, Vender R. Quality of Life and Body Region Affected by Psoriasis: A Systematic Review. Actas Dermosifiliogr 2023 -01;114(1):33–38.
10. Bury M. Chronic illness as biographical disruption. Sociol Health Illn 1982 -07;4(2):167–182.
11. Siteneski A, Montes-Escobar K, de la Hoz-M J, Lapo-Talledo GJ, Gutiérrez Moreno G, Carlin Chavez E, et al. Depression and Anxiety in Patients with Psoriasis: A Comprehensive Analysis Combining Bibliometrics, Latent Dirichlet Allocation, and HJ-Biplot. Healthcare (Basel) 2025 -02-20;13(5):441.
12. Magdaleno-Tapial J, Ortiz-Salvador JM, Valenzuela-Onate C, Mari-Cornejo P, Esteve-Martinez A, Perez-Ferriols A. Comparison of Phototherapy in Pediatric and Adult Patients. Actas Dermosifiliogr 2020;111(1):41–46.
13. Zhou J, Yi X, Li Y, Ding Y. Efficacy assessment of UVA1 and narrowband UVB for treatment of scalp psoriasis. Lasers Med Sci 2018;33(9):1979–1982.
14. Iborra--Palau EV, Garcia--Redondo E, Alabau--Dasi R. Factors Influencing Adherence to Phototherapy in Patients With Psoriasis: A Cross--Sectional Study. J Adv Nurs 2024.
15. Rousset L, Halioua B. Stress and psoriasis. Int J Dermatol 2018 Oct;57(10):1165–1172.
16. Saada Issa Lahidan Al-Hayti, Amal Naser Mohammad Alhawsawe, Mona Ahmad Mosa Alhawsawi, Ashwaq Alnashmi Hmdan Alshammari. Impact Of Nursing Interventions On The Quality Of Life Of Patients With Psoriasis: A Systematic Review. The Review of Diabetic Studies 2024 February 25:122–131.
17. Gonzalez N, Wilkerson K, Castillo Valladares H, Sanchez-Anguiano ME, Chang AY, Amerson EH. Latine Patients’ Beliefs, Attitudes, and Experience With Psoriasis. JAMA Dermatol 2025 -03-01;161(3):291–298.
18. Zhang X, Du H, Liu X, Liu L, Zhang T. Knowledge, Attitudes and Practices Towards Psoriasis Among Patients and Their Family Members. Clin Cosmet Investig Dermatol 2024;17:769–782.

19. Tian J, Zhang L, Zhao X, Yang L. Knowledge, attitude, and practice of psoriasis patients toward their diseases: a web-based, cross-sectional study. Front Med (Lausanne) 2024;11:1288423.
20. Gelfand JM, Armstrong AW, Lim HW, Feldman SR, Johnson SM, Claiborne WCC, et al. Home- vs Office-Based Narrowband UV-B Phototherapy for Patients With Psoriasis: The LITE Randomized Clinical Trial. JAMA Dermatol 2024 -12-01;160(12):1320–1328.
21. Nguyen MO, Watson AJ, Joyce C, Buzney EA. Long-term use of home narrowband ultraviolet B phototherapy demonstrates high patient satisfaction, compliance, and low rates of adverse effects: A survey study. J Am Acad Dermatol 2020 -07;83(1):267–269.
22. Al-Sheikh Hassan M. The use of Husserl’s phenomenology in nursing research: A discussion paper. J Adv Nurs 2023 -08;79(8):3160–3169.
23. Glaser B, Strauss A. Discovery of grounded theory: Strategies for qualitative research. : Routledge; 2017.
24. Malterud K, Siersma VD, Guassora AD. Sample Size in Qualitative Interview Studies: Guided by Information Power. Qual Health Res 2016 November 1;26(13):1753–1760.
25. Qualitative Data Analisi Software2021; .
26. Hsieh H, Shannon SE. Three approaches to qualitative content analysis. Qual Health Res 2005;15(9):1277–1288.
27. Lincoln YS, Guba EG, Pilotta JJ. Naturalistic inquiry Newbury Park. Newbury Park: Sage Publications; 1985.
28. Cingöz K, Gündüz K, İnanır I. Patients’ knowledge about psoriasis and comorbidities; their participation in treatment decisions. J Dermatol Treat 2019:1–3.
29. Barros NdM, Sbroglio LL, Buffara MdO, Baka JLC, Pessoa AdS, Azulay-Abulafia L. Phototherapy. An Bras Dermatol 2021;96:397–407.
30. Brownell J, Wang S, Tsoukas MM. Compliance and phototherapy. Clin Dermatol 2016;34(5):582–586.
31. Moschogianis SF, Chisholm A, McKie S, Griffiths CEM, Elliott R, Kleyn CE. ‘Ugh…how do you catch that?’: a qualitative study of the impact of psoriasis on social interactions. Clin Exp Dermatol 2025 -08-01;50(8):1606–1613.