Moving on… With Diabetes: Transition Education Program for Parents/Caregivers of Youth/Young Adults with Diabetes

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ABSTRACT

Aims: To meet the needs of parents in the development of an information module, we articulated overarching principles, and developed an iterative approach to the final product. Method: A telephone interview guide was developed, using 40 questions. Interviews were conducted with 7 parents. Eight themes emerged from the information module: findings, issues and concerns about transition, what parents need to know, what parents need to do, perceived support needs, perceived supports available, and tips for healthy care providers. A two-part module was created. Part 1: Awareness for parents of youth ages 13–15. Part 2: Facilitated session for parents of youth/young adults ages 15–18.

BACKGROUND

Transition from pediatric to adult diabetes care can pose significant challenges. We estimate 60% of youth successfully transfer by 24 months post-referral to adult care. Those who do not successfully transition are at increased risk of diabetes complications, both short and long term.

AIM

To meet the needs of parents in the development of an information module, we articulated overarching principles. Content must:

- Be needs-based
- Include first-voice experiences
- Include information about transition processes and materials with a clear understanding of the parents’ role throughout transition

METHODS

Telephone interview guide was developed using 18 questions. Interviews were conducted with 7 parents. Eight (8) themes emerged, forming the basis for the information module:

1. Feelings experienced: "I was terrified to go up to adult care."
2. Issues and concerns about transition: "Now I’m on the inside holding it.
3. Questions parents have about transition: "Will my child get the proper help?"
4. What parents need to know: "The more knowledge the better."
5. What parents need to do: "Communication is important. You’re still a parent."
6. Perceived support needs: "No one understands it like a parent."
7. Perceived supports available: "Enough support and when I went through it, so I had to go find somebody."
8. Wise words for health care providers: "More information could have been provided by the clinic before transition since teenagers are still children (i.e., what the transition will look like)."

CONCLUSION

We would like to acknowledge the contributions of the parents/caregivers who participated in telephone interviews, who helped form the learning needs and objectives for our information sessions.

We would also like to recognize and thank the DCPSN Transition Project Coordinator, Advisory Group members as well as Gerald Murphy and his team at barrel Failure Inc., who led the design and development of the modules.

PROVINCIAL PROGRAM

BACKGROUND (www.diabetescareprogram.ns.ca)
The Diabetes Care Program of Nova Scotia (DCPSN) was originally one of the Provincial Programs funded by the Nova Scotia (NS) Department of Health & Wellness. In April 2016, the DCPSN transferred to the Nova Scotia Health Authority (NSHA). Implemented in 1991, the DCPSN was initially mandated to standardize and improve the quality of care provided through Nova Scotia’s 38 Diabetes Centres.

The DCPSN:
- Adapts on service delivery needs to diabetes guidelines
- Establishes and monitors adherence to diabetes guidelines
- Provides support, services, and resources to diabetes healthcare providers
- Collects, analyzes, and distributes diabetes data for NS

DCPSN mission: To improve, through leadership and partnership, the health of Nova Scotians living with, affected by, or at risk of developing diabetes.

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METHODS (CONT.)

Supporting materials include a facilitator’s guide, participant materials, slide decks, learning aids, and social media posts.

ACKNOWLEDGEMENTS

* First voices of parents interviewed were essential in shaping the content of our sessions.
- Activities within the modules will encourage engagement and interaction.
- Two (2) modules were used to fill the needs of parents with children of different ages.

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