

THE NEEDS OF PARENTS WITH ALLERGIC CHILDREN

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ABSTRACT

The incidence of allergy in children appears to be increasing, the obvious implication of which is that the load this places on families is also increasing. Little research exists on the needs of parents with allergic children, although much has been written on the burden of chronic childhood conditions on parents. Utilising the findings of such research when considering the needs of parents with allergic children is possible, although it should be remembered that each family has individual needs. The literature suggests that after the diagnosis of allergy, parents suffer a loss of control which they struggle to regain through management of those issues over which they have jurisdiction. The unpredictable nature of allergy renders this control fragile and healthcare professionals should be aware that there are many triggers that may cause parents to experience a heightened level of anxiety. Parents also have an overwhelming desire for accurate information regarding their child's illness; the literature indicates that this is not always available and that there is significant disagreement among healthcare professionals as to the best management of allergic children. Healthcare professionals should aim to achieve a partnership both with their colleagues and parents in order to address these issues.

Allergy, a specific, acquired change in host reactivity mediated by an immunological mechanism and causing an untoward physiological response,¹ may exhibit itself in a variety of ways. These include asthma, eczema, rhinitis, urticaria and food allergy.² These manifestations are commonly referred to as atopic diseases, which pertain to the genetic predisposition towards the development of immediate hypersensitivity reactions against common environmental allergens.

Allergy in children appears to be increasing. Indeed, in population-based studies, a cumulative prevalence of allergic diseases in childhood of around 25-30% has been reported,³ thereby implying that 1 in 4 families with children cope with the manifestations of an allergic disease on a daily basis.

PARENTS' NEEDS – COPING WITH CHANGE

Parents are pivotal to the physical and emotional well-being of the family unit.⁴ A literature search on the needs of parents with allergic children revealed few results; however much has been written on the needs of parents of a chronically sick child. A chronic condition is defined as 'an impairment or deviation from normal with variations in course, intensity and severity';⁵ allergy may therefore be considered a chronic illness. While it is impossible to generalise and each family should be

treated individually,⁶ common themes have emerged from the literature.

It is widely recognised that the extent to which parents adapt to living with their chronically ill child will ultimately have an impact on the health of the sick child⁷ and any siblings.⁸ Equally, the unpredictable nature of chronic illness and demanding treatment protocols have been identified as altering healthy relationship dynamics among parents.⁹ The importance of understanding the needs of parents with allergic children, and the ways in which healthcare professionals can assist parents in meeting these, cannot be overemphasised.

Accepting the diagnosis

The initial diagnosis of an allergy, even when the parents have suspected the diagnosis themselves, may be a time of considerable stress. The diagnosis essentially marks the end of the previously known world for parents, although for some the diagnosis is met with relief, marking the turning point from a state of uncertainty.¹⁰ For many, however, the diagnosis will herald a period of acclimatisation, which involves both physical adaptations, such as an adjustment to performing time-consuming therapies in addition to normal parenting tasks,^{11,12} and psychological adaptations to a way of life that many parents would never have envisaged.¹³⁻¹⁵ The extra time involved in carrying out normal childcare with a sick child is frequently not realised; one parent interviewed described the nuisance of having to study labels in a supermarket following the diagnosis of a food allergy in her child thus: 'just try as an experiment going round the supermarket and put the things in your trolley that don't contain milk or dried skimmed milk. I guarantee you won't have a lot to pay for, but then think about what you have got, and what sort of meals you can prepare for a week with those foods'.¹⁶

Lifestyle modifications

For most allergic diseases there is no cure, and therapy focuses on strict avoidance of the allergen through its removal from the child's environment where possible, and treatment of intercurrent symptoms. Families with allergic children may have to undergo drastic modifications to their lifestyles, the ramifications of which will affect all family members. Pets may have to be given away, and favourite foods may be banned from the house. Resentment may occur not only because of the extra time and attention the allergic child receives during treatment regimens, but also because of the changes to the home environment and lifestyle. All family members will need to undergo a period of adjustment, and siblings may require extra time and attention to help them understand the changes.

Caring for a child with a chronic illness consumes time, energy and financial resources, deprives families of privacy, and creates emotional and social isolation.¹⁷ In addition, the unpredictable nature of chronic illness and demanding treatment protocols have been identified as altering healthy relationship dynamics among parents.⁹ As allergy is part of the atopic group of diseases it is common for children to have more than one allergy or manifestation of atopy. In addition, the onset of allergic symptoms may be extremely unpredictable because of

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the difficulties of completely eliminating allergens from the environment. For these families, the adjustments that need to be made may be even more far-reaching and such parents will require even greater support.

STRESS FACTORS

The literature suggests that lack of control is a major stressor for parents after the diagnosis.¹⁴ The unpredictable nature of allergy makes this especially true for parents of allergic children. Parents with food-allergic children are required to constantly plan their lives, and the spontaneity that is generally taken for granted is no longer possible.⁶ Meals in restaurants must be carefully planned to ensure the venue can cater for the specific dietary requirements required; friends and relatives must be made aware of the importance of adhering to the strict dietary regimens. Environmental allergens are perhaps even less easily controlled; parents whose children are allergic to animals may be reluctant to allow their children to pay impromptu visits to friends or family until they are certain that these households do not have pets.

