

The emotional impact of pyoderma gangrenosum (PG): Real-world experience of the PG patient journey

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Conclusions



This study emphasizes the substantial emotional impact of PG on study patients and caregivers, and highlights their challenges throughout the patient journey.



Addressing the core issue of delayed or misdiagnosis through improved disease education, and offering mental health and peer support, are crucial to empowering patients and improving their emotional and clinical outcomes.

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Objective

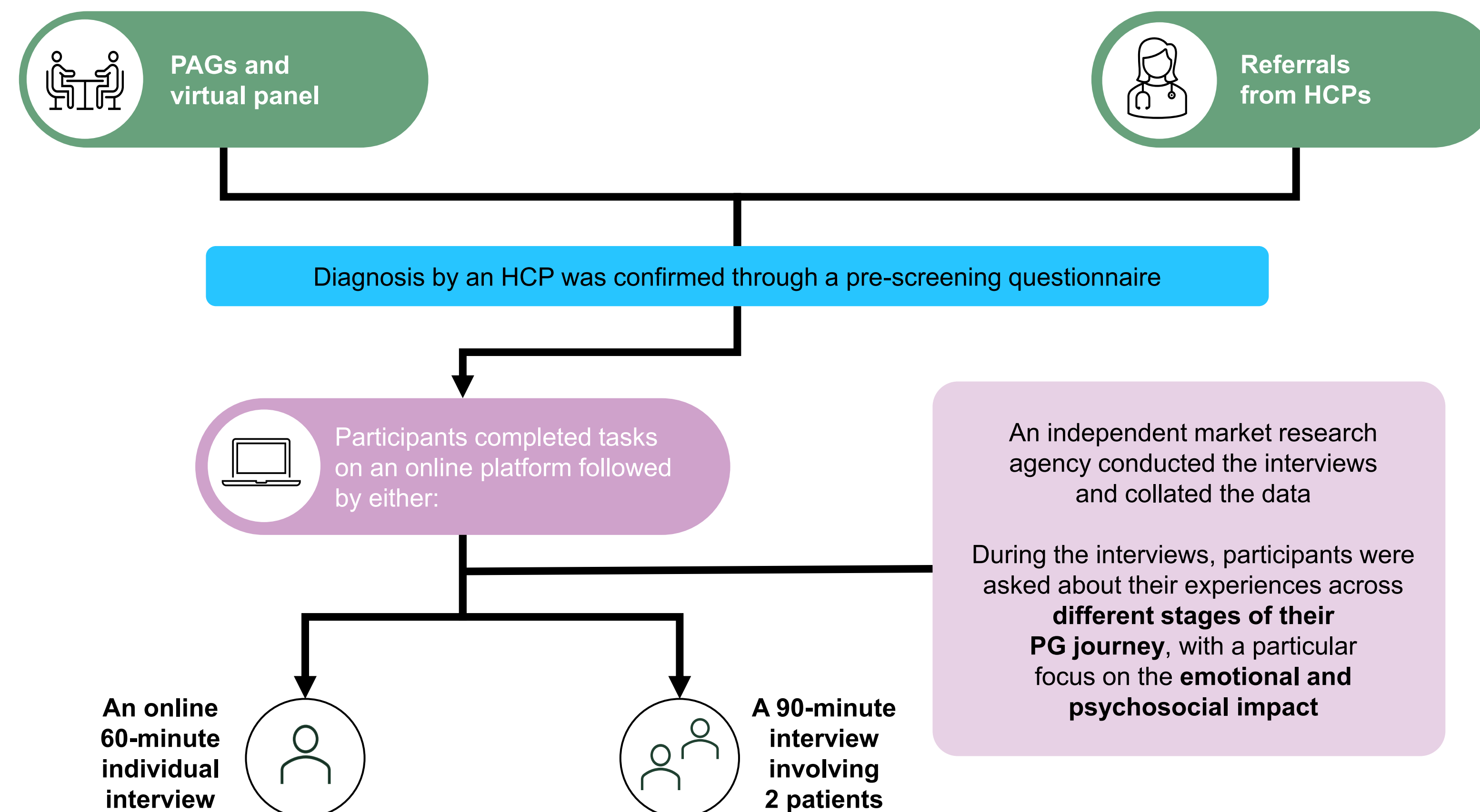
- This qualitative research study explored the PG patient journey, with a focus on the emotional burden at multiple disease stages, and the critical need to provide more support to patients with PG.

