ORIGINAL REPORT

ActaDV Acta Dermato-Venereologica ActaDV Advances in dermatology and venereology

Living with Pyoderma Gangrenosum: A Qualitative Study

Jacqueline JIANG[1], Robert KELLY[1], Emma VEYSEY[1,2], Susan ROSSELL[3,4], Garry ZHU[3] and Darren HAYWOOD[3,5–7]

[1]Department of Dermatology, St Vincent's Hospital Melbourne, Fitzroy, VIC, [2]Department of Dermatology, The Royal Women's Hospital, Parkville, VIC, [3]Department of Mental Health, St Vincent's Hospital Melbourne, Fitzroy, VIC, [4]Centre for Mental Health and Brain Sciences, Swinburne University of Technology, Hawthorn, VIC, [5]Human Performance Research Centre, INSIGHT Research Institute, Faculty of Health, University of Technology Sydney (UTS), NSW, [6]Department of Psychiatry, Faculty of Medicine, Dentistry and Health Sciences, University of Melbourne, VIC, and [7]Discipline of Psychology, School of Population Health, Curtin University, Bentley, WA, Australia

Pyoderma gangrenosum is a rare, autoinflammatory disorder characterized by rapidly progressive painful ulcers that are challenging to diagnose and treat. This qualitative study aimed to explore the experiences of patients living with pyoderma gangrenosum. Using an inductive qualitative approach, semi-structured interviews were completed with a purposive sample of 21 patients with pyoderma gangrenosum recruited from a public dermatology outpatient clinic in Melbourne, Australia. A reflexive thematic analysis was performed, yielding 5 themes: pain, physical challenges, social functioning and relationships, mental health, and treatment. The impact of pyoderma gangrenosum on quality of life was multifaceted and varied throughout disease progression, remission, and recurrence. Experiences of delayed diagnosis and misdiagnosis were common, causing distress and resulting in unnecessary treatments including surgery. Severe pain disrupted sleep and limited daily activities, eroding patients' sense of self-control and perpetuating depressed mood and anxiety. Management should include early specialist referral, providing information sheets for managing pain and wound care, and communicating disease expectations. In conclusion, this study has deepened understanding and given personal perspectives on what it is like to live with a condition poorly understood by many health professionals. Increased efforts should be made to increase clinician awareness regarding pyoderma gangrenosum to facilitate early diagnosis.

Key words: pyoderma gangrenosum; qualitative research; quality of life.

Submitted Sep 16, 2024. Accepted after revision Nov 13, 2024

Published Dec 4, 2024. DOI: 10.2340/actadv.v104.42018

Acta Derm Venereol 2024; 104: adv42018.

Corr: Jacqueline Jiang, Department of Dermatology, St Vincent's Hospital Melbourne, Fitzroy, VIC, Australia. E-mail: jacqueline.j.jiang@gmail.com

SIGNIFICANCE

The impact of pyoderma gangrenosum on quality of life is relatively underexplored from the perspective of those living with the condition. It is important that people living with a rare condition are given an opportunity to share their experiences and current challenges to find potential solutions. Our study shares the stories of people living with pyoderma gangrenosum, including the experiences of dealing with delayed diagnosis and misdiagnosis, the devastating impacts of severe pain on quality of life, the impacts on day-to-day life and relationships, and the challenges involved in treatment.

Pyoderma gangrenosum (PG) is a rare, autoinflammatory disorder characterized by rapidly progressive painful cutaneous ulcers, usually affecting the lower legs (1–3). The exact cause of PG is unknown, although it is associated with inflammatory bowel disease, inflammatory arthritis, and haematological malignancy (1, 3). Some 30% of cases occur following minor skin trauma or surgery, a phenomenon known as pathergy (1, 4).

PG is difficult to diagnose and the clinical course is unpredictable, varying from indolent to rapidly spreading (1, 3). Definitive guidelines for management are lacking; however, most patients are treated with a combination of wound care, topical therapies, systemic glucocorticoids, and steroid-sparing agents (1, 2, 5). PG can be a chronic, relapsing, and remitting disease, resulting in scarring and disfigurement (1, 2).

Given its chronic, unpredictable disease course, it is unsurprising that patients with PG experience higher rates of depression and anxiety (6, 7). The condition can profoundly impact quality of life (QoL), although this is relatively underexplored from the perspective of patients (8, 9). Prior smaller studies have identified some PG-specific QoL domains: pain, physical manifestations, physical limitations, self-image, mental health, social relationships, sexual intimacy, disease course, wound care, and treatment (10, 11). However, an in-depth exploration of the patient experience is required to inform the development of PG-specific patient-reported outcome measures (PROMs) and to help healthcare providers to make better management decisions (12–14). It is important that patients living with a rare condition are given an opportunity to share their experiences and current challenges to find potential solutions. Therefore, the objective of this qualitative study was to understand the experiences of PG from the perspectives of patients.

