

APPENDIX 1 Patient Perspective

The challenges include:

1. Poor recognition of the patient perspective.

My Acanthamoeba Keratitis (AK) diagnosis at age 15 meant my whole world was disrupted - no swimming, no reading, no traveling. After 17 surgeries, things didn't get much better; I repeated years of high school and learnt to be my own advocate. And now, 6 years later, the effects of AK are even more profound. It is my independence I miss the most. (M. Leitner)

There is a lack of awareness and understanding of AK from the patient perspective making it challenging for those affected to find the correct support and information they need.¹ There is also a lack of appreciation of the impact of AK on all elements of a patient's life.

Recommendations: Signpost all patients to relevant AK support groups.

1. Support groups for orphan/rare diseases like AK play an essential role in sharing personal experiences, compassion, and supporting individuals and families affected.
2. AK support groups offer practical advice on managing the unique challenges of living with AK, including guidance on navigating the complex healthcare system based on non-standardized protocol for treatment, finding what type of treatments are being applied in the different countries, and accessing available resources.
3. These groups also provide opportunities for patients and their families to participate in raising awareness, campaigning and improving outcomes for other patients with AK.
4. Support groups recognize the importance of sharing up-to-date and correct facts through targeted social media groups such as [Acanthamoeba Keratitis Eye Foundation Facebook](#), [Instagram](#), [TikTok](#) and [LinkedIn](#).

2. Lack of understanding of AK pain and pain management

Every tiny light, sound and touch of my face is like a stabbing knife into my exploding eye and head. I feel desperate in a dark universe of endless, excruciating pain. (S. Widmer)

Patients with AK undergo excruciating and debilitating pain. There are many different types of ocular pain however two are most common:

1. **nociceptive pain** (i.e. active pain which is acute or reversible) during active infection characterized by throbbing, burning, sharp/shooting, and sensitivity to light.
2. **persistent neuropathic or neuroplastic pain** (i.e. pain associated with nerve damage which is often persistent and non-reversible) is described as shooting or aching pain associated with the trigeminal nerve region.²

Patients may also experience symptoms like sweating, nausea, tiredness, and rapid heartbeat. Some patients may be prescribed opioids for pain management and can become addicted to them during and after treatment. Some patients opt not to take pain medications due to the fear of addiction, even if their pain is excruciating.

Recommendations: Proper pain management to make the journey less painful and emotionally less traumatic for patients

1. It is crucial to acknowledge that the level of pain is excruciating and debilitating.
2. Patients often feel that their pain is not being taken seriously due to the lack of correlation between their clinical picture and the severity of their pain.

3. Medical experts should listen attentively to patients, refer them to pain management, and consider nerve modulators as a pain relief option. Nerve modulators can help to block both persistent and acute pain.

2. Profound psychological challenges

AK took my vision, my profession, my hobbies, my familiar appearance, my energy and gave me a daily routine with medication, side effects, eye appointments full of anxiety and lost hopes. (S. Widmer)

AK is not only a physically painful disease, but it can cause great mental distress. In addition to the primary symptoms of eye pain, light sensitivity, and blurred vision, patients may experience a range of psychological symptoms that can further impact their mental health and quality of life.³

Depression: The constant pain, sleep disturbances, and isolation can leave patients feeling helpless and hopeless, leading to depression, side effects of drugs and potential addictions.

Anxiety: *Dealing with a disease like AK made me insecure, not only about my eye, but also about myself. With that, I developed social anxiety as well. (M. Leitner)*

Patients may worry about losing their vision or their eye, not being able to work and provide for their family or missing out on day-to-day activities. In some countries, AK is not a recognized disease by many insurance companies leaving patients to cover the costs of management.

Social Isolation: *Felt disconnected from the outside world. Felt none of my friends would understand my condition, so I basically hibernated or for a better word, vegetated. (M. Castle-Genn)*

Due to pain and light sensitivity, patients isolate themselves in a dark room in their homes, leading to social isolation.

Post-traumatic stress disorder (PTSD): *Through all the traumatic surgeries at a relatively young age, PTSD came fairly soon. It grew from fears of never leaving the cycle of surgery and doctor appointments and manifested in nightmares. (M. Leitner)*

As a result of the traumatic experience of dealing with the infection, patients with AK may develop PTSD. The way they were treated, misdiagnosed, type of treatments and the procedures used to treat them can result in flashbacks, nightmares and avoidance behaviours related to the experience. Many patients are scared to shower/swim even without wearing contact lenses.

Recommendations: *The management of psychological symptoms will improve patients' overall well-being and journey.*

1. Patients with AK require proper care and support for both their physical and mental health and may may require assistance from a mental health professional.
2. Compiling data from patients' lived experience can help create a critical care roadmap which can be followed by caregivers. This will assist with standardized diagnostics, treatments, and mental health care, ensuring equitable healthcare globally.