Palliative and end-of-life care: Essential aspects of holistic diabetes care

Trisha Dunning

Citation: Dunning T (2018) Palliative and end-of-life care: Essential aspects of holistic diabetes care. *Journal of Diabetes Nursing* **22**: JDN015

Article points

1. Life expectancy is already reduced at diabetes diagnosis, but people with diabetes often live for a long time with multimorbidity and considerable physical and mental suffering that usual diabetes care may not alleviate.
2. Older people with diabetes often have many comorbidities. It is important to manage these complications, including using palliative care approaches to managing pain and discomfort.
3. Diabetes clinicians are ideally placed to identify when people with diabetes could benefit from palliative care and help them explore their values, preferences and care goals, and to document these carefully.

Key words

- End-of-life care
- Diabetes
- Palliative care

Authors

Trisha Dunning is Chair in Nursing, Centre for Quality and Patient Safety Research, Barwon Health Partnership, School of Nursing and Midwifery, Deakin University, Geelong, Victoria, Australia.

People with diabetes who are nearing the end of life often have complex care needs. This short report discusses some of the key issues that diabetes healthcare professionals should be considering in order to provide a truly personalised and holistic approach to diabetes care towards the end of life.

The child was 6 months old and severely malnourished. He was dehydrated, unresponsive and had thrush throughout his gastrointestinal tract. He was dying. "We will make him comfortable and stay with him so he doesn't die alone," said the doctor. I protested, saying: "We have to save him, we can't just watch him die."

"We won't be just watching him die. We will stop him suffering. You can't always follow the mantra: conserve health, prevent death and alleviate suffering. Making this baby comfortable is as important, probably more important, than trying to do everything possible to keep him alive. We have to act in his best interests and decide what his best interests are alone, because he cannot tell us and his family did not stay when they brought him here."

A baby died that day.

I confronted my own helplessness and the inevitability of death. I was 17, a few months into my nurse training. I have been present at many deaths since that day, but I vividly recall the doctor's message and his compassion. The message can be applied to everybody, including to people with diabetes.

Holistic and personalised diabetes care

Clinicians who care for people with diabetes and their families need to accept death, dying and bereavement as integral aspects of life. They need to know how to use palliative care alongside usual diabetes care. This includes knowing when to change the focus from tight glycaemic control to the person's individual care and life goals, relevant risk and likely benefits from treatment in their lifetime.

Generally, implementing personalised palliative care early improves comfort (relieves suffering), function, quality of life and sometimes life expectancy (Worldwide Palliative Care Alliance and World Health Organization, 2014). Palliative and end-of-life care are essential aspects of holistic and personalised diabetes management. While some guidance for diabetes-related palliative and end-of-life care exists, it is not included in most diabetes guidelines.

Although the focus on early diagnosis and tight metabolic control to prevent complications is important, we tend to overlook or maybe ignore the fact that tissue damaging dysglycaemia and dyslipidaemia are often present more than 20 years before type 2 diabetes is diagnosed and complications can be present at diagnosis (Malmstrom et al, 2014). Life expectancy is already reduced at diabetes diagnosis, but people with diabetes often live for a long time with multimorbidity and considerable physical and mental suffering that usual diabetes care may not alleviate.

Diabetes is linked to one death every 6 seconds somewhere in the world (International Diabetes Federation, 2015). Diabetes is the underlying

or associated cause of death in 3% and 10% of all deaths, respectively, especially deaths due to cardiovascular disease, cancer, stroke and renal disease (Australian Institute of Health and Welfare, 2018). Therefore, palliative care is very relevant to holistic personalised diabetes care.

Chronic disease trajectory

Diabetes follows the chronic disease trajectory to end of life. The chronic disease trajectory is characterised by periods of stable and unstable disease and gradual deterioration to the end of life (Lynn and Adamson, 2003). Each period of instability generally contributes to functional decline, but the changes can be subtle and go unnoticed.

