

# An audit review of end-of-life care for inpatients with diabetes

Debbie Hindson, Pat Colliety, Jill Shawe, Peter Williams

## Article points

1. This audit evaluated end-of-life care decisions in the management of diabetes.
2. Data were collected for 71 cases to assess demographics, diabetes characteristics, monitoring and diabetes treatment withdrawal and the potential ability for “self or other” advocacy for these decisions.
3. The findings suggest that most inpatients with diabetes in whom deterioration and death is rapid continue capillary blood glucose monitoring to the end of life.

## Key words

- Audit
- Capillary blood glucose monitoring
- End of life

Authors' details can be found at the end of this article.

The decision to withdraw capillary blood glucose (CBG) monitoring and glycaemic treatment at the end of life in people with diabetes may have implications for comfort-care management in the dying individual in the acute care setting. The paradigm shift to the self-management of diabetes through CBG monitoring enables patients or their relatives to contribute to decisions for the withdrawal of CBG monitoring or antidiabetes treatment. Although it is unknown whether glycaemic symptoms are perceived in dying persons in the same way as those in full health, there is still an obligation to consider their effects on comfort at the end of life. In this article, the authors report the findings from a medical-notes audit in which they evaluated some key assumptions about advocacy (self or other) for end-of-life care decisions and the management of diabetes.

The decision to withdraw capillary blood glucose (CBG) monitoring and glycaemic treatment at the end of life in people with diabetes may have implications for comfort-care management in the dying individual in the acute care setting. The symptoms commonly seen in the terminal phase of life (the last 72 hours) include pain, weakness, dyspnoea, nausea, vomiting, restlessness, dry mouth and dizziness (Tsai et al, 2006), and are similar to symptoms seen in diabetic ketoacidosis (DKA), hyperglycaemia and hypoglycaemia.

The role of CBG monitoring may enable symptom differentiation and appropriate glycaemic treatment measures as part of the comfort-care plan. The paradigm shift to the self-management of diabetes through CBG monitoring (Wallymahmed, 2007) enables patients (or their relatives) who have the mental capacity and self-management knowledge to contribute to decisions for the withdrawal of CBG monitoring or diabetes treatment. This may be important as there is evidence that the perception of hypo- and hyperglycaemic symptoms varies in

character, pattern and intensity, both within and between individuals, and over time (Pennebaker et al, 1981; Cox et al, 1993; Weinger et al, 1995; McAulay et al, 2001). Although it is unknown whether glycaemic symptoms are perceived in dying persons in the same way as those in full health, there is still an obligation to consider their effects on comfort at the end of life (Ford-Dunn et al, 2006).

### Aim

In this article, the authors report the findings from a medical-notes audit that formed part of an evaluation research study in which a favourable ethics opinion was received. The audit sought to evaluate some key assumptions about advocacy (self or other) for end-of-life care decisions and the management of diabetes.

### Sample

The total hospital deaths for the period between 1 January and 31 December 2008 in a 450-bed acute hospital in Surrey was 1257. Of these individuals, 229 (18.2%) had a reported comorbidity of diabetes. Among these, there were 22 referrals to the DSN team and 19 to the palliative care team. The Hospital Episode Statistics database was searched for additional adults with a comorbidity of diabetes and cancer (n=30). These 71 individuals were audited.

The age range for the cohort was 52–95 years (mean age, 76.9 years). Thirty (42.2%) were female and 41 (57.7%) had a cancer diagnosis (additional uncoded cancer cases were found). There were seven individuals (9.9%) with type 1 diabetes and 62 (87.3%) with type 2 diabetes, which reflects the population ratio (Diabetes UK, 2010). Of the remaining two individuals, one had steroid-induced diabetes and the other had diabetes of unknown type.

### Data collection and analysis

Data were collected to assess individual and disease characteristics, including those suggesting ability to be a self-advocate for end-of-life diabetes treatment withdrawal (socio-demographic data; ability to give one's

own history on admission; documentation of intact cognition; diabetes type, duration and treatment; and inclusion of individual or relative views) and management variables (glucose monitoring practices, cancer status, relationship between diabetes medication withdrawal and individuals' nutrition intake, DSN and palliative care involvement and influence of the Liverpool Care Pathway [LCP] at the end of life). Descriptive and inferential statistics were used.

