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Management of diabetes during the last days of life: attitudes of consultant diabetologists and consultant palliative care physicians in the UK

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Diabetes is an increasingly common condition and hence, managing dying patients with diabetes as a co-morbidity will become a frequent challenge. It is uncertain whether there is net beneficence in preventing hyperglycaemia in diabetic patients during the terminal phase or whether the distress involved in administering therapy and blood glucose monitoring may outweigh this ordeal. Since there is no available evidence upon which to base clinical decisions, a semi-structured questionnaire based around three clinical vignettes was sent to consultants in diabetes and palliative care in the UK. There was consensus of opinion from both groups of consultants that treatment and monitoring should be stopped in patients with type 2 diabetes, once in the terminal phase. There was less consensus regarding management of type 1 diabetes. Practical issues were raised by both groups of consultants and clinical guidelines are suggested. *Palliative Medicine* 2006; **20:** 197–203

Key words: diabetes; dying; withdrawing treatment

Key points

Dying patients have a right to expect maintenance of comfort and relief from distress, and this should be reflected in the management of concurrent medical conditions. Patients with type 2 diabetes may be less likely to develop hyperglycaemia once in the terminal phase due to minimal oral intake, and hence, oral hypoglycaemic agents or insulin should generally be stopped. If insulin is to be continued in a patient with type 1 diabetes, use of long-acting insulin will reduce the risks of hypoglycaemia and the need for injections and monitoring. As with all management decisions during the last days of life, open communication with the patient, carers and staff is important.

Introduction

The current UK prevalence of diabetes in people over 65 years of age is 10%,[1] and with worldwide numbers of diabetic patients expected to double by 2010,[2] managing dying patients with diabetes will be a common challenge.

Dying patients have a right to expect relief from distress and maintenance of comfort,[3] yet it not known whether continuation of diabetic drugs and glucose monitoring enhance symptom control during the last days of life, or cause unnecessary distress. There have been no published studies comparing practice at the end of life, although some suggested guidelines based on clinical experience have been published.[4]

A retrospective survey of practice in our unit revealed inconsistencies in management across secondary care:[5] decisions ranged from the extremes of stopping all treatment and monitoring, to commencing an intravenous insulin sliding scale. Junior doctors usually made the management decisions. The survey of hospice practice revealed a tendency towards less aggressive management.[5] Varying practice has also been revealed in other centres.[6]

The aim of the study was to look at the attitudes of consultant specialists in diabetes and palliative care to three clinical vignettes, in an attempt to derive expert consensus opinion on the management of diabetes during the terminal phase.

Methods

A semi-structured postal questionnaire was sent to all consultant members of the Association of Palliative Medicine ($n = 305$) and to a list of consultants in diabetes generated from a database of hospital trusts from the central government search engine www.tagish.co.uk ($n = 205$).

The questionnaire design was based around three case scenarios designed to cover the three main clinical situations encountered (a type 2 diabetic patient on oral hypoglycaemic agents, a type 2 diabetic patient on insulin, and a type 1 diabetic patient, all entering the terminal phase). Each scenario involved options

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regarding diabetes management, frequency of blood glucose monitoring and glycaemic threshold for intervention. Space was available for additional comment by the participant. See Appendix 1 for questionnaire design.

The questionnaires were analysed anonymously. Differences between the groups were compared using χ^2-tests with a P value of <0.05 considered significant. Free text comments were analysed to identify key concepts and themes, indexed and grouped for interpretation.

Approval was obtained from the London Multi Centre Research Ethics Committee.

Results

The response rate for the palliative care consultants (PCC) was 71% (217/305) and for diabetes consultants (DC) 54% (111/205).

Case scenario 1–patient with type 2 diabetes (tablet controlled) now in the terminal phase

The majority of PCC (166 doctors) and DC (74) chose to stop treatment and stop blood glucose monitoring, although there were significantly more PCC who chose this option (79 versus 69%, $P<0.05$). For those continuing to treat the diabetic state, PCC and DC choices were significantly different ($P<0.001$), with PCC more likely to use short-acting insulin (eg, Actrapid) as required, whilst DC recommended a spread of management options, including twice daily mixed insulin or once daily long-acting insulin (eg, glargine) (Figure 1).

