Family Teamwork and Type 1 diabetes

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Lessons from Research:

What are the family factors that predict optimal adherence & glycemic control?

1. Developmentally-appropriate parent involvement in DM management tasks.

2. Lower levels of parent-child conflict about DM management.
Parent Involvement in DM Management: Research caused a "Paradigm Shift"

1) The "Old Message" (pre-1990): “The child with diabetes must be independent in disease management.”

2) The "New Message" (post-1990): “The child with diabetes must work inter-dependently with parents, and this teamwork must change with development.”
Pre-1990’s Research with Children with Diabetes

The old research that advised child/teen “independence” in diabetes management:

- Studied only children with diabetes who had been referred for psychiatric care due to multiple DKA hospitalizations
- The major problem was ‘over-involved’ mothers!
- Based on the prevailing pre-1990’s psychoanalytic theory—Also, this was the “dinosaur age” of diabetes management, prior to use of HbA1c, basal-bolus dosing, widespread use of BGM, etc.
The ‘New Paradigm’ for Parent Involvement

Since the 1990’s, developmental and behavioral theories have prevailed, and this research consistently finds that developmentally-appropriate parent-child teamwork in managing diabetes predicts optimal adherence & glycemic control (blood sugar control).

Behavior and Mental Health Problems

- The interrelated behavior/mental health problems & poor glycemic control during childhood track over time into adolescence & young adulthood.

- Child behavior problems at diagnosis are a risk factor for later behavior and diabetes control problems & also have a negative impact on parent-child interactions around DM management.

- High levels of family conflict are associated with behavior problems & poor glycemic control.
Parent-Child Conflict around DM

In school-aged child, studies consistently document that lower levels of diabetes conflict are related to better adherence and glycemic control.

Family Communication and DM-specific Conflict

How parent feels and thinks about BG...

- “I’m scared when I see a blood sugar of 400. What does a blood sugar of 400 mean for my child?”
- “Why can’t he have stable blood glucose levels?”
- “Why is her DM getting worse?”

Impacts: How parent talks to child (with words or facial expressions) about BG...

- “That blood sugar is so bad! What did you eat?”
Avoid Shame and Blame Around BG

Dad’s really mad at me! He’d be happier if my blood sugar were 120 or if I didn’t check at all!

Dad, my blood sugar is 385.

385?! Why is it so bad? What did you eat?

That scares me! A high blood sugar like that could cause problems!

1) OCCASIONAL HIGH BLOOD SUGARS DON’T LEAD TO COMPLICATIONS. It is normal for growing children to have out-of-range blood sugars. An occasional blood sugar of 300 or even 400 or more will not cause complications.

2) THERE IS NO SUCH THING AS A “BAD” BLOOD SUGAR. Any result from blood sugar monitoring is good because it gives helpful and important information that lets you make the best choices in insulin, activity, and food.
Normal Developmental Tasks

- Sequence of milestones in physical, cognitive, psychological, and social areas that child achieves before moving on to the next stage of maturation.

- Helps parents have realistic expectations for developing child.
Effective Parenting of a Child with DM Demands that Parents also

1. Learn to live with uncertainty.

2. Maintain and model hope, courage, optimism.

3. Master complex technology and clinical decision-making.

4. Educate and advocate about DM mgt.

5. Foster autonomy while staying involved in DM mgt.

6. Integrate child’s normal developmental tasks into DM mgt.

7. Other qualities parents need?
INFANCY (0-1 yr.)

Normal Developmental Tasks:
- Physical Growth
  Develop trusting attachment or bond with caregiver(s)

Challenges for parent when child has DM:
- Very stressful period; Intense grief, few supports.
- Vigilance around hypoglycemia, especially at night. Continuous BGM may be useful.
TODDLER (1-3 yrs.)

Normal Developmental Tasks:
- Physical Growth; Brain Development
- Mastery of Physical World
- Sense of Autonomy, Independence, Separate “Self”

Challenges for parent when child has DM
- Unpredictable eating and activity patterns. Pumps may be useful.
- Shots, BGM can be stressful. Power struggles.
- Vigilance around hypoglycemia.
EARLY SCHOOL-AGE (4-6 yrs.)

Normal Developmental Tasks:
Cognitive Growth, Cause-Effect Thinking
Social Relationships Outside Family (peer & adult)

Challenges for parent when child has DM:
- Transition to diabetes mgt. in the school setting = apprehensions for child, parent, and school. Intensive regimens require support.
- Parent maintains primary involvement in DM tasks; yet parent must educate and advocate about DM. Must educate & then trust other caregivers.
SCHOOL-AGE (7-11 yrs.)

Normal Developmental Tasks:
  Rapid development of skills (cognitive, athletic, artistic, physical)
  Importance of dyadic friendship and team play
  Foundation of self-esteem

Challenges for parent when child has DM:
  Child with DM needs to participate with peers!
  Parents must sustain involvement in DM tasks while fostering child autonomy.
  Intensive regimen allows flexibility; requires work!
Tasks of Young Transitioning Teens (11-13 yr.) and parents

- Pubertal changes impact self-image.

- Peers increase in value (vulnerable).

- Privacy is important.

- Power shifts in P-C relationship increase family conflict.

- Parent learns to acknowledge this is a period of insecurity and intensity, to negotiate, to have consistent expectations, to set limits, to maintain involvement & support.
At this age, if one kid is wearing sunglasses... they all want to wear sunglasses.
General Tips for Enhancing Family Teamwork

1. Avoid ‘blame and shame’ around BG monitoring.
   a.) Don’t say “good“ & “bad” BG levels
   b.) Praise the behavior of BG checking, not the number.

2. Be alert for ‘diabetes burnout’ & ‘miscarried helping’
Summary

1. Behavioral research on optimal parent behavior for children with diabetes:
   age-appropriate involvement in diabetes management tasks with minimal diabetes-specific conflict.

2. DM adds uniquely to the ‘Challenges of Parenting’ at each stage of child development, infancy through puberty (0 - 14 years).