The Experiences of Siblings Living with a Child with Type 1 Diabetes

Donna Freeborn, PhD, FNP, CNM

Authors

- Donna Freeborn, PhD, FNP, CNM, Brigham Young University
- Tina Dyches, EdD, Brigham Young University
- Susanne Roper, PhD, Brigham Young University
- Barbara Mandleco, PhD, RN, Brigham Young University
- No conflict of interest or sponsorship exists for any author

Funding

Brigham Young University College of Nursing Creative Works Council

Purpose

- To explore the experiences of siblings living with a child with type 1 diabetes
- To identify clinical implications for nurses who work with families of children with type 1 diabetes

Participants

- Siblings
 - 7 males, 6 females: ages 5-16 years (M=10.69 years)
- Children with type 1 diabetes
 - 3 males, 4 females: ages 5-12 (M=8 years);
 diagnosed with diabetes 1 to 7 years (M= 4 years)
- Parental consent and child assent was obtained from each participant

Methods

 Six separate audio recorded focus groups held over a four month period

Focus Group Questions

- Tell us about your sibling who has diabetes
- What do you know about diabetes?
- How does having a sibling with diabetes affect you?
- How does having a child with diabetes affect your family?
- What kind of information would be helpful to you in living with a sibling with diabetes?

Themes

- Basic knowledge about diabetes
- Misunderstandings about diabetes
- Not personally affected by diabetes
- Awareness of increased parental stress due to diabetes
- Would like to be more involved in diabetes management

Basic Knowledge about Diabetes

- Familiar with terms such as glucose, highs/lows, and pumps
- "It's something caused by your pancreas and your pancreas won't create insulin and the shot's that's what helps it...insulin makes sugar so it doesn't go high and kill you or make you uncomfortable."
 10 year old male

Misunderstandings about Diabetes

- Had basic knowledge but didn't really understand about diabetes
- "... so like he eats something he'll die. Well, he won't die, he'll just have to battle for it. And he won't have anything to help it. I know there's something to help it. And I know what it's called... I know what it's called but I forgot." 6 year old female

Not Personally Affected by Diabetes

- Participants did not feel affected by their sibling's diabetes
- "... you just kind of get used to it after a while.
 You just hardly notice it. I don't even know that she has diabetes... promise you, you will not notice it." 12 year old female

Awareness of Increased Parental Stress due to Diabetes

- Financial worries, diabetes management difficulties, parental stress
- "My mom and my dad have to pay a lot of money for all the supplies and stuff." 8 year old male
- "My mom gets frustrated with my sister when she doesn't do something." 9 year old male
- "It freaked them out at first." 12 year old female

Would Like to Be More Involved in Diabetes Management

- Siblings expressed a desire to learn more about diabetes and be more involved in its management
- "...when I'm ten I can do tending...I want to know how to do the shots. I want to grow up so I can help him." 6 year old female

Clinical Implications

- Provide age appropriate education to siblings
- Encourage parents talk with all their children about diabetes
 - Clarify misconceptions
 - Educate them about diabetes management
 - Include them, when appropriate, in discussing diabetes issues

Future Research

 Explore intervention strategies for expanding siblings understanding of diabetes

Questions?

