

Abstract of Thesis

Children with asthma and their carers' experience of hospital care: decision making at home and in the hospital clinic.

Background

Previous research has evaluated how children manage their asthma at home. Some studies have also examined children's decision making and involvement in the hospital clinic. However there is little research that examines how children's experience of decision making in the family home may influence their involvement in decision making in the hospital clinic. Some authors discuss a potential influence where different experiences of family life will give children diverse perspectives on social action 'with ramifications beyond the family environment' (James and Prout 1996, p.47). It is these 'ramifications' that are of interest, in particular for interactions in the hospital clinic.

Aims

The aims of this study were to examine how the experience and management of childhood asthma impacts on families' everyday lives and how children's experience of participation in decision making at home impacts on their involvement in their care in the hospital clinic.

Methods

In this ethnographic study, the research methods used were:

- 1) non-participant observation over a period of eight months to observe children, carers and clinic staff in the clinic waiting area;
- 2) non-participant observation to observe and audio-record clinic interactions between nurses, doctors and twenty children with moderate to severe asthma (aged seven to eleven years) and their families;

- 3) in-depth interviews (N=40) with the same twenty children and their main carers in their homes and the use of research evaluation questionnaires;
- 4) interviews with fourteen clinic staff.

Innovative participatory research techniques were used to mitigate child-adult power relations. Photographs and drawings done by the children stimulated discussion about what was important to the children about 'having asthma'. Sticker charts about 'how much say' the children had were also used to facilitate discussion about decision making in the home and clinic setting. Children and carers also evaluated the research process using questionnaires.

Results

The key findings of this study were:

- 1) The concept of 'differently normal' developed by James (1993) was relevant to many of the children's and carers' experiences. It was the responses of families with more severe asthma that highlighted how the 'normalisation' of asthma in contemporary society may have negative consequences for child-adult relations.
- 2) Family decision making was dependent on the carers' approaches to children's participation. Most carers had a pragmatist or democratic approach to family decision making. Children's rights to autonomy may have more recognition in the family social world than in the past. Carers' level of trust in their children's competence to care for their asthma was also related to the carers' approaches to children's decision making.
- 3) The organisational setting may have positively influenced shared decision making.

- 4) Decision making processes at home can impact on the level of children's involvement in the clinic. Carers with a protectionist approach influenced interaction by their 'taking over' behaviour. A few children exercised their autonomy not to participate by using active countervailing silence. Children with experience of decision making at home achieved more involvement in clinic interactions.

Discussion

This research highlighted the importance of children with chronic illness being seen as 'children in their own right' rather than 'becoming adults' who are passing through universal stages. Experience, not age, seems to be the relevant factor. Social competence is also something children work at possessing and the achievement of competence is an active accomplishment not just an attribution by adults. The achievement of children's competence is often constrained by adults. Most of the health care professionals in the study clinic fostered a culture of children's involvement in consultations. However, an umbrella approach to involving children in their care could cause conflict for some children who do not want involvement.

Sometimes silent children are not being passive but are displaying action by non-participation. Conversely children who participate fully in the consultation may be doing so primarily to please their carers. Bluebond-Langner et al.'s (2005) approach of shuttle diplomacy and negotiation could be one way to allow children to be part of the decision making process which is consistent with the child's life experience of decision making. Negotiation requires that all parties be represented and a resolution is found that all participants accept. The child is involved (as much as they want to be) in the collaborative decision making process, but does not have the burden of

determining the outcome. If children and carers want involvement a more participative consultation may be achieved. This discussion highlights the complexity of involving families in shared decision making which is not recognised in health policy rhetoric.

Contribution to nursing scholarship and health care practice

Before this study, research linking children's experience of chronic illness and involvement in decision making at home and their involvement in the specialist clinic was limited. Many factors impact on families' relationships with health care professionals, but this study shows that children's experiences at home and their carers' approaches to their children's involvement is an important consideration. Another relevant factor for health care practice is that children's silence does not always mean powerlessness and children's participation may not be willing.

This research contributed to nursing scholarship by using participatory techniques to involve young children in speaking about their experiences so their meanings could be illustrated. Research on finding alternative methods of communication for discussing complex issues with children could evaluate the use of different participatory techniques such as drawings, charts, vignettes, and character cards. These techniques have been shown to decrease power relations and alleviate boredom from conversation based interviews. An ethnographic approach gaining children's perspectives on the use of these aids would explore how these could work in health care practice.

The results of this study also highlighted that children with severe asthma have different experiences in managing their asthma at home than children with less severe

illness. With a multi-disciplinary team, I have submitted proposals for funding a definitive evaluation of nurse-led interventions which aim to improve home management practices for families with children with severe asthma.

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References

Bluebond-Langner M., DeCicco A. and Belasco J. (2005) Involving children with life-shortening illnesses in decisions about participation in clinical research: a proposal for shuttle diplomacy and negotiation. In E. Kodish (ed.) *Ethics and research with children: a case-based approach*, pp. 323-342. Oxford University Press: New York.

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Winner of the 2011 RCN Research Society Akinsanya Award for Innovation in
Doctoral Studies in Nursing