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Editorial

Inflammatory skin disorders and self-esteem☆☆☆

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"I think you have ringworm. We can't accept a donation from you." The entire room went silent as everyone stared at Jennifer, age 34, who has suffered from severe plaque psoriasis since the age of 15 years and is now a patient advocate for the National Psoriasis Foundation (NPF). Jennifer was inspired to donate blood after her uncle received a lifesaving transfusion and hoped to help others like him, but she will likely never try again after this traumatizing experience. This was not the first time strangers had treated her as if she had a contagious skin infection. Growing up, Jennifer endured constant ridicule and bullying by her peers, and even as an adult, she has to give herself pep talks before walking into stores, bracing herself for comments and stares from strangers. At the bakery where Jennifer worked, a customer accused her of purposely reaching over his cake and shedding her skin on it. Her employer now requires that she wears long-sleeved shirts, even on the hottest summer days in southern California. These experiences have taken a large toll on her mental health and cause her anxiety and panic attacks. Jennifer is not alone in her experiences. Several studies have shown a higher incidence of clinical depression, anxiety disorder, and suicidal ideation among patients with common skin diseases such as psoriasis and atopic dermatitis (Dalgard et al., 2015). Jennifer says that her biggest fear is ending up alone and not being accepted. She says: "You begin to wonder what's wrong with you?"

The struggle with personal relationships, from family and friends to romantic partners, is a common reality among patients with psoriasis. Aimee, age 29, is another patient advocate for NPF, and she described staying in an unhealthy relationship for almost 10 years with a man who told her that no one else was going to love her

with "all those things on her skin." She was diagnosed with plaque psoriasis at age 17 years and suffered flares that left her with lesions that covered 70% of her body. Although Aimee ended that unhealthy relationship, her disease has affected friendships as well. She has missed many important life events such as weddings because of her disease and has lost friendships as a result. "I've missed a lot of things and some friends think I wasn't there for them because they don't understand my situation," she explains. The reality is that her psoriasis comes with many comorbidities, including arthritis, which causes her significant pain and fatigue that limit her activities and inhibits her from pursuing romantic relationships because she does not want to negatively affect others. "I don't want to be a burden to anyone," Aimee explains, "I'm a preschool teacher; kids love me so it's a big deal when I say, maybe it's better if I'm not a mom. Maybe it's better that I'm not a wife either or a girlfriend. What if I have a child who has psoriasis as bad as mine? I would feel terrible."

With psoriasis covering 70% of her skin, Aimee does not sleep well and is constantly physically uncomfortable. Her sores can be so painful that they feel like burns and raw skin. She feels physically and mentally exhausted from the daily aspects of living with her disease and consequently, at times, has missed a considerable amount of work, which has negatively affected her career: "I feel very sad and upset with myself about how much time I have missed from work. Why can't I be normal? I don't even apply to certain jobs because I don't want my skin to be an issue. It's draining to always feel like you have to hide. I feel a bit stagnant in my life, not moving forward because of this."

Alan, age 43, was diagnosed with psoriasis at age 7 years and had a very difficult childhood with 60% of his body surface covered by the disease. He experienced significant bullying and describes painful memories in the locker room where kids would point at his skin and yell things such as "Look at his back! That's disgusting, you need to cover that up!" He quit playing soccer and spent the majority of his time with his family. He developed severe depression in his mid-twenties and recalls making a list of 10 ways how he could kill himself. Fortunately, he was prescribed antidepressant medications by his physician and learned to live with these challenges with the support of his family. Alan offers advice to anyone who is struggling with a new diagnosis: "Your psoriasis is a part of you but does not make you who you are. Be your own cheerleader and educate those around you."

The link between psoriasis and mental health has been long established and studies have shown that patients with psoriasis have an increased risk of depression, anxiety, and suicidality (Kurd et al., 2010). Although many studies suggest a correlation between such risk and severity of disease, even mild cases have been associated with quality of life impairment while more severe disease is associated with comorbidities such as cardiovascular involvement and

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psoriatic arthritis. Data show that psoriasis has a large impact on patients' daily lives, careers, personal relationships, and perceptions of themselves (Krueger et al., 2001).

Studies have also attempted to estimate the financial burden of this chronic disease. According to a 2015 systematic review, the annual direct costs of psoriasis in the United States ranged from \$51.7 to \$63.2 billion and indirect costs from \$23.9 to \$35.4 billion while medical comorbidities contributed \$35.4 billion to the financial burden (Brezinski et al., 2015). Indirect costs refer to costs associated with lost work productivity and missed work days due to healthcare appointments and sick leave. In a survey of 75,000 patients with psoriasis from 2003 through 2011, 12% of patients were unemployed and 11% worked part-time (Armstrong et al., 2012). More than 90% of the unemployed patients reported psoriasis as the sole reason for why they were not working, and of those patients who were employed, 49% reported missing work days regularly because of their psoriasis.