Older people

Many older people with diabetes have complications that compromise life expectancy, such as cardiovascular and renal disease, frailty, dementia and some forms of cancer (Iglay et al, 2016). Polypharmacy is common and is associated with adverse events, admissions to hospital, and increased morbidity and mortality (Jyrkkä et al, 2009). It is important to manage these complications, including using palliative care approaches to managing pain and discomfort.

It is also important to decide a safe blood glucose and HbA_{1c} range for the individual. Hypoglycaemia is a significant risk in older people with type 1 diabetes and those with type 2 diabetes on insulin and sulphonylureas due to changes in the counterregulatory response and hypoglycaemic unawareness, among other factors. Hypoglycaemia is associated with reduced life expectancy (Cryer, 2016).

The individual and combined burdens of disease, treatment, medicines, self-care and service use increase as function declines and affects people's capacity to recover from physical and other stressors. Social isolation can occur and quality of life is compromised. Families often need support and education. Families, especially spouses, play an important caring role that can become burdensome and compromise their health.

Death can be sudden and unexpected. However, as indicated, people with diabetes usually experience many periods of deterioration from which they recover before they reach their end of life (Lynn and Adamson, 2003; Dunning and Martin, 2016). Therefore, there is time to proactively discuss end-of-life needs and give people time to think through issues important to them and make decisions while they still have the capacity to do so. Importantly, end-of-life care planning does not need to be "done all at once".

Planning and documenting care plans

Diabetes clinicians are ideally placed to identify when people with diabetes could benefit from palliative care and help them explore their values, preferences and care goals (Advance Care Planning) and document these in Advance Care Directives. Unfortunately, however, clinicians often miss opportunities to initiate such conversations (Claessen et al, 2013) and, sadly, such conversations often occur during Rapid Response Team interventions (Jäderling et al, 2017), when such stressful situations can affect decision-making. Thus, costly treatment that is unlikely to be beneficial is often commenced and/or burdensome care often continues unnecessarily. Our research shows people with diabetes want to discuss palliative and end-of-life care, but are reluctant to initiate such discussions because they do not want to "upset the doctors and nurses" and more commonly because "doctors and nurses do not ask people about that [dying]" (Savage et al, 2012).

Advance Care Planning involves clinicians discussing preferred future care with older people with diabetes and/or families while they are capable of deciding their values and goals, and making autonomous decisions. People value having reasonable control over their death, being comfortable, having time to complete unfinished business and time to say goodbye to important people and pets (Swerissen and Duckett, 2014).

People who document and communicate their values and care preferences are more likely to receive care consistent with their values and preferences. Advance Care Directives that inform surrogate decision makers and clinicians about the individual's values and care preferences reduce decisional conflict in stressful clinical situations.

Estimating prognosis

Estimating prognosis is important to clinical and personal decision-making, especially for frail

Page points

1. Many older people with diabetes have complications that compromise life expectancy, such as cardiovascular and renal disease, frailty, dementia and some forms of cancer.
2. It important to decide a safe blood glucose and HbA_{1c} range for the older person. Hypoglycaemia is a significant risk in older people with type 1 diabetes and those with type 2 diabetes on insulin and sulphonylureas.
3. Diabetes clinicians are ideally placed to identify when people with diabetes could benefit from palliative care and help them explore their values, preferences and care goals.

"Diabetes care that does not encompass palliative care and the individual's end of life ignores an important life transition and could deprive the individual of the opportunity of a peaceful, dignified death."

older people with comorbidities. Not considering prognosis could result in lower quality care (Yourman et al, 2012). It is difficult to predict the course of death of many chronic diseases that affect older people. Therefore, any care should be based on individual and family needs and not on prognosis. Having said that prognostic tools can help identify an individual's likely risks and benefits from care options, and help personalise his or her care.

