

Impact of GPP on quality of life and psychological well-being: results from a non-interventional survey/interview-based study

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Objective: To understand the real-world impact of GPP on patients' physical and emotional well-being, particularly in relation to flares

Synopsis

- Generalized pustular psoriasis (GPP) is a rare, chronic, systemic inflammatory disease with a heterogeneous clinical course^{1,2}
 - The symptoms of GPP and occurrence of flares are often unpredictable. As a result, GPP treatment goals include management of flares and long-term prevention of new flares²
 - The unpredictability of flares is one of the factors that contributes to the substantial emotional and mental health burden in patients with GPP^{3,4}
- A 2022 survey of US-based patients with GPP illustrated the emotional toll on people living with this condition⁵
 - The most prominent and troublesome symptom experienced during a flare was reported to be changes in mood, the burden of which was described as high (8–10 on a scale of 0–10) by over half of respondents
 - The majority of respondents expressed feelings of fear and anxiety over GPP (67%), with 71% reporting a fear of flares

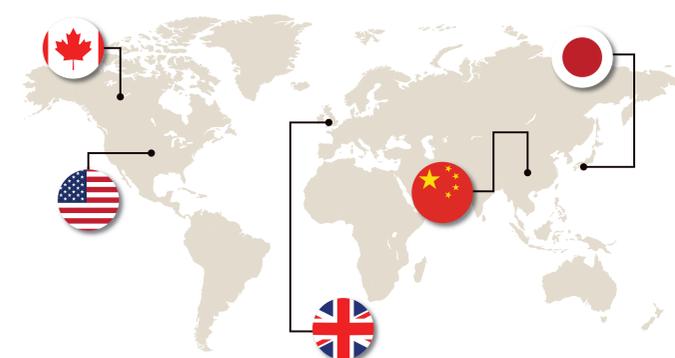
Methods

Study design

- Cross-sectional, non-interventional study involving adult patients with GPP or palmoplantar pustulosis (PPP) from five countries: Canada, China, Japan, UK, and US
- Participants were recruited by a combination of patient advocacy groups, recruitment vendors, and clinical sites
- Data were collected via a web-based survey and semi-structured, qualitative telephone interviews
- All participants who were eligible for the survey had the opportunity to opt into a telephone interview

Eligibility and enrollment

- Individuals >18 years of age who received a diagnosis of GPP ≥12 months prior to screening
- Have experienced ≥1 flare within the past 12 months



Results

Demographics & baseline characteristics

- The mean age of all participants with GPP (N=21) was 40.7 (standard deviation [SD]: 12.0) years, with over half of participants being female (n=12; 57.1%)
- Participants had been diagnosed with GPP an average of 16.1 (SD: 15.0) years prior
- Of participants who took part in the interview (n=9), five were female (55.6%)

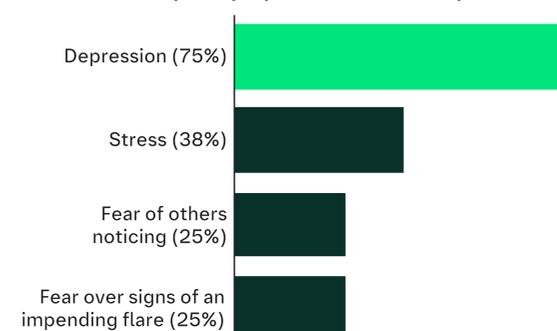
	US	Japan	UK	China	Canada*	Total
Participants (survey)	2	5	5	9	0	21
Participants (interview)	1	2	1	5	0	9

*All participants recruited from Canada were patients with PPP.

