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Patients', family members' and healthcare practitioners' experiences of Stevens–Johnson syndrome and toxic epidermal necrolysis: a qualitative descriptive study using emotional touchpoints.

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LETTER TO THE EDITOR

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Editor

Stevens–Johnson syndrome (SJS) and toxic epidermal necrolysis (TEN) are devastating conditions resulting from a severe immune-mediated mucocutaneous reaction which normally occurs as a result of medication.¹ In the acute phase, the patient presents with a febrile illness, followed by skin and mucous membrane necrosis and detachment.² The patient can quickly become critically ill and is treated as a medical emergency. There may be long-lasting psychological effects on patients and their significant others.³ However, there is a dearth of research on the experiences of patients with SJS/TEN, those close to them and healthcare practitioners (HCPs) providing care.

This study explored key stakeholder experiences of living with, or caring for, patients with SJS/TEN via a qualitative descriptive design,⁴ using emotional touchpoint interviews. A touchpoint is a moment when an individual interacts in some way with the health service and an experience is created.⁵ A purposive sample of patients ($n = 2$) who had been diagnosed with SJS/TEN, family members of two other patients ($n = 2$) and HCPs ($n = 8$) who reflected on their experiences of caring for a number of patients with SJS/TEN, were included in the study. Participants were presented with a range of emotion words and were asked how they felt and their perception of how the patient felt (in the case of family members and HCPs) at different stages of the illness journey, for example 'at the beginning', 'in hospital' and 'going home'. Additional questions were asked to expand on their responses. Interview transcripts were analysed using thematic analysis.⁶

Three themes with two sub-themes were constructed (Table 1). The initial presentation of SJS/TEN symptoms was a frightening and traumatic experience for patients and their close family members. Patients feared for their lives. For HCPs, preservation of life was a priority and concerns were expressed about the importance of ensuring that the patient

received optimum care in the best clinical environment, with input from the multi-disciplinary team. Meaningful communication within a caring environment provided patients and their families with hope and reassurance. Caring behaviours, such as compassion, dignity, respect, and HCPs 'just being there' for the patient were important for patient recovery. Patients who survived SJS/TEN, experienced mixed emotions when going home from hospital. While they were relieved, as they were alive and well enough to leave hospital, they feared what may lie ahead. After discharge, their mental health and quality of life were affected, and they feared taking any medication.

Healthcare practitioners in our study spoke about the importance of advocating on behalf of patients to ensure that they were admitted to the ICU. Valeyrie-Allanore *et al.*⁷ highlighted that an ICU referral of patients with severe cutaneous adverse reactions, including SJS/TEN, contributes to improved patient survival and reduces potential sequelae. Referring to the need for the long-term follow-up of survivors, Lee and Creamer⁸ encourage the inclusion of psychological assessment in the outpatient follow-up care pathway. They pose the question on whether psychological interventions during the acute phase can preclude the occurrence of psychological problems following discharge.⁸

Adding to the current body of knowledge, these findings provide an understanding of how SJS/TEN affects key stakeholders and informs recommendations to improve patient outcomes (Table 2). Limitations to the study included the use of one clinical site and a small number of patient participants. There are difficulties in researching rare conditions, but Walsh *et al.*⁹ advise that this should not deter researchers and HCPs to engage in follow-up discussions with patients to find out more about the psychological consequences of SJS/TEN. Given the psychological impact on patients' lives, there is a need to prioritize research in this area.¹⁰

Conflicts of interest

None declared.

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Ethical approval

Ethical approval was obtained from University Hospital Limerick Ethics Committee and University of Limerick.

