



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

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



COMMON QUESTIONS & PARTICIPANT THEMES

- “Things I get asked often in my daily life as [someone with diabetes]: does it hurt when I test my sugar, if my insulin pump is a phone, what can your friends or parents do to help, what’s the best part of diabetes” (Patient 2)
- “Some kids asked if [diabetes] is contagious, but my friends were really supportive” (Patient 4)
- “A peer was like, ‘that’s really annoying’ when he heard the CGM alarm” (Parent 1)
- “[Classmates] ask ‘what is that’ when she’s wearing her pods or sensors” (Parent 2)
- “It’s not really talked about...if you’re growing up [as someone with diabetes] you don’t see anyone who’s doing anything outstanding who has diabetes” (Patient 2)
- “My classmates were not really [supportive]” (Patient 1)
- “He lost the ability to be free” (Parent 1)
- “Shouldn’t [diabetes] be represented in books that everybody is reading?” (Parent 2)

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