

Inside Psoriatic Disease

FAMILY

Outline

| | |
|--|-----------|
| Abbreviations | 3 |
| Psoriatic disease, society, and stigma | 4 |
| Living with someone with psoriatic disease | 5 |
| The family | 7 |
| The caregiver | 10 |
| The partner | 12 |
| Psoriatic disease and family planning | 14 |
| The impact of treatment on quality of life | 17 |
| Fighting for the greater patient well- being | 18 |
| Improving quality of life | 20 |
| Recommendations | 22 |
| Fight misinformation in the community | 22 |
| Access to subsidized healthcare and treatment | 23 |
| Implement training programs for HCPs on psoriatic disease, the greater patient, and the wide burden of psoriatic disease | 24 |
| Implement therapeutic patient education (TPE) programs locally | 25 |
| Concluding remarks | 26 |
| References | 27 |

ABBREVIATIONS

| | |
|-----------------|---|
| BSA | Body Surface Area |
| CDLQI | Children’s DQLI |
| CME | Continuous Medical Education |
| CZP | Certolizumab pegol |
| DFIQ | Dermatitis Family Impact Questionnaire |
| DLQI | Dermatology Life Quality Index |
| HCP | Health Care Professional |
| IFS | Impact on Family Scale |
| FDLQI | Family Dermatology Life Quality Index |
| QLCCDQ | Quality of Life in a Child’s Chronic Disease Questionnaire |
| QoL | Quality of Life |
| PASI | Psoriasis Area and Severity Index |
| PCC | Patient-Centered Care |
| PDI | Psoriasis Disability Index |
| PLSI | Psoriasis Life Stress Inventory |
| PFI | Psoriasis Family Index |
| PQLQ | Psoriasis Quality of Life Questionnaire |
| PsAQoL | Psoriatic Arthritis Quality of Life |
| PSORIQoL | Psoriasis Quality of Life |
| TPE | Therapeutic Patient Education |
| WHO | World Health Organization |

PSORIATIC DISEASE, SOCIETY, AND STIGMA

At least 60 million people live with psoriatic disease¹, but many more are affected by it (family, partners, caregivers). Despite being a common disease, there is still a general lack of information about it globally. Misinformation results in strong stigma and unjust discrimination of those living with psoriatic disease and, indirectly, of their families. Having to face these challenges, it is of no surprise that people with psoriatic disease have **self-stigma**.

These feelings are associated with, for example, disease severity and the subtype of psoriatic disease². The location of the lesions, whether they are in a more visible area of the body or not, also plays a role in self-stigmatization.

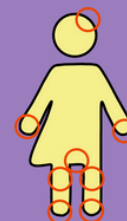
The reduced quality of life and impact on mental health on people with psoriasis has already been extensively reported³. However, the impact of psoriasis and psoriatic arthritis on the family are not as well-described.

Society's perception is an important factor contributing to stigma against psoriatic disease. Some studies have shown that, despite a wide variation between countries, there is still a general unawareness and misinformation on what psoriatic disease is. Even though people may have heard the term 'psoriasis' before, very little is known about the disease. Not having a personal or social relationship with someone with psoriatic disease is strongly associated with poor knowledge about the disease.

This, in turn, results in the prevalence of prejudices against those with psoriasis. Some People are, for example, not willing to have a friendship with someone with psoriatic disease, entertain a romantic relationship, or even accepting cash from someone with psoriatic disease at the checkout. Other prejudices are listed in the box below.

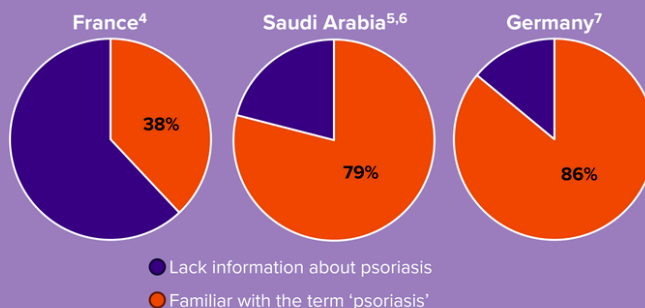
WHAT IS PSORIATIC DISEASE?

Psoriatic disease is a systemic, chronic, noncommunicable, painful and disabling condition affecting multiple body sites. It predominantly affects the skin, joints, or both, but can also affect the nails.



The two main types of psoriatic disease are **psoriasis (Pso)** and **psoriatic arthritis (PsA)**. **PsA** develops in about 30% of the cases and is characterized by inflammation of the joints and tendons.

Psoriatic diseases is associated with an increased risk of **comorbidities**, such as obesity, hypertension, diabetes, metabolic syndrome, cardiovascular disease, and inflammatory bowel disease. It also severely affects the mental health and quality of life.



Common prejudices and attitudes towards people with psoriatic disease:

- Believe that psoriatic disease is contagious
- Believe that psoriatic disease is related to poor hygiene
- Unwilling to live in the same house or have a personal or romantic relationship with someone with psoriasis
- Reluctant to shake hands, kiss on the cheeks, share a table for a meal
- Averse to share public spaces and facilities such as swimming pools

LIVING WITH SOMEONE WITH PSORIATIC DISEASE

The burden of living with psoriatic disease has been relatively well documented, and several tools are routinely used to evaluate the impact of the disease. Some focus on **clinical presentations** that are relatively easy and objective to quantify, such as the BSA (Body Surface Area), a quantification of the percentage of the body with lesions, and the PASI (Psoriasis Area and Severity Index), that combines the BSA and the severity of the skin lesions, ranging from mild to very severe.

