Parents of children with diabetes described the transition to the insulin pump in terms of enhanced freedom and quality of life for all family members

Sullivan-Bolyai S, Knafl K, Tamborlane W, *et al.* Parents' reflections on managing their children's diabetes with insulin pumps. *J Nurs Scholarsh* 2004;**36**:316–23.

Q What are the day to day experiences of parents in managing their children's diabetes using continuous subcutaneous insulin infusion (insulin pump)?

DESIGN

Qualitative description.

SETTING

A paediatric diabetes clinic in the eastern US.

PARTICIPANTS

21 parents (14 mothers and 7 fathers) of 16 children <12 years of age (mean age 7 y, 14 boys) with type 1 diabetes who were using the insulin pump. All parents were Caucasian and well educated.

METHODS

Parents participated in interviews that lasted 90–230 minutes and included questions on the daily management of diabetes before and after the pump. Analysis was based on verbatim transcripts of interview audiotapes and field notes. Credibility of descriptive summaries was validated through member checks.

MAIN FINDINGS

Parents' responses were characterised by 5 themes. (1) *Introduction to the pump.* Parents learned about the pump from nurse practitioners or physicians and through friends or relevant websites. (2) *Decision-making process.* All parents believed that the pump would help their children attain better glucose control than multiple daily injections (MDIs), but they varied in how quickly they accepted the pump as a management strategy. Several parents initially displayed hesitation about having their children on "mini life-support," worrying that the catheter would fall out or malfunction. Some fathers feared their children would be bullied at school. Many school aged children were receptive to using the pump, whereas preschool children often expressed fear and a preference for MDIs. (3) *Transition from MDIs to the pump.* The transition to the pump was described as a process of re-education for parents, children, and other caregivers. Parents varied in the time it took to become comfortable (10 d to 2–3 mo) and confident (6 wks to 6–9 mo) with the pump. Many found the early weeks to be scary, similar to the period after initial diagnosis. Parents had to rethink what daily life involved: "...Before, I had to match [my child's] food to the insulin and now it [the pump] is matching the insulin [boluses] to what he is eating." Several parents described having to learn to sleep through the night and not check their children's glucose. Children >6 years of age became more involved in daily glucose management, quickly learning about pump mechanics and counting carbohydrates. (4) *Day to day diabetes management with the pump.* All parents felt that their children had better glucose control with the pump than with MDIs: crises did not last as long and "sick day care" was more manageable. Stories of mealtimes highlighted the flexibility the pump allowed the child, parents, and family. One parent described the pump as the "Zen of diabetes management," which allowed her to put constant thinking about diabetes in the background. For some, the pump allowed easier sharing of diabetes management with their children; communication

about diabetes was facilitated because of the historical log in the pump, which also led to fewer errors. All fathers were actively involved in diabetes management with the pump. Parents emphasised that the pump still required work; some reported testing glucose levels more frequently, and 6 parents were tempted to set glucose goals too high. (5) *Quality of life with the pump.* Parents reported that the pump allowed them to live their former lives and "gave them their children back." They worried less about overall care, hypoglycaemia, and mealtimes. For many, sleep returned to normal, they had more free time, and family and friends were more willing to baby sit. Children were said to be in "a better mood" and have better concentration in school. They could eat when and what they wanted, "sleep in," and participate in social activities without the rigidity of eating at specific times. In general, family life became more spontaneous and less time driven.

CONCLUSION

Parents of children with diabetes described the transition from multiple daily injections to an insulin pump in terms of increased flexibility in their daily lives and improved quality of life for all family members.

Commentary

The effectiveness of insulin pump therapy in reducing glycosylated haemoglobin and hypoglycaemic events in young children with type 1 diabetes has been well documented.¹ What is less well recognised is the importance of patient and caregiver experience. The study by Sullivan-Bolyai *et al* acknowledges this by focusing on parents' perspectives of the transition to pump therapy.

The parental response to a diagnosis of childhood diabetes closely resembles the grief normally associated with bereavement. Parents report many losses, including a loss of spontaneity, and they find it difficult to come to terms with the diagnosis as they adapt their lifestyle to meet the needs of the child with diabetes.² If insulin pumps improve parental coping and family quality of life and can achieve optimal glycaemic control over time, they should be considered and made more readily available for children with diabetes. Additionally, healthcare providers can use the findings of this study to support parents in making the decision to switch from MDIs to pump therapy and to provide anticipatory guidance about the time it takes some families to adjust to the technology and potential changes to family routines.

Sullivan-Bolyai *et al* collected data from both fathers and mothers. Often, the importance of including paternal perspectives is forgotten because mothers are viewed as the main care providers. The study could have been strengthened if data had also been collected from children who were using the pump. Although such research with children can be difficult and time consuming, their voices need to be heard.

Lesley Lowes, RGN, PhD
Cardiff University
Cardiff, UK

1 Weinzimer SA, Ahern JH, Doyle EA, *et al.* Persistence of benefits of continuous subcutaneous insulin infusion in very young children with type 1 diabetes: a follow-up report. *Pediatrics* 2004;**114**:1601–5.

2 Lowes L, Gregory JW, Lyne P. Newly diagnosed childhood diabetes: a psychosocial transition for parents? *J Adv Nurs* 2005;**50**:253–61.

For correspondence: Dr S Sullivan-Bolyai, University of Massachusetts, Worcester, MA, USA. susan.sullivan-bolyai@umassmed.edu

Source of funding: in part, Medtronic MiniMed Inc, Sylmar, CA.