METHODS

Study design

PG patient perspectives are an underexplored research area; therefore, this qualitative study was designed with an inductive approach. One-on-one semi-structured interviews were most suitable to allow for freedom to explore novel areas, and give maximum opportunity for participants to tell their story (15, 16). Interviews were conducted by a researcher (JJ, medical doctor, female, age 26), who did not have any existing relationship with the participants, with supervision from the research team.

Participant selection

Participants were recruited from a dermatology clinic at St Vincent's Hospital, a tertiary hospital in Melbourne, Australia. Adult patients with pyoderma gangrenosum diagnosed by a dermatologist, fluent in English, and without significant cognitive deficits were eligible. Purposeful sampling was used (17), aiming for individuals with at least 4 months since diagnosis and an ability to articulate their experiences. Data collection continued until the narratives collected reached sufficient diversity and depth within the sample to enable interpretation of the experiences (18, 19). Twenty-one participants were recruited including 16 women and 5 men, ranging in age from 35 to 82 years. Appendix S1 shows the clinical characteristics of participants. All participants signed an informed consent form. We received ethical approval from the St Vincent's Hospital Human Research Ethics Committee (HREC-086/23).

Data collection

Interviews were conducted from August to December 2023 in person or via videoconferencing using Microsoft Teams with live audio transcriptions. Interviews were guided by a schedule (Appendix S2) consisting of open-ended questions, which were developed with the input of PG clinic dermatologists and nurses, and refined after a pilot interview with a PG patient and their partner. The interviewer positioned themselves as a non-judgemental interested "enquirer" and the participant as the "expert" (16). Field notes with additional contextual information were documented by the interviewer. Interviews lasted on average 34 min. Audio transcriptions were checked for accuracy and pseudonymised.

Data analysis

Reflexive thematic analysis was used due to its utility as a flexible tool to facilitate thematic development and provide a rich account of data (20, 21). As suggested by Braun and Clarke (20), transcripts were read multiple times to facilitate familiarisation and initial codes were allocated to interesting features in each transcript. Codes with similar content were combined into groups. Themes and subthemes were iteratively developed from these groups (JJ, GZ), then were refined through discussion with the interdisciplinary research team. Themes and subthemes were member-checked by a participant for accuracy and resonance with their experiences.

Table I. Overview of themes and subthemes

Theme	Subtheme
Pain	Pain extent and character Psychological impacts of pain Pain management
Physical challenges	Physical manifestations Physical activity limitations
Social functioning and relationships	Partner Family Work and retirement Social activities
Mental health	Depression, anxiety, and worry Body image Coping strategies
Treatment	Diagnosis, flaring, recurrence, and remission Managing dressings Financial impact Medication side effects Feedback for health professionals and health services

RESULTS

The analysis resulted in 5 themes and 17 subthemes (**Table I**). Direct quotations to support our interpretation are presented in **Tables II–VI**.

Pain

Pain extent and character. Many participants cited pain as their biggest disease-related challenge. Pain was severe when the ulcer was enlarging and improved with healing. In addition to ulcer pain, participants described debilitating pain from fractures related to steroid-induced osteoporosis. Pain was exacerbated by dressing changes and movements, limiting abilities to walk, drive, sit, shower, and exercise.

Psychological impacts of pain. Pain was a major contributor to decreased mental well-being due to its severity, plus physical and social limitations. Pain caused sleep disruptions, resulting in a pervasive negative impact on mood. One participant reflecting on the extreme pain during dressing changes remembered feeling helpless and having "lost control". Even though her pain had now improved, she felt depressed on days that dressing changes occurred and nauseated when certain advertisements played because they were the same advertisements that played when she had excruciating pain. Participants attributed improvements in well-being to decreasing pain levels as the ulcer healed.

