ABSTRACT

Background: Written asthma action plans are an important component of asthma self-management. However, these action plans may be difficult for patients with low health literacy, especially children, to understand. The addition of illustrations to health information can improve comprehension, recall and treatment adherence, which can lead to improved disease management.

Aim: To discern the perceptions of the somatic symptoms of paediatric patients with chronic asthma and aspects of their asthma management.

Method: Paediatric patients with chronic asthma aged 5 to 13 years who were either inpatients or outpatients of a Canadian paediatric hospital were asked to draw 2 pictures relating to how they felt when their asthma was well-controlled and how they felt during an asthma attack. The illustrations were evaluated using established visual theme categories. Following theme development, study team members individually analysed the pictures.

Results: 104 pictures drawn by 53 paediatric participants were analysed. Well-controlled asthma was commonly depicted by smiling faces (53%), sunshine (33%) and children playing sports outdoors (25%). During an asthma attack, images of sad expressions (60%), children unable to play or confined (28%), children coughing (22%), and lung pain or tightness (19%) were common.

Conclusion: Paediatric patients’ perceptions of their asthma was highly emotional. To improve comprehension and be effective, illustrations added to health information must be specific to the audience.


INTRODUCTION

Asthma is the most prevalent chronic paediatric condition, with a worldwide incidence of 10 to 30% of children. Children with asthma are more likely to miss school, visit the emergency room, become hospitalised, or develop a disability than children without asthma. International treatment guidelines for asthma suggest guided self-management of symptoms and medications should be used to improve outcomes. Children need to be active participants in their health care and have more autonomy in using their medications. The International Pharmaceutical Federation (FIP) has mandated that to improve use of medications: education about use of medicines should begin in childhood and extend into adolescence.

An effective component of asthma self-management is a written asthma action plan. A written action plan is adapted to meet patient-specific needs and outlines how and when to take medications based on symptoms. Although action plans can improve health outcomes, only a small percentage of patients receive them. Furthermore, written action plans are often text-heavy and difficult for some users to comprehend, especially children and adults with low health literacy.

Health literacy refers to an individual’s ability to read and comprehend medical information, which is often overestimated by physicians. Several key health outcomes for patients with chronic asthma can be enhanced through improved health literacy and self-management. Similarly, low health literacy is associated with poor longitudinal asthma outcomes, especially in regards to knowledge of asthma and self-management. This evidence highlights the importance of enhancing comprehensibility of self-management tools by providing information that is consistent with the health literacy level of patients. Unfortunately, health information is often above the comprehension level of most patients, where ideally the text should be written at an 8th grade level.

Using illustrations to reinforce the medical spoken word is well established and may be more appealing to a paediatric audience. The success of pictorial aids is dependent on the comprehensiveness of the illustrations and the way in which they were developed. Pictographic asthma action plans that have been developed for children are often based on adult perceptions of asthma. There is evidence supporting the inclusion of the target audience in developing illustrations to communicate health information and there is widespread agreement that this is important. Incorporating pictograms that have been validated by the target audience can improve comprehension and treatment adherence, and ultimately improve disease management and health outcomes.

The aim of this study was to discern the perceptions of the somatic symptoms of paediatric patients with chronic asthma and aspects of their asthma management.

METHOD

Patient Population

Patients were recruited from a paediatric inpatient ward and an outpatient clinic at the Children’s Hospital of Eastern Ontario, Ottawa, Canada. Inclusion criteria were children who: were aged 5 to 13 years, had chronic asthma for at least three months prior to the study, and were prescribed asthma medications (i.e. beta-2 agonists, inhaled corticosteroids, leukotriene inhibitors and/or inhaled anticholinergics). Exclusion criteria were: known...
developmental delays where the task of drawing could be problematic, communication barriers with carer/child, and/or inappropriate for inclusion as determined by the child-life specialist. Children too young to remember their last asthma exacerbation were not invited to participate in the study.

Characterisation of the study population included the patient’s grade school level, age when asthma was first diagnosed and primary language spoken (English, French or other as disclosed by the family and/or child). Ethics approval was granted by the Research Ethics Board at the Children’s Hospital of Eastern Ontario.

Illustrations
Following informed parental/guardian consent and assent from the child, participants were asked to draw two pictures (without adult assistance) relating to how they felt when asked the following questions:

1. What happens when you have an acute asthma attack?
2. What happens to your body when the asthma is controlled?

Participants were provided with coloured pencil crayons and/or markers and two blank pieces of paper entitled ‘Asthma Project’, with the two questions, and the Research Ethics Board protocol number written on them.

The pictures were drawn during clinic visits (pre- or post appointment with physician) for outpatients or at the bedside for inpatients. If the illustrations needed clarification, a note was added to the page based on the child’s explanation. On completion of the illustrations, a certificate of merit was given to the participants.

