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## **Nursing Children and Young People**

### **Title:**

**Child-parent shifting and shared decision-making for asthma management - a qualitative interview based study.**

### **Running Title:**

**Shared decision-making**

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**Key words:** child, parent, shared decision-making, asthma management

The transfer of asthma management decisions from parent to child is not linear but a shifting and shared process, found Victoria Garnett, Joanna Smith and Paula Ormandy.

## **Abstract**

**Aim:** To explore and describe child-parent shared decision-making for the management of childhood asthma.

**Methods:** A qualitative descriptive interview based study was undertaken. Eight children and nine parents participated. The framework approach underpinned data analysis.

**Findings:** A dynamic model of the way children and parents transfer, shift and share asthma management decisions was uncovered; asthma management decisions between children and parents were non-linear with responsibility transferring from parent to child under different conditions. Children made a range of decisions about their asthma, often sharing decisions with their parents. However, during acute illness episodes children often relied on parents to make decisions about their asthma.

**Conclusion:** Neither the child nor parent have complete autonomy over asthma management decisions. Decision-making is a dynamic shifting and shared process, dependent on contextual factors and child and parent decision preferences.

## **Introduction**

In relation to long-term conditions health policy in England explicitly advocates actively engaging individuals in the management of their condition and improving their overall experience of services (Department of Health (DH) 2007, 2010). Empowering individuals to become managers of their own condition is fundamental to the future of healthcare delivery (World Health Organisation 2002) and is embedded within 'The Expert Patient Programme' within the UK (DH 2001). When the individual is a child, supporting them to manage and make decisions about their condition involves engaging and developing effective partnerships with the child, their parents and wider family as appropriate. This article summarises a study that focused on child-parent shared decision-making for asthma management from the perspectives of children aged between seven and eleven years of age and their parent/carer.

## **Background**

Asthma is the most common long-term illness in children, affecting 1.1 million children living in the UK (National Institute for Health and Care Excellence 2013), with a child admitted to hospital every 18 minutes for emergency treatment to help them breathe (Asthma UK 2007, Asthma UK 2010). Asthma is largely managed at home, yet there is a paucity of research exploring the management of asthma in the family setting and in particular the way children and parents share decisions related to asthma management. For children and young people with a long-term condition, such as asthma, child-parent shared decision-making has been identified as the optimal approach to managing the child's condition to ensure positive health outcomes (Helgeson *et al* 2008). For the majority of these children asthma continues into adult life. Therefore developing good decision-making skills at a young age could

optimise long-term health outcomes (Hanna *et al* 2012). Understanding child-parent shared decision-making could help healthcare professionals assist children to develop effective decision-making skills and support both children and parents to foster autonomy in the young person.

### **Aim**

To explore and describe child-parent decision-making for the management of childhood asthma.

### **Methods**

The study adopted a qualitative descriptive interview based design in order to elicit children and their parent's perception of how they make decisions about the child's asthma.

Participants were recruited from a children's outpatient department within an NHS hospital trust between March 2012 and May 2013. A convenience sample with clear identified inclusion criteria ensured participants met the study aim, resulting in eight children and nine parents participating. The setting for this study had an ethnically diverse population, black and ethnic minority groups are estimated to be 12%, with the predominant race being Pakistani (North West Public Health Observatory, 2009). As Pakistani groups are the highest ethnic group reporting their health 'is not good' (Public Health England, 2013), recruitment from participants within this minority ethnic group was important. However, this study has not captured participants from the ethnic minority participants and may be attributed to one of the exclusion criteria stating participants must be able to speak and write the English language. When asked by the nursing staff children from ethnic minorities and their parents did initially demonstrate interest in participating. However, it became apparent many of the parents did not speak English and could not be included within the study. Employing an

interpreter for future studies would promote inclusivity within this population; although 'rich data' had been captured within this qualitative descriptive study.