Table II. Pain: interview excerpts

Subtheme	Quote
Pain extent and character	"I described it as walking around with a smashed wine glass in your underwear" (2) "I was screaming, crying like a little girl because the pain was just so intense" (12) "It's played havoc with me, seriously … I have (steroid-related) fractures in my bones – my back and also my heel, and that's extremely painful" (17) "My biggest challenge is pain. Terrible, terrible pain…I feel better when I scream. I can stand lots of pain, but this is another level of pain" (23)
Psychological impacts of pain	"The pain is very hard to live with … if you think about, you have to kill yourself. You will kill yourself. But you don't think about this" (3) "Chronic pain is debilitating. It makes you grumpy on a good day. It can turn you into a right bitch on a bad day" (4) "Someone will make a comment 'I don't like green shoes' and you'll get into this childish like 'oh she doesn't like me' and it's the most irrational and it's hard to pull yourself out of that when there's a stinging and sharp pain that's disrupting your sleep" (16)
Pain management	"When you're in a lot of pain, it's much easier to keep yourself distracted" (4) "I was up [at night] every 4 hours taking painkillers … waiting another 4 hours so I could take the next batch" (16) "I like to play a lot of Christian music to keep me mind away from it. I usually pray each day about it … because I just have a strong faith in God, even though I feel as though he's left me, forgotten me" (22)

Table III. Physical challenges: interview excerpts

Subtheme	Quote
Physical manifestations	"It's very disconcerting when you look down the first time you see tendon in your own leg moving…. It's unsightly, it's uncomfortable" (4) "While it was weeping, it was consuming 3 or 4 changes of dressings every day … and it left a sticky yucky thing on your clothes…. When it was weeping it was horrible, really gross" (13) "The other day, [the district nurses] were changing the dressing and there was a maggot on [the] leg … the wound is sort of leaky and smelly, so the flies are attracted to it" (17)
Physical activity limitations	"I suppose indirectly [it impacts quality of life] because of the spinal and rib fractures … so you know I couldn't even carry a bag…. I have a one-year-old granddaughter. I couldn't pick her up" (7) "Not wearing things where you can see them … they're quite scarred…. I would prefer not to have [my legs] exposed … they just look horrible" (10) "I lost my driver's licence because of the pyoderma, because of the pain medication … I fought the whole year to get it back … we live in the country…. I'm struggling" (11) ""This is my driving leg. It's on the ankle so accelerating and braking is hard…. It's very close to my ankle so walking is very, very hard…. It restricts everything. It's just a small ulcer on your leg but it's pretty much controlling where I go, what I do" (12) "My house is mess. I can't do anything around the house" (19) "I'm becoming incredibly unfit. I used to walk 5 km every morning and do yoga, I can't do any of that now" (21)

Table IV. Social functioning and relationships: interview excerpts

Subtheme	Quote
Partner	"My wife looks after me, the house, the garden … she does a lot of work" (3) "Our relationship fell apart 9 years ago. We probably have a friendship … [my husband] never ever looks at my wound" (11) "You become so self-conscious that [sex] is something you want to avoid … you don't want to put it off for 8 weeks 'cause now it's messing with your head '*oh he's going to find someone else and he's going to end things*'…. Somebody's not going to leave you because you've got an ulcer on your leg … but there's a part of it that just messes with your head and now you're so isolated" (12)
Family	"It pains me that I can't play like I used to play with my granddaughters…. I want to help, but I cannot. I want to cook more for her. I want to spoil them like I used to, but I cannot" (19) "There's been times when I've taken it out on my family because I've been so frustrated and so angry and in so much pain…. It's little things, but I'd just be in a grumpy mood … probably because I hadn't slept probably, then I'd been to work and had pain all day" (20)
Work and retirement	"If there's a driving task in the course of my work, I can't do it with an active ulcer, because of the opioid medication" (1) "It doesn't have any impact at all…. My attitude is '*I've got it but I know it can be controlled*', and it's not stopping me from interacting with people which is what I like" (15) "I work at a computer, so I'm able to elevate my legs…. It doesn't so much affect my work unless I've had a massive flare up, in a lot of pain, but the pain level has been really good" (20)
Social activities	"I seem to cancel a lot of things … especially if it's a bad day" (1) "No impact at all. My husband's always there to help me. I've just worn long pants and I openly discuss it with anybody who would say something to me. I never really felt embarrassed" (13) "I was bed-bound for so long that going off to different functions…. I wouldn't go and that would affect my wife because she wants to stay with me…. We were very sociable people with our friends and that dropped right off" (14)