These data show that the economic burden of psoriasis in the United States is substantial, and efforts should be made to minimize these costs by increasing access to cost-effective therapies, thereby improving patient outcomes. A major player in the efforts to shape healthcare policies and minimize costs for patients is the NPF. NPF has made incredible strides for patients, including insurance coverage for phototherapy services and biologic treatments, which were previously only covered for rheumatologic conditions (Kaufman et al., 2008). Access to such treatments can be life-changing for patients with psoriasis such as in Alan's case where biologic treatments decreased his disease burden from 60% body surface area involvement to 1% and allowed him to lead a normal life more than ever before. Although there have been numerous studies on the burden of the disease in patients with psoriasis, only recently has there been an increase in studies on patients with atopic dermatitis, which is another very common inflammatory skin condition among the general population.

Like psoriasis, atopic dermatitis is a chronic condition and has similar features in its impact on patients' quality of life and mental health. However, this condition is associated with a different set of comorbidities and primarily affects a younger population. This can have a major impact on a child's psychosocial development. Abigail, age 19, is a patient advocate for the National Eczema Association (NEA) and was diagnosed with atopic dermatitis at age 3 years. She explains that growing up with eczema has been a struggle as she endured a significant amount of bullying that led to depression and social anxiety. She recalls people asking her if she had leprosy or chickenpox, and peers told her that she is "going nowhere in life."

Abigail's allergies limit her life significantly because even being outside with exposure to grass and heat trigger flares of her condition. Due to disease involvement of her hands, often with ulcers and peeling skin, she was rejected from retail and food-handling jobs. Abigail had to drive more than an hour to see an allergy specialist for treatment. She has had to miss school once a week to receive cortisone shots from this doctor and fell behind in school because of the missed days and side effects of the steroid medications. Abigail gained weight, lost her appetite, had to quit swimming and band, and constantly felt sick from the steroid injections. The side effects were too much to handle, and Abigail states that she is still searching for an effective treatment. Her insurance does not cover most of the treatments, and she reports spending approximately \$200 each month on medications alone. The financial burden of her disease has affected her family to the point where they have had to cancel family vacations. She also describes strained family relationships with her siblings because her medical problems have demanded so much attention from her parents.

Given patients' young age at the time of disease onset, a large portion of the burden is shared by the caregivers of patients with atopic

dermatitis. Amber, a mother who is active with the NEA, offers her perspective as a caregiver for her 10-year-old daughter Emily, who was diagnosed at age 2 years with severe atopic dermatitis. Emily has been seen by more than seven dermatologists who have been unable to offer successful treatment options for her disease.

Her disease course has been challenging, and she became so sick that she had to be pulled out of school at the end of fourth grade. She was homebound for a significant amount of time; teachers would visit her home to teach, but Emily inevitably fell behind in her academics. She was unable to go outdoors, and her mother noticed that she gradually became more withdrawn and less social. Her mother recalls incidences with strangers who made comments about bringing kids out in public when they have chickenpox as well as rude comments about her skin within earshot of her daughter. She expressed frustration at being unable to protect her daughter from such ignorance and judgement. As a mother, it was extremely hard for her to watch her daughter "miss out on being a kid." She says Emily is often left out because she cannot attend birthday parties, go to water parks, or participate in activities that trigger her allergies. Amber also noticed that this disease forced her daughter to grow up very quickly. She takes six medications daily and knows the names and doses of each one.

As a caregiver, Amber tries to stay positive for her daughter, telling her that it is going to be okay, but she knows that it is not an easy road ahead for her child. The journey so far has been challenging, and Amber notes that there has been strain on her relationship with her husband. One major contributing factor is the financial strain on the household because Emily's medical care averages approximately \$1,000 each month. She also notes that each family member has their own way of coping with Emily's condition, and her husband is currently going to therapy with Emily to help improve communication between them. She is proud of how Emily has handled her condition, especially recently after attending a camp for children with skin conditions. Emily has gained confidence in addressing people who confront her about her skin and tells them that there is nothing wrong with her face and that "her skin is just different. Everyone is different."

It is inspirational to see adolescents gain confidence and acceptance of their disease early on in life because it arms them with the tools to educate those around them and break down the stigma that is associated with these skin conditions. Although the onset of atopic dermatitis is typically during early childhood, it has become increasingly recognized as a disease that can persist throughout adulthood (Margolis et al., 2014). Tomi, age 53, has struggled with atopic dermatitis since birth. She recalls having the typical dermatitis rashes as a child with severe allergies to sweat, heat, and numerous other environmental triggers. However, she only started realizing the extent to which her condition affected her life when she became employed. Tomi cycled through numerous jobs, including working as a cold food preparer for a Mexican restaurant and attending beauty school to follow in her mother's footsteps as a hairdresser. However, she constantly developed secondary infections on her hands, and wearing gloves exacerbated the problem because her own sweat was an irritant.

Tomi worked for 22 years, dealing with the infections and taking periods of time off, until she finally tried treatment with oral prednisone, which was very effective in eliminating her symptoms. However, the side effects of the medication were much worse than her initial symptoms, and she decided to discontinue treatment. At the age of 30 years, Tomi went back to school through a vocational rehabilitation program to become a park ranger and worked for approximately 10 years until she could no longer handle the environmental triggers that caused her disease to flare. She is currently unemployed, has applied for disability, and stays home because that is the only way to control her environment and avoid allergens. Tomi has tried office

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