

Mothers of ill children experienced uncertainty before asthma was diagnosed in their children

Horner SD. *Uncertainty in mothers' care for their ill children. J Adv Nurs* 1997 Oct;26:658–63.

Question

What are the experiences of mothers of ill children before asthma is diagnosed in their children?

Design

Grounded theory.

Setting

[Georgia]*, USA.

Patients

12 English speaking mothers of European (n=9) and African descent (n=3) who had 15 children with asthma (age range 6–18 y) and 8 healthy children (age range 3–9 y). There were 3 single parent families, 1 extended family, and 8 nuclear families. 3 families had 1 child each, 7 families had 2 children each, and 2 families had 3 children each. The children with asthma began experiencing symptoms during the first year of life.

Methods

3 60–90 minute interviews were conducted in the families' homes. An item, *tell me how all of this began for you*, was added to the questionnaire before the second round of interviews and yielded rich data. The interviews were audiotaped and transcribed within 1 week. Transcribed interviews were analysed and coded for descriptions of the mothers' behaviours and perceptions and the relation between them. The interview data were compared to determine the consistency of data within and across interview sessions for each participant. Validity was determined by comparing codes across all interviews and by confirmation from the mothers in the final interview session that the findings reflected their experiences. 2 families who enrolled late and attended the final interview validated the transferability of the data.

Main results

Before asthma was diagnosed in their children the key experience of mothers was described as *groping in the dark*, which lasted from the children's first year of life until asthma was diagnosed (between the ages of 15 months and 5 years). There were 2 components to this experience: *unending illness* and *searching for answers*. The experience of an *unending illness* was characterised by unknowing (ie, illness episodes had no recognisable pattern and mothers received inadequate information from healthcare professionals), watching the struggle (ie, all mothers had stayed up through the night with their children, who were struggling to breathe, and were afraid for their children's wellbeing), and wearing out (ie, mothers were hypervigilant, worried excessively, and had disrupted sleep). In response to the experience of unending illness, mothers tried *searching for answers*, which was characterised by questioning; trying alternatives, which included home preparations and over the counter medications; and demanding attention, which included demanding a change in treatment plan, seeking referral to experts, and finding another paediatrician. The search for answers led to the referral of children to specialists who confirmed the diagnosis of asthma and prescribed a new treatment regimen.

Conclusions

Groping in the dark described the experience of mothers as their uncertainty grew with their children's repeat episodes of illness. Mothers reported relief after the diagnosis of asthma because the answer had been found to their problem.

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Commentary

An area of asthma care that is often neglected is the prediagnosis phase. The study by Horner provides insight into mothers' experiences while caring for their children during this phase.

Caution, however, must be exercised: the findings suggest that once the diagnosis of asthma was established, mothers stopped experiencing uncertainty. Uncertainty related to the aetiology of illness is only 1 source of uncertainty. Uncertainty related to other sources may continue to be experienced. Other sources of uncertainty include the situation (*Will the symptoms recur? Will the child die?*), the treatment (*Will the treatment be effective? Will it cause secondary complications?*), and the prognosis (*What will be the quality of the child's future?*).¹ Although much work has recently been done in a variety of disciplines (economics, philosophy, medicine, sociol-

ogy, psychology, and nursing) to further develop our understanding of uncertainty in illness and to develop interventions to help people cope with the stress of living under uncertainty, more work remains to be done.

This study poignantly describes mothers' experiences during the prediagnosis phase as *groping in the dark*, which reminds us of the importance of listening to patients' concerns and helping them to navigate the complex healthcare system. Establishing a diagnosis of asthma in children <4 years of age is often difficult because of other possible explanations of the symptoms and the inability to measure children's lung function. Giving a child a diagnosis of asthma should not be taken lightly. We need to be aware of the effects of labelling someone with a life threatening disease and the possibility

that they may continue to take unnecessary medications. During the prediagnosis phase, nurses need not only to explore the family's expectations but also to share with them some of our own uncertainties about the diagnosis and the rationale for potentially delaying the diagnosis. Further research will help elucidate nursing interventions that assist parents with their uncertainty.

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¹ Cohen MH. The unknown and the unknowable—managing sustained uncertainty. *West J Nurs Res* 1993;15:77–96.