Table V. Mental health: interview excerpts

Subtheme	Quote
Depression, anxiety, and worry	"I had 6 admissions for sepsis … [a nurse] said she'd never known anybody who survived 6 times of sepsis … so that's why I feel scared … there's no hope of fixing it…. I think it will take my life" (11) "If you've been up all night [due to pain] and you see two of your team members (at work) cracking jokes … I'm like 'uhh they're good friends, no one's my friend…no one likes me'" (12) "I was bedridden…. I'd say to [wife] '*I've had enough of this, I can't cope anymore*'. Had there been an easier way, obviously we would have taken it at the time if they had availability [referring to ending his life] … it was the pain. I couldn't see any light at the end of the tunnel, and also the effect that it was having on my wife and family…. I just felt useless" (14) "I often get depressed about it and flat about it … wondering if it will ever clear up, if I'll ever be free. It's clearing well, but for how long?" (18) "There is no day that passes that I don't cry because of pain, because of itch, because of helplessness. I feel so helpless and hopeless as well. I don't know what to do anymore. Sometimes I feel like not living this life anymore" (19) "My biggest concern is that it'll never fully heal … I'm just always on high alert … anytime I knock myself or cut myself or whatever, it's just worrying that it's gonna start another ulcer" (20)
Body image	"[Prednisolone] gave me sort of fat deposits … you don't feel good and you don't feel that you look like yourself, and you can't control the puffiness you get around the face … [you're] left feeling a bit hopeless" (1) "There's no way I'll ever wear a dress again, for example, 'cause of the appearance of my legs" (15) "I don't want to look at myself in the mirror anymore" (19)
Coping strategies	"I'm looking at the bright side of the life … if you complain you get angry. No, this is not good" (6) "I'm a pretty positive person … my cousin's little boy's got leukaemia and I just think, you know what? Mine's treatable … we'll just treat this one and treat them as they come along" (7) "In the morning if I can say something nice about myself or about something that I've seen or a photo I've got … to snap me into a positive frame of mind" (9) "I don't think about it … it's always there, the deformity on my legs, but it's not something that I dwell on. So my strategy is 'that's the way it is'…. I've basically accepted that I have it" (15) "I started eating stuff that I would never have a look at…. I can't control myself … now I have two blocks of chocolate at once … two boxes of cookies, or butter, half [gesturing to half a block of butter] butter with lots of bread…. I use food to cope when I'm feeling depressed." (19)

Table VI. Treatment: interview excerpts

Subtheme	Quote
Diagnosis, flaring, recurrence, and remission	"In my journey I had a lot of misdiagnoses…. When people actually ask like, 'what have you got?', it was the one of the best things was to be able to confidently tell them I had PG" (8) "One minute I'm flying high, thinking this is it – all good. Then another bloody outbreak" (14) "The fear and the uncertainty was nowhere near what it was initially. Each time it came back, I knew what to do and I knew where to go to get it fixed" (15)
Managing dressings	"We've been putting like the heaviest absorbency dressings and then continence pads around the outside. It holds 3 litres of fluid and [the PG has] been leaking through" (4) "They were having nurses that didn't know how to do it, so I was telling them how to do it" (21)
Financial impact	"Sometimes I go to the dermatologist, and they want me to have this dressing that costs [AUD] $10 each and I'm like, I can't do that. I can't put on a $10 dressing for a day or two" (20)
Medication side effects	"The level of immunosuppression, especially during [the COVID-19 pandemic] lockdown, I had to be very careful…. I didn't leave the house hardly for like 18 months" (4) "My skin is extremely thin…. I've got the fractures in the bottom part of my back and the heel, I'd love to be able to do swimming to strengthen it, but I haven't been able to go because I've got bloody bandages on me all the time…. I've lost 40 millimetres in height because of the bones" (22)
Feedback for health professionals and health services	"There's very few doctors I've met who have been willing to just say 'I don't know'" (1) "More practical stuff would be helpful … a fact sheet of how to use dressings, ointments" (2) "I started bawling … and [the doctor] was so empathetic. He said, 'look, like, I can't exactly imagine, know what you've been through, but I know it must be really hard for you'" (4) "Once I got talking with [the dermatologist] I didn't feel alone anymore. I was dealing with someone that understood" (13) "It would be lovely to know somebody else, how they're coping and things like that" (16) "Tell them about the pain that they'll have. Don't cover up anything" (18)

Pain management. Pain management medications included paracetamol, non-steroidal anti-inflammatory drugs (NSAIDs), opioids, neuropathic pain medications, and transdermal patches. Many participants required high doses of opioid analgesics and ketamine for dressing changes, showering, and sleep. Participants utilized non-pharmacological pain management strategies such as cognitive refocusing with guided breathing exercises, stretching, listening to music, and watching television. They found it helpful to consciously focus on positively reframing their internal dialogue. Some participants had difficulty finding any strategies to deal with their pain.

Physical challenges

Physical manifestations. Some ulcers wept constantly, leaving an unpleasant sticky, smelly residue on clothing that necessitated frequent dressing changes. Other ulcers were deep enough for tendon to be visible. One participant recounted a disturbing incident involving maggots infesting a leaky, malodourous ulcer.

