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Review

Improving the Transition from Pediatric to Adult Diabetes Healthcare: A Literature Review



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ABSTRACT

Effective transition to adult care is a significant component of an emerging adult's diabetes care. Poor transition places them at risk for disengagement with the health care system and for poor diabetes-related outcomes. The purpose of this paper was to review the literature to date on existing methods of transition care delivery for emerging adults with diabetes. We conducted a literature review using MEDLINE via OvidSP and searching the grey literature. Papers published in English between January 1, 2000 and March 25, 2015 that evaluated transition care programs for emerging adults with diabetes were included. 16 original studies, 1 study protocol and 1 technical brief describing transition programs were reviewed. Common components of care included transition care coordination, young adult clinics, transition preparation, familiarity with adult health care providers and support groups. Overall, when emerging adults are supported during the transition period, clinic attendance and glycemic control can be maintained or improved, and diabetes-related complications reduced. Despite widespread support in the literature for the need for structured transition care delivery, methodologically strong research evaluating transition care services remains limited. The literature to date encompasses a variety of care models that lack consistency in outcome measurements as well as lacking frameworks describing the interventions, which impedes comparison across studies. Further research, using a consistent framework for transition care program design, delivery and evaluation as well as reporting of outcomes, is needed to inform how best to deliver transition care services to this vulnerable population.

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R É S U M É

La transition efficace vers les soins pour adultes est une composante importante des soins pour adultes émergents diabétiques. Une mauvaise transition les expose au risque de désengagement envers le système de soins de santé et de mauvais résultats liés au diabète. L'objectif de la présente étude était de passer en revue la littérature disponible à ce jour sur les méthodes existantes de prestation des soins de transition des adultes émergents souffrant de diabète. Nous avons mené une revue de la littérature à l'aide de MEDLINE via OvidSP pour faire une recherche de littérature grise. Elle comportait les documents publiés en anglais entre le 1er janvier 2000 et le 25 mars 2015, qui évaluaient les programmes de soins de transition des adultes émergents souffrant de diabète. Nous avons passé en revue 16 études originales, 1 protocole d'étude et 1 résumé technique qui décrivaient les programmes de transition. Les composantes communes de soins comprenaient la coordination des soins de transition, les cliniques pour jeunes adultes, la préparation à la transition et la familiarité avec les prestataires de soins de santé pour adultes et les groupes de soutien. Dans l'ensemble, lorsque les adultes émergents sont soutenus durant la période de transition, la fréquentation des cliniques et la maîtrise de la glycémie peuvent être maintenues ou améliorées, et les complications liées au diabète, réduites. Malgré un large appui dans la littérature quant à la nécessité d'une prestation de soins de transition structurés, le fort potentiel méthodologique de la recherche évaluant les services de soins de transition demeure limité. La littérature disponible à ce jour comprend divers modèles de soins qui dénotent le manque de cohérence dans les mesures des résultats aussi bien que le

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manque de cadre décrivant les interventions, qui nuit à la comparaison entre les études. Des recherches plus approfondies, qui utilisent un cadre cohérent pour la conception, la prestation et l'évaluation des programmes de soins de transition, ainsi que la communication des résultats, sont nécessaires pour informer sur la meilleure façon de fournir les services de soins de transition à cette population vulnérable.

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Introduction

The incidence of type 1 and type 2 diabetes mellitus in children is increasing and is becoming a growing public health burden. Worldwide, type 1 diabetes is increasing by 3% per year in children and adolescents and by 5% per year in preschoolers (1,2). The medical care of children and adolescents with diabetes is complex and resource intensive, and it requires regular access to specialized healthcare services to prevent diabetes-related complications. The transition from pediatric to adult care adds further complexity to this management. Young adults are at high risk for dropping out of medical care, only to resurface in the medical system with diabetes-related complications (3–6). Many methods of delivering transition care have been described in the literature, but there is no identifiable gold standard. In this article, we review the current transition care literature with a focus on research evaluating transition healthcare models for emerging adults with diabetes.

