The impact and psychosocial burden of a child's asthma diagnosis: How can we help the family?



Joanne Dudeney¹*, Louise Sharpe¹ & Caroline Hunt¹ ¹The University of Sydney, New South Wales, Australia

BACKGROUND

- Asthma is the leading chronic disease in children and can lead to a decreased quality of life in children as well as an increased risk of developing an anxiety disorder
- Psychological distress is also documented for parents of children with asthma, with higher rates of anxiety reported for parents of children with asthma versus those of healthy children
- While there is only limited research investigating the impact different

METHOD

Sample

 nothers of children with asthma were recruited through advertisements in the community or due to their previous involvement in research

Data Collection and Analysis

Guided by the process specific to grounded theory method

periods of a child's asthma journey may have on parent and child anxiety (e.g., during asthma attacks, child maturing), no research has examined the experience of diagnosis as a precipitant for anxiety in the parent or child

AIMS

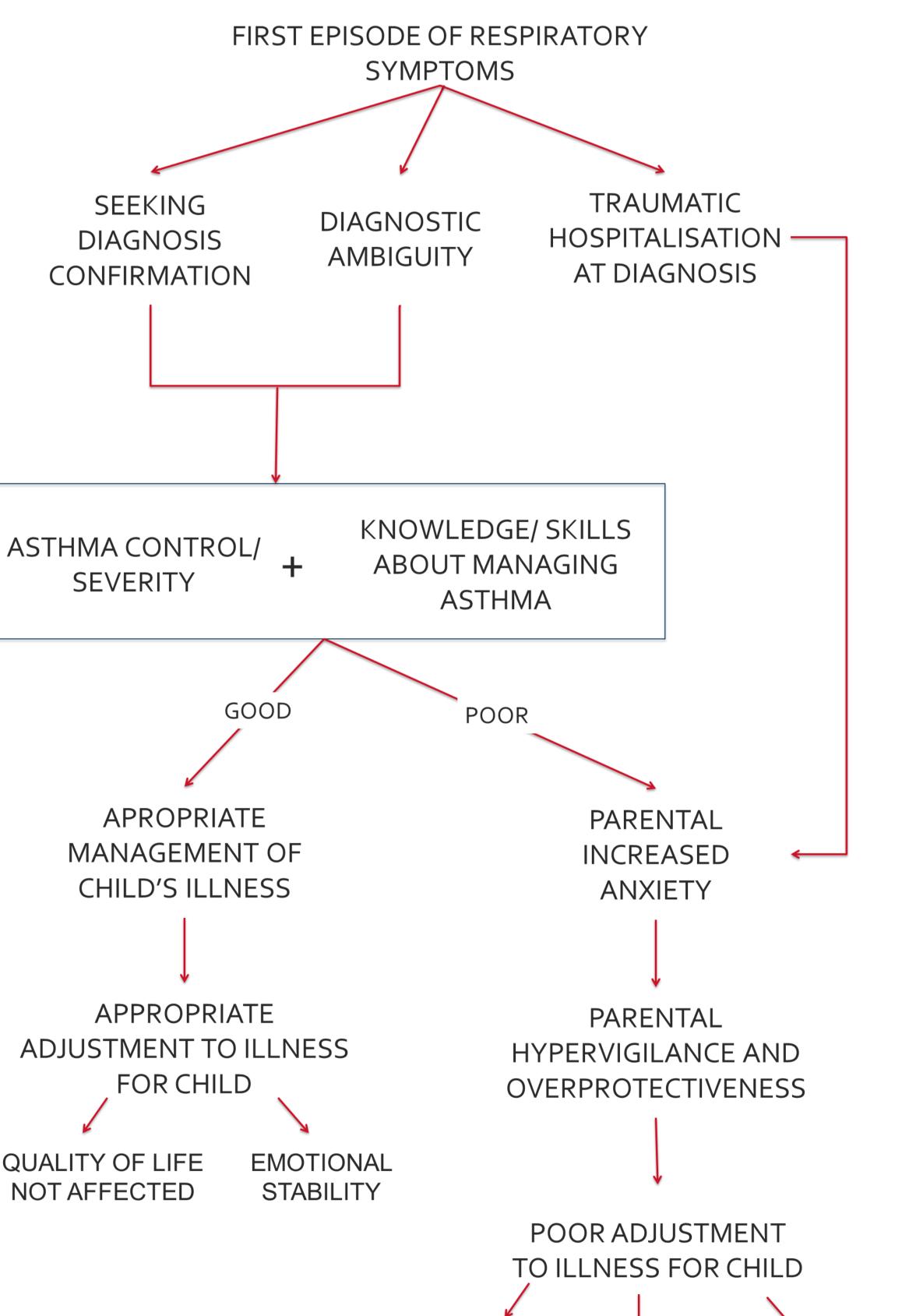
- 1. Understand whether the experience of a child's asthma diagnosis impacts parents and children to different extents
- 2. Determine why parents and children may react differently following initial diagnosis
- Semi-structured interviews were conducted to identify the impact of diagnosis and specific information and support needs until theoretical saturation was met and no new data was emerging
- All interviews were conducted by phone at The University of Sydney, Australia by a Clinical Psychology Registrar
- Interviews were audio-recorded and transcribed verbatim for content and thematic analysis
- The initial 3 interviews were coded by 2 members of the research team in order to agree upon a set of emergent themes

RESULTS

Experience of Asthma Diagnosis

The model presented outlines how the different experiences of a child's asthma diagnosis can affect the psychosocial burden of the illness for parents and children

- There were three distinct diagnostic experiences
 - <u>Seeking confirmation</u> parents take child to primary care physician to confirm child's symptoms are asthma. Parents experienced neutral emotional responses to the expected diagnosis.



- 2. <u>Ambiguity</u> children are not immediately given an asthma diagnosis and diagnosis requires additional visits to health care practitioners, further testing or the appearance of more symptoms. Parents experienced relief at finally receiving a diagnosis.
- 3. <u>Traumatic hospitalisation</u> during an emergency hospital admission for severe respiratory symptoms a child is diagnosed with asthma. Parents experienced trauma, shock and confusion at diagnosis.
- The level of a child's asthma control/ severity and parental knowledge/ skills about managing asthma affects how parents respond to their child's asthma
- Increased parental anxiety, hypervigilance and overprotectiveness can be the result of poor asthma control/ severity and management knowledge/ skills OR a traumatic diagnostic experience
- Children of these parents do not adjust to the illness as well as others

OUTCOMES

- The experience of a child's asthma diagnosis can have long ranging effects on both the child and parent
- Clear, unambiguous, diagnoses from health professionals and providing parents with knowledge about asthma may lead to more adaptive management of their child's asthma and could reduce both parental and child anxiety
- By determining both the role diagnosis plays and also what parents need to reduce the psychosocial burden of asthma, we can hopefully develop interventions that will enable parents to feel empowered to manage their child's asthma appropriately, and prevent the development of anxiety in parents and children with asthma



NEXT STEPS

- Work with health care providers to upskill parents about asthma management following diagnosis
- Investigate how to assist parents after emergency hospitalisations with the aim of reducing the development of anxiety
- Develop and pilot resources with parents and children about asthma and anxiety comorbidity and anxiety prevention strategies

* Correspondence to joanne.dudeney@sydney.edu.au