Other tools have been developed to quantify the **burden** of disease on quality of life (QoL). These are questionnaire-focused assessments. Participants answer questions about the impact of psoriatic disease on household chores, work or school life, relationships, social life and leisure, among others. Some have been tailored for all skin diseases, such as Dermatology Life Quality Index (DLQI)⁸, pediatric skin diseases (Children’s DLQI or CDLQI)⁹, or Patient-Reported Impact of Dermatological Diseases (PRIDD)¹⁰ but others have been developed specifically for people with psoriatic disease, for example the Psoriasis Disability Index (PDI)¹¹ and the Psoriasis Quality of Life Questionnaire (PSORIQoL)¹². These indices are generally similar, differing in the number of questions, ranging from 10 to 25, however some have been structured to address specific questions or to fit a particular population. The PLSI, Psoriasis Life Stress Inventory, has been tailored to understand the stress levels of doing everyday activities rather than the impact of the disease on physical ability to performing them¹³. The PSO-LIFE¹⁴ and PQLQ¹⁵ are adapted to the Spanish and Islamic population, respectively. To evaluate the specific impact of psoriatic arthritis on QoL, the PsAQoL was established^{16,17}.

Similarly, **family-oriented questionnaires** have been developed to evaluate the impact of disease on the family. The majority target the parents or caregivers of children with chronic illnesses, such as the Impact on Family Scale (IFS)¹⁸, or with dermatological diseases, such as the Dermatitis Family Impact Questionnaire (DFIQ)¹⁹ or the Family Dermatology Life Quality Index (FDLQI)²⁰. Other questionnaires are specific for families of people with psoriatic disease, such as FamilyPso²¹ and PFI (Psoriasis Family Index)²². Both are questionnaires investigating leisure, social, and emotional areas and how they are affected in family members and partners of people with psoriasis.

| | |
|---|--|
| <p>Patient-centered questionnaire</p> <p>DLQI - Dermatology Life Quality Index⁸</p> <p>CDLQI - Children’s Dermatology Life Quality Index⁹</p> <p>PRIDD – Patient-Reported Impact of Dermatological Diseases¹⁰</p> <p>QLCCDQ - Quality of Life in a Child’s Chronic Disease Questionnaire¹⁷</p> | <p>Specific for psoriatic disease</p> <p>PDI - Psoriasis Disability Index¹¹</p> <p>PSORIQoL¹²</p> <p>PLSI - Psoriasis Life Stress Inventory¹³</p> <p>PSO-LIFE¹⁴</p> <p>PQLQ - Psoriasis Quality of Life Questionnaire¹⁵</p> <p>PsAQoL¹⁶</p> |
| <p>Family-centered questionnaire</p> <p>IFS - Impact on Family Scale¹⁸</p> <p>DFIQ - Dermatitis Family Impact Questionnaire¹⁹</p> <p>FDLQI - Family Dermatology Life Quality Index²⁰</p> | <p>Specific for psoriatic disease</p> <p>FamilyPso²¹</p> <p>PFI - Psoriasis Family Index²²</p> |

Having these quantifiable indices has made it possible to have a quantifiable understanding of the impact of psoriatic disease on the lives of people living with the disease and their families. Importantly, it is clear that low QoL of people with psoriatic disease is strongly associated with low QoL of family members, caregivers, and partners^{20, 22-26}.

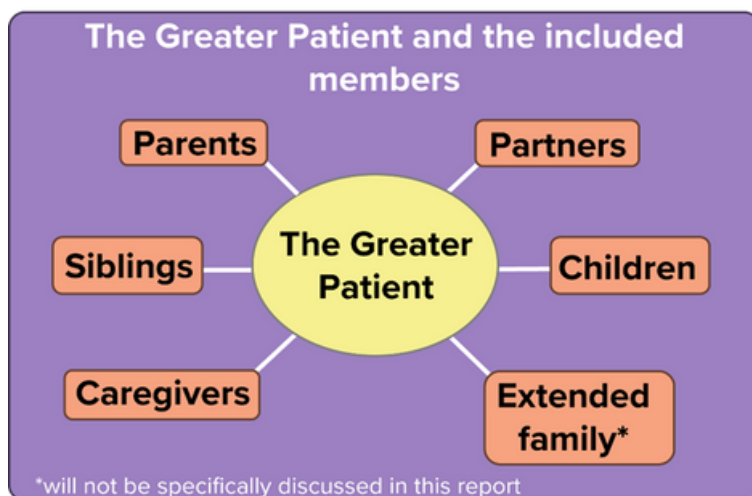
The majority of the scores developed to date report on the negative impact of disease. Following the World Health Organization (WHO) definition that health should not be the absence of disease, rather the experience of full physical, mental, and social well-being, the WHO-5 questionnaire was established²⁷. This questionnaire is composed of 5 questions on the frequency people experience positive feelings such as cheerfulness, calmness, and positivity. The WHO-5 tool has been used on a wide range of diseases²⁸ and is proposed to be an important and reliable method to assess QoL in psoriasis²⁹.

