

Understanding the Journey of Patients with Vernal Keratoconjunctivitis: A Qualitative Study of the Impact on Children and Families¹

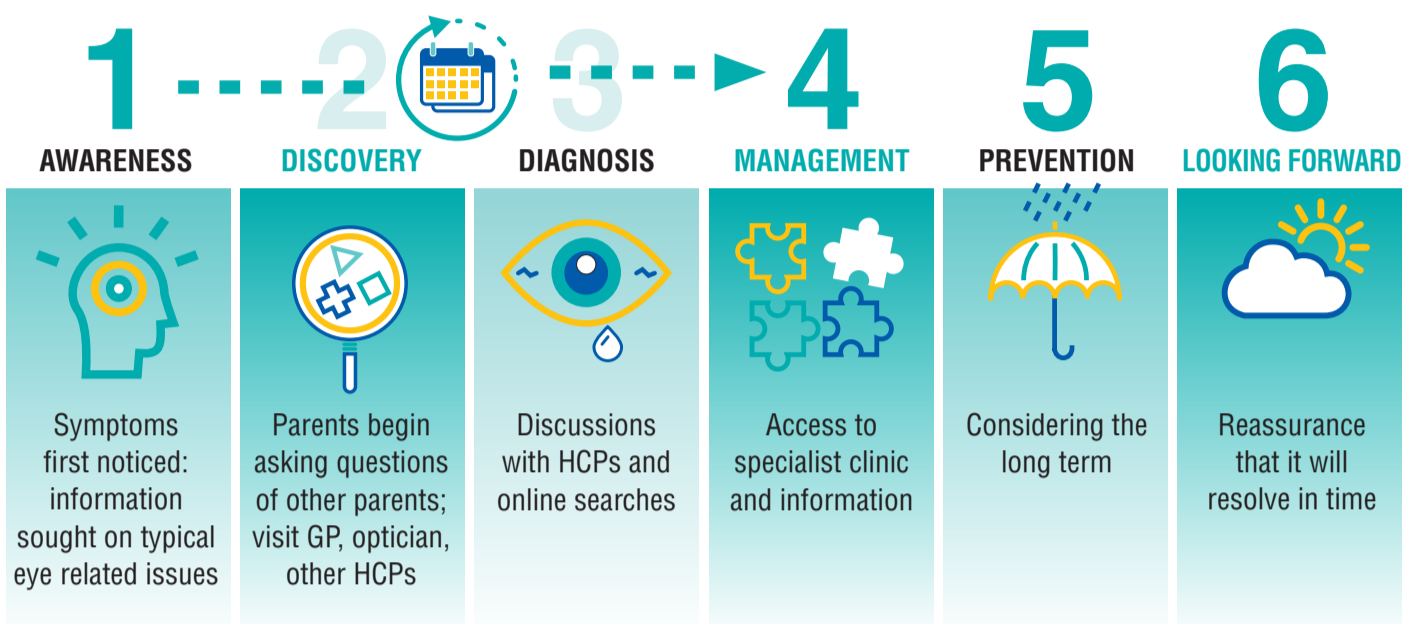
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Vernal keratoconjunctivitis (VKC) is a chronic, allergic inflammation of the ocular surface, which mainly affects children and young adults. It is estimated to occur at a prevalence of 3.2/10,000 in Western Europe.^{2,3} VKC significantly impacts the lives of young people and families.



The VKC Patient/Parent Journey:

Patients and their families go on a complex journey which is filled with anxiety and frustration. The overwhelming desire to do the 'right thing' for their child drives parents throughout this journey. A lot of time is spent trying to find answers between phases 1 to 4. Some parents took matters into their own hands when they felt they weren't getting the help they need. Better clinician education is important in order to speed up diagnosis, commence appropriate treatment, and direct patients to specialist care when necessary.



As children with VKC get older and become more independent, the informational needs of both them and their parents varies.

Major Themes Emerging From The Study:

Impact of VKC on Daily Life:

- 1. Education** – Parents are concerned about the educational impact of missed school days and symptoms compromising learning. Young people may feel singled out because of their condition
- 2. Social and leisure time** – Joining in with everyday activities can be hard because of symptoms and interruptions from medication regimen
- 3. Family life** – It can be very difficult for working parents to manage the medication regimes and attending numerous appointments. Siblings may feel they receive less attention



This is the first study to explore the experience of families and young people living with VKC

The Young Person's/Parent Experience of VKC:

- 1. Need for control** – Concern over whether they are doing the 'right thing' for their child creates a constant state of tension for parents
- 2. Journey to diagnosis** – Parents feel guilty for not recognising earlier that their child's eye condition was more than just an 'irritation', followed by a struggle for it to be properly diagnosed by some healthcare professionals
- 3. Lack of cohesive approach to clinical care** – Parents feel that they are left to join the dots themselves with HCPs failing to recognise the association of eye symptoms with other atopic conditions
- 4. Information vacuum** – Families living with VKC feel that there is a lack of information and support for them. This belief was also borne out in our research which revealed minimal information and support aimed at patients and parents



In Conclusion:

- To improve the diagnostic journey for patients and their families, it is essential that HCPs have a greater awareness and recognition of the signs and symptoms of VKC
- There are clear unmet needs in terms of information and support for VKC patients and their carers
- Due to the chronic nature of this condition, a holistic approach to patient care is required in order to address the needs of children and their families
- There is an opportunity for healthcare professionals to play an important role in supporting families to manage VKC and to enable patients to experience as normal a childhood as possible



"I felt so bad. I knew he was rubbing his eyes a lot, then he began keeping his eyes closed at dinner and avoided opening his eyes at all. He must have been in so much pain. I just thought it was linked to his allergies."

"She put up with discomfort for more than 18 months – we just didn't know where to turn next."

"It's the not knowing that makes it hard – you just want to feel in control, and don't want to slip up due to the speed of escalation."

"There is absolutely nothing available which explains this condition or enables me to explain it to my daughter."



Read more about how VKC impacts the lives of patients and their families – scan the QR code opposite to download the full paper:



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References:

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