BACKGROUND

• Unique challenges to type 1 diabetes (T1D) management in young children include physical growth, development in cognitive and communication abilities, behavior management, and unpredictable eating and activity levels.
• Parent distress following a new diagnosis of T1D in young children is common and can interfere with optimal diabetes management and quality of life.
• New strategies are needed to promote glycemic control and parent quality of life in the context of these challenges.
• Other parents with experience parenting young children with T1D may be well-suited to offer support during the especially difficult period following new T1D diagnosis.
• The aim is to describe the processes of collaborating with Parent Advisors and Parent Coaches to design and deliver a 9-month peer support intervention to parents of children age 1-6 years newly diagnosed with T1D, as part of a multicomponent, stepped care behavioral intervention trial.

METHODS

• In preparation for a two-site stepped care behavioral RCT, parents were recruited to assist with development and review of intervention materials and protocols.
• Diabetes providers at each site referred potential Parent Advisors:
  • Parents of children diagnosed with T1D ≥ 1 year ago under age 7
  • Child currently age 12
  • Fluent in English
• Study staff sent introductory letters and screened referred parents by interview.
• Interested parents were invited to join the Parent Advisory Board to give feedback on intervention components, including:
  • Local and online resources for parenting young children with T1D
  • Recruitment materials
  • Study website design and content
  • Design of the supportive peer parent coaching program
• A subset of Advisors with interest, recognized suitability, and availability to be more involved were trained as Parent Coaches.
• Suitability determinations:
  • Interest in connecting with other parents of young children with T1D
  • Endorsed moderate views of diabetes management, no statements perceived to be extremely in favor of/against specific diabetes management strategies
  • Experience with mentoring programs preferred
• Able to commit to time requirements for training and delivery of supportive intervention program
• Able to be reached consistently by telephone, email, and/or text message
• Sought Parent Coaches with diversity in child age at diagnosis, family make-up, employment status, and geographical location around each city
• Parent Coaches were paid for time in training and completing questionnaires, and receive small stipend per participant assigned.

PARENT COACH ROLES

- Parent Coaches paired with study participants (parents of newly diagnosed young children) to offer supportive contact related to adjusting to a T1D diagnosis and parenting a young child with T1D
- Contact primarily via telephone, text message, email
- Paired with 1-2 participants at a time
- Parent Coach contact continues throughout all intervention steps

RESULTS

What made you want to be a Parent Coach?

“I hope that by providing support it will make the parents and newly diagnosed children’s lives a little more manageable and less overwhelming”

“I would like to share the knowledge/experience that I’ve gained in the past 3+ years”

“I think it is so important to have someone to speak with about diabetes and to share experiences with. Sometimes being a parent of a child with diabetes makes you feel alone, like no one understands.”

“To help other parents feel less lost at diagnosis”

“Because other people helped me and I want to pay it back”

Parent Coaches paired with study participants (parents of newly diagnosed young children) to offer supportive contact related to adjusting to a T1D diagnosis and parenting a young child with T1D.

Contact

- Paired with participant
- First contact with participant
- One-in-person meeting

Time

- 0-3 months post-diagnosis
- Within 1 week of pairing
- Within 1 month of pairing

At least weekly contact

• Months 1-3

At least monthly contact

• Months 4-9

Training

• Group training, in-person
• Ongoing Support & Supervision

Frequency

• At start of PC role, semi-annual booster: Approx 4 hours: Monthly, more often as needed

Content

• Reflective listening and communication skills
• Demonstrations and role-play common scenarios
• Introduce study protocol
• Research ethics

MEASURES

Surveys

- Participant contact
- Participant completion

Month

- End of each participant’s 9 mos.

Content

- Frequency and mode of contact, topics covered, participant engagement

Parent Diabetes Quality of Life (PDQOL)

- Pre/post PC role

Experiences and worries related to parenting a child with diabetes (42 items)

Pediatric Inventory for Parents (PIP)

- Pre/post PC role

Frequency and difficulty of stressful situations related to caring for a child with a chronic illness (42 items)

Center for Epidemiological Studies-Depression Scale (CES-D)

- Pre/post PC role

Depressive symptoms experienced over the past week (20 items)

Protective Factors Survey (FPS)

- Pre/post PC role

Family functioning, support, parent-child relationship (20 items)

PC experience

- After PC completion

Satisfaction with experiences in this role, feedback for improvement, impact on own parenting

PC CHARACTERISTICS

- 35 parents were nominated by diabetes provider teams
- 16 were eligible and joined Parent Advisory Board
- 11 consented and trained to be Parent Coaches (data from 9)

Parent Coach Characteristics

- Percent (n)
- Mean ± SD

Age, years

- 37.8 ± 3.8

Gender, % female

- 89% (8)

Race/Ethnicity

- Non-Hispanic White: 89% (8)
- Hispanic: 11% (1)

Family makeup, % 2 parents

- 100% (9)

Child insulin regimen, % pump

- 67% (6)

Child use of CGM, % current

- 100% (9)

Parent Advisors offered valuable input into the design and implementation of a novel peer coaching intervention.

More Parent Advisors need to be screened than will ultimately serve as Parent Coaches.

Trained lay Parent Coaches are:

- Low-cost (peers, not highly trained providers)
- Highly translatable to clinical practice
- Potentially able to offer highly relevant support after diagnosis of T1D

Peer Coach support could be delivered universally, permitting more costly, targeted clinical resources to be allocated to parents with higher needs.

The ongoing trial will evaluate outcomes of peer coaching in combination with more intensive intervention components according to individual participant needs.