Data Analysis
Participants were divided into three age groups (5 to 7, 8 to 10 and 11 to 13 years) based on Piaget’s Cognitive Development Theory. Visual theme categories were adapted from Pradel et al. using a sample of 15 drawings reviewed by a multidisciplinary study team (psychology, pharmacy, nursing and a child-life specialist). The themes identified were representative of the child’s perception of their asthma. Following theme development, study team members individually analysed the pictures. The frequency of children’s responses about their asthma symptoms and its management were collated. A chi-square test was performed to test whether the frequencies

Table 1. Characteristics of paediatric participants with chronic asthma

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>No. of patients (n = 53)</th>
</tr>
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<tbody>
<tr>
<td>Department</td>
<td>Inpatient 18 (34%)</td>
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<tr>
<td></td>
<td>Outpatient 35 (66%)</td>
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<tr>
<td>Age (Male:Female)</td>
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<tr>
<td>5-7 years</td>
<td>24 (10:14) (45%)</td>
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<tr>
<td>8-10 years</td>
<td>17 (8:9) (32%)</td>
</tr>
<tr>
<td>11-13 years</td>
<td>12 (8:4) (23%)</td>
</tr>
<tr>
<td>Grade level</td>
<td>Kindergarten 6 (11%)</td>
</tr>
<tr>
<td></td>
<td>1 13 (25%)</td>
</tr>
<tr>
<td></td>
<td>2 6 (11%)</td>
</tr>
<tr>
<td></td>
<td>3 7 (13%)</td>
</tr>
<tr>
<td></td>
<td>4 7 (13%)</td>
</tr>
<tr>
<td></td>
<td>5 2 (3.8%)</td>
</tr>
<tr>
<td></td>
<td>6 6 (11%)</td>
</tr>
<tr>
<td></td>
<td>7 2 (3.8%)</td>
</tr>
<tr>
<td></td>
<td>8 4 (7.5%)</td>
</tr>
<tr>
<td>Age when asthma diagnosed</td>
<td>0-11 months 8 (15%)</td>
</tr>
<tr>
<td></td>
<td>1-2 years 23 (43%)</td>
</tr>
<tr>
<td></td>
<td>3-5 years 8 (15%)</td>
</tr>
<tr>
<td></td>
<td>6+ years 9 (17%)</td>
</tr>
<tr>
<td></td>
<td>data missing 5 (9.4%)</td>
</tr>
<tr>
<td>First language</td>
<td>English 40 (76%)</td>
</tr>
<tr>
<td></td>
<td>French 11 (21%)</td>
</tr>
<tr>
<td></td>
<td>Other 2 (3.8%)</td>
</tr>
</tbody>
</table>

Figure 1. Sample illustrations from children with chronic asthma who were asked to draw about how they felt during an asthma attack (7-year-old female, 13-year-old male).
varied across age groups, gender and language. To
determine how children’s perceptions change through
their cognitive development, multiraters were used to
ensure inter-rater reliability by showing the percentage
of collective agreement subdivided by age group. An
80% (4 out of 5) inter-rater agreement threshold was used
to identify the visual themes.

RESULTS
Fifty-three paediatric patients were enrolled in the study
and their characteristics are described in Table 1.

Illustrations
One hundred and four illustrations were analysed – 53
for ‘What happens when you have an asthma attack?
(Figure 1) and 51 for ‘What happens when your asthma
is well controlled?’ (Figure 2). Two patients were not able
to complete both tasks due to time restraints. Forty of
the 104 illustrations did not reach the inter-rater
agreement threshold of 80% (4 out of 5) following
individual analysis and were discussed by raters until a
consensus was reached.

Common Features
Illustrations to the question: ‘What happens when your
asthma is well controlled?’ yielded five broad themes:
somatic symptoms, emotional status, weather, level of
activity and medication use. Children of different ages,
gender and language spoken created similar drawings to
represent their asthma status (p > 0.05). The data collected
for each category theme and drawing feature organised
by age group is outlined in Table 2.

The drawings representing children’s emotions to
the question: ‘What happens when you have an asthma
attack?’ yielded four broad themes: somatic symptoms,
emotional status, level of activity and emergency need
for medical care. No significant difference was evident
between the three age groups, gender and language
spoken for any of the four themes (p > 0.05). The data
collected for each category theme and drawing feature organised by age group is outlined in Table 3.