### Individual and family advocacy variables

The literature reports that most individuals are willing to discuss their end-of-life preferences (Heyland et al, 2003) and the opportunity to do so has been found to be important (Fallowfield et al, 2002). In this study, only three individuals had any documented reference in the notes for their end-of-life diabetes management; two of these had type 1 diabetes. One individual who knew that her prognosis was "days" requested an intravenous insulin infusion to ensure her insulin needs were continuously met in the terminal phase; an imminently dying patient admitted from a clinic explicitly stated no CBG monitoring by the physician, without reference to the decision source. One person with type 2 diabetes requested CBG monitoring.

### Expertise with diabetes

The majority of individuals were likely to have significant expertise to support shared decision-making. All individuals with type 1 diabetes had been diagnosed for >30 years. Among the people with type 2 diabetes, half had been diagnosed for >10 years. Most of the cohort (76%) were managed with tablets, insulin therapy or both and were likely to be familiar with their own CBG profile. A structured glycaemic history was not part of the standard admission history by doctors or nurses for hypoglycaemic awareness or usual CBG profile. The majority of the cohort (66%) were reasonably well controlled pre-admission, with a mean HbA<sub>1c</sub> level of 55 mmol/mol (7.2%) within the previous 6–12 months.

*Table 1* summarises the socio-demographic profile for the study group. The data suggest

### Page points

1. There were 71 individuals audited: seven with type 1 diabetes, 62 with type 2 diabetes, one with steroid-induced diabetes and one with diabetes of unknown type.
2. Only three individuals had any documented reference in the notes for their end-of-life diabetes management; two of these had type 1 diabetes.
3. All individuals with type 1 diabetes had been diagnosed for >30 years. Among the people with type 2 diabetes, half had been diagnosed for >10 years. Most of the cohort (76%) were managed with tablets, insulin therapy or both and were likely to be familiar with their own capillary blood glucose profile.

Table 1. Individuals' socio-demographic profile.						
		Diabetes type				Total n (%)
		Type 1 n=7 (9.9%)	Type 2 n=62 (87.3%)	Steroid-induced n=1 (1.4%)	Unclear n=1 (1.4%)	
<b>Support</b>						
Lives alone	Male	1	5	1		7 (9.9%)
	Female		11			11 (15.5%)
Lives with spouse	Male		26		1	27 (38.0%)
	Female	4	6			10 (14.1%)
Lives with relative	Male		3			3 (4.2%)
	Female		3			3 (4.2%)
Lives in care home	Male	1	3			4 (5.6%)
	Female	1	5			6 (8.5%)
<b>Mental capacity to make decisions</b>						
–On admission:	Yes	6	46		0	52 (73.2%)
	No	1	15		1	17 (23.9%)
	Unclear		1	1		2 (2.8%)
–Last 72 hours of life:	Yes	2	27			29 (40.8%)
	No	5	34	1		40 (56.3%)
	Unclear		1		1	2 (2.8%)
<b>Terminal phase apparent on admission</b>	Yes	1	7			8 (11.3%)
	No	6	55	1	1	63 (88.7%)

who may have had available family who were knowledgeable about the patients' attitude to their diabetes and could contribute to comfort care issues, and those who may have needed to rely on professional advocacy in the hospital setting.

### Management of diabetes at the end of life

#### CBG monitoring

A total of 5760 timed and dated CBG recordings for the whole admission period were collected from 70 individuals' medical records. The number of CBG tests per person ranged between 0 and 721 in a cohort whose length of hospital stay ranged between 1 and 84 days. Owing to the skewed nature of the distribution of the CBG variables, non-parametric Mann–Whitney U tests were performed to test the association between cancer diagnosis and CBG test values. There was no statistically significant difference between people with and those without cancer for the occurrence

of hypoglycaemia. However, those with cancer had a statistically significantly ( $P=0.022$ ) higher proportion of CBG tests with normal values (defined as 4.0–9.9 mmol/L), whereas those without cancer had a statistically significantly ( $P=0.014$ ) higher proportion of CBG tests with values in the hyperglycaemic range (defined as  $\geq 10$  mmol/L). The mean CBG values for the last 72 hours of life (terminal phase) were variable, as shown in *Figure 1*. CBG in high and low ranges were mostly attributable to iatrogenic causes secondary to unskilled management of intravenous insulin and enteral feeds. No DSN referrals were received for glycaemic advice at the end of life in these individuals. There was no evidence that hypoglycaemia was a “natural” process in the terminal phase, as occurrences were episodic in nature. The CBG monitoring may have prompted nurses to alter nutritional intake in patients with lower CBG values.

*Table 2* summarises the key characteristics of those individuals who were monitored from

Figure 1. Mean blood glucose levels for last 72 hours in individuals who were monitored to end of life.

