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## Considering palliative and end-of-life care for people with diabetes

Theresa Smyth and Dion Smyth investigate the challenges of palliative and end-of-life care for people with diabetes and observe the importance of communication between practice nurses and their patients

During the 20th century, the demographic of disease and dying fundamentally changed. Advances in modern medicine, therapeutic technologies and supportive care meant that many previously acute causes of death were successfully transformed into chronic incurable illness so that death often comes only after a long period of progressive decline (Lynn, 2005).

There are over 15 million people in the UK living with a long-term condition, such as diabetes mellitus (Department of Health (DH), 2010). According to Diabetes UK (2011), the population diagnosed with diabetes is 2.8 million.

More than half a million people die in the UK each year, most over the age of

75 years (DH, 2008). The majority of these deaths occur in people with a long-term condition, and it is estimated that 6–9% of those dying will have diabetes mellitus (Rowles et al, 2011).

About half of all patients do not die in their preferred place of care (Gomes and Higginson, 2006). At present, the majority of deaths (58%) occur in institutional settings such as NHS hospitals, 18% occur at home, 17% in care homes, 4% in hospices and 3% elsewhere (DH, 2008).

A report, which investigated complaints to the Healthcare Commission about hospital care, found that over half (54%) were associated with aspects of end-of-life care (Commission for Healthcare Audit and Inspection, 2007). Similarly, wide disparities and dissatisfaction with access to specialist palliative care services are reported, with only 5% of all referred patients having a diagnosis of non-malignant disease (Payne et al, 2004).

The provision of effective, equitable end-of-life care that facilitates choice and control should be available to all, regardless of medical diagnosis and place of care (DH, 2008). Some authors argue that palliative care is an international human right (Brennan, 2007; Gwyther et al, 2009) including elements of palliative care, such as

adequate access to appropriate pain relief (Lohman et al, 2010).

### The challenge of palliative care

The management of diabetes at the end of life has been reported to be a continuing 'challenge' (Budge, 2010), 'complex' (McCoubrie et al, 2005), and 'inconsistent' (Quinn et al, 2006a; Ford-Dunn et al, 2006). It is also acknowledged that palliative care in patients with diabetes is perceptibly different from the treatment of patients who do not have advanced illness (McPherson, 2008).

Vandenhaute (2010) reviewed the relevance of the application of standardized diabetes care guidelines to an end-of-life population suggesting that caregivers have an inclination to 'overmedicate', at a time when interventions are likely to be invasive, irksome, inopportune, and ineffective.

All the same, the prevailing philosophy, patient opinion, political priorities and professional impetus emphasize that compassionate end-of-life care is the concern of all nurses, not only the specialist practitioners (National Council for Hospice and Specialist Palliative Care Services (NCHSPCS), 2002; DH, 2008; Royal College of Nursing (NRC), 2011). The shifting emphasis of health

care provision from hospital to primary care across the health continuum means it is imperative that practice nurses are able to discuss, plan, and deliver high quality end-of-life care to patients (Pellett, 2009).

### End-of-life care: palliative care

The World Health Organization (WHO) (2002) defines palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness. This is achieved through the prevention and relief of suffering by means of early identification, impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. These are a few of many fundamental facets of palliative care (Table 1).

Where palliative care might once have been seen as synonymous with, or relegated to terminal care, Sepúlveda et al (2002) suggest that the definition declares now that the principles and practices of palliative care do not belong solely to the discrete end-of-lifestages but should be applied as soon as feasible in the course of any chronic, ultimately fatal illness.

Accordingly, while 'end-of-life care' may refer primarily

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**Table 1. Principles of palliative care practice**

Provides relief from pain and other distressing symptoms
Affirms life and regards dying as a normal process
Intends neither to hasten nor postpone death
Integrates the psychological and spiritual aspects of patient care
Offers a support system to help patients live as actively as possible until death
Offers a support system to help family members cope during the patient's illness and in his/her own bereavement
Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
Will enhance quality of life, and may also positively influence the course of illness
Applies to early stages of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications

to the care of the dying and incorporates all elements of the daily life of a person in the last part of his/her life, it is recognized that expected length of life is often an inexact criteria.

For some conditions, such as dementia, the use of clinical indicator checklists, such as those within the Gold Standards Framework, would aid the assessment of people who would profit from a palliative care approach earlier in their disease experience (Alzheimer's Society, 2006) (Table 2).