The quantification of QoL has revealed that the impact of psoriatic disease is as great as the one of cancer, cardiovascular diseases, or depression³⁰. Such findings clearly show the burden of the disease and the importance of addressing it and finding strategies to improve the QoL of those living with psoriatic disease as well as the QoL of their families and partners.

Even though the indices mentioned here are powerful tools to assess QoL, they still

only superficially address the everyday struggles of those who live with someone with psoriatic disease. Importantly, to be able to make policy changes with the goal of improving the families' QoL, it is essential to understand in detail what are the specific challenges and struggles experienced by partners, caregivers, and family members (e.g. parents, siblings, children). In an attempt to encourage the study and understanding of the impact of psoriatic disease on the family members of people with the disease, the concept of the 'Greater Patient', that includes people whose lives have been affected by living with someone with psoriatic disease, was proposed³¹. Only then and taking in the Greater Patient suggestions on how to better support them, can we make real and meaningful changes.

Being frequently overlooked, family members and partners not only have an important role in the QoL of people with psoriatic disease but also experience a reduced QoL and mental wellbeing. In fact, surveys showed that approximately 90% of family members report that their QoL is impacted by their relative's disease^{23, 24}. In this report we want to bring awareness to the burden of psoriatic disease on the Greater Patient and recommend measures to improve their wellbeing.



THE FAMILY



The family members around the person living with the disease commonly include parents, siblings, partners, and children. In some cultures, extended family members such as grandparents, grandchildren, uncles, aunts, and others are also part of the household and should be considered as the Greater Patient. In this section of the report, we mention the practical and emotional challenges parents (see caregiver section for more detail), siblings, and children have reported^{23, 24, 32-36}.

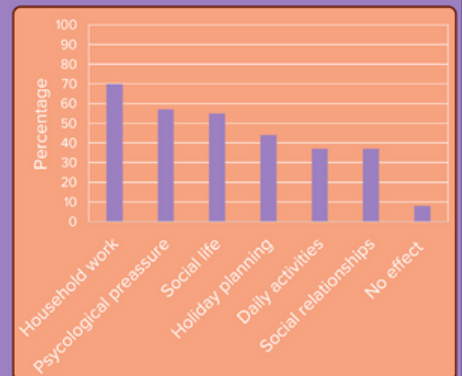
We often think that the burden of disease is almost exclusively on the person living with the disease, but the family is also impacted to a high degree. Most practical challenges are shared between the family members and invariably change the family routines and habits. These include an increase in the **housework** load, such as laundry, cleaning, and vacuuming, as well as the need to brush oneself before leaving the house to remove flakes from the clothes. Family members report

feeling particularly frustrated with these chores ahead of having visitors, in an attempt to have a clean and welcoming home. Another important change in the lifestyle of the family unit is related to leisure activities and holiday planning. They reduce or completely avoid going to the gym or swimming pools, not only because it may worsen the skin flares, but also because they do not feel welcomed by other patrons. The holiday planning is also affected, from choosing a destination that works for the family and the member with psoriatic disease, and can be coordinated with hospital visits, treatments, or flaring episodes if needed.

PSORIATIC DISEASE AND FAMILY

Survey on the impact of psoriatic disease in 63 family members³¹

Living with someone with psoriatic disease affects the household routines the most. Only 8% of relatives report that the disease had no impact on their lives.



“him flaring up again reminds me how it was at the beginning, and so now, it has been pretty different. And I think there is that sort of constant awareness of his flaking around, like balance of me thinking about, ‘Ok, I have to clean the house but not do it so much that he thinks I am paranoid about it’”. from Snyder et al³⁵

Siblings of people living with psoriatic disease, particularly of children with psoriatic disease, reported feeling neglected and jealous, as the parents spend more time caring for the sibling with psoriasis, for example helping to apply creams or lotions and administering other treatments or by having to take them to doctor appointments or the hospital.

“My other 2 girls are younger, but it takes time away from them. They see some of the attention that [patient] gets because every night we have to give medications or we have to do treatments, this, that, or the other things, so then that’s time we’re not spending with them, and they see that. I’ve seen my girls start to act out or say that their hands hurt, things like that because they want the attention, too.”, from Tollefson et al³⁷

The toll on **mental health** of family members results in a general feeling of anxiety, worry, sadness, and frustration impacting sleep, mood, and personal relationships. **Social life** is often severely affected by living with someone with psoriatic disease, as relatives refrain from hosting events at home or going to social events, and they need to spend time looking after the needs of the person living with the disease. The worry about what other people think and the unwanted attention or staring by others are also important reasons to make people avoid social events.