Fear and related negative emotions¹

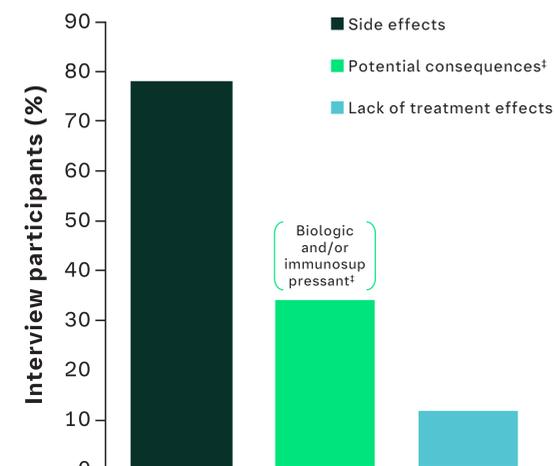
- When asked about GPP diagnosis/diagnostic process, five out of eight (62.5%) interview participants who were questioned expressed concerns, including fear over lack of cure (n=1), fear over unpredictable disease recurrence (n=1), the length of time it took to receive a diagnosis (n=3), the financial burden, and the potential impact GPP would have on their future children (n=1 for each)
- All interview participants (9/9) reported an impact on their emotional well-being, either in general (n=8) or specifically due to flares (n=5)

Most frequently reported emotional impacts

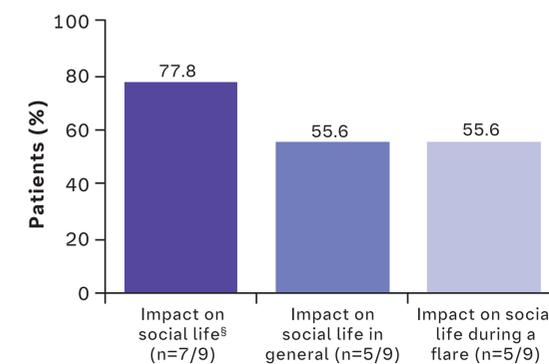


¹These answers were not mutually exclusive; ²Including the need for laboratory tests, e.g. liver and kidney function tests, and risk of contracting other illnesses due to immunosuppression; ³Either in general or due to flares.

- All interview participants were receiving treatments for GPP (9/9), including systemic non-biologics, biologics, and/or emollients
- When describing their negative experiences with past or current treatments, 7/9 (77.8%) reported side effects
- Just under half (4/9) expressed worries over treatment consequences⁴ or lack of efficacy



- Over three-quarters of participants (n=7/9) reported an impact on their social life. This manifested most commonly in the form of limited social activities or isolation as a result of their own or others' negative feelings towards their skin's appearance



- When asked what worries them most about having GPP, five interview participants (55.6%) responded with a specific worry:
 - Recurrence
 - Distress associated with symptoms and appearance of skin
 - Passing GPP to their children
 - Pain
 - Suboptimal treatment

Conclusions

- In this multinational study, participants reported feelings of fear and related negative emotions throughout the disease course of GPP, and specifically due to flares
- The small sample size in this analysis must be considered when interpreting the findings
- In order to address the significant emotional burden of GPP, there is an ongoing need for greater disease awareness and understanding among healthcare professionals
- A recent global consensus study concluded that GPP is a complex, heterogeneous and chronic condition, and that long-term treatment goals should include prevention of flares⁶
- Patients' concerns over chronic symptoms, flares and existing treatments highlight the need for effective, continuous treatment strategies that provide sustained symptom relief and improve their quality of life, echoing the treatment goals established by the consensus⁶

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Abbreviations

GPP, generalized pustular psoriasis; PPP, palmoplantar pustulosis; SD, standard deviation.

Disclosures

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Data sharing statement

To ensure independent interpretation of clinical study results and enable authors to fulfill their role and obligations under the ICMJE criteria, Boehringer Ingelheim grants all external authors access to relevant clinical study data. In adherence with the Boehringer Ingelheim Policy on Transparency and Publication of Clinical Study Data, scientific and medical researchers can request access to clinical study data, typically, one year after the approval has been granted by major Regulatory Authorities or after termination of the development program. Researchers should use the <https://ivivi.org/> link to request access to study data and visit <https://www.mystudywindow.com/msw/datasharing> for further information.