An emerging theme in diabetes care: End of life

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Many individuals with diabetes may be designated at some stage to be at the end of life. They often have a complex set of care needs including those relating to health and social care. Unfortunately, inconsistencies in the standard of clinical and social care provided, variation in the care pathways used, and a lack of training and education among both health and social care professionals in some of the important areas of end of life care, make it imperative to address some of these shortfalls.

End of life care, according to the National Council for Palliative Care (2006), can be defined as:

"… care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support."

Setting the scene

It has been estimated that up to 75 000 people with diabetes die each year in England, and a high proportion of these have experienced an end of life phase before they died. Regrettably, in the absence of good clinical audit data, it cannot be certain that they received the best standard of diabetes care available and it is likely that some of their health or social care needs, or both, were not met. It is therefore timely that the publication of recent guidance by NHS Diabetes (2011) and Diabetes UK (2012) is able to offer guidance in key areas. The documents describe a consistent high-quality approach towards end of life diabetes care and inform the wider healthcare workforce about key issues. Issues relating to moral and ethical challenges that clinicians might face were only partly addressed but these can be summarised (see *Box 1*).

Box 1. Ethical and moral issues concerning end of life diabetes care.

- Accepting a less stringent glucose target range.
- Abandoning the need to reduce the risk of long-term complications.
- Increasing the threshold for investigation.
- Treatment of pain and consequences of over-treatment.
- Withdrawal of treatment.

Article points

1. A significant proportion of people who die from diabetes each year will have experienced an end of life phase before they died.
2. The authors review current inconsistencies in the standard of clinical and social care, and what clinicians need to achieve to enhance the level of care provided.
3. It is concluded that the care delivered by healthcare professionals can be improved by increased representation at relevant meetings, as well as engagement with user groups, primary and secondary care colleagues, and new commissioning groups.

Key words

- End of life
- Palliative care

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The national strategy published in 2008 (Department of Health, 2008) described a number of accepted key pathways for the dying patient – these are often missing in published clinical guidelines for diabetes. Commissioning of this care is often not structured and organised within local care pathways.

See *Box 2* for a summary of the current "state of play" for end of life diabetes care.

Box 2. Current "state of play" for end of life diabetes care.

The current situation for end of life diabetes care can be illustrated as follows:

- Insufficient clinical research to provide evidence-based guidance.
- Value of "tight" glucose control is of questionable benefit.
- Competencies in end of life diabetes care of the diabetes care team are likely to be highly variable.
- Closer working between the palliative care team, diabetes team and primary care is urgently needed in end of life diabetes care.

Box 3. Key parts of the strategy for end of life diabetes care.

To address the requirements of end of life care, the following strategy needs to be adopted:

- Early recognition of the influence of diabetes, a long-term condition, on premature mortality.
- Ensuring that end of life care services map, align and integrate with existing healthcare pathways in diabetes.
- An agreed set of effective interventions or actions that aim to address key healthcare needs from clinical and administrative perspectives.
- A commissioning framework for end of life care that meets quality standards and aligns closely with diabetes care policies.
- A series of specifications for end of life care in diabetes that are robust and appropriate to the wide nature of many people in this situation.

Identifying important challenges

The scale of the problem and the challenges facing health and social care professionals in end of life diabetes care should not be underestimated. These challenges can be summarised as follows:

1. Recognition of the varied influences on glycaemic control during end of life, including steroid use, urinary and respiratory infections, and the catabolic or metabolic effects of the malignancy, if present.
2. Dual needs of adequate but safe glucose lowering and management of pain; this tailoring of therapy is a sign of a well-trained or experienced workforce in diabetes care.
2. Previous absence of end of life as a specific training and educational objective in the curricula of doctors and nurses currently engaged in diabetes care.

Actions that can address some of the major challenges

No one should underestimate the task of providing high-quality end of life diabetes care within the NHS in Britain. A large part of this challenge can be met, however, by having nationally accepted published guidance that describes a consistent high-quality approach towards end of life diabetes care and is supported by a series of quality standards. This can be enhanced by a series of communications and events, which inform the wider healthcare workforce about the key issues in end of life diabetes care, hopefully providing a platform for sensitive, appropriate and supportive care.

There is also a clear need for better clarification of the main roles and responsibilities of healthcare workers, carers and the patients themselves in end of life diabetes care. This initiative is likely to highlight the awareness of newly identified training and educational needs for high-quality end of life diabetes care and foster partnerships in end of life diabetes care with established palliative care pathways.

Key parts of a strategy that might address some of the requirements in end of life diabetes care are presented in *Box 3*.

What clinicians need to achieve to provide enhanced care at end of life in diabetes

The following needs to be achieved by clinicians in order to improve the quality of end of life diabetes care:

- Provision of a symptom-free and painless death.
- Tailoring glucose lowering therapy and minimising diabetes-related adverse treatment effects.
- Minimising the risk of the following: frequent and unnecessary hypoglycaemia; metabolic de-compensation; and diabetes-related emergencies, including diabetic ketoacidosis, hyperosmolar hyperglycaemic state and persistent hyperglycaemia.
- Avoidance of foot complications in frail, bed-bound people with diabetes.
- Avoidance of symptomatic clinical dehydration.
- Provision of an appropriate level of intervention according to the stage of condition, symptom profile and respect for dignity.
- Supporting and maintaining the empowerment of the individual (in his or her diabetes self-management) and carers to the last possible stage.

Competencies: End of life diabetes care

Providing effective and worthwhile end of life diabetes care should be a key objective of the NHS. However, a series of competencies are required by healthcare professionals if this care is to be of high quality; these are summarised in *Box 4*.

Conclusion

There is an increasing national interest in end of life diabetes care and, as a group of healthcare professionals engaged in delivering diabetes care, it should be ensured that this important area is well represented at future meetings of Diabetes UK, TREND-UK, Royal Colleges of Nursing, general practitioners, physicians and the Association of British Clinical Diabetologists. Further improvement can also come from engagement with user groups, primary and secondary care colleagues and new commissioning groups. ■

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Recommended further reading

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Box 4. Competencies: End of life diabetes care.

- Become familiar with key local policies relating to palliative or end of life care (applicable to all).
- Be aware that steroid therapy can worsen glucose control in established diabetes or cause diabetes (applicable to competent healthcare professionals).
- Devise appropriate synchronised glucose-lowering treatment schedules for percutaneous endoscopic gastrostomy feeds (applicable to experienced healthcare professionals).
- Support the self-management of insulin pump therapy and recognise when this should be discontinued (applicable to senior or expert healthcare professionals).
- Identify service shortfalls in appropriate management of diabetes at end of life and develop strategies with local commissioning bodies to address these (applicable to consultant nurses or diabetologists).