Introduction

- PG is a rare, painful, ulcerative neutrophilic disorder that significantly impacts patients' physical, emotional, and psychosocial well-being.^{1,2}
- However, due to the rarity of PG, data describing the emotional challenges faced by patients and their caregivers are limited.

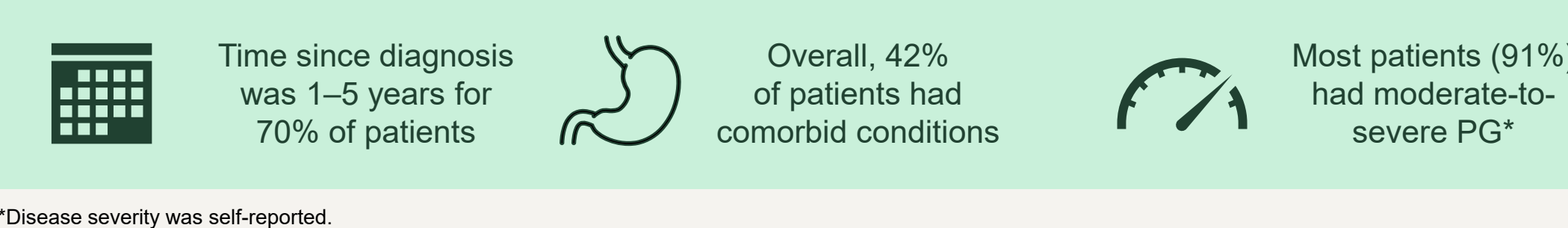
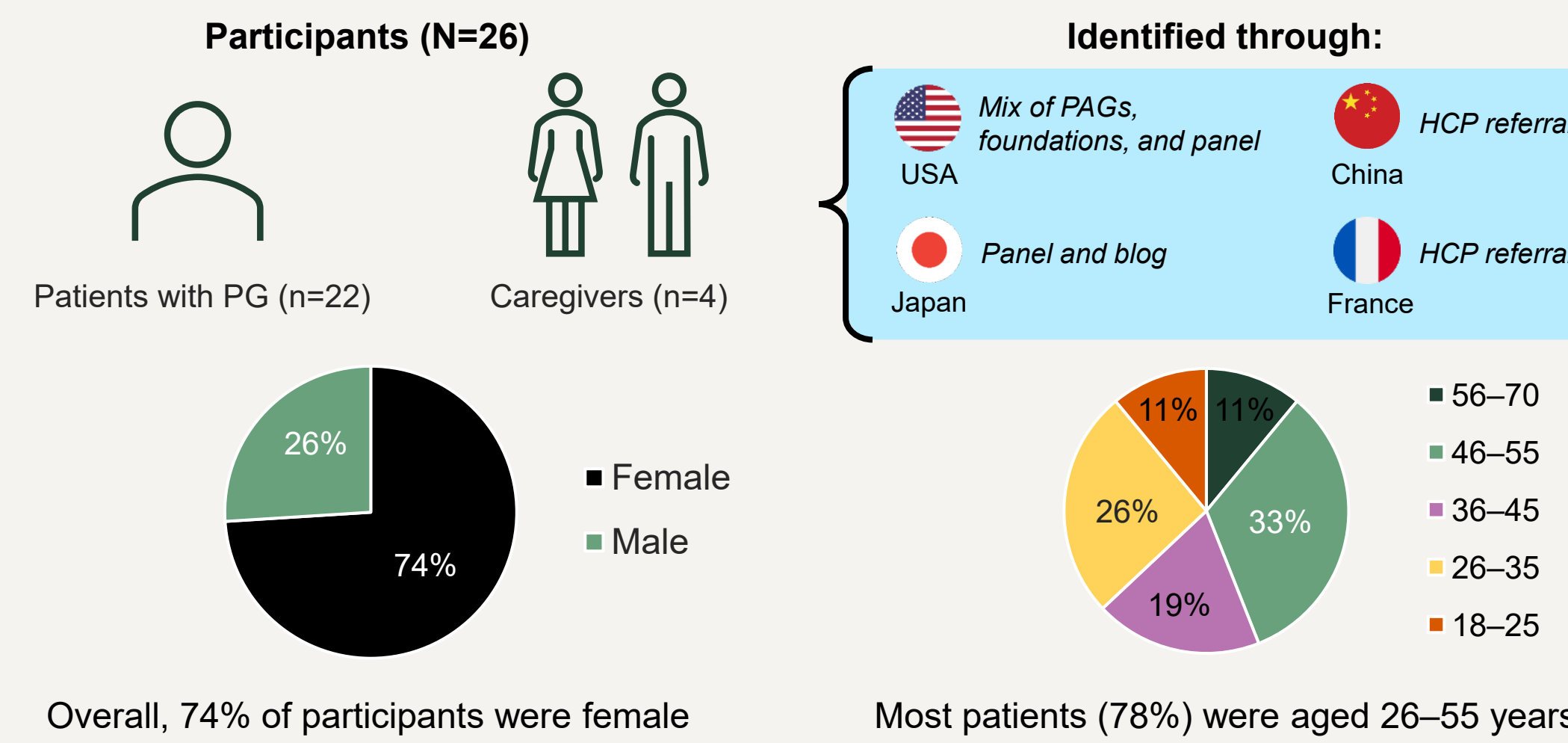
Methods