Table 1 Themes, sub-themes, description and illustrative quotes

Themes	Sub-themes	Description	Illustrative quotes
The profound impact of SJS/TEN	Confused, worried powerless – the mixed emotions of patients and families	Strong words were used by all participants to outline the emotional and physical impact on patients' lives. One doctor acknowledged that it is difficult to understand the extent of the trauma that these patients have experienced.	<i>'Physically in pain and traumatized. He was disoriented and overwhelmed, he didn't know what was happening and he was very frightened'</i> (Family Member 1)
	The challenges experienced by HCPs	In dermatology, SJS/TEN is one of the most serious conditions that the team will deal with. Many HCPs may have never seen or cared for a patient with SJS/TEN. Some participants spoke about feeling vulnerable. Even with experience, it is a condition that gives rise to feelings of anxiousness in HCPs.	<i>'It can be overwhelming because, while I'm quite comfortable in dealing with skin loss, the patient can also be systemically very unwell. . . It can be stressful because you have to instigate care quite quickly. . . and you've to get a team involved like ophthalmology, ICU. . .'</i> (Nurse 1)
The care that matters	Immediacy of recognition – a pathway of care	Patients with SJS/TEN deteriorate quickly; they can go from sitting up and talking to becoming critically ill. The priority of care, at the beginning, is to keep the patient alive. HCPs expressed concern that they would make the best case in convincing others that the patient required admission to the ICU – not all HCPs appreciated the rapid deterioration of patients with SJS/TEN. An MDT approach to care was crucial as the skin is not the only organ that is affected.	<i>'They're used to admitting someone into the ICU from a ward but we were saying that he [patient] was still able to sit and talk but we knew in a matter of hours he was going to get further involvement and needed that critical care setting'</i> (Doctor 3)
	Important caring behaviours	It was important to have a 'liaison' person to communicate with from both an informational and emotional perspective. It was essential that staff were confident, calm and well prepared in delivering information and letting the patient know that they had dealt with similar situations before – to give patients hope. It was important to recognize that losing the body's protective layer of skin increased the patient's vulnerability, both physically and psychologically.	<i>'The dermatology staff said it so that you could understand, it wasn't technical. They knew what they were on about, this is their forte'</i> (Patient 1)
Surviving and living with the aftermath	Going home	Going home was <i>'overwhelming'</i> for some patients as they were leaving a secure environment and they were frightened of getting SJS/TEN again. One patient referred to going home as <i>'daunting' and scary'</i> . Patients might not always be prepared for what lay ahead, in that they could experience profound exhaustion and it could take time to get back to normal.	<i>'I think just the vulnerability, the going home and wondering if this happens again, will I go back to where I was and nobody can tell you that it's not going to happen again'</i> (Nurse 4)
	Reality hits	After some time at home, reality hit. A family member spoke about their relative's anxiety regarding the fear of getting SJS/TEN again. Patients may have been on a lifesaving medication and they were often anxious going on a different medication regime. One patient spoke emphatically about the great sense of loss that he experienced after getting SJS/TEN, missing out on education and always playing catch up with study. He described effects on his relationships and experiencing social anxiety.	<i>'I didn't realise the effect it would have on every aspect, not just my appearance, or my skin, I think the mental health side of things is important, it has such a big impact on your life, it's hard to cope, for years. . .'</i> (Patient 2)

HCP, healthcare practitioner; ICU, intensive care unit; MDT, multi-disciplinary team; SJS, Stevens–Johnson syndrome; TEN, toxic epidermal necrolysis.

Table 2 Research summary and recommendations

What is already known about this topic?


- For survivors of SJS/TEN, there may be long-lasting psychological effects on patients and their significant others
- There is a dearth of research on patients' and other key stakeholders' experiences of SJS/TEN

What does this study add?

- Preservation of life is the priority for HCPs, and time is of the essence in diagnosing and referring the patient to an intensive care unit.
- Meaningful communication within a caring environment provides patients and their families with hope and reassurance.
- Patients' mental health and quality of life may be affected in the long term, and they can fear taking medication.

Recommendations to improve patient outcomes

- Caring behaviours such as compassion, dignity, respect and HCPs 'just being there' for the patient are important for patient recovery.
- Keeping patients informed at a level that they understand helps to allay fears and distress.
- It is important that all doctors and nurses be made aware of the signs, symptoms and the care needs of patients with SJS/TEN, through continuing education and training programmes.
- More research is required to address the psychological impact and care needs of the patient in the acute and follow-up phases of the illness

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