### Informing people with diabetes about palliative care

The vast majority of patients with diabetes will have long standing type 2 diabetes and many of these patients may already be known to the practice nurse (Diabetes UK, 2010). In many instances, diabetes mellitus is a common co-morbidity of other complex diseases such as cancer (Smyth and Smyth, 2005a; Psarakis, 2006) or can arise as a result of diabetogenic treatments, such as the use of glucocorticosteroids

(Smyth and Smyth, 2004; Dunning et al, 2010).

Whatever the aetiology, it is reasonable to expect that many patients with diabetes and their families have been managing the diabetes independently and well for some time. The change in emphasis associated with end-of-life care, from disease modification and management to the improvement and maintenance of quality of life in the final months before death can therefore be confusing and distressing for patients (Ronaldson and Devery, 2001; Randall and Wearn, 2005).

This is especially relevant if patients are not fully aware of their situation and involved in the decision-making process, and lack the necessary correct information about what palliative care involves. Patients and their families may perceive the cessation of disease-modifying treatment and relaxation of rigorous blood glucose monitoring, control and dietary restriction to be a lack of professional concern or abandonment (McCoubrie et al, 2005; Back et al, 2009).

### Impact of caring for patients at end of life

Nurses should encourage patients to shift their focus to palliative or end-of-life care during their decline in health (Wittenberg-Lyles et al, 2011). However, it is recognized that care of people at the end of their lives, discussing a person's impending death, and understanding patients' preferences for their end-of-life needs, can be a source of significant stress and anxiety for many nurses (Marks, 2005; Costello, 2006; Burnard et al, 2008; Thompson-Hill et al, 2009).

In one study, which explored the experiences of GPs and community nurses discussing patients' preferred place of death, the majority of the professionals revealed they found it a difficult area of practice (Munday et al, 2009).

The delivery of effective, high quality palliative care is dependent on confident and competent communication skills (Malloy et al, 2010). Equally, being suitably prepared may mitigate the potentially distressing effects of dealing with death and dying.

Therefore, before any pragmatic clinical

considerations about managing diabetes at the end of life can be addressed, practice nurses should reflect on their communication skills, knowledge of end-of-life care and continuing professional development needs. There are resources to assist the nurse, including a compendium of links to assessment tools, policy documents and clinical guidance from organizations such as the Liverpool Care Pathway and Preferred Priorities for Care.

### Clinical management of diabetes in patients at the end of life

#### Blood glucose values

Angelo et al (2011) have remarked that there is a dearth of evidence-based medical literature regarding best practice in the management of patients with diabetes who are at the end of life, and the optimal approach remains uncertain.

However, there are some general observations and consensus guidelines that suggest that stringent glycaemic control via regular invasive blood glucose monitoring might be of dubious benefit, if not burdensome, and potentially

**Table 2. Further information**

#### Gold Standards Framework

For a brief discourse on the various tools on predicted prospects of patients search 'prognostic indicators' for some helpful links  
[www.goldstandardsframework.org.uk](http://www.goldstandardsframework.org.uk)

#### National End of Life Care Programme

*Preferred Priorities for Care*

To aid dialogue with patients about preferences for care at the end of life  
<http://bit.ly/nRJ250>

#### Royal College of Nursing

*Route to success: the key contribution of nursing to end of life care*  
 Contains a list of useful resources from a range of organizations  
<http://bit.ly/p3WcGF>

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even harmful if it causes symptomatic hypoglycaemia (Rowles et al, 2010; Angelo et al, 2011). A target range for blood glucose of 5–15 mmol/litre is reasonable (Smyth and Smyth, 2005b; Rowles et al, 2011).

## Type 1 diabetes

For patients with type 1 diabetes who suffer absolute insulin deficiency caused by the auto-immune destruction of the pancreas beta cells, Rowles et al (2011) emphasized that insulin withdrawal is 'likely to lead to death'. So insulin therapy should be continued preferentially with a simplified regimen suitable to the patient, using a once-daily long-acting analogue insulin, a twice-daily isophane insulin or a twice-daily fixed mixture.

Rowles also advocated the involvement of the specialist diabetes team for advice and guidance with individualized care planning, rather than adherence to generic treatment procedures in patient care; this is especially valid for patients with type 1 diabetes.