“It has affected my social life tremendously because I don’t have a social life when I’m so worried about how she’s feeling and how other people are making her feel. So I really do not have a social life.”, from Tollefson et al³⁷

“I’ve noticed sometimes the girls [their daughters] would be embarrassed to be around when he was using shorts because his plaques looked so bad.”, from Snyder et al³⁵

“All our family has to brush themselves off before going out’. Other subjects reported ‘a lot of hassle’ as they had to ‘clean the house as close as possible before visitors arrived”, from Eghlileb et al³²

Another important part of the household life affected in families with someone living with psoriatic disease is the family **economy**. On the one hand, depending on the severity of the disease and the toll on the person's wellbeing, it is often necessary for those in the household to take time away from **work** and even refrain from career changes or progression. On the other hand, the increase in household expenses related to the costs of treatments and hospital visits also has a significant impact on the family budget and economic well-being, especially in countries where there is no universal health coverage.

“Having to take days off, both my husband and I. It’s not that it’s a quick trip here. We have to drive 4 hours because this was the nearest pediatric dermatologist. So we have to take a day off of work and travel all that way, so that can be quite a burden.”, from Tollefson et al ³⁷

“I miss a lot of work. I’ve just been out on a 2- month medical leave with her, to go back next week, just because we needed to figure out what was going on. Her pediatrician said to just take her out of daycare because every time she got sick more things popped up.”, from Tollefson et al ³⁷

Importantly, the family and person with psoriatic disease QoL index scores are correlated³⁸, and interestingly the link can be bidirectional: not only the person with psoriatic disease's health affect the family but reports also showed that a positive and supportive family positively impacts the well-being of the person with the disease³⁹. It is then essential to give family members the tools and knowledge to address the challenges of living with psoriatic diseases. A psychologically healthy family unit provides the best emotional cushion for the person with the disease and vice versa.

THE CAREGIVER



The concept of caregiver, someone dedicated to helping the person living with the disease to manage the disease and the daily activities, is used almost exclusively within the context of childhood psoriasis. However, for more severe and debilitating cases of psoriasis, adults may also require someone to care for them.

Typically, the caregivers are the parents, most commonly mothers. In fact, research into the impact of psoriasis on parents showed a prevalence of mothers as the main caregivers, with 83 to 96% of the participants in such studies being mothers^{26,40-43}, a disparity likely ascribable to gender norms. This, in turn, results in a more pronounced loss of QoL in mothers than in fathers of children with psoriatic disease.

Being a caregiver involves profound changes in one's lifestyle and routines. There is an added **emotional distress** associated with having a child with psoriatic disease. On the one hand, the distress is a result of the extra time spent caring for the child, the impact on the work and social life, and the increase in household tasks and expenses^{26, 37, 42, 44}. On the other hand, the worry about how the child will be treated at school and anxiety about the future will be for the child are commonly mentioned by parents. The effect of these challenges is measurable by tool indicators such as PFI or FDLQI, which reflect a very large impact on caregivers' QoL.

"I stopped taking care of myself. That has affected me in so many ways. I don't have time or energy to lose weight."; "I think I am probably stressed more inside... I feel like a failure as a mother because I can't get rid of [them] [psoriasis lesions].", from Tollefson et al³⁷

Even though some studies report somewhat contradictory results, the QoL of the caregivers is generally correlated with the QoL of the children they care for. The QoL of people with psoriatic disease is affected by multiple factors. These include, for example, the type of psoriasis and severity, the PASI or BSA score, the family structure, the own understanding of the disease, and how to manage it. It is therefore not surprising that the same range is observed for caregivers.

THE PARTNER



One important member in the household of adults living with psoriasis is the partner. Unfortunately, not many studies have focused on understanding the impact of psoriatic disease on the romantic partner.

The lack of studies most likely reflects a vacuum of information given to the partners about psoriasis. In fact, there is a prevalence of **misconceptions** by the partners on what are the possible causes for the onset of psoriasis⁴⁵. When compared to people with psoriasis, the partners generally minimized the effect of smoking, alcohol, own behaviors, germs, and viruses on the onset of the disease. Conversely, stress, overwork, and poor medical care are believed by partners to have an increased weight on the onset of psoriasis. Some partners also seem to not fully understand the pain and emotional toll of psoriasis on their partners, either maximizing or minimizing their impact⁴⁵. This disconnect shows how essential it is to provide partners with more information about the disease and the wider burden of having psoriatic disease in physical well-being and mental health.

Not surprisingly, the majority reported that their partners' disease resulted in changes to their everyday lives, most of them already mentioned in the family section of this report. Reports have shown that some couples see their relationship deteriorate, especially regarding **intimacy**³². Interestingly, others reported a stronger impairment in QoL in male partners to females with severe psoriasis than in female partners of males with severe psoriasis, which is not fully understood²⁵.

"I feel we are living an older couple's life and our love life has been affected because of my husband's psoriasis; My wife feels embarrassed when she undresses with me in the bedroom", from Eghlileb et al³²

Some factors that specifically contribute to the strain in intimacy are the low self-esteem of those with psoriasis and the high prevalence of **sexual dysfunction** (such as erectile dysfunction, decreased sexual desire, satisfaction, and pain). Up to 95% of people with psoriatic disease and approximately 41% of partners report having sexual dysfunction. The fear of partners touching or causing new skin lesions or the itchiness and bleeding of the lesions^{25,36,46}, are also factors that affect the intimate relationship of the couples.



Approximately 50% of people with psoriatic disease experience **genital psoriasis** at some point in their lives, which has a severe impact on the QoL and sexual life. People with psoriatic lesions in the genital area report fear of having sexual relations, resulting in a reduction in the frequency of intercourse, and a significant increase in sexual dysfunction⁴⁷. This may be a contributing fracturing issue for couples' relationships.

