



## Patient Perspectives on Nurse-led Consultations Within a Pilot Structured Transition Program for Young Adults Moving From an Academic Tertiary Setting to Community-based Type 1 Diabetes Care

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### ABSTRACT

**Purpose:** We aimed to evaluate patient self-management activities, patient perceptions of the therapeutic relationship and satisfaction with nurse-led consultations as part of a structured, pilot program transitioning young adults with type 1 diabetes (T1DM) to adult-oriented community-based practices.

**Design and Methods:** A descriptive, cross-sectional study of patients receiving nurse-led consultations. Patients provided sociodemographic/health information, glycated hemoglobin (HbA1c) measures and completed questionnaires assessing self-management (Revised Self-Care Inventory) and the therapeutic relationship (Caring Nurse-Patient Interaction – short scale). HbA1c values were compared to guideline recommendations.

**Results:** Twenty patients participated. HbA1c was  $\leq 7.5\%$  in 3/14 (21%) and 5/14 (36%) exhibited poor glycemic control ( $\geq 9.5\%$ ). The greatest concordance for self-care was in relation to insulin therapy ( $4.5 \pm 0.5$ ) while patients reported the lowest adherence to diet recommendations ( $2.9 \pm 0.8$ ). Overall satisfaction with nurse-led consultations was high ( $4 \pm 0.5$  out of 5). Patients considered diabetes knowledge and technical competence as very important and were most pleased with the humanistic aspects of nursing care. Respect for privacy was deemed the most important (and most frequently observed) nursing attitude/behavior during consultations.

**Conclusions:** Young adults found the nurse-led consultations with therapeutic education to develop T1DM self-care skills are an important complement to medical management during transition.

**Practice Implications:** Patient autonomy and privacy should be respected during this developmental period. Nurses taking a humanistic approach towards accompanying and supporting the patient can enhance the therapeutic relationship during transition and promote continuity of care. Transition nurses can use technical competence and therapeutic education to empower patients for self-management.

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### Introduction

Type 1 diabetes mellitus (T1DM) is thought to result from immune-mediated destruction of pancreatic beta cells that produce insulin. Patients with T1DM have increased morbidity and mortality resulting from micro- and macro-vascular sequelae secondary to glycemic

variations including hypo- and hyperglycemia (Rawshani et al., 2017). While the precise genetic, environmental and behavioral factors underlying T1DM remain to be fully elucidated (Peng & Hagopian, 2006), it is clear that patients require lifelong insulin therapy. As demonstrated in two large trials, the Diabetes Control and Complications Trial (DCCT) and the Epidemiology of Diabetes Interventions and Complications (EDIC) (Dunger, 2017; Lachin, Orchard, Nathan, and DCCT/EDIC Research Group, 2014), management focuses on tight glycemic control to minimize both short- and long-term complications. T1DM is primarily diagnosed in young children and adolescents with the peak incidence observed between 10 and 14 years of age (Maahs, West, Lawrence, & Mayer-Davis, 2010). Notably, recent data suggest the incidence and prevalence of T1DM in children and adolescents < 16 years

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appears to be rising by approximately 1.4% annually (Mayer et al., 2017).

For patients with T1DM, adolescence can be a challenging period due to complex treatment requirements, the physical and hormonal changes of pubertal onset, as well as the psychological and social changes during this time of development (Hauschild et al., 2015). Unfortunately, this confluence of issues often results in deteriorating glycemic control. International data have identified significant shortfalls as only about 14% patients with T1DM aged 11–18 years actually achieve glycosylated hemoglobin (HbA1c) levels of <7.5% (Dunger, 2017; Maahs et al., 2014; Miller et al., 2015) which is the consensus target identified by the American Diabetes Association (ADA) and the International Society for Pediatric and Adolescent Diabetes (ISPAD) (American Diabetes, 2016; Rewers et al., 2014).

Transition is often associated with being lost to follow-up and adverse health outcomes (Garvey, Markowitz, & Laffel, 2012; Lotstein et al., 2013; Lyons, Becker, & Helgeson, 2014). For young adults with T1DM continuity of care is critical for minimizing acute and long-term complications. Transfer can be challenging for young adults as evidence suggests that at least four to five visits are needed to establish a trusting relationship with a new medical provider (Klostermann, Slap, Nebrig, Tivrosak, & Britto, 2005). Yet when continuity of care is actively promoted, acute complications and hospitalizations can be dramatically decreased (Nakhla, Daneman, To, Paradis, & Guttmann, 2009).