Physical activity limitations. Feelings of frustration were common due to the physical restrictions imposed by active and painful ulcers. Pain limited exercise such as walking, yoga, hockey, and cycling, whereas water activities were restricted even if there was no pain, due to wound contamination. One participant was disappointed that ulcers on the groin prevented him from cycling, a previous hobby that provided a source of enjoyment, stress relief, and an opportunity to be social. Deteriorating physical fitness was compounded by steroid-related fractures and myopathy. Clothing choice was limited to softer, looser items to hide the ulcers or bandages. Participants experienced difficulties driving and contributing to household tasks such as cooking, cleaning, gardening, and shopping, due to pain and chronic tiredness from disrupted sleep. They felt it dictated where they could go and what they could do, emphasizing the condition's control over day-to-day life and difficulties coping with losing independence.

Social functioning and relationships

Partner. Some participants felt supported by their partners, who took on additional household responsibilities and attended to medical needs such as managing appointments, medications, and dressings. Others felt the physical, psychological, and social burden of PG had taken a toll on their relationship. Sexual intimacy was limited by pain and feelings of self-consciousness associated with ulcer appearance, ooze, and steroid-associated weight gain. One participant felt that the impact PG had on the relationship with her husband was minimal, other than affecting their sexual intimacy due to PG having negative impacts on her body image. Another participant described a situation in which a partner was repulsed by the ulcer. This resulted in her avoiding intimacy and consequently feelings of insecurity concerning the relationship.

Family. The limitations imposed by PG extended to family outings, household responsibilities, and looking after children. Chronic pain and sleep deprivation led to increased moodiness and emotional outbursts directed at family members. Families were also an important source of emotional support. One participant made the difficult decision to delay trying for a pregnancy to continue PG treatment, due to potential teratogenic effects of immunosuppressive medications.

Work and retirement. The extent to which PG impacted work varied according to the physical demands of the role. Day-to-day issues included pain and physical limitations, while hospitalizations caused extended periods of work absence. During ulcer flares, one participant was unable to operate machinery because they required high doses of opioid analgesics for pain. Another participant lost her job at a veterinary practice when the ulcer became infected with resistant Pseudomonas. Participants in sedentary roles and work-from-home arrangements attributed little to no impact on work.

Retirement hobbies such as cooking, painting, and gardening were limited by pain and medication side effects. One participant was deeply saddened by the fact she would not be able to hold her newborn grandchild due to steroid-related myopathy. PG had greatly impacted on her ability to function as a grandparent. When the ulcer oozed significantly, travel was limited by wound-care requirements. In contrast, a participant with healed PG felt that it did not have any impact on her retirement, as her travelling plans were no longer restricted by dressing regimes, and she experienced no pain or physical limitations other than not being able to swim.

Social activities. The impact of PG on social activities varied. Some participants were limited by pain and fatigue, whilst others expressed a tendency to cancel plans, or physical and logistical difficulties. Many participants reported no impact of PG on their social activities because their pain was well controlled, and they did not feel embarrassed about the appearance of the ulcer.

Mental health

Depression, anxiety and worry. Low mood, helplessness, and hopelessness were associated with severe pain, physical and social limitations, and uncertainty regarding recovery. Participants significantly impacted in these domains admitted to thoughts of suicide, despite reporting no mental health comorbidities prior to the PG diagnosis. Participants lamented the profound impact the condition had on their lives, rendering them "useless", having previously been physically active, and identifying as "contributing" people.

Anxiety and worry were linked to diagnostic delays, ulcer progression, and hospital admissions. Pain and sleep deprivation exacerbated experiences of social anxiety. When the ulcer was not active, participants worried about recurrence. Traumatic experiences such as large-volume bleeding and secondary sepsis caused significant distress concerning mortality. Participants highlighted feelings of loss of control and fears that such events could recur, or that the ulcer would never heal.

Body image. Negative perceptions of body image were attributed to the ulcer appearance and scarring, as well as steroid-related weight gain, facial swelling, and hair loss. Participants felt embarrassed, self-conscious, and lost self-confidence, choosing clothing to hide the ulcers, scars, and dressings.

Coping strategies. Participants used positive mind-framing, distraction techniques and engaged with their support networks to cope with the PG. One participant's strategy was "accepting" the physical impacts of PG and the potential for recurrence. Additional caution was exercised day-to-day to avoid worsening the ulcer or to reduce risk of recurrence. One participant described episodes of binge eating that started after the PG diagnosis, which would often occur at night when she had difficulty sleeping due to the pain, causing exacerbated body image concerns. Twenty of the twenty-one participants interviewed denied using alcohol, smoking, or using illicit substances to cope with the PG.