According to contemporary developmental theories, adulthood does not immediately follow adolescence but begins when individuals are in their early 30s (7). Emerging adulthood, between the ages of 18 and 30 years, is a period of life in which individuals establish their independence and personal identity and make important educational and vocational choices (7). For those with diabetes, this stage is further complicated by the daily demands of a chronic disease and the challenge of transferring from pediatric to adult care. Adult care is often structured differently and lacks the intensive multidisciplinary resources commonly found in pediatric settings (8,9). This transfer occurs at a point in life concurrent with numerous physiological and psychosocial changes, including deterioration of glycemic control (10,11), decreased adherence to diabetes management tasks (12,13) and to clinic attendance (14) as well as increased risk for psychiatric disorders (15–17) and involvement in hazardous behaviours (18,19). Ongoing regular medical care is essential in addressing these clinical issues and high-risk behaviours, ultimately decreasing the risk for complications, hospitalizations and healthcare costs.

The transition to adult care is an active, coordinated process. The Society for Adolescent Medicine defines transition as “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems” (20). Transition care should be continuous, coordinated, comprehensive and developmentally appropriate. The Canadian Paediatric Society and the American Academy of Pediatrics also recommend that transition programs promote youths' skills in communication, decision making, advocacy and self-care (21,22). The transfer to adult care is merely an event, but transition care is an active process that should begin in early adolescence and continue through to emerging adulthood (23). Although there is little empiric evidence to support an optimal age for starting the transition process, it is suggested in the literature that it begin as young as 12 years of age, to allow adequate time to prepare individuals gradually (23). The potential benefits of well-executed transitions of care include improved disease management, better quality of life, decreased rates of complications and increased patient satisfaction (23).

Early descriptive studies in Canada first identified the significant challenges emerging adults face in establishing adult care. A retrospective cohort study of 41 patients (mean age 21.7±0.5 years)

conducted in Toronto reported that 24% did not have follow-up visits in adult care within 1 year of leaving pediatric care (3). Furthermore, Pacaud et al conducted a cross-sectional study in Montreal, where they surveyed 135 emerging adults who were transferred to adult care at a mean age of 18.5±0.1 years (5). They found that 28% experienced gaps of more than 6 months between their last pediatric and first adult care visits, and 17% had gaps in care greater than 1 year. The authors administered the same survey several years later in Calgary to 81 emerging adults, 31% of whom reported delays longer than 6 months in establishing adult care and 14% of whom reported delays longer than 1 year (6). Recently, Garvey et al determined that 34% of post-transition emerging adults in Boston, Massachusetts, USA, had prolonged delays (>6 months) in establishing adult care (24). Those who were least likely to experience delays had had more than 3 pediatric visits in the year before transfer (odds ratio [OR] 0.35; 95% confidence interval [CI] 0.19 to 0.63) and had “felt prepared for transition” (OR 0.47; 95% CI 0.25 to 0.88).

The risk for acute complications resulting from diabetes, as measured by hospitalizations, has also been shown to increase following the transfer to adult care. We conducted a retrospective cohort study examining the effect of differing healthcare delivery models on diabetes-related hospitalizations among emerging adults (n=1500) in Ontario (4). Overall, the risk for hospitalizations increased in the 2 years following the transfer to adult care. Those leaving their pediatric teams and starting fresh with new teams were more likely to be hospitalized than those whose adult teams included some members of their pediatric teams. Further, several cross-sectional and observational studies have examined glycated hemoglobin (A1C) levels in relationship to healthcare transition and have reported mixed results. In a retrospective cohort study conducted by Busse et al, pre- and post-transition A1C measures were not significantly different (pre-transition A1C 8.5±1.5% vs. 8.3±1.6%; p=0.44) in the 44 of 101 subjects studied, for whom A1C measures were available (8). More recently, an American longitudinal cohort study found that the odds of having A1C levels >9% was 2.5 times higher for those who transitioned to adult care as compared to those who remained in pediatric care, after controlling for both sociodemographic and disease-related factors (25).

Although the importance of transition care is well recognized by both national and international diabetes associations, empiric data remain limited (9,23). With no gold standard, the majority of recommendations guiding practice are based on clinical experience or expert consensus. In the next section, we review the literature concerning the transition care models that have been evaluated.

Methods

We performed a search of the literature using controlled vocabulary terms and keywords in MEDLINE via OvidSP (New York, New York, USA) as well as searching the grey literature. Reference lists of retrieved publications were reviewed for other relevant publications that may have been missed by the search strategy. Literature in English, published between January 1, 2000, and March 25, 2015, was reviewed (Appendix 1). Papers were included if transition care models were evaluated.

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