All children between seven and eleven years of age, with a diagnosis of asthma (over six months) and their parents, presenting at the asthma clinic were offered the opportunity to participate in the study. Potential participants were provided with an information pack, which consisted of separate child and parent information leaflets and consent forms. Data were captured by undertaking in-depth individual semi-structured interviews. An arts based activity, to build rapport with the children, preceded the child interviews. The framework approach underpinned data analysis: an iterative process involving forward and backward movement across the systematic stage of data management, descriptive accounts and explanatory accounts in order to identify themes from the data while remaining true to participant accounts (Spencer *et al* 2003).

### **Ethical Considerations**

Ethical approval was gained from the National Research Ethics Service Committee Paediatric Panel, Site Specific Research and Development Department of the participating NHS Trust and the University Ethical Approval Panel. Once a child and their parent had decided to participate in the study, separate child and parent informed written consent was obtained. Pseudonyms were used throughout the study to maintain anonymity.

### **Findings**

There were 17 participants: eight children, seven mothers, one father, and one grandmother (who was the child's main carer), recruited from twenty two asthma clinics. Children were between seven to eleven years of age.

Three interrelated core concepts emerged from the child and parent findings:

- Making sense of asthma;

- Decision preferences;
- Facilitators and barriers of child's asthma self-management.

### ***Making sense of asthma***

Children identified making sense of asthma as essential to developing their knowledge and skills to self-management their asthma. In order to make sense of asthma, both children and parents, albeit from differing perspectives and understanding, recognised that preventing and responding to asthma symptoms was central to good asthma management. Children wanted to understand asthma and its treatment and asthma triggers, and develop the skills to recognising asthma symptoms. Parents revealed that it was important for their child to be able to 'listen to their own body' and take appropriate actions to minimise exacerbating asthma symptoms. As the child achieved greater understanding and experience, there was greater participation within the decision-making process of their asthma management, summarised in the following interview extracts:

- 'I can feel myself wheezing but mum might just see me like puffing, she will say do you want your inhaler and I will say yes. It is bad having asthma as you can't do a lot of sports without stopping for a couple of minutes to get your breath...I still enjoy running...I would carry on doing it but not as fast' *Dean 7*
- 'He listens to his own body, he knows how he feels, and he doesn't know it any other way. He knows what each inhaler is for. He knows his symptoms. He knows one is a preventative and one to take afterwards' (*asthma symptoms*). *Susan, mother to Dean, 7*
- 'I know to take my inhaler when I start coughing and I feel bad' *Paul 8*

Children appeared to understand the *when* and *why* of the reliever inhaler but children nearer seven years of age did not always understand the reasoning behind the preventative inhaler. Across the seven to eleven age range, children did at times require prompting to administer their reliever inhaler, but did make specific autonomous management decisions to reduce the asthma symptoms, for example by '*not running as fast*' to reduce wheeze. Parents account identified how they strove to involve their child to take responsibility for recognising and responding to asthma symptoms.

### ***Decision preferences***

Child and parent extracts highlight a range of decision preferences. There was a sense of preferred decision-making across the majority of children, who made decisions in response to symptoms and triggers. At times decisions were independent of parent and other times parent driven or shared. However, children perceived that they had limited control of their asthma management decisions. Both children and parents identified when the severity of asthma symptoms increased the preferred responsibility for decision-making was securely with the parents. However, the decision to involve parents was sometimes initiated by the child, summarised in the following extracts:

- 'I am happy with the decisions that I am involved with...I decide to involve my mum or dad if it is really bad but normally I would just have my inhaler' *Nathaniel 11*
- 'If it was really bad and I had taken my inhalers, then I would go and wake my mum up' *Nicole 11*
- 'We would involve Dean...unless I thought this was more. It would be my decision if we were going to the hospital. It is my decision if he has time off school due to his