The literature suggests that eventually parents will manage to regain a sense of normality. This is usually achieved through control of those issues over which they have jurisdiction: management of illness;^{10,12,18,19} reorganisation of family life;^{12,19} management of information; and awareness of the environment.¹⁸

This control is fragile, however, and various triggers have the potential to destroy established coping mechanisms.²⁰ Routine medical appointments may cause a resurgence of fear that parents are trying to ignore, and this fear may peak while awaiting results of physical examinations or diagnostic tests. Minor symptoms or deviations from the norm, specific medical words or phrases, changes in therapeutic regimen, even changes that represent an improvement in their child's condition could threaten the emotional equilibrium of parents, who might resist such changes if this involves their child undergoing what they perceive to be an unnecessary procedure.²⁰ Changes in developmental stages also signify a time of potential stress for parents as a result of relinquishing control; the vigilance that they have developed as a coping mechanism must be handed over to nursery schools, teachers, or even to the child himself. Parents will require extra support and information at this time.²⁰

It should be observed that most of the triggers for a heightened level of uncertainty are events that healthcare professionals may consider to be routine, and therefore disregard or dismiss when considering possible causes of parental anxiety. Nevertheless it is important to be aware of them, as the re-emergence of anxiety has the potential to destroy the parents' reconstructed sense of normality.²⁰ Many discover that the experience of living with such a child involves constant uncertainty, albeit at a subconscious level.^{14,18,20} This uncertainty, coupled with the new demands of the treatment regimen, means that parents will undergo drastic changes to their outlook on life.^{10,12,18-20} 'As far as normal is concerned, if we had an outside observer, not knowing anything of what we're going through, if they walked in the door and were with us from the moment we woke up until we went to bed, they would not consider us normal at all. And that's just the way life is.'¹⁸

INFORMATION NEEDS

Parents have an overwhelming desire for information regarding their children's condition and treatment. They may be dissatisfied with the information they receive for a variety of reasons: difficulty in obtaining information;^{18,19} being given insufficient information;^{13,14,21} receiv-

ing information too quickly^{11,13} and being given inaccurate information.²¹ Parents who have difficulties in obtaining information from healthcare professionals may seek to expand their knowledge using alternative sources such as other parents, support groups¹³ and libraries.¹⁹ It is therefore important to ensure that parents fully understand the information that they are given. The provision of written information may be one means of improving understanding and thereby reducing anxiety.²² In addition, the provision of books and Internet website addresses may be useful in directing parents to information that will be factually correct, informative and understandable.

Many parents 'manage' information in order to reduce uncertainty.¹⁸ After extracting information, parents may discount, transform or modify information they perceive as negative. Parents may also fear that information might incapacitate them, and therefore actively limit the information they receive.

The hunger for information is closely linked to parents' desire for normality and certainty, described earlier. Acquisition of information will empower parents to regain control over their situation and enable them to request and participate in a partnership with healthcare professionals.^{10,12,14,18,19}

If more evidence is needed, the literature suggests that better-informed parents have greater feelings of well-being and are more likely to comply with medication and treatment regimens.²³ However, a study within the Eastern Health and Social Services Board in Northern Ireland found great variability in the management of children with allergy.²⁴ The report suggests a lack of consensus among healthcare professionals as to the best practice in the management of potentially life-threatening food allergy and indicates a need for better multidisciplinary communication. It recommends specialist referrals for all children with suspected allergy, further investigation, written allergy advice, referral to a dietician and formalised training in basic life support and the administration of epinephrine. It is likely that such findings are not unique to their specific area; indeed management of allergic conditions may vary greatly between not only individuals within a department but also different hospitals, as well as internationally. In order to minimise confusion and concomitant anxiety for parents, healthcare professionals should strive to reach a consensus both nationally and globally.

Parents keenly aspire to be regarded as partners in the care of their child, and this desire is closely linked with the need to regain control in order to minimise uncertainty. Measures by which parents gain partnership is varied. Some develop alliances and choose healthcare professionals they perceive as helpful,¹⁰ others insist on making decisions¹⁴ or may demand the final word by refusing treatment for their children or challenging decisions made by healthcare professionals.¹² An unfulfilled desire for partnership may cause parents to become vigilant and assertive.^{13,21}

Unfortunately the literature suggests that the experiences of some parents are less than positive, with parents advocating for healthcare professionals to pay attention to their expertise^{2,13} and be more sensitive to their anxieties.¹¹ The ramifications for children's health if parental concerns are not taken seriously and healthcare professionals do not try to form partnerships with children and their families are serious; a lack of understanding on the part of parents may cause them to withhold vital treatment such as the MMR for egg-allergic children,²⁵ or impose unnecessary restrictions on their children's lifestyle. Indeed parents with food-allergic children who do not receive specialist help and

advice may introduce inappropriate dietary restrictions, which in turn may cause significant morbidity.²⁶ Healthcare professionals must therefore attempt to achieve realistic treatment regimens that parents will be able to adhere to, but that will also be beneficial to the child.