Because patients receive initial care in a pediatric setting, effective programs are needed to transition patients to adult-oriented care settings. Prior studies have employed a range of approaches to care coordination and transition planning to navigate the passage to adult-oriented care (Garvey et al., 2012). Some have provided administrative support to arrange appointments and send reminders (Holmes-Walker, Llewellyn, & Farrell, 2007). The Maestro project utilized an administrative project coordinator for continued telephone and e-mail contact to identify barriers to access and help support the navigation process (Van Walleghem, Macdonald, & Dean, 2008). Others have used a transition coordinator to provide anticipatory guidance and information about transition ahead of a joint pediatrician-adult endocrinologist consultation and hand-off of care (Cadario et al., 2009).

Transitional care for young adults with special healthcare needs has gained increasing attention and has been the topic of several systematic reviews (Betz, O'Kane, Nehring, & Lobo, 2016; Campbell et al., 2016) and a recent position statement from the Society of Pediatric Nurses (Betz, 2017). For patients with diabetes, who provide >95% of their own care (Funnell & Anderson, 2000), developing self-management skills is a critical part of the transition process. Psychological support and therapeutic education are key elements of developing self-care skills and can help foster independence and autonomy during transition to adult-oriented community-based practices. However, it remains unclear how this is best achieved. Moreover, patient perspectives are not always considered when examining such transitional care programs (Betz, Lobo, Nehring, & Bui, 2013).

To enhance care for young adults with T1DM in the canton (state/province) of Vaud Switzerland, a structured transition program was developed to ease the transfer of patient care for young adults with T1DM from the regional tertiary academic children's hospital to adult-oriented community-based practices. This program utilized nurse-led consultations to coach and guide patients during this process. We examined patient perspectives on this transitional care model.

## Methods

Broadly, this cross-sectional descriptive study intended to evaluate patient self-management activities, patient perceptions of the therapeutic relationship and satisfaction with nurse-led consultations as part of a structured, pilot program transitioning young adults with type 1 diabetes (T1DM) to adult-oriented community-based practices. To do this, we evaluated patient outcomes including: glycosylated hemoglobin levels

(HbA1c), self-care activities as well as patient perceptions of and satisfaction with caring attitudes and behaviors (i.e. therapeutic relationship). To conceptualize the complex patient-caregiver dynamic during transition, we used the Interaction Model of Client Health Behavior as a guiding theoretical framework (Cox, 1982). This model recognizes the contribution of individual characteristics (e.g. demographics, past experiences and resources) and states that cognitive and affective aspects of patient-provider interactions mediate outcomes. To examine the nurse-led consultations, we started with the notion that a sound therapeutic relationship is critical for effective patient education and psychological support of young adults during transition. The study was reviewed and approved by the local human research ethics committee (Commission cantonale d'éthique de la recherche sur l'être humain).

## Nurse-led Transition Consultation

In Switzerland, as in many countries, patients with T1DM are primarily diagnosed (and initially treated) at a regional, tertiary academic medical center. For many patients, this requires significant travel for ongoing care and many eventually seek community-based care at a local physician's office to make ongoing management more convenient. In 2012, the Pediatric Endocrinology, Diabetes and Metabolism Service of the University Hospital of Lausanne developed a pilot structured transition project to transfer care to community-based practices while promoting self-management and continuity of care. To complement the care from the medical team, a dedicated transition nurse provided individualized coaching and therapeutic education during transition and served a navigator role to ensure that patients attended initial visits to adult-oriented community-based practices and were psychologically supported through the transition process. This complex nursing intervention included aspects in the pediatric care setting that bridged to adult-oriented community-based practices (Fig. 1).

More specifically, the transition nurse is introduced to the patient in the pediatric setting and begins ongoing discussions to assess readiness for transition, preferred setting (i.e. adult academic medical center vs. adult-oriented community-based practice) as well as self-care needs and anticipatory guidance. The nurse reinforces key diabetes self-care aspects with particular attention to autonomy (i.e. managing supplies and prescriptions, keeping and making appointments). Based on patient preference, the transition nurse is available via home visits, telephone, email or text messaging (SMS) facilitating continued interaction ranging in frequency from weekly to every three to six months based on individual patient needs. This provides a safe, known individual for supporting the transition process. Nursing interventions include active listening support, motivational interviewing, therapeutic education, observing the practice of day-to-day self-care techniques (and providing feedback), helping with administrative concerns as well as accompanying patients to the first contact with the adult provider and ensuring subsequent visits. Care is individualized and may comprise brief text messages or extended hour-long home visits.

## Participants and Recruitment

Fifty eight young adults with T1DM between the ages of 16 and 25 years who had received at least two consultations were invited to participate. Participants 18 years and older provided written informed consent while minors gave assent in addition to parental consent. Participants provided sociodemographic information and completed questionnaires (paper or web-based). To gain insight into glycemic control over the prior 90 days, participants were asked for permission to contact their provider to obtain the most recent HbA1c level ( $\pm 2$  months from date of questionnaire completion) Recruitment lasted four months (November 2015–February 2016).

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