

# Adults with Type 1 Diabetes: Lifetime Support and Management

Donna Freeborn, PhD, APRN; Jordan Scanlon, RN; Tina Dyches, PhD; Susanne Olsen Roper, PhD; Barbara Mandleco, PhD, RN

### Purpose:

• To explore family support and its effects on diabetes management of adults with type 1 diabetes

### Background:

- T1DM requires lifestyle changes
  - Diet modification
  - Blood glucose monitoring
  - ° Carbohydrate counting
  - ° Insulin administration
- Adults with T1DM have a unique perspective on how family support affected their diabetes management as children, adolescents, and adults

#### Method:

• Biographical method consisting of two in-depth interviews

### Sample:

- 23 adult females and 12 adult males
  - Ages at interviews varied from 19 to 70 years (M=36.54, SD=16.65)
  - ° Ages at time of diagnosis varied from 2 to 35 years (M=15.06, SD=9.84)
  - ° Years since diagnosis varied from 1 to 54 years (M=21.46, SD=12.87)

#### Procedure:

- First interview: "Tell me about growing up and living with type 1 diabetes"
- Second interview—Specific questions included:
  - ° "Tell me about when you were diagnosed with type 1 diabetes"
  - "How were your family and friends supportive/non-supportive?"
  - ° "How compliant have you been throughout your lifetime to your health care regime?"
  - "What were the biggest factors in helping you stay compliant?"

"My mom was really involved. She helped me by planning meals together. We would go to the grocery store, and she would help me pick out foods that I liked that were in the meal plan."

~30 year old female diagnosed at age 10

"I appreciate the fact that my mother did everything she could to allow me to be as normal as possible."

64 year old female diagnosed at 10



"I wasn't diagnosed until 12 years of age, so I was getting to the point where I kind of wanted to be a little bit independent. I know that was probably scary for her, but at least for me, I think it would have been healthy for her to give me a little bit of a leash. Let me figure it out on my own instead of feeling so reigned in."

~28 year old female diagnosed at age 12



### Findings:

- Factors that increased compliance included:
  - Positive family involvement, both with siblings and parents
  - Increased early independence in managing their diabetes
  - ° Education about type 1 diabetes for both children and families
  - Involvement of other influential adults in teaching the importance of diabetes management
  - Motivation to live up to their dreams
  - ° Increased knowledge that compliance was possible
- Factors that decreased compliance included:
  - ° As a child, viewing diabetes as a chore
  - Feeling different from other children and family members
  - Over-protective parents who didn't encourage independent self-management of diabetes
  - Changing routines such as going on vacation or transitioning to college
  - Being stressed due to the emphasis on diabetes management and health

# Implications for Nurses and Health Care Practitioners:

- Provide clear education to children and adolescents about their disease
- Emphasize that they can still participate in favorite activities
- Explain their role in assuming independent self-management skills
- Teach children and their families that they can lead healthy, normal lives
- Be optimistic and supportive about the future
- Provide support for the family

"My parents tried to teach me to not be defined by my DM. I want to take care of it really quickly as needed so it doesn't have to be a big part of my life, and that's kind of how I still live."

~24 year old male diagnosed at age four