Since partners play an important role in the feeling of acceptance, confidence, and empowerment of their loved ones, it is essential that they are given the tools needed to understand and navigate life with someone with psoriatic disease.

When considering the impact of psoriatic disease in a relationship with a partner, one important topic that needs to be considered is **family planning**. Some of the most serious concerns have been brought up by women with psoriatic disease, with both the disease presentation and the medication taken being the main factors considered when planning to have children. The lack of studies on family planning in males may be due to a real disparity between females' and males' concerns on the topic or a misrepresentation due to skewed research.

In the next section, we want to show how people with psoriatic disease and their partners take on family planning.

PSORIATIC DISEASE AND FAMILY PLANNING



In addition to having psoriasis, several other factors can affect the planning to have a child, such as which medication the individual with psoriasis is taking and the presence of comorbidities, as they may affect, for example, a successful conception⁴⁸. This is valid for both females and males.

The onset of psoriatic disease is multifactorial, with both genetic and environmental factors being necessary for the disease. Therefore, it is not surprising that one factor that often is considered by people with the disease is the genetic contribution to the development of psoriatic disease in their future children. Variants in several genes are known to increase the susceptibility to psoriatic disease. Even though there is no absolute correlation, there is an increased risk for people with psoriatic disease to have children that develop psoriasis, 50% or 16% if both or one parent has psoriasis, respectively.

“me and my wife, you know, we wanna have kids but were kind of scared because we don’t want them to come up with it too.”, from Snyder et al³⁶

Comorbidities such as obesity, metabolic syndrome, osteoporosis, depression, and the higher prevalence of risky behaviors in those with psoriatic disease, such as smoking or drinking, may also contribute to challenges in becoming pregnant or having an uneventful pregnancy. Psoriatic disease is not a static disease.

In fact, it is known to go through cycles throughout the life of those with the disease, with periods of intense flaring and periods of remission. The nature of psoriatic disease adds an extra challenge when planning to have children, as the future parents do not know how they will feel when the child is born.

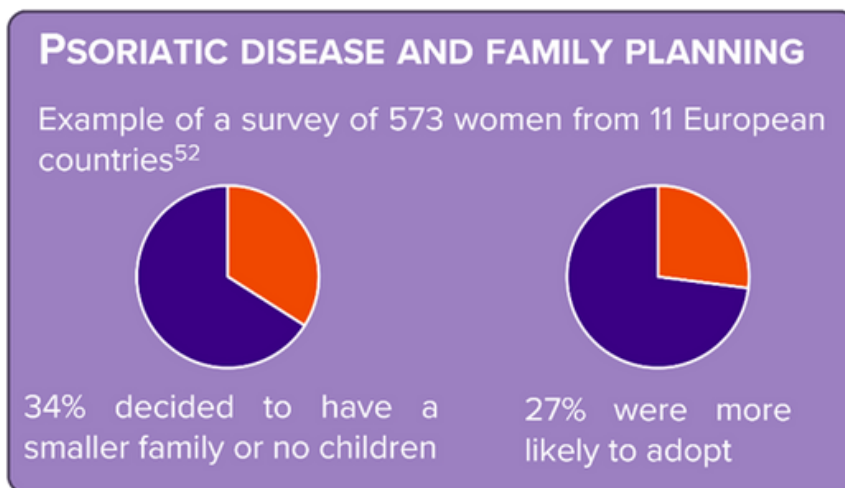
“After my baby was born, I had my life planned: I wanted to be the sporty dad, active dad. All of a sudden I was using crutches. That brought up all sorts of issues. I did not know who I was anymore.”, from a person living with psoriatic disease, UK

Some therapies are known to impact the development of the fetus, causing the child to be born before term, to have a low birth weight, presenting with malformations such as neurodevelopmental problems, craniofacial, and cardiac malformations or, in more severe cases, causing the fetus to be unviable. Depending on the compound, it is recommended either stopping for a specific number of weeks ahead of conception, during pregnancy and/or during breastfeeding⁴⁸⁻⁵⁰. Conversely, undertreatment may also affect the expecting mother and child’s health. It is, therefore, recommended that an evaluation of the medication being taken is done before having a child. When planning to have children, the future mother usually plans to become pregnant in periods where the disease presentations are not as severe, which is a part of the normal cyclic nature of psoriatic disease. In some cases, future mothers consider possible changes in the treatment or taking a break from the treatment. Importantly, there are safe medications that can be taken ahead of conception, during pregnancy, and when breastfeeding. It is, therefore, essential that both future parents and their doctors have discussions about the available options that allow for a safe and successful pregnancy.

