

Contents lists available at [ScienceDirect](#)

Canadian Journal of Diabetes

journal homepage:
www.canadianjournalofdiabetes.com

 Canadian
Diabetes
Association


Original Research

Adult-Onset Type 1 Diabetes: A Qualitative Study of Decision-Making Needs



Janet Jull OT, PhD ^{a,*}, Holly O. Witteman PhD ^{b,c}, Judi Ferne BA, MA ^d, Manosila Yoganathan MA ^e, Dawn Stacey RN, PhD ^f

^a Bruyère Research Institute and University of Ottawa, Ottawa, Ontario, Canada^b Department of Family and Emergency Medicine, Office of Education and Continuing Professional Development, Laval University, Québec, Québec, Canada^c Population Health and Optimal Health Practices Research Unit, CHU de Québec, Québec, Canada^d Ottawa, Ontario, Canada^e Faculty of Social Sciences, University of Ottawa, Ottawa, Ontario, Canada^f Faculty of Health Sciences, University of Ottawa and Clinical Epidemiology Program, Ottawa Hospital Research Institute, Ottawa, Ontario, Canada

ARTICLE INFO

Article history:

Received 8 May 2015

Received in revised form

17 September 2015

Accepted 22 September 2015

Keywords:

adult
decision making
needs assessment
qualitative research
type 1 diabetes

Mots clés :

adulte
prise de décision
évaluation des besoins
recherche qualitative
diabète de type 1

ABSTRACT

Introduction: Type 1 diabetes is an autoimmune disease resulting from insulin deficiency and must be carefully managed to prevent serious health complications. Diabetes education and management strategies usually focus on meeting the decision-making needs of children and their families, but little is known about the decisional needs of people with adult-onset type 1 diabetes.

Objective: The aim of this study was to explore the diabetes-related decision-making needs of people diagnosed with adult-onset type 1 diabetes.

Methods: An interpretive descriptive qualitative study was conducted. Participants who self-identified as having adult-onset type 1 diabetes were interviewed using a semistructured interview guide. Transcripts were coded to identify needs, supports and barriers using thematic analysis.

Results: Participating in the study were 8 adults (2 men, 6 women), ages 33 to 57, with type 1 diabetes for durations of 1 to 20 or more years. Their decision-making needs are summarized in 6 broad themes: 1) people diagnosed with type 1 diabetes are launched into a process of decision-making; 2) being diagnosed with type 1 diabetes means you will always have to make decisions; 3) knowledge is crucial; 4) personal preferences matter; 5) support is critical for decisions about self-care in type 1 diabetes; 6) living with type 1 diabetes means making very individualized decisions about daily life.

Conclusions: The findings describe the sudden and ubiquitous nature of type 1 diabetes decision-making and the need to tailor approaches for making care decisions in type 1 diabetes. People diagnosed with adult-onset type 1 diabetes require access to reliable information, support and opportunities for participation in decision-making.

© 2016 Canadian Diabetes Association. Published by Elsevier Inc. All rights reserved.

R É S U M É

Introduction : Le diabète de type 1 est une maladie auto-immune résultant d'une carence en insuline et doit être pris en charge de manière prudente pour prévenir les complications de santé sérieuses. Les stratégies d'enseignement et de prise en charge du diabète se concentrent généralement sur la satisfaction des besoins relatifs à la prise de décision des enfants et de leur famille, mais on en connaît peu sur les besoins décisionnels des personnes souffrant du diabète de type 1 à début tardif.

Objectifs : L'objectif de la présente étude était d'explorer les besoins relatifs à la prise de décision liée au diabète des personnes ayant un diagnostic de diabète de type 1 à début tardif.

Méthodes : Nous avons mené une étude qualitative, descriptive et interprétative. Nous avons interrogé les participants qui se considéraient comme des personnes souffrant d'un diabète de type 1 à début tardif au moyen d'un guide d'entretien semi-structuré. Nous avons codé les transcriptions pour déterminer les besoins, le soutien et les obstacles à l'aide de l'analyse thématique.

* Address for correspondence: Janet Jull, OT, PhD, Bruyère Research Institute and University of Ottawa, 85 Primrose Avenue, Room 312, Ottawa, Ontario K1R 7G5, Canada.
E-mail address: jjull013@uottawa.ca

Résultats : Huit adultes (2 hommes, 6 femmes) de 33 à 57 ans qui souffraient du diabète de type 1 dont la durée variait de 1 à 20 ans ou plus participaient à l'étude. Leurs besoins relatifs à la prise de décision se résumaient en 6 grands thèmes : 1) Les personnes ayant un diagnostic de diabète de type 1 sont lancées dans un processus de prise de décision; 2) Avoir un diagnostic de diabète de type 1 signifie que vous aurez toujours à prendre des décisions; 3) Les connaissances sont essentielles; 4) Les préférences personnelles importent; 5) Le soutien est essentiel aux décisions portant sur les soins autonomes liés au diabète de type 1; 6) Vivre avec le diabète de type 1 signifie la prise de décision très individualisée sur la vie quotidienne. **Conclusions :** Les résultats décrivent la nature abrupte et omniprésente de la prise de décision liée au diabète de type 1 et la nécessité d'adapter les approches pour prendre des décisions en matière de soins du diabète de type 1. Les personnes ayant un diabète de type 1 à début tardif doivent avoir accès à des renseignements fiables, à du soutien et à des opportunités de participation à la prise de décision.

