Parents Raising a Child with Type 1 Diabetes: Experiences and Recommendations for Services

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Leishman, Joan; Jubber, Ann; Dalton, Colette; and Mork, Stacey, "Parents Raising a Child with Type 1 Diabetes: Experiences and Recommendations for Services" (2010). FHSS Mentored Research Conference. 200.
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Parents Raising a Child with Type 1 Diabetes: Experiences and Recommendations for Services

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Abstract

Twenty parents raising a child with type 1 diabetes participated in one hour focus groups. Parents identified challenges related to having a child with diabetes and possible recommendations for services to overcome those challenges.

Rationale/Background

- When a child is diagnosed with diabetes, parents experience unique physical and emotional demands (Whittemore et al., 2003) which include an intense feeling of constant vigilance associated with their child’s diabetes as well as a profound feeling of responsibility.
- Parents’ responsibilities may include blood glucose monitoring, meal planning, and insulin administration, among other things.
- Parents may also experience feelings of fear concerning the effects of diabetes on their child, including hypoglycemia or severely low blood glucose levels (Marrero et al., 1997), as well as parents’ beliefs about their inability to execute certain aspects of the diabetes regimen (Streissand et al., 2005).
- Because of these potential demands, we sought to identify the self-identified major challenges of parents raising a child with type 1 diabetes, in an effort to identify the most important intervention needs.

Research Questions

- What are the perceived challenges identified by parents raising a child with type 1 diabetes?
- What do parents recommend as beneficial services for helping them cope with their challenges and needs when raising a child with type 1 diabetes?

Sample

- 15 families raising a child with type 1 diabetes
  - 14 mothers
    - 6 fathers
  - Age of mother: $M = 37.79$; $SD = 9.44$
  - Age of father: $M = 36.00$; $SD = 9.53$
  - Gender of child with diabetes: 10 males and 5 females
  - Age of child with diabetes (years): $M = 9.83$; $SD = 3.35$
  - Years since diagnosis: $M = 4.51$; $SD = 2.58$
  - Children in family: $M = 3.67$; $SD = 1.29$
  - Race of family: 13 Caucasian

Procedures/Measures

- Parents participated in focus groups led by a registered nurse in a university or hospital classroom.
- Focus groups were audio-taped and transcribed verbatim.
- Parents were asked to talk about:
  - Their experiences, needs, and challenges in raising a child with type 1 diabetes
  - Recommendations for possible services to assist them in meeting their needs and challenges.
- Data was coded by two independent coders and managed using NVivo qualitative software.
- Some quotations were double-coded.

Challenges of Parents Raising a Child with Type 1 Diabetes

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sample Quotations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional Care</td>
<td>You know it’s just like when somebody dies you go through those phases, you know the guilt and the anger and the grief and your acceptance. I just bawl. You know? Why me? Why us? Why him? What did he do? What did I do? So I have to keep telling myself it’s okay to cry.</td>
</tr>
<tr>
<td>“It’s Hard”</td>
<td>It’s hard. But…you…wake up the next morning [and] everyone’s still alive and you start over again. But, I think that, for me that’s the hardest part. It’s just those days to day…</td>
</tr>
<tr>
<td>Lifestyle and Learning Curve</td>
<td>“…the other thing that’s hard is we’re afraid to ever leave my son in someone else’s care…my son is now a boy scout, when we go on camp trips, guess who ends up having to rearrange his schedule so he can go with him?</td>
</tr>
<tr>
<td>Physical Care</td>
<td>He was up and down [his blood sugar]. That’s when she [the mom] quit sleeping because she didn’t trust that he was going to be there in the morning. He can have a seizure at night and then be dead.</td>
</tr>
<tr>
<td>Finances and Insurance</td>
<td>“And cost has been a huge issue...having a hundred plus dollars of medical expenses every month, when we were kinda tight to begin with. And we weren’t planning on that.”</td>
</tr>
</tbody>
</table>

Recommendations for Services

Parent-identified needs that could be satisfied by services:
- Early and continuous education and lifestyle management
  - Physical care
  - Emotional aspects
  - Parenting techniques related to diabetes management
- Types of support
  - Non-medical:
    - Parent-visitor programs
    - List of parents of children with diabetes who could be resources
    - Parent support groups (online or in person)
    - Programs to promote school and community awareness
  - Medical:
    - More consistent contact with medical professionals
    - Better information from medical professionals (need for diabetes education)
    - Lists of medical professionals that could be called for information
    - Camps and health expos sponsored by medical professionals
    - Diabetes clinics that employed professionals who addressed physical care, nutrition, and emotional aspects (social worker) of diabetes management

Discussion and Conclusion

- Major themes of challenges that emerged from the data were emotional burden, physical care, changes in lifestyle, and finances/insurance.
  - Emotional burden and physical care were the major challenges most frequently mentioned by parents.
- In addition to recommendations for services listed above, parents expressed the desire to be understood by extended family and friends as well as to be respected by health care professionals. As one mother explained, “People need to listen… I am a good parent trying to do what’s right... teach me, but listen to me.”

References