Treatment

Diagnosis, flaring, recurrence, and remission. Delays in diagnosis, misdiagnosis, and feelings of uncertainty were common and often one of the biggest challenges for participants. Several participants had unnecessary surgeries and others recalled distressing thoughts about the possibility it could be cancer, or result in amputation or death. Many felt relieved, understood, and less isolated when they finally received the diagnosis and were provided with education and treatment at a specialist PG clinic.

Ulcer flares and recurrence brought about feelings of frustration and disheartenment, highlighting the emotional burden of the chronic disease course. One participant reflected that recurrences were emotionally and practically easier to deal with than the initial ulceration due to less diagnostic uncertainty and knowledge regarding treatment. During remission, participants remained vigilant concerning potential recurrence and exercised caution day-to-day. They experienced improvements in physical symptoms and resumed daily activities. The journey towards recovery involved regaining confidence in their bodies.

Managing dressings. Dressing materials and private wound care were grossly expensive. Nursing visits to change dressings were time-consuming and constrained ability to plan other activities, but for some participants this offered an opportunity for emotional support. Lack of knowledge among health professionals concerning PG-specific dressings was a common issue. Experienced patients educated healthcare providers regarding their dressing requirements; however, this was another source of stress, particularly when patients did not feel listened to.

Financial impact. Significant financial stress was associated with dressings, ointments, medications, specialized wound care, and appointments. Some participants recounted spending thousands of dollars (AUD) on dressings alone and resorted to reusing bandages to mitigate costs. One patient reported nursing in the home services for dressing changes cost AU$30,000 in a year – learning to do the dressings themselves alleviated this significant financial burden.

Medication side effects. Prednisolone was a "necessary evil" (participant 7), causing facial swelling, hair thinning, facial hair growth, and weight gain that negatively impacted self-esteem and body image. Steroid-related skin thinning made participants feel fragile and increased susceptibility to bleeding from everyday knocks. Steroid-induced fractures caused pain and physical limitations, and insomnia significantly impacted QoL. During the COVID-19 pandemic, participants felt isolated and restricted to staying at home due to being on high doses of immunosuppressive medications. Significant time was spent travelling long distances to receive infusion treatments.

Feedback for health professionals and health services. Many participants who experienced diagnostic delays or misdiagnosis felt there was a need for increased awareness concerning PG. Referral to the PG outpatient clinic gave participants increased confidence and emotional support. Participants felt it would be useful to receive fact sheets on wound care and managing pain, and to establish groups connecting with other patients for emotional and practical support. They suggested transparent communication regarding the levels of pain they could expect from the condition. Training to manage their own dressings, if they were physically able, could contribute significantly to improved QoL by giving back to participants a sense of control.

Participants shared stressful accounts of having to educate healthcare providers who had never heard of PG, which made them feel anxious as to whether they received appropriate care. Some participants felt healthcare providers were unwilling to acknowledge their own knowledge limitations regarding the condition. Participants highlighted the power of empathy and listening, the importance of consistency in messaging between different health professionals involved in their care, and feeling that a healthcare provider cared.

DISCUSSION

This was the first Australian study to explore the experiences of PG patients from their own perspectives, highlighting the multifaceted impact of PG on QoL. Our findings add rich contextual data to patient experiences, which we divided into 5 themes: pain, physical challenges, social functioning and relationships, mental health, and treatment. These themes provide a framework for the selection and implementation of PG-specific PROMs (12, 13, 22).

Delayed diagnosis was the first major challenge encountered by many participants in their PG journey. Failure to make an early diagnosis in PG is common (1, 2), but this experience has not been well explored from the perspective of PG patients. Delayed and misdiagnoses caused significant distress and uncertainty, resulting in unnecessary treatments and even surgeries. Their experiences highlight the importance of increased awareness of PG, its diagnostic criteria (23), and early specialist referral. DLQI and patient satisfaction scores improve with appropriate treatment (8, 12, 24).

Pain is a central symptom in PG that has been identified as a major determinant of QoL and psychosocial well-being (6, 8, 12, 25, 26). Participants who experienced severe pain arising from the ulcers or steroid-related fractures induced by PG treatment often emphasized pain as their biggest challenge from the condition. The impact of pain on QoL was pervasive and multifaceted, leading to disrupted sleep, immobility, and limiting of daily activities; eroding patients' sense of self-control; and perpetuating depressed mood, anxiety, and reduced social functioning. High doses of opioid medications used for pain control often resulted in further losses in independence (e.g., not being able to drive), impacting work and retirement. Our findings highlight the clinical importance of a holistic, patient-centred approach to PG pain management. Positive affect has been associated with decreased pain and physical impairment and is highly trainable (27, 28). In light of this and from the experiences of our patients, we believe future studies could explore the efficacy of psychological therapies as an adjunct for managing PG-related pain.