Case scenario 2–patient with type 2 diabetes (insulin controlled) now in the terminal phase

Again the majority of both consultant groups chose to stop treatment, although this option was chosen by significantly more PCC (73 versus 61%, $P<0.05$). Almost all the remainder of PCC chose to use short-acting insulin as required (23%), whilst DC were more likely to recommend continuation of intermediate mixed insulin ($P<0.001$).

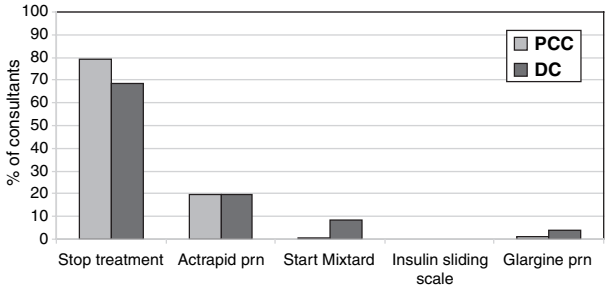

Figure 1 Case scenario 1–a patient with type 2 diabetes on oral therapy.

Case scenario 3–patient with type 1 diabetes (insulin controlled) now in the terminal phase

Some 30% of PCC and 25% of DC chose to stop treatment and monitoring. Of those choosing to continue treatment, PCC were more likely to choose short-acting insulin as needed (55 versus 20%), whilst DC were more likely to opt for continuation of intermediate-acting insulin (42 versus 14%, $P<0.001$). Regular glargine (long-acting insulin) was requested by three PCC and five DC (Figure 2).

Frequency of blood glucose monitoring

Unsurprisingly, the majority of consultants recommended stopping glucose monitoring in case scenarios 1 and 2, since most had recommended stopping treatment. For case scenario 3, only 27% of PCC and 24% of DC were of the opinion that monitoring should cease. Across all three cases, however, there was a statistically significant trend of the DC to request more frequent blood glucose monitoring than the PCC ($P<0.001$).

Glucose threshold for 'as required' treatment

DC were more likely to choose a lower glucose threshold to instigate 'as required' treatment ($P<0.001$) across all three case scenarios. Figure 3 shows the glucose threshold for treatment as grouped data from all three scenarios.

Attitudes to diabetes management in the terminal phase

Further information on the doctor's attitudes to the management of diabetes in the terminal phase could be derived from the additional comments made on the questionnaires. Eight key issues were identified, with comments in italics taken verbatim from free text on the questionnaire.

(1) Desire to be certain the clinical deterioration is not caused by poor glucose control

Many doctors stated a need to be certain that the deterioration was reversible and not due to hyper or hypoglycaemia before making decisions about management in the terminal phase:

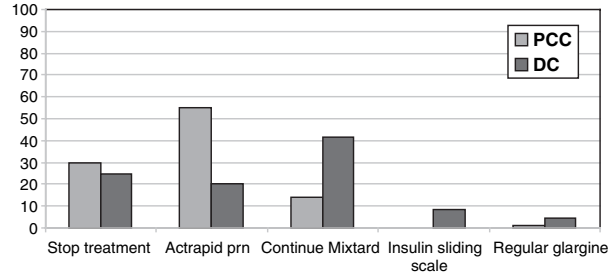

Figure 2 Case scenario 3–a patient with type 1 diabetes on insulin.

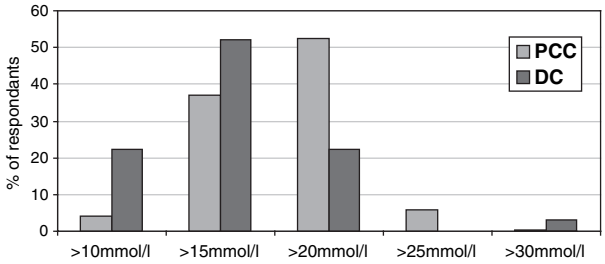

Figure 3 Preferred glucose threshold for 'as required' insulin.