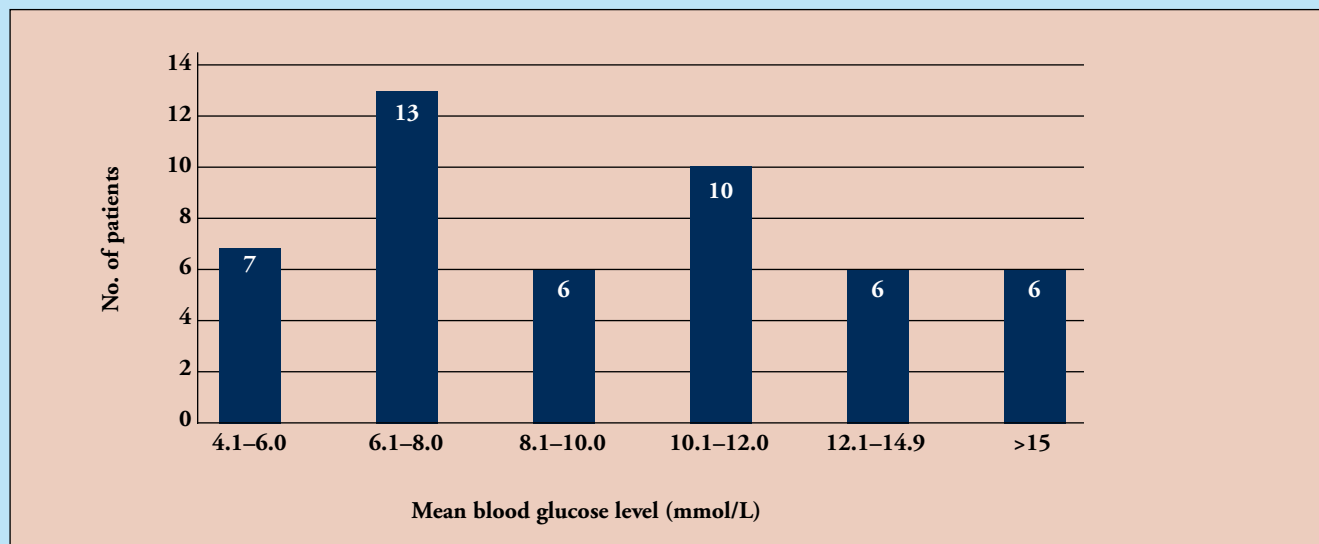


Table 2. Characteristics of individuals who were monitored versus unmonitored.

	Monitored to day of death <i>n</i> =48 (68%)	Not monitored to day of death <i>n</i> =23 (32%)
Cancer	30 (63%)	11 (48%)
Non-cancer	18 (38%)	12 (52%)
Type 1 diabetes ( <i>n</i> =7)	2 (4%)	5 (22%)
Deterioration to death:		
<72 hours	43 (90%)	16 (70%)
>72 hours	5 (10%) (range, 4–12 days)	7 (30%) (range, 4–18 days)
Intravenous insulin given on day CBG withdrawn	5 (10%)	1 (4%)

the point when irreversible deterioration was documented until the day of death and those who were not.

**Monitored individuals**

The data for individuals whose CBG levels were monitored until death suggest that the short survival time of 24–72 hours was influential.

**Unmonitored individuals**

In the 30% of unmonitored individuals who survived beyond 72 hours, the average time unmonitored was 7.9 days. The final CBG value was not influential in continuation of CBG monitoring management despite their wide-ranging variation (3.5–22.0 mmol/L). All symptoms that were documented in the notes were listed in the audit but frequency of

recurrence was not counted. Those surviving beyond 72 hours had more symptoms listed than those who did not. The role of CBG monitoring may be useful to determine symptom origin and guide reversible treatment.

Referral to the palliative care team for support with comfort measures occurred in 62% of the cohort, and 50% of referrals were in the last 72 hours. These late referrals may limit an integrated specialist approach to optimising symptom management across palliative and diabetes specialisms.

**Food and diabetes medicines withdrawal**

Many individuals (41%) were still taking their diabetes medications and some nutrition until the day of death. Diabetes drugs were stopped the day after food was no longer consumed

**Page points**

1. Only two people with type 1 diabetes were monitored to the end of life. One person was managed on intravenous insulin, with capillary blood glucose readings >15 mmol/L. The other was managed in the intensive care unit.
2. The findings from this audit suggest that most inpatients with diabetes in whom deterioration and death is rapid continue CBG monitoring to the end of life.
3. The lack of glycaemic history-taking in the hospital limits the professional advocate role and suggests “blindness” to its importance at both a physiological and ethical level, particularly in people with type 1 diabetes, for whom patients’ or relatives’ preferences were not documented.

in 24% of cases (23% in monitored and 30% in unmonitored individuals). This suggests that nurses were diligent in monitoring patients’ nutrition and diabetes medication management according to CBG values.

