

Eczema mindlines

Amending patients' internalised guidelines can improve the experience of eczema management for patient and professional, writes **Professor Fiona Cowdell**



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Some 97% of cases of eczema are treated in primary care

Atopic eczema is among the fifty most burdensome diseases worldwide. Effective care requires diligent self-management. The cornerstone of treatment is regular and consistent use of topical emollients and use of topical corticosteroids (TCS) as required. Treatment failure is common and wastage of prescribed preparations is high. Primary care consultations can be unsatisfactory for patients and practitioners.

MINDLINES

Mindlines are 'collectively reinforced, internalised tacit guidelines' that underpin clinical decision-making.¹ They are built on a combination of knowledge sources, such as communication with colleagues and opinion leaders and from personal tacit knowledge. Eczema primary care mindlines are likely to be prominent for GPs, nurse practitioners, health visitors and pharmacists.

Patients also have their own mindlines, particularly those living with long-term conditions such as eczema. Inevitably, individual mindlines influence care outcomes.

What do eczema mindlines look like?

Patients' eczema mindlines are constructed from an amalgamation of knowledge gleaned, for example, from personal experience, internet searches, advice (often unbidden) from family and friends, information from practitioners, advertisements, trial and error, intuition and instinct.

Most people know someone with eczema and this seems to legitimate advice-giving where information shared is often contradictory and sometimes simply wrong. One example is fear of using TCS. Accepting the existence of patients' eczema mindlines and analysing how they interact with practitioner mindlines offers new opportunities to improve care.

SELF-MANAGEMENT AND CONSULTATIONS

People with eczema – or parents of children with the condition – describe four approaches to self-management:

- those who are content to self-manage
- those who accept practitioner management
- those self-managing by default, and
- those referred to secondary care.

For people content with self- or practitioner management, more eczema knowledge is a low priority because their

condition is not too troublesome and is usually effectively managed with emollients and occasional TCS.

Those self-managing by default are a large group who often report unsatisfactory consultations. They are frustrated by the difficulties of getting an appointment and of seeing a different person each time. They describe 'learning the hard way' through sometimes years of trial and error and they perceive practitioners as having poor knowledge of eczema, of underestimating its impact and simply offering standard treatment without taking into account the patient's expertise and experience. Sometimes these patients report receiving contradictory advice or feel that treatment is not explained and minimal advice is offered on long-term self-management.

People who self-manage by default are the most active seekers of new knowledge. Parents of children with eczema are more likely than adults with the condition to invest substantial time and effort in investigating potential treatments. This is influenced partly by the strain of watching their child suffer and the impact this has on the whole family.

People reach a point of desperation realising that they have to take an active role in self-management. In some, this triggers a more proactive approach to self-management and knowledge development. Gaining new knowledge can lead to greater confidence in consultations and positively influences their perception of interactions with practitioners and sense of shared decision-making. For others, increased confidence is expressed in an absolute, sometimes uncomfortable, determination to be listened to and given the treatment they need.

MINDLINE AMENDMENT

Given the prevalence of eczema, the high self-management demand and the challenges of primary care consultations, it is prudent to investigate ways in which mindlines can be amended. When devising strategies to modify patients' mindlines by adding reliable and useful knowledge and by removing outdated or inaccurate information, attention must also be given to parallel amendment of practitioner mindlines.

To change patients' eczema mindlines, information must come from a trusted source and must be perceived as real. Realness is judged by the extent to which the person providing information understands the experience of living with eczema. The outcome of amending lay and practitioner mindlines in parallel by imparting consistent, straightforward, accurate messages should be increased shared understanding and improved self-management and consultation experience.

REFERENCES

1. Gabbay J, le May A. Practice-Based evidence for healthcare: clinical mindlines. London: Routledge; 2011.

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