## Type 2 diabetes

For patients with type 2 diabetes, the aim of medication should be to avoid hypoglycaemia, which normally means blood glucose levels should be less than 15 mmol/litre.

Infections and treatment with steroids may lead to marked hyperglycaemia which in turn could lead to dehydration and may result in a hyperosmolar hyperglycaemic state, which is associated with unpleasant symptoms such as polyuria, polydipsia and confusion (but

not ketosis) and can lead to death. As palliative care is defined by the 'impeccable assessment and management of symptoms' and 'intends neither to hasten nor postpone death' (World Health Organization, 2011), management to correct hyperglycaemia is appropriate and justified.

Individuals suffering from advanced cancer or other chronic illness commonly become anorexic and therefore oral hypoglycaemic medication is discontinued due to the risk of hypoglycaemia with insulin-secreting agents such as sulphonylureas and the gastrointestinal side effects of metformin (Angelo et al, 2011).

Patients treated with insulin may be able to discontinue this aspect of treatment as their endogenous insulin may accommodate the reduced dietary intake, weight and energy demands. Should the patient become symptomatic, insulin can be reinstated, e.g. a once-daily long-acting insulin analogue (Rowles et al, 2011).

## Haemoglobin A<sub>1c</sub> recording

Measuring haemoglobin A<sub>1c</sub> (HbA<sub>1c</sub>), which would ordinarily indicate whether diabetes was under control, is largely irrelevant in end-of-life care since the question or concern of long-term complications is essentially of no real therapeutic value or consequence (Smyth and Smyth, 2005b; McPherson, 2008). Even in type 1 diabetes the frequency of blood glucose monitoring could be reduced to daily or twice-daily.

However, avoiding acute complications of diabetes such as hyperglycaemia, diabetic ketoacidosis and

hyperosmolar non-ketotic states is important to the overall goal of maintaining patients' quality of life (Smyth and Smyth, 2005b).

## Diabetic ketoacidosis

Diabetic ketoacidosis, which occurs in type 1 and type 2 diabetes when there is an absolute or relatively severe insulin insufficiency, results in body fat being used as a fuel source. As a result, ketones, the by-product of fat metabolism, and acid build up in the body.

Hyperosmolar hyperglycaemic state, which is distinguished by hyperglycaemia, hyperosmolarity and dehydration without significant ketoacidosis, usually presents in older patients with type 2 diabetes and is associated with significant mortality (Hemphill et al, 2011). Close collaboration between the diabetes, palliative care specialist practitioners and primary care staff is vital (Quinn et al, 2006b).

It is reiterated that the professional may be called on to communicate sensitively these changes to care to patients and their families in a way that does not imply the situation is hopeless or that there is 'nothing more that can be done'. Instead they should help patients and their families to shift their focus of hope and coping to quality of life matters (Olsson et al, 2010).

## Prognostication and palliative care

Estimations of prognosis can aid self-directed decision-making by patients and families, and afford them the opportunity to make provision for their future care

needs. However, a number of researchers have reported the intricacy and inconsistency with end-of-life prognostication, including doctors consistently overestimating the duration of survival (Glare et al, 2003; Head et al, 2005).

With this caveat in mind, a prognosis-based process of prioritizing patients' treatments, grounded by the severity of patients' circumstances and condition has been advocated (Angelo et al, 2011). Assorted tools to aid prognostication, such as the Palliative Performance Scale (Anderson et al, 1996) have been produced to provide objective data for the predicted prospects of the patient.

The 'surprise' question 'would I be surprised if this patient died in the next year?' is an example of a straightforward, practicable, and intuitive tool that can help health professionals to contemplate the patient's care needs and identify patients with a poor prognosis (Moss et al, 2008; 2010; Murray and Boyd, 2011)

Angelo et al (2011) propose three groups:

- Advanced disease but relatively stable
- Impending death or organ or system failure
- Actively dying.

### Advanced disease but relatively stable

For patients whose condition is stable, and they are mainly ambulant and independent, the following might be considered:

- Continue current regimen if possible but open an honest conversation about

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a reduction in the intensity of glycaemic control

- ▶ Instruct about preventing hypoglycaemia
- ▶ Cease monitoring of HbA<sub>1c</sub>
- ▶ Reduce frequency of blood glucose monitoring
- ▶ Maintain reasonable prevention of hyperglycaemia (blood glucose <10 mmol/litre)
- ▶ Prescribe a relaxed 'pleasure based' diet, where the patient eats for satisfaction and gratification, limiting only highly concentrated carbohydrate.