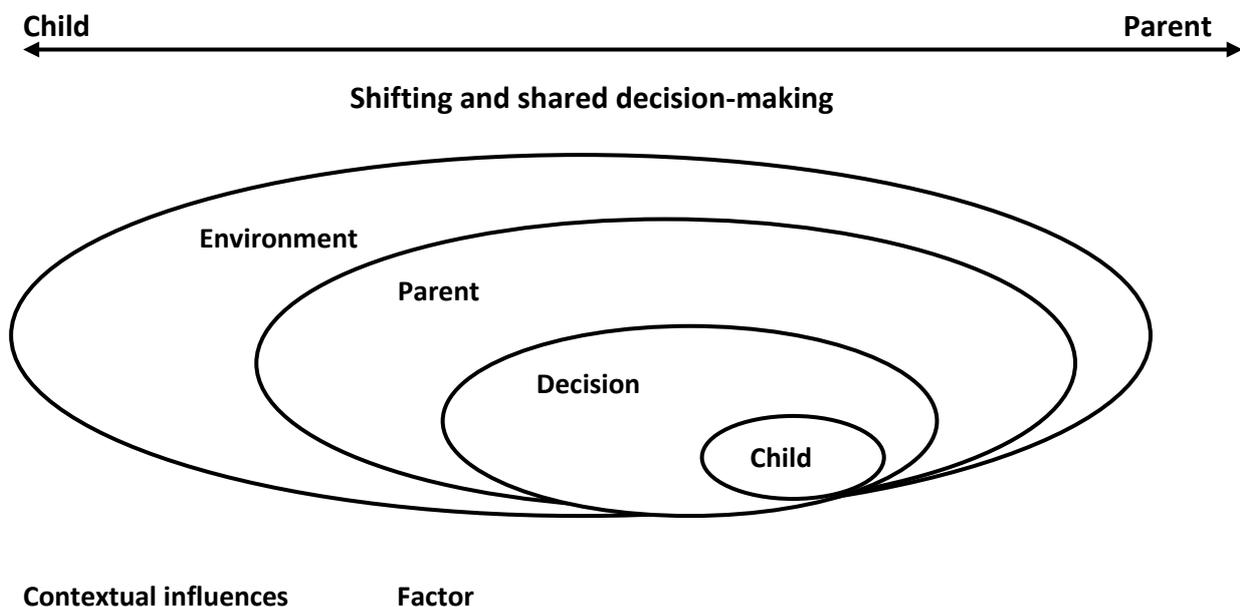
asthma. Obviously if he was having a bad asthma attack, I would take over, regardless of what Dean wanted' *Susan, mother of Dean 7*

A range of contextual factors and the level of child autonomy impacted on child and parent decision-making preferences. Seven contrasting contextual situations were identified:

- Parenting style influences child agency and self-confidence;
- Cognitive development, decision-making and child agency;
- Shared decision-making used to build self-confidence and develop child agency;
- Parent absence increased autonomy and child agency;
- Shifting decisions and parenting style with severity of illness ;
- Undermining confidence and child's ability to make decisions reduces autonomy;
- Accessibility of inhaler and reduced autonomy.

Figure 2 illustrates how contextual factors relating to decision-making were interlinked and placed the child at the centre of the decision.

**Figure 2: Contextual influence to child decision-making**



<b>Child</b>	Cognitive development, self-efficacy, locus of control, experience.
<b>Decision</b>	Type of decision: 'who', 'what', 'when', 'why'.
<b>Parent</b>	Parenting styles, confidence in child's ability, presence/absence.
<b>Environment</b>	Home, school, locus of control.

### ***Facilitators and barriers of child's asthma self-management***

Different environments and situations influenced the level to which children took responsibility for the asthma management and/or whether the control over decisions was taken away from the child. These facilitators and barriers to decision-making processes included; the child being able to identify and monitoring medication, having access to their inhaler, inconsistent approaches to facilitating child autonomy between parents, professionals and teachers, which related to the school environment and summarised in the following interview extracts:

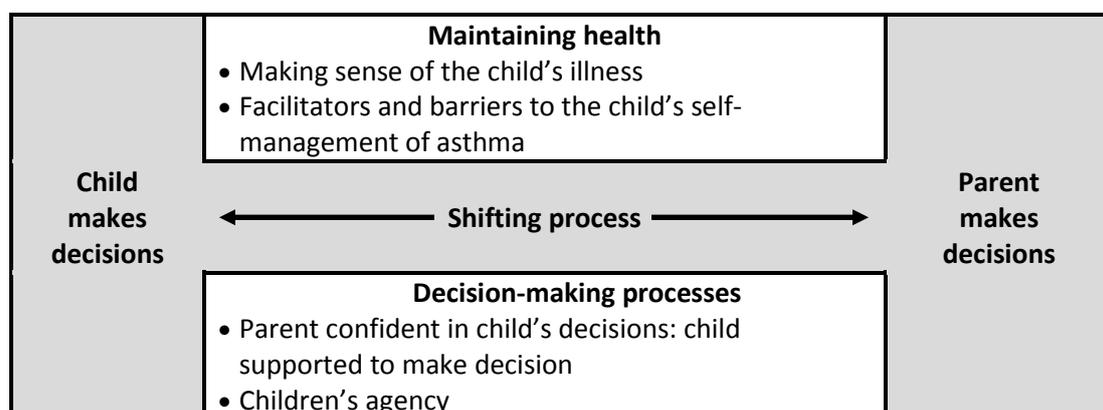
- 'He has a spacer and inhaler under his pillow, he uses it and lets me know' *Sandra, mother of Paul 8*
- 'My inhaler is kept in a box on the windowsill at school. The teacher sends you in for it. I do the inhaler myself' *Paul 8*

Contextual factors and individual preferences appeared to dominate the direction of the decision; if a parent, particularly the mother was present the child often relinquished control of the decision. The child's experience of managing their asthma and cognitive development was an important factor in the level of child participation, although decision-making responsibility for asthma management tasks was not age-bound. Children seven and eleven years of age made decisions but wanted to share the responsibility of the decisions with parents.

### ***Conceptual Framework***

The conceptual framework presented in Figure 3 represents a dynamic model of the way children and parents share asthma management decisions. The conceptual framework integrates the findings from child and parent accounts of the factors that enable or hinder the sharing of the asthma management decisions. The framework recognises that neither the child nor parent has complete autonomy over the asthma management decisions, but that the decision-making is a dynamic shifting and shared process, dependent on contextual factors, and child and parent decision preferences. Thus reflecting that as children gain knowledge and experience they begin to take more responsibility for their condition, with parents recognising their child’s developing role in managing the condition. The shifting responsibility for asthma management decisions is not a linear process that transfers from parent to child; whether the child or parent dominates, decisions shift and change across contexts according to individual child and parent preferences. More importantly, embedded within this conceptual framework is the notion that in many instances managing asthma decisions is a shared process, with decisions driven by the child’s developing autonomy and maximising the child’s health and wellbeing.

**Figure 3: Conceptual framework of child-parent shared decision-making for asthma management**



- |  |   |  |
|--|---|--|
|  | <ul style="list-style-type: none"><li>• Parenting styles</li><li>• Child's cognitive development</li><li>• Family systems: boundaries, controls and hierarchies</li></ul> |  |
|--|---|--|

## Discussion

A model of child-parent shared decision-making appears appropriate in asthma management recognising the role of both the child and parent in children's health care. This model recognises the importance of the child's 'voice' regardless of who actually makes the decision (Miller 2009). The transition of asthma management decisions from parent to child is not and should not be considered as a linear process. Sharing the decision involves the child and parent: 'sharing information; a mutual seeking and valuing of opinions; and valuing sharing decisions' (Miller 2009 page 258). The findings identified children and parents enjoy sharing decisions where previous research has identified children know when adults are patronising rather than valuing their contribution within decision-making processes (Miller 2009). Previous research identified the child's sole responsibility for management decisions occur opportunistically, for example during sleepovers with friends, rather than as a planned process (Callery *et al* 2003, Buford 2004, Newbould *et al* 2008). However, this may not be the most appropriate time for children to self-manage and often results in the child making decisions in isolation from trusted family members or with people who know how to respond to acute asthma episodes.

