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Living Ordinary Family Life With an Allergic Child—The Mother's Perspective



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Key words:

Family; Infant; Interview; Food allergy; Eczema Ecocultural theory considering family as an entity may serve as a new point of view instead of "impact of disease"—perspective. Aims were to reveal ecocultural themes and activities of daily routines in the treatment of a child's food allergy and eczema. Interviews (N = 24) were held with mothers with allergic children aged 12 months and mothers repeat interviews at 24 months. The theme; "living an ordinary family life", was implemented across the family activities of routines essential for treating the child's allergy. New or altered treatment regimens can be tailored to families on the basis of existing activities.

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ATOPIC DERMATITIS (AD) appears in early childhood, with an incidence of 16% (Smidesang et al., 2008) to 31% (in birth cohort studies up to the age of two) (Halkjaer et al., 2006). The early onset of AD may be a risk factor for the development of other allergic disorders, including food allergy (FA), which affects children most often (Steinke et al., 2007). However FA is an important provoking cause of AD, being present in 35% of affected individuals (Greenhawt, 2010). For FA and eczema care to be successful, parents need to learn the treatment for the diseases concerned. This presents challenges for the family's daily life, as the needs of other family members must also be taken into account.

Earlier studies have characterized and measured the effect of a child's AD and FA on the child, their siblings, and their parents (Chamlin, Frieden, Williams, & Chren, 2004; Chamlin et al., 2005; Cheung & Lee, 2012; Ricci, Bendandi, Bellini, Patrizi, & Masi, 2007; Su, Kemp, Varigos, & Nolan,

1997; Zuberbier et al., 2006). The effects of AD on children have been divided into child-related domains (i.e., symptoms, activity limitations, and behavior), and parent-related domains (i.e., family and social functions, sleep, and emotions) (Chamlin et al., 2004; Chamlin et al., 2005). A child's AD affects their parents' decisions regarding work and their performance at work (Chamlin et al., 2004). Parents also report co-sleeping because of itching and scratching, staying at home, the increased volume of housework, being unwilling to leave the child with other people and time-consuming forms of treatment. Relationships with relatives and friends are affected (Chamlin et al., 2004).

Although a child's allergic disease will affect the everyday life of the family, ecocultural theory considers the family as a collective entity, able to modify the influencing forces in challenging situations (Gallimore, Weisner, Kaufman, & Bernheimer, 1989). These forces can be divided into those within the community and within the family, including economics, social relations, and the characteristics of family members (such as a child's allergic disease). According to this theory, families respond to conflicting circumstances in various ways in order to create

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and sustain the daily routines in which they pursue their own goals and values (Gallimore, Weisner, Bernheimer, Guthrie, & Nihira, 1993). The activity settings of the family's daily routines provide opportunities for children to learn and develop in mediated social learning, embedded in goaldirected interactions. There are parts of family life (preparing meals, eating dinner, and mundane settings) in which adult and child interaction is embedded. They contribute family themes, which organize family life and give meaning to parents' decisions. Parents try to construct and maintain the daily routines of activity settings that express their thematic goals- to balance constraints against resources and to accommodate the personal characteristics of the family members (Gallimore et al., 1989). The meaning of an activity setting can be observed in terms of the persons present, their cultural values, the tasks being performed, codes for conduct, and the motives and purposes of actions (Gallimore, Goldenberg, & Weisner, 1993).

The prevailing perspective on the "impact of disease" is limited and does not typically consider family life as an entity. Ecocultural theory considers family life as an entity, and can be applied to the families of young children with AD and/or FA. The purpose of this study was to reveal the family themes that are implemented across the activities that form daily routines essential in the treatment of AD and FA in children, based on interviews conducted with their mothers when the children were aged 12 and 24 months.

Methods

The data for this qualitative study were collected in the context of an ongoing randomized mother and infant study in Finland where mothers were recruited from maternal welfare clinics in the city of Turku and neighboring areas in south-west Finland (Laitinen, Poussa, & Isolauri, 2009; Piirainen, Isolauri, Lagström, & Laitinen, 2006). The inclusion criteria for this qualitative study were the mother's consent and the child's AD and/or FA. The women were from families with allergic disease in the mother, father, or a sibling of the child but without any other chronic diseases. The mothers and their infants were examined at intervals by a nurse and physician.

Data Collection

Permission for the interview was asked from all the mothers fulfilling the criteria. This took place during the study visit when the child's allergy status was examined by a physician at the child's age of 12 months. The sampling method was purposive sampling, which aimed to find as large a number of cases with as much variety as possible (Polit & Beck, 2010). The mothers who agreed were

contacted and interviewed (N = 13). Repeat interviews were performed when the child was 24 months old (n =11), providing a total of 24 interviews between 2005 and 2007. Eleven mothers were interviewed twice; one repeat interview was cancelled because the child had recovered from the allergy and one due to the illness of a family member. Mothers were interviewed in their home environments, except for two who were at their place of work. The semi-structured interviews included three open questions that were related to the appearance of the child's allergic symptoms, the diagnosis of AD and/or FA, and daily family life in the light of the child's allergic disease. In the repeat interviews, open questions concerned with the changes in the child's allergic symptoms and daily family life in the light of the child's allergic disease were asked. The mothers were encouraged to tell their stories freely and the researcher made inquiries when something needed to be further explained or interpreted. The researcher entered her experiences and thoughts in a notebook after each interview. Information was based on listening to the first interview with the mother and included details about the child's allergy as obtained from the clinical examination by a nurse and physician when the child was 24 months old, which enabled the researcher to focus on the second interview a year later. The interviews were taped and transcribed verbatim, yielding 350 pages of text.

Ethical Considerations

The ethical issues related to qualitative research were considered (Orb, Eisenhauer, & Wynaden, 2001). The research plan and the consent form were approved by the Ethical Committee of the Hospital District of Southwest Finland. Both the mothers and the researcher signed the informed consent form before the first interview. Mothers were informed that their participation was voluntary and they could withdraw from the study at any time.

Data Analysis

Deductive content analysis was applied to the data (Graneheim & Lundman, 2004). Ecocultural theory served as a framework through which the data were analyzed. In the first phase, the analysis began by listening to the interviews twice and reading their transcriptions to obtain an insight as to whether there were any recognizable family themes. This active listening enabled the researcher to focus on what the mothers had said. According to the theory, the thematic character of a family's life is detected through the ways in which the family implements its routines over a range of activity settings (Gallimore et al., 1989). In the second phase, the unit of analysis was a caring activity or task related to the child's allergy that was performed. The family activities

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