

Contents lists available at [ScienceDirect](#)

Canadian Journal of Diabetes

journal homepage:  
[www.canadianjournalofdiabetes.com](http://www.canadianjournalofdiabetes.com)

 Canadian  
Diabetes  
Association


Original Research

## Identifying Persons with Diabetes Who Could Benefit from a Palliative Approach to Care



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## ARTICLE INFO

## Article history:

Received 2 December 2013

Received in revised form

22 January 2014

Accepted 23 January 2014

## Keywords:

chronic disease registry

diabetes

end of life

palliative care

population-based study

## ABSTRACT

**Objective:** To determine the need for diabetes mellitus palliative care, we identified persons with a diagnosis of diabetes who accessed palliative care programs and those who may have benefited from a palliative approach to care.

**Methods:** This retrospective, descriptive research used 6 linked databases comprising 66 634 Nova Scotians from 3 health districts who died between 1995 and 2009, each with access to a palliative care program and diabetes centres.

**Results:** The percentage of persons with diabetes enrolled in palliative care increased from 3.2% in 1995 to 34.3% in 2009; 31.5% were enrolled within their last 2 weeks of life. Most did not have their diabetes recorded in palliative data. Among the 5353 persons with a diagnosis of diabetes who died between 2005 and 2009, 61.0% were in the Diabetes Care Program of Nova Scotia registry. An additional 19.6% were identified in the Cardiovascular Health Nova Scotia registry, and a further 3.7% in palliative data. Applying the criteria of Rosenwax et al to the 5353, 65.8% to 97.9% may have benefitted from a palliative approach.

**Conclusions:** Rates of palliative enrollment for persons with diabetes are increasing. Diabetes care providers need to prepare patients and their families for changes in diabetes management that will be beneficial as end of life approaches. Collaboration among chronic disease programs, palliative care and primary care is advised to identify persons at end of life who have diabetes and to develop and implement care guidelines for this population.

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## R É S U M É

## Mots clés :

registre sur les maladies chroniques

diabète

fin de vie

soins palliatifs

étude en population générale

**Objectif :** Pour déterminer les besoins en soins palliatifs des personnes souffrant de diabète sucré, nous avons relevé les personnes ayant un diagnostic de diabète qui avaient accès à des programmes de soins palliatifs et celles qui auraient pu bénéficier d'une approche palliative.

**Méthodes :** Cette recherche rétrospective descriptive utilisait 6 bases de données liées regroupant 66 634 Néo-Écossais de 3 districts de santé qui avaient tous eu accès à un programme de soins palliatifs et à des centres de diabète, et qui sont morts entre 1995 et 2009.

**Résultats :** Le pourcentage des personnes souffrant de diabète qui étaient inscrites au programme de soins palliatifs est passé de 3,2 % en 1995 à 34,3 % en 2009; 31,5 % des personnes ont été inscrites au cours des 2 dernières semaines de leur vie. Le diabète de la plupart des personnes n'avait pas été enregistré aux données sur les soins palliatifs. Parmi les 5353 personnes ayant un diagnostic de diabète qui sont mortes

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entre 2005 et 2009, 61,0 % faisaient partie du Registre du programme de soins du diabète de la Nouvelle-Écosse. Un pourcentage additionnel de 19,6 % a été trouvé dans le registre de la Cardiovascular Health Nova Scotia, et un autre pourcentage de 3,7 % dans les données sur les soins palliatifs. En appliquant les critères de Rosenwax et d'autres, aux 5353 personnes, de 65,8 % à 97,9 % auraient pu bénéficier d'une approche palliative.

**Conclusions :** Les taux d'inscription aux programmes de soins palliatifs des personnes souffrant de diabète augmentent. Les prestataires de soins aux diabétiques doivent préparer les patients et leur famille aux changements dans la prise en charge de leur diabète qui seront bénéfiques en tant qu'approches en fin de vie. La collaboration entre les programmes relatifs aux maladies chroniques, aux soins palliatifs et aux soins primaires est recommandée pour déterminer les personnes en fin de vie qui ont le diabète, et pour élaborer et mettre en œuvre les lignes directrices sur les soins à offrir à cette population.

