

US PATIENT STUDY RESULTS

A recent survey of people with moderate-to-severe psoriasis published in the USA showed that people with psoriasis experience a crisis in self-confidence so severe it can darken almost every aspect of life, from the quality of a person's love life to performance on the job and day-to-day social interactions. People report feeling like social outcasts and being misunderstood by the public.

The survey is the most comprehensive study in the US to date to specifically examine the social and emotional effects of psoriasis. It also illustrates the need for a public education and support program for people with psoriasis. The Person Behind the Patient, is a unique collaboration of health providers, advocates and people with psoriasis including the National Psoriasis Foundation and the Dermatology Nurses Association (DNA). The new program was launched at the 62nd Annual Meeting of the American Academy of Dermatology (AAD).

"Comprehensive care of psoriasis goes beyond treating the symptoms. This survey validates the need for an understanding about how psoriasis can impact a patient's social life and emotional and physical well-being," said Alan Menter, MD, Chief of the Division of Dermatology at Baylor University Medical Center and a member of the Beyond Psoriasis Advisory Board. "I am committed to this program and its objectives to provide education, sensitivity and support to these individuals similar to what is available for other chronic diseases like heart disease or arthritis. Otherwise, the patient's psoriasis is not fully managed."

Conducted in December 2003 by the NFO, a leading market research firm, the survey sampled 502 people with moderate-to-severe psoriasis to determine the effect the disease has on four crucial aspects of life: self-esteem, work/school, relationships (including sex life and intimacy) and social interactions. Most strikingly, three-quarters (73%) of people with severe psoriasis and about half (48%) of people with moderate psoriasis reported low self-confidence serious enough to affect virtually all aspects of life. Further, the survey found that one of the driving forces behind these feelings is a perceived lack of

understanding among the general public. Less than one in ten people surveyed (8%) feel that society understands the disease. Sixty-seven percent say the public is ignorant about psoriasis, 64% say the public is afraid that the disease may be contagious, 56% say the public is disgusted by psoriasis and 45% say that people with psoriasis are often the "object of ridicule."

Findings of an Omnibus Survey of 1,000 adult Americans, conducted by Opinion Research Corporation International (ORC) in December 2003, found that the vast majority of respondents (88%) have heard of psoriasis and that almost half (46%) knew someone with psoriasis. The findings showed that although the public is not aware of the prevalence of the disease (93% were not aware that 4.5 million Americans have psoriasis), 86% of the respondents did know that psoriasis is not contagious and 52% were aware that psoriasis is more emotionally crippling than physically disabling.

"I'm really surprised that so many people know that psoriasis is not contagious. I have psoriasis, and when I have a flare up, I am really self-conscious. I know that people stare and stay away from me because they think I am contagious," said Mike Frisbie, a member of the Beyond Psoriasis Advisory Board and psoriasis patient. "Part of what we want to do with this program is to help people with psoriasis feel more comfortable with discussing the disease and to learn ways to cope with the self-defeating attitudes that can cast a shadow over many aspects of our lives. We want to help empower others to speak up about their disease with their doctor, their friends, acquaintances and loved ones, and in doing so, help them continue their lives in a positive way."

Negative effects were most dramatically experienced by people with psoriasis who are 18-24 years old – a population just beginning to develop their self-esteem and interpersonal relationships that will influence the rest of their lives. Women, single people and those who have visible psoriasis (usually on their face and/or scalp) were most impacted.

- More than half (58%) of women compared with 45% of men experienced lower self-confidence because of their psoriasis
- Self confidence of young adults (68%), people with early childhood onset psoriasis (58%), and people with visible psoriasis (58%) were also more dramatically affected

Relationships
Many people with psoriasis had

problems with sex and intimacy. In fact, four in ten people with psoriasis (38%) agreed that the disease affects their sex life/intimacy. The problems are more prevalent for those who are single. Feelings of worry are common.

- More than half (53%) of those single admitted to having problems with their sex life (versus 30% of married people with psoriasis)
- Half (49%) of young adults (ages 18-24) are also more likely to experience angst in intimate situations (versus 36% of 25-35 year olds)
- Half (52%) turn off the lights when they are intimate with their partner; 48% worry that their partner is embarrassed by their psoriasis; 26% say psoriasis interferes with their ability to getting emotionally close to their partner.

In general, the people surveyed felt that their family and friends understand their psoriasis and are supportive. Understanding of family could be driven by genetics: almost half (45%) of the people surveyed have at least one family member with psoriasis. Of those, the majority (62%) has at least one parent who has psoriasis. 81% are worried and 76% feel guilty that they might pass psoriasis on to their children.

Most people with psoriasis avoid public interaction, dress to hide their condition and feel like outcasts (64%). Psoriasis affects daily interactions for four in ten (38%) respondents. For those with severe psoriasis, this increases to 57%.

- Three fourths (74%) do not like to be in public when their psoriasis flares up
- 64% hide their condition with long sleeved shirts and long trousers

Work and school can be particularly problematic for people with psoriasis. One-third (37%) of all people with psoriasis agree that the disease affects work/school.

- Those people with severe psoriasis, visible psoriasis (face and/or scalp), early childhood onset and young adults (18-24) were more likely to agree (55%, 40%, 48%, 41% respectively).

Gail Zimmerman, President and Chief Executive Officer of the National Psoriasis Foundation said. "With support from healthcare professionals and others with the disease, people with psoriasis can help to build widespread public awareness and at the same time become more confident spokespersons about their disease. That public awareness, in turn, will lessen the social pressures, completing the circle of positive communication and support."