Depressed mood was linked to severe pain, physical and social limitations, and uncertainty regarding recovery. Wound appearance and steroid-related side effects negatively impacted body image for some participants, whereas for others there was no impact. Useful coping strategies for dealing with the PG day-to-day included positive mind-framing, distraction, and engaging with social supports. The findings from our study and others call for an interdisciplinary approach to address psychosocial consequences of PG (8, 10).

PG management should include providing information sheets for managing pain and wound care, communicating disease expectations, and linkage to patient-to-patient support groups. Increased knowledge concerning PG is urgently needed. Similar to patients with vulval lichen sclerosis (29), another rare dermatological condition, many PG patients experienced stress from having to educate multiple healthcare providers about the diagnosis. Our findings highlight the importance of empathy and good communication. Factors associated with patient satisfaction in dermatology outpatient clinics have been quantified previously but this study adds the first qualitative PG-specific patient feedback (30).

Limitations

Limitations of the study included single-centre recruitment from a public tertiary hospital, which likely biased the sample to more complex and difficult PG cases, and participants with greater socioeconomic disadvantage, limiting generalizability. There were no objective disease severity measures. Impact on finances was influenced by local government health funding policies.

Conclusion

Our study has deepened understanding of patient experiences with PG and given personal perspectives on what it is like to live with a condition poorly understood by many health professionals. Increased efforts need to be made to spread awareness concerning the needs of PG patients and provide resources to allow for a holistic, interdisciplinary approach to PG care.

ACKNOWLEDGEMENTS

The authors thank the patients living with pyoderma gangrenosum who have generously shared their experiences and perspectives for this study.

IRB approval status: This study was approved by the St Vincent's Hospital Human Research Ethics Committee (HREC-086/23). The patients in this study have given written informed consent to participation and publication of this study.

The authors have no conflicts of interest to declare.

