Child-parent shifting and shared decision-making for asthma management

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Aim
Explore and describe child-parent shared decision-making for the management of childhood asthma

Specific objectives
- Examine how children and parents make joint decisions about asthma management;
- Understand the process of parent to child transition to enable the child’s independent decision-making for their asthma management;
- Identify the facilitators and barriers that influence child-parent shared decision-making in relation to asthma management;
- Add to the theory of child-parent shared decision-making, through the development of a conceptual framework that could guide health care professionals when supporting child-parent decision-making, in relation to asthma management.
Background

- Asthma is a disorder of chronic airway inflammation, characterised by wheeze, cough, difficulty breathing, chest tightness (SIGN/BTS, 2013)
- Management involves prescribed inhaled medication
  - Prophylactic inhalers taken daily to prevent acute symptoms
  - Inhaled bronchodilators to treat acute breathing difficulties
- Combined cost of asthma care (adults and children) is approximately £2.5 billion with £900 million towards public health delivery annually (SIGN/BTS, 2013; Asthma UK, 2010)
  - 50% of resources directed towards acute care delivery and the 20% of individuals with severe asthma (NICE, 2013)
Shared decision-making

Involving the child within the decision-making process will facilitate a child developing good decision-making skills from a young age and could optimise long-term health outcomes (Hannah et al., 2012; McPherson and Redsell, 2009)
Study design

- Qualitative descriptive study using in-depth individual interviews
- Semi-structured interviews with families (parents (n=9) and children (n=8) with asthma)
- Art based activity at the beginning of the child interview to build rapport
- Framework approach underpinned data analysis
Study findings: who, what, when, why

- Making sense of asthma
- Independent decisions
- Control and responsibility
- Decision preferences
<table>
<thead>
<tr>
<th>Child (age)</th>
<th>Age diagnosed</th>
<th>Independent decisions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dean (7)</td>
<td>3 years</td>
<td>When to administer &amp; preventative inhalers, when symptoms require treatment, when to restrict physical activity</td>
</tr>
<tr>
<td>Paul (8)</td>
<td>1.5 years</td>
<td>When to administer reliever inhaler, symptoms require treatment, to cease physical activity in presence of asthma symptoms</td>
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<tr>
<td>Julie (8)</td>
<td>1.5 years</td>
<td>When to administer &amp; preventative inhalers, when not to avoid specific triggers, when require treatment, when to administer reliever inhaler in presence of symptoms</td>
</tr>
<tr>
<td>Amanda (9)</td>
<td>4 years</td>
<td>When to minimises physical activity in presence of symptoms, when symptoms require treatment</td>
</tr>
<tr>
<td>Alicia (10)</td>
<td>3 years</td>
<td>When to administer reliever inhaler, when asthma symptoms require treatment &amp; avoiding triggers, when to resume activity</td>
</tr>
<tr>
<td>Sally (11)</td>
<td>1.5 years</td>
<td>When to administer reliever inhaler, when asthma symptoms require treatment, when to administer reliever inhaler in presence of symptoms, when to take action to relieve symptoms</td>
</tr>
<tr>
<td>Nathaniel (11)</td>
<td>5 years</td>
<td>When to administer reliever &amp; preventative inhalers, when asthma symptoms require treatment &amp; administer reliever inhaler in presence of symptoms, when to avoid specific triggers,</td>
</tr>
<tr>
<td>Nicole (11)</td>
<td>5 years</td>
<td>When to administrers reliever &amp; preventative inhaler &amp; asthma symptoms require treatment, when to avoid specific triggers,</td>
</tr>
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</table>
Sharing decisions: child extracts

‘I 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

Sometimes when I have a bad cough and I am a bit shaky I will ask my mum if I should take my inhaler. She will say if you are wheezing or your chest is tight then I should and she kind of helps me to make that decision’
Nicole 11

‘I only let my mum know if I have taken like two puffs if it is really bad...’
Dean 7
Contextual factors

- 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
Children’s agency

A child demonstrates agency by ‘actively taking control, by taking charge and having a direct effect on their situation’ (John, 2003; p195).

‘…contexts and relationships can act as thickeners or thinners of a child’s agency’ (Klocker, 2007: p85)
Parent style influence child agency

- Permissive parenting style increases child agency
- Authoritative parenting style increases child agency
- Authoritarian parenting style reduces child agency
Conceptual framework of child-parent shared decision-making for asthma management

<table>
<thead>
<tr>
<th>Maintaining health</th>
<th>Parent makes decisions</th>
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<tbody>
<tr>
<td>▪ Making sense of the child’s illness</td>
<td></td>
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<tr>
<td>▪ Facilitators and barriers to the child’s self-management of asthma</td>
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<table>
<thead>
<tr>
<th>Child makes decisions</th>
<th>Shifting process</th>
<th>Parent makes decisions</th>
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</thead>
<tbody>
<tr>
<td>▪ Parent confident in child’s decisions: child supported to make decision</td>
<td></td>
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<tr>
<td>▪ Children’s agency</td>
<td></td>
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<tr>
<td>▪ Parenting styles</td>
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<td>▪ Child’s cognitive development</td>
<td></td>
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<tr>
<td>▪ Family systems: boundaries, controls and hierarchies</td>
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# Contextual influence to child decision-making

<table>
<thead>
<tr>
<th>Contextual influences</th>
<th>Factor</th>
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<tbody>
<tr>
<td><strong>Child</strong></td>
<td>Cognitive development, self-efficacy, locus of control, experience</td>
</tr>
<tr>
<td><strong>Decision</strong></td>
<td>Type of decision: ‘who’, ‘what’, ‘when’, ‘why’</td>
</tr>
<tr>
<td><strong>Parent</strong></td>
<td>Parenting styles, confidence in child’s ability, presence/absence</td>
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<tr>
<td><strong>Environment</strong></td>
<td>Home, school, locus of control</td>
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Study strengths

- Listened to the ‘voice’ of the child
- Parent perspective did not dominate the findings
- Interviews/child participatory drawing activity to build a rapport with child
- Experiential knowledge as a parent and school nurse of liaising with children
- Naturalistic environment reducing the potential child-researcher power balance
Key messages

- Children from aged seven years can make complex decisions about the management of their asthma.
- Although children may have the capacity to make asthma management decisions, many children want to share decisions with their parent.
- Asthma management decisions are a ‘shifting and shared process’, dependent on family dynamics and in differing contexts.
- Health care professionals need to incorporate child and parent decision preferences within the asthma management.
Thank you for listening

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