Storytelling: Collaborating with Patients and Parents to Create a Children’s Book Representative of Their Experiences

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BACKGROUND

- Children’s literature can supplement the care of children living with chronic illnesses, has been shown to promote mental health and facilitate coping with hospital stays, and can be used as a key resource to help educate young patients, families, and communities about the illness experience.

- Children experiencing disease or disability are rarely depicted in children’s literature and are often overlooked or presented inaccurately in children’s books.

- There is an unmet need for resources which accurately reflect the experiences of children in these circumstances and could explore what may lie ahead, normalize experiences, and provide a sense of comfort during times of stress and uncertainty.

METHODS

1. Informal discussions with multidisciplinary providers within the Endocrinology Department of the Children’s Hospital at Dartmouth Hitchcock (CHaD) occurred June — August 2021 to identify potential participants and literature gaps.

2. Semi-structured individual interviews were conducted August — October 2021 to gain insight of the experiences of those with Type 1 Diabetes in the Upper Valley.

3. Feedback sessions were initiated in October 2021 and have been ongoing to discuss the children’s book development, plot, illustrations, and additional information.

INTERVIEW PROBES

- What does Type 1 Diabetes look like for you?
- Describe a typical day
- What are things you like to do as a family? What are things you like to do for you?
- Where do you find support?
- What is the best way to incorporate management of Type 1 Diabetes in a children’s book?
- Should the book focus on a normal day (at school) or an adventure (like a field trip)?

PARTICIPANT INFORMATION

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<thead>
<tr>
<th></th>
<th>Patients (n=4)</th>
<th>Parents (n=2)</th>
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<tbody>
<tr>
<td>Male sex (patient), n (%)</td>
<td>1 (25)</td>
<td>1 (50)</td>
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<tr>
<td>Patient age at time of interview, mean (median, range)</td>
<td>12.3 (12.5, 6-18)</td>
<td>9.5 (9.5, 6-13)</td>
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<tr>
<td>Patient age at time of diagnosis of Type 1 Diabetes, mean (median, range)</td>
<td>7 (6, 3-13)</td>
<td>8 (8, 3-13)</td>
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