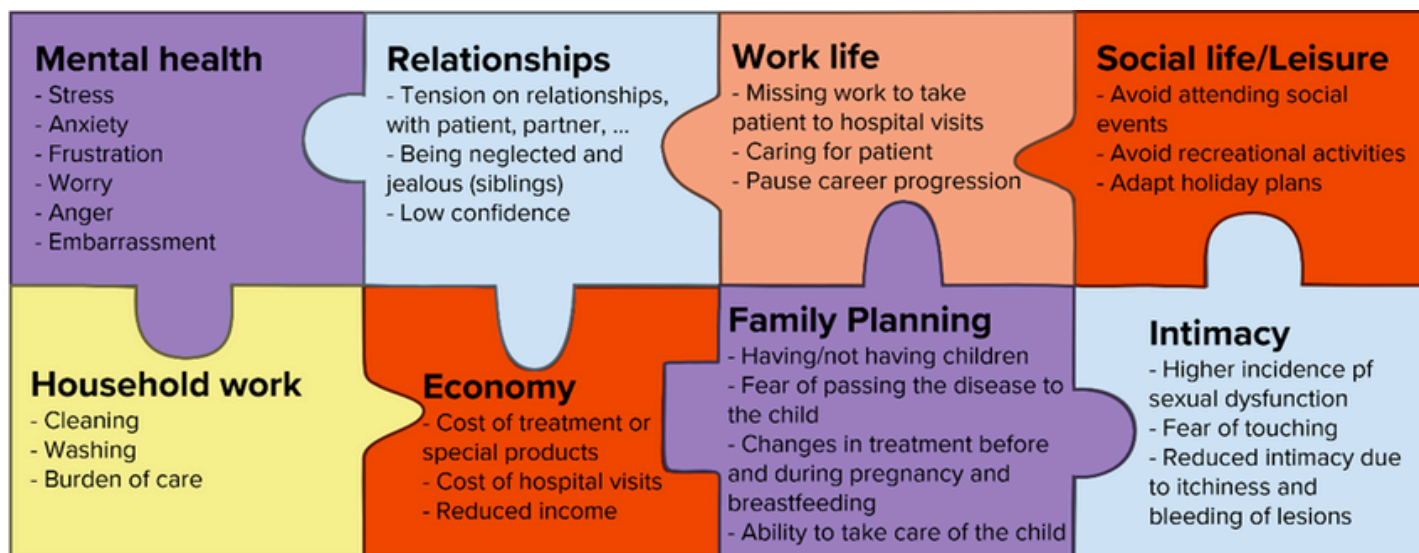


“I wanted to start a family, but the doctor said ‘forget it’”, from a person living with psoriatic disease, USA

Studies on family planning typically focus on the concerns, expectations, and experiences of people with the disease. Studies focus almost exclusively on females with psoriatic disease's concerns with family planning and, to a smaller or larger extent, their partners. Research has also shown that women with psoriatic disease are more inclined to have a smaller family, no children at all, or consider adoption instead^{51, 52}.



Having studies evaluating the impact of psoriatic disease on partners within the family planning context would provide valuable knowledge that could be used to inform policy makers and the health care community on what the partners' needs are.



Areas impacted on the life of the Greater Patient.

THE IMPACT OF TREATMENT ON QUALITY OF LIFE

The impact of living with someone with psoriatic disease, particularly for those who do not have access to the most adequate or efficacious treatment, is immense. As already mentioned in this report, the impact is as much physical as psychological. Therefore, the improvement should not only be measured by how severe the skin lesions are or the BSA index, but also in changes to the QoL of the person with the disease and their families, their economy, participation in social activities, and other aspects important for wellbeing and mental health.



Recent studies have started taking other metrics than PASI or BSA into account when evaluating the effect of a therapeutic compound. Outcomes such as the number of days taken from work and the number of days that people with psoriatic disease had difficulties doing the household chores were reduced following treatment⁵³, an incredibly meaningful result. Another study showed that, following treatment, both DLQI and FDLQI decreased, revealing a reduction in the negative impact of psoriatic disease in both those living with the disease and their families^{54, 55}. This is an extremely impactful way of assessing treatment efficacy for those living with the disease. The improvement of the clinical presentations is very important, but the improvement in the QoL and the ability to live a more normal life is one of the main outcomes that people with psoriatic disease and their inner circle wish for.

These findings show that it is of utmost importance for people to have access to the most adequate and efficacious treatment and that the effect also improves the lives of those in their immediate social group or the Greater Patient.

FIGHTING FOR THE GREATER PATIENT WELLBEING

Several barriers exist that make it difficult to understand how the Greater Patient experiences psoriatic disease. An important barrier is the lack of inclusion of family members and partners in the diagnostic journey and throughout the disease's life course.



The long journey individuals go through to get the right diagnosis and appropriate treatment plan is very taxing. As reported by WHO, there is a general lack of health professionals and, therefore, a lack of specialists in psoriatic disease. This results in reduced awareness about the disease and associated comorbidities by the healthcare community, increasing the likelihood of under-diagnosis and prescription of ineffective therapies⁵⁶. How the diagnosis journey affects the family of those with psoriatic disease is still generally unknown. Nevertheless, most feelings should resemble those of the person who is diagnosed, such as stress, depression, anxiety, and frustration.

An increasing number of studies have been conducted to understand the impact of psoriatic disease on family members and partners. They are, however, fairly neglected by the healthcare system as the support network for those with psoriatic disease and how their lives are also impacted by the disease. The lack of inclusion is particularly relevant and impactful in family planning. Studies published to date focus almost exclusively on the views and decisions of females living with psoriatic disease on having children. How males with psoriatic disease experience family planning is unknown. We also lack the perspective of the partners on how the disease affects the decision to have children.