Planned shared decision-making in a safe environment would enable the child to have influence and contribute to decisions with guidance and support from their parent or responsible adult (Pradel *et al* 2001). More importantly this can facilitate the child to share the responsibility for decisions until a time when they feel ready to 'go it alone'. School nurses are ideally placed to work collaboratively with children, parents, education and other

health care professionals in promoting the health care needs of a child with asthma. The role of School nurses and children's community nurses included providing education for children, parents and school staff, and to work collaboratively in meeting the child's health needs to ensure full inclusivity within school life (Royal College of Nursing and UNISON 2012, Walker 2013, Blakemore 2013). It is essential every child with asthma has an up to date personal asthma action plan (Walker 2013), reviewed regularly in collaboration with the child, parent, health care professional and school staff to ensure the plan is utilised effectively within the school setting, if the child's health and wellbeing is to be maximised.

The child and parent extracts highlight the importance of shared decision-making for asthma management and yet the evidence base suggests that children are not always being included within the decision-making process (Lipstein *et al* 2015). The child will generally share the decision if they require support and guidance on a management task they feel is beyond their knowledge and experience. The findings illustrated that a child of seven years of age has the ability to make autonomous management decisions, for example understanding his asthma symptoms will reduce if he modified his running pace. These findings resonate with previous research undertaken with children of a similar age that also demonstrated autonomous decision-making skills to reduce asthma symptoms through the reduction or avoidance of asthma triggers (Meah *et al.*, 2009). Sharing the decisions does not appear to hinder autonomy or child agency but has a positive effect through the provision of parental support and guidance for effective asthma management. Sharing decisions also reassures the parent that the child has acknowledged their limitations within their asthma management decisions. Parents sharing knowledge and facilitating the child's involvement in decisions will ultimately increase the child's experiences of asthma management. Children may not necessarily always want autonomy. 'Shifting' the control

of the decision back to the domain of the parent tended to occur if the asthma treatment had not been effective, asthma symptoms were more severe, nocturnal symptoms occurred, and when to resume physical activity following symptoms. The sharing of decisions is a reciprocal process benefitting both child and parent.

Health professionals should work collaboratively with the family to encourage child autonomy commensurate with their cognitive ability and level of maturation (Lipstein *et al* 2015), while valuing the child and parent decision preferences. Collaborative working may alleviate tension during decision-making when the child's cognitive and complex thinking is developing. Recognise the difference between a child requiring guidance and support for the decision-making and when the parent dominates the decision could aid health professionals when supporting the transition of asthma management from the parent to the child. For example, when a child is demonstrating cues to self-management and is able to identify their symptoms are related to asthma, could trigger a learning opportunity to teach the child to administer the inhaler independently, instead of parents dominating decisions about inhaler administering. Health professionals should facilitate the child and parent to express any concerns they may have with the child's developing autonomy of the asthma management, through open discussions and sharing of experiences; parents report the information gleaned from health professionals as more valuable than information from other sources such as the world wide web (Thon & Ullrich 2009). Parents want to work in collaboration with health professionals (Smith *et al* 2013, Swallow *et al* 2013), enabling appropriate support for the child and family to develop strategies promoting safe, effective decision-making of the asthma management, pivotal in family-centred care (Mikkelsen and Frederickson 2011).

## **Strengths and Limitations**

The study strengths include listening to the 'voice' of the child and addressing the gap in research about child-parent shared decision-making for asthma management. One of the underpinning principles of this study was to accurately represent child and parent perspectives in a way that was meaningful, using the framework approach to data analysis facilitated transparency of data analysis increased the credibility of the findings. Limitations of the study included difficulty in recruiting children and parents; the sample is not representative of ethnically diverse population and fathers were under-represented.

## **Conclusion**

Health policy should take into account the child's ability to contribute to decisions about their care and care management plans in relation to their long-term condition. Autonomy in decision-making reflects the child's competence, preference for making decision and contextual factors including parenting styles, not chronological age. Support and guidance from health professionals to include the child in the management decisions for their asthma could promote optimum health behaviours in late life. Valuing and encouraging the child to participate in asthma management decision will provide children with the experiences to make decisions about their condition in the future. Effective management of asthma has the potential to reduce emergency admissions and consequently decrease expenditure on the National Health Service.

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