Characterizing worries in parents of youth with type 1 diabetes

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BACKGROUND & AIMS
- Parents of youth with type 1 diabetes (T1D) often express concerns and worries about their children's health and diabetes management.
- Prior research has mostly quantified parental concerns about specific aspects of T1D, such as hypoglycemia.
- Little research has aimed to characterize the broad range of parental worries associated with T1D management.
- Describing the scope of parental worries may inform the development of behavioral interventions that target multiple concerns commonly experienced by parents.
- The goal of these targeted interventions include reducing parental distress and enhancing effective family teamwork around youths’ diabetes management.
- The aim of this research was to characterize worries in parents of youth with type 1 diabetes.

METHODS & PARTICIPANTS
- As part of a larger qualitative study on diabetes-related quality of life, 43 people (age 12-89 yrs.) with T1D and 37 of their parents or partners were interviewed.
- Interviews addressed many domains of quality of life including: social issues, mood, food & eating, as well as feelings about T1D worries.
- Interviews were recorded and transcribed verbatim.
- Three psychologists and three research staff reviewed transcripts to develop thematic codes, which were applied using NVivo software (25% double-coded).
- A subset of 23 interviews with parents of children and adolescents (age 4-17 yrs) were analyzed for themes related to T1D-related worries.

Table 1. Participant Demographics

<table>
<thead>
<tr>
<th>Characteristics (n=23)</th>
<th>% (n) or Mean±SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Youth Age, years</td>
<td>10.9±3.8</td>
</tr>
<tr>
<td>Youth Gender, % female</td>
<td>35% (8)</td>
</tr>
<tr>
<td>Youth Race/Ethnicity</td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>30% (7)</td>
</tr>
<tr>
<td>Non-Hispanic Black</td>
<td>30% (7)</td>
</tr>
<tr>
<td>Non-Hispanic White</td>
<td>39% (9)</td>
</tr>
<tr>
<td>Parent Gender, % female</td>
<td>91% (21)</td>
</tr>
<tr>
<td>Insurance, % private</td>
<td>52% (12)</td>
</tr>
<tr>
<td>Duration of T1D, years</td>
<td>4.0±2.9</td>
</tr>
<tr>
<td>Hemoglobin A1c, %</td>
<td>8.7±1.7</td>
</tr>
</tbody>
</table>

RESULTS
- Four themes emerged related to diabetes-related worries in parents.
- Parents described:
  - (1) Experiencing constant worry about their child’s diabetes, describing diabetes-related concerns as “always in the back of my mind.”
  - (2) Short-term worries about current diabetes problems, day-to-day management demands, and safety, such as the parent and child’s ability to detect and treat dangerously low and high blood glucose levels, especially overnight.
  - (3) Worries about the long-term impact of diabetes management on their children’s health outcomes, including concerns about chronic hyperglycemia in childhood resulting in future medical complications and/or a shortened lifespan.
  - (4) Concerns regarding diabetes interfering with their child’s social relationships or the child being teased about having T1D or doing management tasks (e.g., blood glucose monitoring, insulin administration) in public.

1. Constant Worry
- “The worry is constant. I don’t think any day goes by that I don’t worry about his diabetes” – Mother of a 17 y.o. male
- “How do I feel? I feel worried. I feel that, you know, either the meter’s off, or what if it’s the wrong number or giving her the wrong, what if I counted wrong carbs, you know; it’s always a fear for me.” – Mother of a 7 y.o. female
- “My phone is on me, in my pocket or in front of me 24/7 sort of thing” – Mother of a 3 y.o. male
- “I’m worried I did something wrong. Everyone else around me is happy while I’m just there thinking, what did I forget? Is something going to happen?” – Mother of a 6 y.o. male

2. Day-to-Day Management Worries
- “The biggest worry is that she’ll drop so low that she’ll have a seizure or possibly die. That is definitely a fear that both my husband and I have during the night hours. It’s a hard – we use the technology that’s available, but there are times when I wake up and I have to go check.” – Mother of a 11 y.o. female
- “I worry about his A1c, I worry if he’s okay. I worry how he’s doing in PE, how he’s doing in school, if he’s able to focus long enough… I don’t know there’s a thousand worries.” – Mother of a 6 y.o. male
- “When we got the CGM, it’s hard not to look at that screen. We have a screen in our room. It’s a little live feed, so it’s hard not to walk by, and then walk by again, and then walk by again.” – Mother of a 9 y.o. male

3. Long-Term Impact Worries
- “I worry about long-term effects. As an ICU adult nurse I see the long-term effects of uncontrolled diabetes which is why I’m very adamant about training him [about his diabetes]” – Mother of a 5 y.o. male
- “I worry what he’s going to do if I’m not there helping him? Right now, I’m trying to take the burden off of him, I guess. I worry about him burning out.” – Mother of a 9 y.o. male
- “She’s had it [diabetes] for so long already and she’s only 12. How’s it going to affect her as she gets older, the toll it will have on her body.” – Mother of a 11 y.o. female

4. Social Context Worries
- I worry about her relationships with friends and maybe boyfriends, as she gets older. I don’t want her to feel like diabetes is the reason that somebody doesn’t like her or does – I worry about her emotional health, as well as her physical health.” – Mother of a 11 y.o. female
- “Sometimes if we go to a restaurant [child is] injecting, you know, little kids might look or whatever, he’s kind of embarrassed.” – Mother of a 12 y.o. male
- “At times I kind of feel bad for him because he gets picked on a little bit. But it just brings me closer to him than my other children because he’s really going through something and it’s bad because it’s just such a young age.” – Mother of a 7 y.o. male

CONCLUSIONS
- Parents described a spectrum of T1D-related concerns, ranging from current risks and stresses to future health complications, and reported having no relief from the constant state of worry.
- Pediatric psychologists working with families living with T1D may benefit from assessing parental worries in these four areas and integrating parent-focused intervention components targeting these issues.
- Providing support to help parents better manage diabetes-related worries and identify supportive roles for family members may reduce parental diabetes distress, facilitate effective family diabetes management, and ultimately improve children’s glycemic outcomes.