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Case Report

End of Life: What Does That Mean for the Management of Adult Patients With Type 1 Diabetes?

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Key Messages

- Diabetes at the end of life is a challenging situation with no Canadian-based guidelines to support management.
- Consideration should be given to the patients' wishes when making decisions for end-of-life management.

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Introduction

Type 2 diabetes is well recognized as 1 of the most commonly occurring comorbidities in patients at the end of life (1). With recent studies showing that life expectancy is increased by approximately 15 years for patients with type 1 diabetes who were diagnosed between 1965 and 1980 compared to those diagnosed between 1950 and 1964 (2), it can be expected that there will be more patients with type 1 diabetes requiring end-of-life care, and the causes of death may be unrelated to diabetes.

End-of-life care for patients with diabetes is a relatively new field, with only the United Kingdom and Australia having current guidelines to aid in decision making (3,4). There is a paucity of randomized controlled trials and observational studies concerning this topic, and that may be related to the vulnerability of this population and the ethical issues involved (5).

No Canadian guidelines exist for the management of diabetes at the end of life. The lack of guidance makes it challenging for both palliative care providers and diabetes specialists to be confident that they are following best practices at the end of life. We present a case of a patient and his family faced with decisions regarding his diabetes management throughout his cancer treatment, culminating at the terminal phase.

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Case Report

AB was a 70-year-old man with a history of type 1 diabetes diagnosed more than 50 years earlier and managed by an insulin pump. He was diagnosed with metastatic melanoma of unknown primary source; it was affecting the central nervous system and lung. He was treated by partial craniotomy, radiation and immunomodulating chemotherapy. During his initial admission for treatment, he was maintained on insulin-pump therapy, with his wife's assistance in management. On his final admission, he presented with worsening neurologic symptoms, including a decreased level of consciousness. In consultation with the endocrinology department, his insulin pump was continued, with his wife managing bolus insulin and adjustment of basal rates, as required. Palliative care was consulted to assist with end-of-life management. Because of ongoing deterioration, the decision was made to stop all oral medications and insulin therapy. The palliative care provider described the patient as unresponsive, mottled, breathing rapidly but appearing to be comfortable. He passed away approximately 24 h after cessation of insulin therapy.

Discussion

The decision to withdraw insulin therapy was difficult because the patient had a strong preference for pump therapy but could no longer manage his device. His wife had been able to manage his device while in hospital, but when his condition changed, she believed that prolongation of life in his current state would be contrary to his personal values. In Canada, there are no national

Table 1

Three options to consider at end of life

Option	Strengths/benefits	Harms/limitations
1. Remain on insulin pump	Continuing a method of insulin delivery that was very important to the patient before his/her decline; respects the principle of autonomy.	Patient has reduced level of consciousness and spouse cannot be present at all times to manage the pump. It is not feasible to train hospital-based nurses to manage the delivery of insulin via an insulin pump.
2. Continue or switch to subcutaneous insulin administration	Ongoing management of blood glucose; the number of injections could be reduced, i.e. basal only, and testing and injections would be administered by hospital nursing staff.	Ongoing, potentially painful interventions of blood glucose monitoring and insulin administration; risk of hypoglycemia, which can be uncomfortable for the patient and the family and may result in further decline.
3. Discontinue insulin	Patient would no longer require the intervention of blood glucose monitoring or insulin injection therapy.	Potential for diabetic ketoacidosis and/or hyperglycemia, both of which can result in discomfort with diabetic ketoacidosis, potentially hastening death.

Note: Explore the options. The options for patients with type 1 diabetes in pursuing comfort-focused care at end of life include: 1) remaining on insulin pump with management assistance; 2) switching to multiple daily injections, with injections administered by nursing staff and doses directed by the endocrinology team; or 3) cessation of insulin therapy.

guidelines governing the decision to withdraw insulin at the end of life or management of diabetes at the end of life.

With more patients who have type 1 diabetes expected to live longer (6), it can be expected that death attributable to diseases unrelated to diabetes may increase. End of Life Diabetes Care by Diabetes UK and Guidelines for Managing Diabetes and the End of Life by an Australian palliative care group are currently the only 2 sets of guiding principles for managing diabetes at the end of life. Both make recommendations for patients based on a patient's estimated prognosis.

This case illustrates the final stage of life for a patient with a prognosis of only a few days. The options, including benefits and limitations, for ongoing management of type 1 diabetes in the setting of a limited prognosis are outlined in Table 1.

At the terminal stage, the Australian guidelines indicate that for patients with type 1 diabetes who are taking insulin, you should consider ceasing blood glucose monitoring, but that management should be based on the patients' current preferences. If the patients are unable to verbalize their preferences, management should be based on previously expressed wishes such as those documented in an advanced care plan (4). This reflects the importance of engaging in discussions about diabetes management preferences early in the course of palliation to ensure patients' preferences are respected throughout their care.

UK guidelines recommend more specific management in the last days of life, with once-daily dosing of long-acting insulin and once-daily testing of glucose, with titration recommended if blood glucose levels are below 8 mmol/L or above 20 mmol/L or higher (3). Based on these guidelines, option 2 (Table 1), using subcutaneous insulin, would be the most reasonable. The recommended upper limit in the terminal phase is higher than the glycemic target of 6 to 15 mmol/L recommended in the same guidelines for patients at the end of life in general. Polyuria, polydipsia and subsequent dehydration develop when the capacity of the kidney to reabsorb glucose is overwhelmed and, in 1 study, this was shown to occur when blood glucose was 6 to 14.3 mmol/L (7). Therefore, a lower blood glucose threshold for titrating insulin may be considered in patients in the terminal phase if symptoms occur.

Additionally, patient autonomy must be respected and, therefore, patients and their families must be engaged to ensure that changes in management are consistent with the goals of care. The use of a pump throughout the palliative process can be considered if there is ongoing support for pump management by the family or staff when the patient is unable to do so. In retrospect, the attempt by the treating team to provide "comfort care" may not have fully encompassed the complexity of diabetes management and the need to ensure nonmaleficence.

Diabetes at the end of life is a challenging situation that must prompt the consideration of multiple factors, including the

principles of ethics. As we encounter more patients with diabetes who require end-of-life care, a guiding set of principles relevant to our Canadian population may help to improve the quality of life for patients and their loved ones while also lessening providers' discomfort. Patients have indicated that it is important to them to have a say in how their diabetes is managed at the end of life, while caregivers have expressed concerns about taking on the tasks associated with diabetes and providing care and support for hyper- and hypoglycemia (8). Developing guidelines may help to facilitate the discussion of diabetes-care preferences at the end of life and to improve documentation of these preferences in the advanced care plan. Guidelines may also provide the opportunity to recognize and support caregivers in the management of diabetes throughout the end-of-life process, in keeping with the patients' wishes. Further engagement of practitioners involved with patients at the end of life and discussions with patients and their families are imperative for optimal care of these patients.

Author Disclosures

Conflicts of interest: None.

Author Contributions

Dr. Trinacty reviewed the case and drafted the manuscript. Dr. Keely managed the case and contributed to the manuscript content and editing. Both authors approved the final version.

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