Personal factors

Personal factors also need to be considered. These include "the will to live", given there is an association between survival and will to live (Karpinnen, 2012). Similarly, there is an association between self-reported health and mortality (Godaert et al, 2017) and the association persists after adjusting for known mortality risk factors (Helvik et al, 2013). Self-reported health may not accurately reflect actual health status, but it encompasses multiple dimensions that individuals consider when rating their quality of life and health status that are not captured on many quality-of-life screening tools.

Diabetes care that does not encompass palliative care and the individual's end of life ignores an important life transition and could deprive the individual of the opportunity of a peaceful, dignified death consistent with his or her values and preferences. It is also important to consider the impact on families because:

"The way people die remains in the memory of those who live on."

(Dame Cicely Saunders) ■

Australian Institute of Health and Welfare (2018) *Older people: Overview*. AIHW, Canberra, Australia. Available at: https://is.gd/rTU18l (accessed 10.04.18)

Claessen, SJ, Francke, AL, Engels, Y, Deliens, L (2013) How do GPs identify a need for palliative care in their patients? An interview study. *BMC Fam Pract* **14**: 42

Cryer P (2016) Hypoglycaemia during therapy of diabetes Endotext. org. Available at: https://is.gd/qgZ6n3 (accessed 10.04.18)

Dunning T, Martin P (2016) Palliative and end-of-life care: Issues, challenges and strategies. *Diabetes Res Clin Pract* (epub ahead of print)

Godaert L, Godard-Scbillotte C, Saint-Albin L et al (2017) Self-rated health as a predictor of mid-term and long-term mortality in older Afro-Caribbeans hospitalised via the emergency department. *Qual Life Res* **27**: 91–96

Helvik A, Engedal K, Selbaek G (2013) Three-year mortality in previously hospitalized older patients from rural areas – the importance of co-morbidity and self-reported poor health. *BMC Geriatrics* **13**: 17

Iglay K, Hannachi H, Howies P et al (2016) Prevalence and co-prevalence of comorbidities among patients with type 2 diabetes mellitus. *Curr Med Res Opin* **37**: 1243–52

International Diabetes Federation (2015) *IDF Diabetes Atlas*. IDF, Brussels, Belgium. Available at: www.diabetesatlas.org (accessed 10.04.18)

Jäderling G, Bell M, Martling CR et al (2017) Limitations of medical treatment among patients attended by the rapid response team. *Acta Anaesthesiologica Scandinavica* **57**: 1268–74

Jyrkkä J, Enlund H, Korhonen MJ, Hartikainen S (2009) Patterns of drug use and factors associated with polypharmacy and excessive polypharmacy in elderly persons: Results of the Kupio 75+ study: A cross-sectional analysis. *Drugs Aging* **26**: 493–503

Karpinnen H (2012) Will-to-live and survival in a 10-year follow-up among older people. *Age Ageing* **41**: 789–99

Lynn J, Adamson DM (2003) *Living well at the end of life adapting health care to serious chronic illness in old age*, RAND Corporation, Santa Monica, CA, USA. Available at: https://is.gd/FgxvZn (accessed 10.04.18)

Malmstrom H, Walldius G, Grill V et al (2014) Fructosamine is a useful indicator of hyperglycaemia and glucose control in clinical and epidemiological studies – cross-sessional, longitudinal experience from the AMORIS cohort. *PLOS ONE* **9**: e111463

Savage S, Dunning T, Duggan N, Martin P (2012) The experiences and care preferences of people with diabetes at the end of life. *J Hosp Palliat Nurs* **14**: 293–302

Swerissen H, Duckett S (2014) *Dying Well*. Grattan Institute, Victoria, Australia. Available at: https://is.gd/hhqact (accessed 10.04.18)

Yourman L, Lee S, Schonberg M et al (2012) Prognostic indices for older adults: A systematic review. *JAMA* **307**: 182–92

Worldwide Palliative Care Alliance, World Health Organization (2014) *Global atlas of palliative care at the end of life*. WPCA and WHO. Available at: https://is.gd/ajeQYV (accessed 10.04.18)