PCC '*Stop treatment, assuming the patient has deteriorated despite relatively normal BM's* (capillary blood glucose tests).'

DC '*Stop treatment – as long as I am happy that diabetic control was satisfactory up to the point of deterioration i.e. not the cause of the deterioration*.'

(2) The presence or absence of symptoms attributable to hyperglycaemia may influence management decision

Many doctors commented that the type of treatment offered and the frequency of monitoring might depend on symptoms of hyperglycaemia:

PCC '*Stop treatment – if I felt she was symptomatic from hyperglycaemia I might measure a BM and consider Actrapid*.'

(3) Blood glucose control in the few days prior to the terminal phase affects management decisions in the terminal phase

There were many comments that knowledge of prior blood glucose control would influence ongoing management until death, particularly if blood glucose had been high, they were less likely to opt for cessation of treatment.

PCC '*If sugars known to be high approaching the terminal phase, more likely to choose Actrapid rather than stop treatment*.'

(4) Difficulties with prognostication of death

Some consultants felt management decisions were made more difficult by the uncertainty of when death will occur and, hence, the varying length of the terminal phase:

PCC '*Interpretation of this situation hinges on the certainty of how long a person has to live. If one could be 100% sure of death within 72 hours then control of blood glucose will add nothing and monitoring by fingerprick testing hurts. In practice one usually ends up monitoring each situation until it becomes clear. This means some patients will have insulin etc. within the last 72 hours*.'

PCC '*When it is clear someone is imminently dying then the focus is purely comfort and as with other medications stop treatment. The more difficult phase is the pre-imminently dying when I am more inclined to write up prn Actrapid*.'

(5) Regular review of the patient and treatment decision

Due to the uncertainties of prognostication and varying length of the terminal phase, many doctors stated the importance of regular review of the patient and any management decisions, in order to respond to changes in symptoms or clinical condition appropriately:

PCC '*Daily review is necessary as symptoms may develop and cause a change in management options*.'

(6) Involving patient/carers/staff in the decision-making process

It was frequently commented that decisions regarding the patient's diabetes management, as with any other treatment decisions, should be discussed with the patient where possible. Many doctors also stated they would discuss this decision with the patient's family and may change their clinical decision according to the family's views. The point is made that relatives often find the withdrawal of treatment distressing and this may be more so with insulin, which the patient may have been on for many years and the family may view as life sustaining:

PCC '*Stop treatment – unless the family have very strong feelings re. Insulin which is seen as a 'life sustaining' drug and stopping it equals euthanasia*.'

PCC '*Need to discuss with family/carers – occasionally family very distressed if diabetes not monitored*.'

Several doctors state the importance of discussing treatment decisions with the multidisciplinary team and ensuring all are in agreement.

(7) Hyperglycaemia is thought unlikely during the terminal phase

A few doctors suggested that hyperglycaemia was unlikely to occur during the terminal phase of a patient with type 2 diabetes. The comments appeared to be based on anecdotal evidence and years of clinical experience.

(8) Hypoglycaemia should be avoided

The importance of avoiding iatrogenic hypoglycaemia in the management of blood glucose levels in dying patients was mentioned, suggesting that erring on the side of hyperglycaemia was preferable:

DC '*essential to avoid hypos – Gliclazide has a long half life*.'

DC '*Moderate hyperglycaemia is preferable to hypoglycaemia*.'