In addition, candid conversations with the patient should be commenced and people should be offered the opportunity to discuss their preferred priorities of care, e.g. where they would wish to die.

## Impending death or organ or system failure

In the transitional stages, when the disease advances, the patient's performance status is reduced, he/she is becoming dependent and may have reduced intake, the importance of glycaemic control is less obvious and preventing hypoglycaemia is more important:

- ▶ Patients with type 1 diabetes may need to reduce their insulin dose, especially if renal or hepatic failure is manifest since insulin will not be metabolized and gluconeogenesis will be hindered
- ▶ Patients with type 2 diabetes may also have to decrease their anti-diabetic treatment owing to reduced oral intake or

organ involvement that compromises drug activity and safety

- ▶ Blood glucose monitoring can generally be stopped in type 2 diabetes and become a decision-making tool only, not routine practice, in type 1 diabetes.

## Actively dying

The phase when a patient is actively dying it is characterized by the patient's need for total care with his/her activities of daily living, multiple organ failure and no capacity for enteral intake, e.g. eating and drinking. Angelo et al (2011) suggested that consensus at this stage is lacking and 'most practitioners' would withdraw all hypoglycaemic agents including insulin in a person with type 1 diabetes.

This raises significant moral, ethical and legal considerations which are beyond the scope of this article but suggest that open communication between the interprofessional team, with the patient where able, and his/her family and/or carers, is vital.

It also highlights one of the key principles of contemporary end-of-life care, namely that realistic anticipatory planning and preparation for the dying process, including eliciting preferred priorities for care and the patient's decision and direction for care, can prevent avoidable dilemmas or distress.

## Conclusions

The US senator, Hubert Humphrey is reported to have remarked that 'the moral test of government is how that government treats those who are in the dawn of life, the

children; those who are in the twilight of life, the elderly; those who are in the shadows of life; the sick, the needy, the handicapped' Encyclopedia Britannica (2011).

Successive governments have raised morale and money and invested in programmes and plans that aim to make the provision of high quality end-of-life care accessible and acceptable to all. Publications such as the Commissioning Diabetes End of Life Services (NHS Diabetes, 2011) call attention to that political will and wherewithal. However, it will be whether health professionals, including nurses in general practice, are with all the patients on their journey that determines the professional success of any policy.

*Conflict of interest: none*

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## KEY POINTS

- Compassionate end-of-life care is the concern of all nurses not only specialist practitioners
- Palliative care includes early identification of life-threatening illnesses, accurate assessment and treatment of pain
- Moving focus from modification and management of diabetes to the improvement and maintenance of quality of life is important for end-of-life care
- Palliative care is dependent on confident and competent communication skills between nurse and patient

## CASE STUDY I

Tom is a 68-year-old retired mechanic, who lives with his wife, Alice. Tom has lived with type 2 diabetes mellitus since the age of 42 years. About 6 months ago he was diagnosed with lung cancer with extensive metastases, which is associated with a poor prognosis. He is aware of his prognosis and wants to 'live as much as possible' while he can.

Tom's weight has decreased over the past few months. He previously had a body mass index of 31 kg/m<sup>2</sup> but this is now 26 kg/m<sup>2</sup>. He complains of having 'no appetite' and when he feels like eating he wants 'just small amounts'.

Tom's diabetes is treated with biphasic human insulin twice a day, and he also takes metformin 1000 mg twice daily. He has had several hypoglycaemic episodes recently, during which his wife had to administer GlucoGel to help him recover. Alice is now anxious about ensuring that Tom has regular meals given his reduced

appetite, and this is a source of some tension between the couple.

Tom had always striven to have good glycaemic control, in order to prevent complications of diabetes, but the practice nurse discusses how preventing the extremes of hypoglycaemia and hyperglycaemia may be more appropriate now.

Her advice to Tom is to stop taking the metformin as this can cause gastrointestinal discomfort and reduced appetite and she changes the twice daily biphasic insulin to a once-daily long-acting insulin analogue.

She reassures both Tom and Alice that eating a 'pleasurable' diet when Tom feels like it is fine. They agree that Tom should continue checking his blood glucose but only once a day, to keep his blood glucose between 5–15 mmol/litre. If it should be above or below this range the practice nurse gives him some simple titration guidelines for him to adjust the insulin himself.

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