Finally, it is important to emphasize that studies are limited by the willingness of people with psoriasis and their families to participate. Studies may involve answering a questionnaire that is relatively short (e.g. 10-15 questions in DQLI or FDLQI questionnaires), or in-person and follow-up interviews that may be too strenuous and time-consuming to take part in. This may be particularly relevant for people with a severely debilitating form of psoriatic disease, and for families that may have limited resources or access to these types of studies. There is, therefore, a possibility that the real impact of psoriatic disease on those living with the disease and family members is being underestimated.

Only by understanding the effect of psoriatic disease in the family can we develop strategies to better support them and create initiatives that may improve their QoL.

IMPROVING QUALITY OF LIFE

Several initiatives have been developed to improve the QoL of those with disorders affecting primarily the skin and their family members. These have been implemented to tackle different aspects of the diseases, not only psoriatic disease, and some have been shown to improve the QoL of family members.

One such example is the eczema school, developed in Germany, with the primary goal of establishing a standardized patient education program, designed to change the attitude and behavior towards eczema and improve health⁵⁷. The school also teaches practical tips on disease and pain management. The empowerment of those living with the disease and the gained sense of control in handling the disease not only resulted in a reduction in the frequency of scratching and drug use and an increase in the QoL of the child living with the disease but also an improvement of the QoL of the parents. The eczema school is now implemented in several other countries, such as Japan, Denmark, and the USA.

Another program with proven results in several chronic diseases called the therapeutic patient education (TPE) program, has been proposed for implementation in atopic dermatitis with positive results^{58,59}. In this program, trained HCPs interact with people with atopic dermatitis and their caregivers, helping them with educational workshops and developing a wide skillset, from disease management to social and relational skills.

The TPE is a 4-step process that tailors the approach depending on what is the previous knowledge of the participants.

Similar programs have been tested in people with psoriasis and their families with promising results.

One such program has been implemented in the Netherlands⁶⁰. Here, HCPs meet with four to five children with psoriasis and their parents on four different occasions. Each session focused on a particular topic, ranging from medical information about psoriatic disease, coping with the disease symptoms and tools to improve self-esteem and social interactions, to establishing long-term goals and relapse prevention. The results show a sharp decrease in the disease severity (using the BSA and PASI scores) and an improvement of the QoL of children with psoriasis (decrease in CDLQI score) as well as their families (using DFI, Dermatitis Family Impact, and SIFS, Stein Impact on Family Scale also known as IFS).



In the *In-group* project, established in Italy, people with psoriatic disease and caregivers attended six group events⁶¹. The study showed a reduction in FDLQI for caregivers who attended the events, while the control group showed an increase over time.

The common thread with these initiatives is the hosting of meetings attended by people living with the disease, family members, and HCPs such as dermatologists, pediatricians, psychologists, and possibly nurses. The common outcome of these events is a decrease in anxiety and improvement of QoL for the individual with the disease and those in their family circle, even if the severity of the physical presentations remains unchanged⁶¹⁻⁶⁴. This type of initiative has clearly shown an improvement in the QoL and well-being of the person with the disease, family members, or both.

FAMILY SUPPORT

The **Psoriasis Australia** organization offers a one-on-one family support helpline. A Family Support Coordinator is available to connect with people with psoriatic disease, families, and care on the phone, online, or face-to-face.



<https://psoriasisaustralia.org.au/family-support/>

RECOMMENDATIONS

FIGHT MISINFORMATION IN THE COMMUNITY

Fighting the stigmatization of people with psoriatic disease in the community is essential. Still, a large proportion of the population believes, for example, that psoriatic disease is contagious or that it results from bad hygiene habits. This type of misinformation results in stigmatization, discrimination, and a prevalent reluctance to interact with people with psoriasis that, directly or indirectly, also has a negative impact on family members.

We call for strong and relentless campaigns aiming to demystify the prejudices and misconceptions about psoriatic disease. Being correctly informed about what psoriatic disease is, the common comorbidities and the impact it has on those living with the disease and their families is the first step for increasing acceptance and the breakdown of negative prejudices that are very damaging.

Awareness campaigns such as billboards in key locations can be held for maximum exposure and outreach, information leaflets can be provided in healthcare facilities, and short informational videos can be spread on social media outlets. Additionally, podcasts offering engaging audio content, webinars providing interactive online seminars where experts share insights and answer questions in real-time, and seminars facilitating in-person events for detailed information and community discussions can be included. On World Psoriasis Day, the 29th of October, an extra effort is made to raise awareness of the disease. We recommend that schools should host short information sessions to promote understanding and combat the prevalence of misconceptions and prejudices in young children, using leaflets and videos appropriate for the student's age.