<table>
<thead>
<tr>
<th>Category theme</th>
<th>Drawing feature</th>
<th>5-7 years (n = 23)</th>
<th>8-10 years (n = 16)</th>
<th>11-13 years (n = 12)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Somatic symptoms</td>
<td>Lungs clear/breathes easily</td>
<td>1 (4.3%)</td>
<td>1 (6.3%)</td>
<td>3 (25%)</td>
</tr>
<tr>
<td></td>
<td>Healthy heart</td>
<td>1 (4.3%)</td>
<td>1 (6.3%)</td>
<td>0</td>
</tr>
<tr>
<td>Emotional status</td>
<td>No need to cry</td>
<td>0</td>
<td>1 (6.3%)</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Happy expression</td>
<td>19 (83%)</td>
<td>13 (81%)</td>
<td>10 (83%)</td>
</tr>
<tr>
<td>Weather</td>
<td>Sun shining</td>
<td>11 (48%)</td>
<td>4 (25%)</td>
<td>2 (17%)</td>
</tr>
<tr>
<td></td>
<td>Rainbow</td>
<td>1 (4.3%)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Level of activity</td>
<td>Hockey</td>
<td>0</td>
<td>2 (13%)</td>
<td>2 (17%)</td>
</tr>
<tr>
<td></td>
<td>Soccer</td>
<td>1 (4.3%)</td>
<td>4 (25%)</td>
<td>3 (25%)</td>
</tr>
<tr>
<td></td>
<td>Other sport/activity/playing outside</td>
<td>8 (35%)</td>
<td>4 (25%)</td>
<td>1 (8.3%)</td>
</tr>
<tr>
<td></td>
<td>Can sleep well/doesn’t need to sleep</td>
<td>1 (4.3%)</td>
<td>2 (13%)</td>
<td>0</td>
</tr>
<tr>
<td>Medication use</td>
<td>Takes regular medication to maintain asthma control</td>
<td>0</td>
<td>2 (13%)</td>
<td>0</td>
</tr>
</tbody>
</table>

Percentages may add up to more than 100% as more than one theme was represented within some pictures.
DISCUSSION

When differences in cognitive ability in accordance with Piaget’s Cognitive Development Theory were taken into account there were no significant variances in the number of images classified in each category between the age groups. The lack of difference between developmental stages suggests children aged 5 to 13 years have similar perceptions of asthma symptoms and its management.

When participants were asked to draw pictures about what happened when their asthma was under control, they drew pictures of sunshine (33%), smiling faces (53%) and children playing sports outdoors (25%). The Calgary Health Region’s asthma plan has pictograms that portray children outdoors, a smiling face and a child happily sleeping. For the most part, these themes are consistent with what our participants produced, although only three (6%) of our drawings had a child sleeping well. An asthma action plan developed for the Hennepin County Medical Center, Minneapolis also includes a picture of children playing soccer in the Green Zone (asthma under control). This is the only picture representing this level of control, therefore, limiting the number of children who would identify with what the pictogram represents. Including multiple images for each level of control may increase the applicability of the pictogram.

On the other hand, when participants were asked to draw pictures about what happened when they had an asthma attack, a wider array of images emerged. They drew pictures that included children with sad expressions (60%), lung pain or tightness (19%), children coughing (22%) and children unable to play or confined (28%). Under the heading ‘Asthma Not in Control’, the Calgary Health Region’s pictogram has an image of a frowning face, a child lying awake in bed coughing, and a child with an elephant standing on his chest. The frowning face is consistent with what our participants produced (sad expressions). Also in agreement were our drawings of the child lying awake coughing, while only two (4%) drawings were of children unable to sleep. The image of an elephant standing on the chest of a child were not consistent with any of our drawings.

The Hennepin County Medical Center’s action plan includes images that closely resemble those produced in our study. Their Yellow and Red Zones (asthma not controlled) have images of chest tightness, children coughing/wheezing and children awake at night, whereas this image was only produced by two (4%) of our participants. The coughing and chest tightness correlate better with our results. Under Zones 3 and 4 (asthma not well controlled) of the Charing Cross Hospital’s asthma action plan there is an image of a person awake in bed coughing beside a person hunched over a chair. Other than the coughing, there is little consistency with their images and how the children in our study perceived their asthma management.
McGrath et al. have created the Dalhousie Dyspnea Scales, three, 7-item, pictorial scales measuring throat closing, chest tightness and effort. They reported that children aged 8 to 18 years were able to understand these scales and had at least interval properties and valid psychophysical measures of self-report of dyspnoea in asthmatic children. The Dalhousie Dyspnea Scale pictorials are beneficial for rating somatic symptoms, however, our study demonstrated that emotional status and weather are also important aspects that should be included in asthma education material. On the other hand, the Dalhousie Dyspnea Scale correlated well with our findings for varying activity intensity based on level of asthma control (i.e. drawings of playing sports, confined to bed, unable to sleep).

One of our study limitations was that the sample did not include children under 5 years or over 13 years of age, thus limiting generalisability of our findings. We also did not investigate whether the pictures drawn by our cohort would be effective in asthma education material.

In conclusion, paediatric patients’ perceptions of their asthma was highly emotional. To improve comprehension and be effective, illustrations added to health information must be specific to the audience.

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References