- From August to September 2024, adults with PG and their caregivers were recruited through several routes, including:



Results

Baseline characteristics



Presentation

Patients with PG reported experiencing:

High levels of distress due to size of ulcer
Severe pain
Immobilization
Difficulty performing daily tasks

Patients with PG explained that PG takes over their lives, affecting their:

Routines | Ability to partake in hobbies | Wardrobe | Ability to socialize | Relationships with family and friends

Comorbid conditions may cause delays in presenting to a dermatologist

Patient author insights

“ Misdiagnosis and mistreatment allow wounds to grow and go deep, resulting in higher risk of infection, loss of mobility, and adding years to recovery. Early diagnosis is the key. ”

Treatment



Symptoms can cause patients to stop working, leading to **financial issues**, which can **limit treatment options**



After treatment failure or relapse, patients reportedly felt **isolated** and **pessimistic**, with emotions fluctuating due to uncertainty of treatment success and the impact on quality of life



Patients expressed high levels of **doubt** and **hopelessness** in response to uncertainty surrounding the success of their treatment outcomes

Onset of symptoms

PG initially presents as a 'small bump' that grows aggressively into an ulcer

PG ulcers cause excruciating **pain** for patients

As symptoms developed, patients reported feeling:

Worried | Anxious | Depressed | Low self-esteem | Isolated

Patient author insights

“ PG negatively affects relationships with your spouse, family, and friends. I feel so much guilt that I can no longer play with my grandkids or participate in family functions. I'm not the person I used to be. ”

Diagnosis

HCPs can struggle to **diagnose** and **advise** patients due to a **lack of objective markers for diagnosis and information** on the disease, leading to feelings of **hopelessness, fear, and uncertainty** among patients

Patients are often **misdiagnosed**, and diagnosis can be **delayed**, leading to:

Feelings of **frustration, mistrust, and neglect** | **Anxiety and stress** over a lack of clear explanation | **A lasting impact on optimism** towards treatment options

Upon learning that PG is a chronic condition, many patients feel **depressed, embarrassed, scared, and isolated**

Ongoing management

Pain continues throughout treatment until wound closure, which can be a **lengthy process**, causing the patient **distress**; even upon wound closure, **symptoms can remain**, such as flare-ups, and dry and itchy skin

Patient author insights

“ The constant, intense pain of PG takes over your life, wears you down, and destroys your quality of life. PG leaves deep physical and emotional scars that may never heal. ”

Patients reported **anxiety** and a **fear** of the risk of **relapse**

Those who experienced relapse felt like they were **failing** and **losing control**

Relapses are often **unexpected** and can be very **distressing** for patients, who often need **emotional support** during this time

Abbreviations

HCP, healthcare professional; PAG, patient advocacy group; PG, pyoderma gangrenosum.

References

- Ruocco E, et al. J Eur Acad Dermatol Venereol 2009; 23:1008–1017;
- Sanchez-Melendez SN, et al. Exp Dermatol 2024; 3:e14876.

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://vivli.org/> link to request access to study data and visit <https://www.mystudywindow.com/mw/datasharing> for further information.

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