AWARENESS INITIATIVES FOR YOUNG PEOPLE

The Canadian Association of Psoriasis Patients has created a Kid's Corner on their website, with age-adjusted information on the disease
<https://www.canadianpsoriasis.ca/en/kids-corner>



The National Psoriasis Foundation (NPF) has created welcome kits for both young children and teens, including a booklet about the diagnosis and live with psoriatic disease, a parent guide, healthy living tips, and other items
<https://www.psoriasis.org/our-spot-kit/>



The Portuguese Psoriasis Association (PSOPortugal) produced a series of videos, PSOfriends, performed by teenagers with psoriatic disease. The videos recreate everyday activities and include snippets with medical information about the disease. The goal was to demystify prejudices and inform about psoriatic disease.
<https://psofriends.psoportugal.pt/>



ACCESS TO SUBSIDIZED HEALTHCARE AND TREATMENT

Not every country in the world has a healthcare system that is affordable and allows for access to both HCPs and treatment options at a reasonable price. We have shown that the household economy is, directly and indirectly, severely affected by psoriatic disease. On the one hand, the cost of medical appointments and treatments is a heavy burden on the budget for most families, and, on the other hand, parents and caregivers need to take time off work to assist with doctor visits and to care for those with psoriatic disease. Some caregivers also report having to put their careers on hold, which impacts the income for the family and, therefore, the family's economic well-being.

By implementing universal health coverage schemes, listed in the Sustainable Development Goals for 2030 adopted by all United Nations Member States in 2015, access to safe, effective, and affordable essential medicines and HCPs would make an enormous impact on middle to low-income families.

RESOURCES ON UNIVERSAL HEALTH COVERAGE

Resources on Universal Health Coverage are available on our website! The toolkit links the 2023 political declaration of the high-level meeting on UHC to psoriatic disease advocacy. Check out our resources for advocacy for UHC.



<https://ifpa-pso.com/resources-tools/ifpas-resources-for-universal-health-coverage>

IMPLEMENT TRAINING PROGRAMS FOR HCPS ON PSORIATIC DISEASE, THE GREATER PATIENT, AND THE WIDE BURDEN OF PSORIATIC DISEASE

The impact of psoriatic disease is felt not only by the person with the disease but also by those who share the household. Nevertheless, they are rarely considered by the healthcare system. The disregard for the Greater Patient well-being is especially prevalent to what concerns intimacy and family planning. Most people living with psoriatic disease report that HCPs do not talk about these topics during the consultations. This is even more extreme for their partners, who are left without any opportunity to get informed and talk about their concerns. Moreover, the lack of an integrated healthcare system, where people with psoriatic disease should be followed by a multidisciplinary team, is detrimental to providing the support and information that is required. This is particularly relevant for people of childbearing age when trustworthy medical advice related to family planning is essential for a successful pregnancy.

We therefore call for HCPs who treat people with psoriatic disease to attend training programs that will raise awareness and provide tools to better care for those with psoriatic disease and the Greater Patient. Moreover, we support the creation and implementation of disease-specific multidisciplinary teams, including dermatologists, rheumatologists, gynecologists, psychologists, and other specialties as needed, to provide the most adequate care to those affected by psoriatic disease.

EDUCATION FOR HCPS

The International Psoriasis Council (IPC) offers a vast collection of resources and educational material about the disease, tools to identify psoriatic disease in people from diverse racial and ethnic backgrounds, treatment options, and others.

<https://psoriasisCouncil.org/>



The National Psoriasis Foundation (NPF) provides a collection of resources about different aspects of psoriatic disease, from information for the diagnosis, disease's features, the latest treatments, and comorbidities, among others. Some give continuous medical education (CME) credits, important for the HCPs career.

<https://www.psoriasis.org/cme-library/>



The Psoriasis and Psoriatic Arthritis Alliance (PAPAA) offers a 10-hour patient-centered education program in psoriatic disease.

<https://www.papaa.org/media/3726/psoriasis-in-practice-2022-dl.pdf>



IMPLEMENT THERAPEUTIC PATIENT EDUCATION (TPE) PROGRAMS LOCALLY

Initiatives such as the eczema school, the TPE program, and similar initiatives already being tested in psoriatic disease, have delivered positive results in reducing the anxiety and stress associated with the disease, and improving the QoL and well-being of those living with psoriatic disease and the Greater Patient (see section *Existing initiatives that improve quality of life* for details).

Even when the programs are not aimed at therapies to treat the clinical presentations, the sharing of information, community building, and the acquisition of coping mechanisms to overcome the psychological tolls of the disease have proven to be game changer for people living with the disease and their families. Following the WHO recommendations for assessment of health, as the state of complete wellbeing rather than the absence of disease, we advocate for the wider implementation of the WHO-5 questionnaire. This type of assessment would provide a valuable measure of the effect of educational programs on improving well-being and mental health.

We call for the implementation of such programs locally, with a team of trained HCPs, following the latest research on the field. These are composed of four to six sessions but are designed to be open to optimization as needed. We also suggest that it would be beneficial for those participating to be invited for long-term follow-ups. These types of initiatives can be organized locally by patient organizations since they have a crucial role in advocacy and are the local hubs for information and support to those living with the disease.

CONCLUDING REMARKS

In this report, we have highlighted the important role of the family, caregivers, and partners, also known as the Greater Patient, in the life of those affected by psoriatic disease. Family and partners not only have an emotional support role, but also help with everyday tasks and treatment. This, however, comes with a cost for their own well-being. We also show initiatives implemented in several countries that improve their quality of life. Finally, we present recommendations that can be applied locally and globally to increase awareness of the impact of psoriatic disease in the family, fight stigma, and improve their well-being.

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