Discussion

Management of type 2 diabetes

In general, there was concordance across both groups of consultants to stop treatment and monitoring in patients with type 2 diabetes, yet the proportion of PCC choosing this option was significantly greater. Willingness to stop treatment in type 2 diabetes reflects the understanding that their drug therapy is not life sustaining, as insulin is with type 1 diabetes, and that the risk of diabetic ketoacidosis is low. It could be argued that once the patient stops eating, these drugs are no longer necessary and, as remarked by several participants, it is imperative to avoid hypoglycaemia. This may become more likely with low oral food intake and impaired drug clearance. This consensus opinion is backed with evidence from a retrospective study of blood glucose levels in type 2 diabetic patients during the terminal phase;[7] despite cessation of all treatment, the median blood glucose level during the terminal phase was below a level likely to cause osmotic symptoms.[7]

It is perhaps not surprising that a greater proportion of PCC are willing to stop treatment, since withdrawing therapy and enhancing the care of the dying underpins the ethos of palliative medicine. PCC are used to discontinuing the regular medications for a wide range of conditions. DC, however, may have less experience with dying patients and their usual approach is one of aggressive management of diabetes aiming to achieve a normal lifespan and prevent long-term complications.

Management of type 1 diabetes

This case scenario revealed less consensus of opinion. Only a quarter of both groups would stop treatment. This demonstrates the uncertainty across both specialties of the ethics of withdrawing a life sustaining medication and the unanswered question of benefit versus burden of treatment.

Of the three-quarters of doctors who would continue treatment, PCC were more likely to choose short-acting insulin 'as required', whilst DC were more likely to recommend a regular longer acting preparation.

Whilst usually in the terminal phase it is wise to use a preparation with a short half life (to prevent accumulation and toxicity in the face of impaired elimination), in this case a longer acting preparation may be safer in terms of avoiding hypoglycaemia. Indeed, using a long-acting preparation to replace constant basal insulin levels resembles normal physiology in the fasting state. The use of insulin glargine (a long-acting peakless insulin) was suggested by approximately 5% of both groups of doctors, despite not being given as one of the five management options. Using long-acting insulin, such as insulin glargine or insulin detemir, during the dying phase may have several advantages; the flat insulin profile minimizes the risks of hypoglycaemia, only one injection per day is needed and blood glucose monitoring could be infrequent (one random sample per day could suffice).

Blood glucose monitoring

The frequency of blood glucose monitoring was in essence determined by treatment choice, although the trend for DC to request more frequent monitoring may reflect their usual focus of care.

Some doctors suggested only performing blood glucose tests if the patient developed symptoms of hyperglycaemia. This raises the question of what symptoms may be attributable to hyperglycaemia in the dying patient. A study questioning healthy diabetics on their usual symptoms of hyperglycaemia revealed four main groups of symptoms:[8] (1) agitation – feeling tense, irritable, restless, poor concentration; (2) osmotic – thirst, dry mouth, need to urinate, weakness; (3) neurological – dizziness, blurred vision, light-headed, weakness; (4) malaise – headache, nausea. The median estimated glucose threshold to develop symptoms was 15 mmol/L.[8] Many of these symptoms are common in non-diabetics in the terminal phase, so judging when to perform a blood glucose test would be difficult. In addition, it is unknown whether the symptoms of hyperglycaemia in 'healthy' diabetic patients can be extrapolated to the terminal phase – no data is available.

Practical issues

The comments made in free text by the consultants provide an insight into the practical issues involved in dealing with diabetes at the end of life.

It is of fundamental importance to ensure that the patient is not dying because of their diabetes. Once it is clear that the patient is dying despite normal glucose levels, then decisions to stop or change treatment are easier.

The difficult issue of determining how close a patient is to death was frequently raised. Although the case scenarios were explicit that the patient is now dying and expected to die within 72 hours, many consultants documented difficulty in practice in determining when a patient is irreversibly deteriorating and that the nearness of death will determine the management plan. These difficulties of prognostication are well documented in the literature.[9,10]

Conclusions and guidelines for managing diabetes during the terminal phase

As with all treatment decisions during the terminal phase, each patient will need individualized treatment, with guidelines adjusted according to patient/carer preference and the views of staff.[4] It is well recognized that for some

diabetic patients and their families, continuing treatment may be viewed as very important,[11] and this should be respected and explored.