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## Introduction

Diabetes mellitus self-management education is often aimed at an ambulatory population with the goal of improving their diabetes and delaying the development and progression of diabetes-related complications. The notion of a palliative approach to care does not likely cross the mind of most diabetes care providers as they go about their day-to-day business. Palliative care focuses on symptom control, comfort and improving the quality of life for persons with life-limiting illness (see Figure 1 for complete definition). Therefore, a palliative approach to care can be initiated early in the disease trajectory (1). By starting the conversation early, health professionals can prepare patients and their families for the time when it may be best to relax or even discontinue treatment as the end of life nears (2). In addition, palliative support can assist in managing the symptom burden and improve the quality of life for persons with diabetes across their disease trajectory (3).

Diabetes is associated with increased morbidity and premature mortality. Cardiovascular complications are not unique to diabetes, but they are more prevalent, occur at younger ages and result in less favourable outcomes (4). Diabetes is also the leading cause of end stage renal disease among Canadian adults, with some degree of renal disease occurring in as many as 50% of people with diabetes (4).

Only a small percentage of deaths among persons with diabetes is uniquely attributable to the disease (5). Direct diabetes-related causes of death, including ketoacidosis and severe hypoglycemia (6), may be as low as 3% (5). More commonly, persons with diabetes die as a result of diabetes-related organ failure (7), including cardiovascular and renal disease (6). When diabetes leads to organ failure, the result is often deteriorating health interspersed with health crises (8,9). Approximately 75% of deaths among persons with diabetes are due to cardiovascular disease (4) and 10% are due to renal disease (5).

In Nova Scotia, nearly 10% of adults have diabetes—a figure that increases to 26% for those aged 70 to 79 years (10). The Diabetes Care Program of Nova Scotia (DCPNS) has a mandate to standardize and

improve diabetes care across the province. Since its inception in 1991, the DCPNS has worked closely with diabetes care providers in multiple settings to produce guidelines for care across the lifespan. For example, the DCPNS Long-term Care Guidelines (11,12) promote a more standardized approach to safe diabetes care for frail elderly residents living in long-term care facilities and advise more moderate glycemia targets, avoidance of hypoglycemia, less onerous blood glucose testing, individualization and improved quality of life.

One of the barriers to the implementation of the DCPNS Long-term Care Guidelines was the resistance of patients and their families to changes in glycemia management protocol (13). This resistance provided an opportunity to educate patients and their families about the potential harms of over-manage blood glucose. A recent study found that nearly a third of French residents living in long-term care homes were being managed too aggressively (glycated hemoglobin [A1C]  $\leq 6.5\%$ ), putting them at risk for severe hypoglycemia that can lead to neurological, cardiac and orthopedic damage (14). In addition, more than half of these residents were prescribed a “diabetic diet” that appeared to be of no benefit with regard to glycemia control but put the residents at risk for under-nutrition and a poorer quality of life (14).

Because frail older adults are more susceptible to over-medication and adverse effects, such as hypoglycemia, the DCPNS Long-term Care Guidelines (11,12) promote more liberalized glycemic targets to avoid hypoglycemia. These guidelines embody elements of the palliative approach to care, including the balance of the benefits and harms of treatment within the context of multiple complex conditions and limited life expectancy (15). Because palliative support is not limited to care for the elderly, persons of all ages with life-limiting disease are considered here.

End of life for persons with diabetes has been categorized into 3 stages, beginning with stable advanced disease, followed by impending death or organ failure and a stage of actively dying (16). The Gold Standards Framework in the United Kingdom uses 5 stages: stable, nonstable/advanced, deteriorating, terminal care/final days, and after care (17). A Canadian modification of the Gold Standards Framework for Primary Care is framed by 5 transitions: disease advancement, experiencing life-limiting illness, dependency and symptom increase, decline and last days, and death and bereavement (18). Figure 2 applies these stages to the functional decline model of Lunney et al (9) to provide a visual representation of diabetes palliative education, functional decline and needs over time.

Persons with diabetes for whom it would not be surprising if their death occurred within 6 to 12 months should be given the opportunity to develop an advance care plan and to be educated about the relative importance of relaxed blood glucose control and monitoring in the future (7,16). In the very last days of life, withdrawal of antihyperglycemic agents, including insulin, is advised (7) or is discretionary, with withdrawal for type 1 diabetes being a clinical decision (16) related to evolving goals of care. However,

### Definition

According to the World Health Organization, “*palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.*”

<http://www.who.int/cancer/palliative/definition/en/>

Figure 1. Palliative care definition.

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