© 2016 Canadian Diabetes Association. Published by Elsevier Inc. All rights reserved.

Introduction

Diabetes mellitus is a chronic disease affecting all age groups and may be classified as 1 of 4 types: type 1, type 2, gestational and “other” types of diabetes. As well, latent autoimmune disease of adults has been defined as a condition in which type 1 diabetes develops in adults (1). Type 1 and type 2 diabetes are most common in Canada and internationally (2). Current estimates are that 6.8% of the Canadian population lives with diabetes, with type 1 diabetes estimated to account for 5% to 10% of all cases of diabetes (3). Knowledge of the incidence of type 1 diabetes has been identified as a major gap in the reporting of Canadian diabetes surveillance (4). Most commonly arising in people younger than 40 years of age and most often diagnosed in children and youth (3), type 1 diabetes is increasing globally (5–8), and Canada has been found to have one of the highest incidence rates of type 1 diabetes in children younger than 14 years of age (9).

People with either type of diabetes are at increased risk for complications (3), including cardiovascular disease, blindness, end stage renal failure and nontraumatic amputation in adults (2). For those with type 1 diabetes, there is a greater risk for life-threatening complications due to the reliance on daily doses of insulin (3). Given these significant health risks, interventions to support individuals diagnosed with type 1 diabetes in participating in decisions to manage their care effectively are essential.

The numerous, complex and ongoing array of decisions faced by those receiving diagnoses of type 1 diabetes has been estimated to reach as many as 600 daily decisions (10). Such decisions range in frequency and complexity. For example, there are 1) infrequent decisions such as choosing an insulin delivery method; 2) semiregular decisions such as choosing a new exercise routine; and 3) regular decisions made daily that are associated with balancing and maintaining blood glucose levels. To date, studies evaluating the needs of adults diagnosed with type 1 diabetes have been focused primarily on defining needs for blood sugar monitoring (11–14), information and support (15–18), lifestyle adaptations (15) and views on healthcare services for people with diabetes (19,20); none of the studies have identified decisional needs for the population diagnosed with adult-onset type 1 diabetes.

Objectives

The overarching aim of this study was to explore the diabetes-related decision-making needs of people diagnosed with adult-onset type 1 diabetes. The specific research questions were:

- 1) What are the decision-making needs of adults diagnosed with type 1 diabetes when making decisions about their diabetes (e.g. insulin regimen, lifestyle choices)?
- 2) What are the barriers to involving adults diagnosed with type 1 diabetes in making decisions about their care?

- 3) What are the potential supports to enhance the decision-making experiences of adults diagnosed with type 1 diabetes?

Methods

The Ottawa Decision Support Framework (ODSF) was used to guide an interpretive, descriptive, qualitative study. Interpretive description is an inductive analytic approach effective for describing healthcare events (21). The ODSF is a framework developed to guide people through health and social decisions (22). It involves 3 key elements: decisional needs, decision support and decision quality. One assumption is that unresolved decisional needs may negatively influence decision quality and that decision support can address decisional needs to address decision quality, with a high-quality decision defined as being informed by the best available evidence and patients' informed values concerning outcomes of options (22,23). The ODSF has been used to structure the assessment of decisional needs within a range of populations (23). Ethics approval was obtained from the University of Ottawa Research Ethics Board.

Participants

Eligible participants were residents of eastern Ontario, 19 years of age or older and identified as having been diagnosed with adult-onset type 1 diabetes. Invitations to participate in the study were distributed through a local diabetes not-for-profit group, the Diabetes Action Network, as well as in online popular classified ad sites (e.g. Used Ottawa, Kijiji). Participants had to be able to participate in an interview in English. To ensure a range of perspectives and experiences, we recruited males and females of a variety of ages. Recruitment was concurrent with interviewing and continued until data saturation in themes was reached.

Procedures

Individual interviews were scheduled either by telephone or at a mutually convenient location. After reviewing and signing the consent form, participants were interviewed for 30 to 60 minutes using semistructured interviews and the collection of demographic information (Table 1). The interviews were audiorecorded and transcribed verbatim, and field notes from the researcher (JJ) were included as part of the gathered data. At the end of the interview, participants were offered the opportunity to review and provide feedback on their individual transcripts.

The interview guide was based on the ODSF and informed by the Decisional Needs Assessment in Populations guide that has been used for numerous decisional-needs assessments (22,24). As well, the interview guide was reviewed by an advisory group consisting of experts (i.e. those with knowledge and experience) in the area of health-related decision making, qualitative research, community support of those with type 1 diabetes and diabetes management, all authors of this article (JJ, JF, DS).

Download English Version:

<https://daneshyari.com/en/article/3254934>

Download Persian Version:

<https://daneshyari.com/article/3254934>

[Daneshyari.com](https://daneshyari.com)