REFERENCES

1. Alavi A, French LE, Davis MD, Brassard A, Kirsner RS. Pyoderma gangrenosum: an update on pathophysiology, diagnosis and treatment. Am J Clin Dermatol 2017; 18: 355–372. https://doi.org/10.1007/s40257-017-0251-7
2. George C, Deroide F, Rustin M. Pyoderma gangrenosum: a guide to diagnosis and management. Clin Med (Lond) 2019; 19: 224–228. https://doi.org/10.7861/clinmedicine.19-3-224
3. Alavi A, Sajic D, Cerci FB, Ghazarian D, Rosenbach M, Jorizzo J. Neutrophilic dermatoses: an update. Am J Clin Dermatol 2014; 15: 413–423. https://doi.org/10.1007/s40257-014-0092-6
4. Cozzani E, Gasparini G, Parodi A. Pyoderma gangrenosum: a systematic review. G Ital Dermatol Venereol 2014; 149: 587–600.
5. Maronese CA, Pimentel MA, Li MM, Genovese G, Ortega-Loayza AG, Marzano AV. Pyoderma gangrenosum: an updated literature review on established and emerging pharmacological treatments. Am J Clin Dermatol 2022; 23: 615–634. https://doi.org/10.1007/s40257-022-00699-8
6. Ighani A, Al-Mutairi D, Rahmani A, Weizman AV, Piguet V, Alavi A. Pyoderma gangrenosum and its impact on quality of life: a multicentre, prospective study. Br J Dermatol 2019; 180: 672–673. https://doi.org/10.1111/bjd.17347
7. McPhie ML, Fletcher J, Machado MO, Carvalho AF, Piguet V, Alavi A. A systematic review of depression and anxiety in adults with pyoderma gangrenosum. Adv Skin Wound Care 2021; 34: 432–436. https://doi.org/10.1097/01.ASW.0000755920.76330.21
8. Sanchez-Melendez SN, Malik R, Patel PM, Milosavljevic S, Patel S, Nambudiri VE. Pyoderma gangrenosum and impact on quality of life: a narrative review. Exp Dermatol 2024; 33: e14876. https://doi.org/10.1111/exd.14876
9. Ighani A, Al-Mutairi D, Rahmani A, Weizman AV, Piguet V, Alavi A. Pyoderma gangrenosum and its impact on quality of life: a multicentre, prospective study. Br J Dermatol 2019; 180: 672–673. https://doi.org/10.1111/bjd.17347
10. Herbert S, Haughton R, Liakos W, Wang J, Ji-Xu A, Le ST, et al. A qualitative exploration of patient experiences in pyoderma gangrenosum. Br J Dermatol 2023; 189: 496–498. https://doi.org/10.1093/bjd/ljad235
11. Nusbaum KB, Ortega-Loayza AG, Kaffenberger BH. Health-related domains of quality of life in pyoderma gangrenosum: a qualitative analysis. J Am Acad Dermatol 2022; 86: 1382–1385. https://doi.org/10.1016/j.jaad.2021.05.040
12. Hobbs MM, Byler R, Latour E, Bonomo L, Hennessy K, Cruz-Diaz CN, et al. Treatment of pyoderma gangrenosum: a multicenter survey-based study assessing satisfaction and quality of life. Dermatol Ther 2021; 34: e14736. https://doi.org/10.1111/dth.14736
13. van der Wees PJ, Verkerk EW, Verbiest MEA, Zuidgeest M, Bakker C, Braspenning J, et al. Development of a framework with tools to support the selection and implementation of patient-reported outcome measures. J Patient Rep Outcomes 2019; 3: 75. https://doi.org/10.1186/s41687-019-0171-9
14. Black N. Patient reported outcome measures could help transform healthcare. BMJ 2013; 346: f167. https://doi.org/10.1136/bmj.f167
15. Pope C, Mays N. Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. BMJ 1995; 311: 42–45. https://doi.org/10.1136/bmj.311.6996.42
16. Smith JA, Osborn M. Interpretative phenomenological analysis. Qualitative psychology: a practical guide to research methods. Thousand Oaks, CA: Sage Publications, 2003: p. 51–80.
17. Palinkas LA, Horwitz SM, Green CA, Wisdom JP, Duan N, Hoagwood K. Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. Adm Policy Ment Health 2015; 42: 533–544. https://doi.org/10.1007/s10488-013-0528-y
18. Malterud K, Siersma VD, Guassora AD. Sample size in qualitative interview studies: guided by information power. Qual Health Res 2016; 26: 1753–1760. https://doi.org/10.1177/1049732315617444
19. Braun V, Clarke V. To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. Qual Res Sport Exerc Health 2021; 13: 201–216. https://doi.org/10.1080/2159676X.2019.1704846
20. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006; 3: 77–101. https://doi.org/10.1191/1478088706qp063oa
21. Braun V, Clarke V. Conceptual and design thinking for thematic analysis. Qual Psychol 2021; 9. https://doi.org/10.1037/qup0000196
22. Maverakis E, Marzano AV, Le ST, Callen JP, Brüggen MC, Guenova E, et al. Pyoderma gangrenosum. Nat Rev Dis Primers 2020; 6: 81. https://doi.org/10.1038/s41572-020-0213-x
23. Maverakis E, Ma C, Shinkai K, Fiorentino D, Callen JP, Wollina U, et al. Diagnostic criteria of ulcerative pyoderma gangrenosum: a Delphi consensus of international experts. JAMA Dermatol 2018; 154: 461–466. https://doi.org/10.1001/jamadermatol.2017.5980
24. Yamasaki K, Yamanaka K, Zhao Y, Iwano S, Takei K, Suzuki K, et al. Adalimumab in Japanese patients with active ulcers of pyoderma gangrenosum: final analysis of a 52-week phase III open-label study. J Dermatol 2022; 49: 479–487. https://doi.org/10.1111/1346-8138.16337
25. Hobbs MM, Byler R, Latour E, Bonomo L, Hennessy K, Cruz-Diaz CN, et al. Treatment of pyoderma gangrenosum: a multicenter survey-based study assessing satisfaction and quality of life. Dermatol Ther 2021; 34: e14736. https://doi.org/10.1111/dth.14736
26. Erickson KM, Kody S, Ortega-Loayza AG. Pain as a patient-reported outcome measure in pyoderma gangrenosum. JAMA Dermatol 2023; 159: 1274–1275. https://doi.org/10.1001/jamadermatol.2023.3115
27. Meints SM, Edwards RR. Evaluating psychosocial contributions to chronic pain outcomes. Prog Neuropsychopharmacol Biol Psychiatry 2018; 87: 168–182. https://doi.org/10.1016/j.pnpbp.2018.01.017
28. Edwards RR, Cahalan C, Mensing G, Smith M, Haythornthwaite JA. Pain, catastrophizing, and depression in the rheumatic diseases. Nat Rev Rheumatol 2011; 7: 216–224. https://doi.org/10.1038/nrrheum.2011.2
29. Arnold S, Fernando S, Rees S. Living with vulval lichen sclerosus: a qualitative interview study. Br J Dermatol 2022; 187: 909–918. https://doi.org/10.1111/bjd.21777
30. Søndergaard MB, Ghazanfar MN, Thomsen SF. Patient expectations and determinants of patient satisfaction in a dermatology outpatient clinic. J Eur Acad Dermatol Venereol 2019; 33: e32–e33. https://doi.org/10.1111/jdv.15144