**Monitored individuals with type 1 diabetes**

Patients with type 1 diabetes were not selectively monitored for CBG and treated. This may be because the term “insulin-dependent diabetes mellitus” was commonly cited in the medical notes and the differentiation of diabetes type could not be made.

Only two people with type 1 diabetes were monitored to the end of life. One person was managed on intravenous insulin, with CBG readings >15 mmol/L. The other was managed in the intensive care unit. Although her CBG was monitored, insulin was withheld for 4 days. The notes reported her diagnosis as type 2 diabetes, possibly because she was overweight. However, the medical notes summarised her 37-year type 1 diabetes medical history in one thin volume.

**Unmonitored individuals with type 1 diabetes**

Five individuals were managed on the LCP for the last 1–4 days of their lives. Insulin was stopped in all cases at different time points ranging from 24 hours to 7 days before death. The individual whose insulin was omitted for 3 days had been readmitted with recurrent DKA, and scant documentation on symptoms or diabetes management was noted.

The symptoms listed in the notes in these unmonitored patients were thirst, weakness, distress, difficulty swallowing, chestiness, shortness of breath, distress, agitation, confusion, nausea, fatigue, poor appetite and chest pain. Although these symptoms cannot be attributed directly to blood glucose level changes or DKA in any retrospective study, some may at least be suggestive.

**Discussion**

The findings from this audit suggest that most inpatients with diabetes in whom deterioration and death is rapid continue CBG monitoring

to the end of life. The majority are monitored up to 72 hours, probably owing to uncertainty about the reversibility of the medical situation. This is a common dilemma in hospital settings in people with advanced disease (Gadoud and Johnson, 2011). The decision to discontinue CBG monitoring is clear in those individuals with a prognosis of “days”.

The literature is clear about the importance of managing type 1 diabetes and symptomatic hyperglycaemia (Usborne and Wilding, 2003; McCoubrie et al, 2005; Smyth and Smyth, 2005; Ford-Dunn et al, 2006; Quinn et al, 2006; Tice, 2006; Rowles et al, 2011) at the end of life. There appears to be no due regard for the contribution of the CBG profile to the individual’s symptom profile in considering rechecking the CBG level when the last known reading is abnormal. The lack of glycaemic history-taking in the hospital limits the professional advocate role and suggests “blindness” to its importance at both a physiological and ethical level, particularly in people with type 1 diabetes, for whom patients’ or relatives’ preferences were not documented.

The LCP is very limited in its guidance for managing end-of-life conditions in which withdrawal of usual treatments for “survival”, such as insulin in the case of type 1 diabetes, has ethical and comfort-care implications. The knowledge, skill and confidence with which to manage insulin and diabetes within acute care is well known (Spollett, 2006; Derr et al, 2007; Cook et al, 2008; George et al, 2011). Shared decision-making for preferred glycaemic thresholds is limited without such knowledge.

**Limitations**

As with all medical-notes audits, the subjective nature of the individual documenting care is a known issue. Conversations are not always reported in the notes and therefore this audit can only report what was written.

**Concluding remarks**

The importance of documentation of the type of diabetes, glycaemic history and symptom

profile for the management of diabetes and supporting comfort care at the end of life in the hospital setting is clear. The majority of patients (90%) in this evaluation had a “do not attempt resuscitation” notification in place. This may be a good point at which to consider revising a diabetes plan of “minimal and simple” in line with the individuals’ wishes. Collaborative team work between the diabetes and palliative care teams to support end-of-life comfort care, and managing insulin therapy and CBG testing preferences may be helpful. The need for more education and better communication is a consistent finding in most clinical research and its application in this setting is clear. ■

#### Authors

Debbie Hindson is a Senior Specialist Nurse in Diabetes, University of Surrey, London; Pat Colliety is a Senior Tutor, University of Surrey, London; Jill Shawe is a Senior Research Associate, University College, London; and Peter Williams is a Consultant Statistician, University of Surrey, London.

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**“Collaborative team work between the diabetes and palliative care teams to support end-of-life comfort care, and managing insulin therapy and capillary blood glucose testing preferences may be helpful. The need for more education and better communication is a consistent finding in most clinical research and its application in this setting is clear.”**