QUALITATIVE

Discovering a sense of difference was the main experience of growing up with cystic fibrosis

D'Auria JP, Christian BJ, Richardson LE. *Through the looking glass: children's perceptions of growing up with cystic fibrosis*. *Can J Nurs Res* 1997 Winter;29:99-112.

Question

How do children with cystic fibrosis (CF) perceive the unfolding of the chronic illness experience?

Design

Grounded theory.

Setting

Regional CF centre in south east US.

Patients

20 children who were 6-12 years of age (mean age 9 y, 60% boys) and had been diagnosed with CF by 3 years of age.

Methods

In 30-60 minute audiotaped interviews, children were asked to visualise their experiences of growing up with CF. They were asked to describe their earliest memory and to give advice to a child newly diagnosed with CF. Field notes documented personal characteristics, emotional response, and data collection conditions. Interviews were transcribed, coded, and analysed using the constant comparison method.

Main results

The central phenomenon of growing up with CF was *discovering a sense of difference*. 4 main themes emerged from children's accounts. *Puzzling out the meaning* described many children's memories of learning from their mothers that they had CF and the surprise they felt at not being like other children. For many children with CF, entering school and exposure to peers began their discovery that they were different; these children were surprised by the response of their peers to their symptoms. Lack of understanding regarding the causality of CF frequently led younger children (6-9 y of age) to the misconception that their peers avoided them because CF was contagious. *Being teased and*

picked on was a main theme for children with CF. At a time when peer acceptance was crucial, children tended to view themselves through the eyes of their peers and often hid their visible differences so that they could make friends. With time, children learnt to view themselves as normal and to be less affected by the reactions of their peers. *Telling others* about their illness was another main theme. To avoid the negative social consequences of their visible symptoms and to control how other children viewed them, children with CF kept secrets or disclosed their illness selectively to people whom they considered to be trustworthy. When asked what they would tell younger children with CF about growing up, these children frequently advised them to keep secrets about their illness. *Keeping up* was a major concern for children with CF. The symptoms and functional limitations of CF highlighted physical differences and made it difficult to fit in and compete with peers. The most restrictive problem for children with CF was not being able to run as fast as their friends. Many children withdrew and isolated themselves after being teased about their symptoms, which further reduced their opportunity to participate in peer activities. Other children with CF learnt to pace themselves to control their symptoms and minimise their differences from other children.

Conclusions

Children with cystic fibrosis described *discovering a sense of difference* when they were asked to talk about what it was like to grow up with a chronic illness. They described being teased and picked on by other children and controlling the image they offered to peers.

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For correspondence: Dr J P D'Auria, School of Nursing, University of North Carolina at Chapel Hill, CB #7460, Carrington Hall, Chapel Hill, NC 27599-7460, USA. Fax +1 919 966 7298.

Commentary

The study by D'Auria *et al* is an important contribution to the literature because of its focus on the young child's experience of CF, rather than the more traditional focus on the parent or caregiver. The central phenomenon described by the children was that of *discovering a sense of difference*. Themes identified focused on components of the difference and their effects on the development of peer relationships. These findings are echoed in previous research. Mulderij, in a review of literature and summary of field observations, reported that chronically ill children frequently felt excluded from peer relationships because of factors such as poor social skills, altered physical ability, and frequent interruptions to activities

because of therapeutic regimens.¹

Although analysis in this investigation was limited to children's experiences with CF, a subset of information was obtained about their coping strategies (eg, keeping secrets and how to choose friends). Further analysis of these data would have provided an added dimension to the understanding of how children manage their growing up with CF.

The findings of D'Auria *et al* are clinically relevant. Suggested implications for practice include interventions to promote adherence to therapeutic regimens, to educate about CF, and to teach problem solving strategies and social skills. Anticipatory guidance about issues faced during middle childhood should be

considered when planning the timing of interventions. Coping methods commonly used by children should be considered when planning interventions.

Although implications for further research were not discussed, interventions should undergo evaluation to identify strategies that result in optimal outcomes for children. Caution should be taken in extending these results to all children with chronic illnesses.

Helene Lacroix, RN, MSc
Paediatric Manager
Victorian Order of Nurses
Toronto, Ontario, Canada

¹ Mulderij KJ. *Child Care Health Dev* 1997; 23:379-89.