Type 2 diabetes

Once the terminal phase is diagnosed and oral intake is minimal, stop hypoglycaemic treatment (oral agents and/or insulin) and stop blood glucose monitoring. If the patient exhibits unresolved symptoms that could be attributable to hyperglycaemia or there are changes in clinical condition, it may be appropriate to check a blood glucose level and act accordingly.

Type 1 diabetes

If insulin is to be continued (there is not enough evidence to base recommendations for or against stopping insulin), use of once daily long or twice daily intermediate-acting insulin should prevent symptomatic hyperglycaemia with the minimum of monitoring and adverse effects. It would be reasonable to calculate a dose based on one-half to two-thirds of their usual dose of long-acting or intermediate insulin (to account for lower oral intake) and to check the blood glucose level once daily.

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Appendix 1
Diabetes at the end of life questionnaire

Case 1

An 81-year-old female with type 2 diabetes on gliclazide 80 mg twice a day, is admitted with pneumonia. Despite treatment, she deteriorates and is now clearly dying. The decision is made to stop antibiotics and all active treatment and 'keep her comfortable'. She is drowsy, not eating or drinking and is unable to take her oral gliclazide. Your recommendation would be:

(a) Stop the gliclazide and stop ward glucose monitoring (ie, no treatment)? ☐
(b) Use short-acting insulin subcutaneously (eg, Actrapid) as required if blood glucose recordings rise? ☐
(c) Start twice daily subcutaneous intermediate or mixed insulin (eg, Insulatard/Mixtard)? ☐
(d) Start an intravenous insulin sliding scale? ☐
(e) Insert a nasogastric tube to administer the oral hypoglycaemic agent? ☐

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Case 2

A 77-year-old female with type 2 diabetes on twice daily Mixtard insulin, is admitted with a dense CVA and initially put on an intravenous sliding scale. She deteriorates further, is unconscious and is now dying. The decision is made to stop active treatment and keep the patient comfortable. Your recommendation would be:

(a) Stop intravenous insulin sliding scale and stop glucose monitoring (ie, no treatment)? ☐
(b) Use short-acting insulin (eg, Actrapid) as required, only if blood glucose recordings rise? ☐
(c) Recommence twice daily subcutaneous intermediate or mixed insulin (eg, Insulatard/Mixtard)? ☐
(d) Continue the intravenous insulin sliding scale until death? ☐
(e) Insert a nasogastric tube to administer an oral hypoglycaemic agent? ☐

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Case 3

A 47-year-old man with type 1 diabetes on twice daily Mixtard insulin is admitted with breathlessness due to lung cancer. Despite aggressive treatment, he deteriorates and the decision is made to stop active treatment. He is drowsy and not eating or drinking. Your recommendation would be:

(a) Stop Mixtard and stop blood glucose monitoring (ie, no treatment)? ☐
(b) Stop Mixtard and use short-acting insulin (eg, Actrapid) as required only if blood glucose levels rise? ☐
(c) Continue Mixtard (or use twice daily intermediate-acting insulin (eg, Insulatard) until death? ☐
(d) Start an intravenous insulin sliding scale? ☐
(e) Insert a nasogastric tube to administer an oral hypoglycaemic agent? ☐

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(4) For each of the case scenarios above, how often would you monitor the blood glucose with a ward test?

	Case 1	Case 2	Case 3
(a) Not at all?	☐	☐	☐
(b) Once per day?	☐	☐	☐
(c) Twice per day?	☐	☐	☐
(d) Three times per day?	☐	☐	☐
(e) Four times per day?	☐	☐	☐
(f) More often?	☐	☐	☐

(5) For each of the case scenarios above, if you answered (b), at what level blood glucose would you instigate treatment?

	Case 1	Case 2	Case 3
(a) >10 mmol/L	☐	☐	☐
(b) >15 mmol/L	☐	☐	☐
(c) >20 mmol/L	☐	☐	☐
(d) >25 mmol/L	☐	☐	☐
(e) >30 mmol/L	☐	☐	☐