CONCLUSION

This article has highlighted that research into the needs of families with allergic children is long overdue. However, from the information that is available regarding parents of children with a chronic illness, it is possible to draw some conclusions. That a change of lifestyle occurs within families whose children are diagnosed with an allergic disease is unequivocal. The lengths to which parents will go to minimise and accommodate the necessary changes are extensive. It is therefore important for healthcare professionals to be alert to the fragile coping mechanisms developed by parents, and to remember that procedures and symptoms that may be dismissed as routine or minor have the potential to destroy the normality that parents have fought to construct. It is important to be vigilant to the individual needs of these families, and to provide realistic treatment regimens and comprehensive understandable information through collaboration with the recipients. Most importantly healthcare professionals should aim to collaborate both with parents and children, and also with other healthcare professionals at national and international levels, to ensure the treatment and advice given is not only effective, but also consistent.

REFERENCES

1. Sly M. Allergic disorders. In: Behram RE, Khogman RM, Jenson HB. *Nelson's Textbook of Pediatrics*. 16th ed. Philadelphia: WB Saunders, 2000.
2. Fox D, Gaughan M. Food allergy in children. *Paediatric Nursing* 1999; **11**(3): 28-31.
3. Horst A, Andrae S, Charkin S, et al. Allergy testing in children: why, when and how? *Allergy* 2003; **58**: 1-11.
4. Hentinen M, Kyngas H. Factors associated with the adaptation of parents with a chronically ill child. *J Adv Nurs* 1998; **19**: 1050-1056.
5. Ray L, Ritchie J. Caring for chronically ill children at home, Factors that influence parents' coping. *J Pediatr Nurs* 1993; **8**(4): 217-225.
6. Dalheim Englund A, Rydstrom I, Norberg A. Being the parent of a child with asthma. *Pediatric Nursing* 2001; **27**(4): 365-373.
7. Johnston CE, Marder LR. Parenting the child with a chronic condition: an emotional experience. *Pediatric Nursing* 1994; **20**: 611-614.
8. Cohen MH, Friedrich W, Jaworski T, Copeland D, Pendergrass T. Pediatric cancer: predicting sibling adjustment. *J Clin Psychol* 1995; **50**: 303-319.
9. Donnelly E. Parents of children with asthma: an examination of family hardiness, family stressors, and family functioning. *J Pediatr Nurs* 1994; **9**(6): 398-407.
10. Jerrett MD, Costello EA. Gaining control: parents' experiences of accommodating children's asthma. *Clinical Nursing Research* 1996; **5**: 294-308.
11. Hodges LC, Parker J. Concerns of parents with diabetic children. *Pediatric Nursing* 1997; **13**: 22-24, 68.
12. Jerrett MD. Parents' experiences of coming to know the care of a chronically ill child. *J Adv Nurs* 1994; **19**: 1050-1056.
13. Diehl SF, Moffitt KA, Wade SM. Focus group interview with parents of children with medically complex needs: an intimate look at their perceptions and feelings. *Children's Health Care* 1991; **20**: 170-178.
14. Butler Simon N, Smith D. Living with chronic pediatric liver disease: the parents' experience. *Pediatric Nursing* 1992; **18**: 453-458.
15. Palmer E. Family caregiver experiences with asthma in school-age children. *Pediatric Nursing* 2001; **27**(1): 75-81.
16. Elliott BE, Luker K. The experiences of mothers caring for a child with severe atopic eczema. *Journal of Clinical Nursing* 1997; **6**: 241-247.
17. Beresford B. Resources and strategies: how parents cope with the care of a disabled child. *J Child Psychol Psychiatry* 1994; **35**: 171-209.
18. Cohen MH. The unknown and the unknowable: managing sustained uncertainty. *West J Nurs Res* 1993; **15**: 77-96.
19. Gravelle AM. Caring for a child with a progressive illness during the complex chronic phase; parents' experience of facing adversity. *J Adv Nurs* 1997; **25**: 738-745.
20. Cohen MH. The triggers of heightened uncertainty in chronic life threatening childhood illness. *Qualitative Health Research* 1995; **5**: 63-77.
21. Scharer K, Dixon DM. Managing chronic illness: parents with a ventilator dependent child. *J Pediatr* 1989; **4**: 236-247.
22. Willock J. Involving families in the production of parent information literature. *Professional Nurse* 1998; **13**(6): 351-354.
23. Kurnat EL, Murphy Moore C. The impact of a chronic condition on the families of children with asthma. *Pediatric Nursing* 1999; **25**: 288-292.
24. Hughes JL, Stewart M. Self administration of epinephrine in children: a survey of current prescription practice and recommendations for improvement. *Ulster Med J* 2003; **72**(2): 80-85.
25. Fox A, Lack G. Egg allergy and MMR vaccination. *Br J Gen Pract* 2003; **53**: 801-802.
26. Wyatt R. Anaphylaxis. How to recognise, treat and prevent potentially fatal attacks. *Postgrad Med J* 1996; **100**: 87-90.