This is the published version:


Available from Deakin Research Online:

http://hdl.handle.net/10536/DRO/DU:30059609

Reproduced with the kind permission of the copyright owner.

Copyright : 2013, Mary Ann Liebert
Information Needs of Family Carers of People with Diabetes at the End of Life: A Literature Review

Marjje F. Dikkers, MSc, Trisha Dunning, AM, PhD, RN, CDE, MEd, and Sally Savage, PhD, BA(Hons), DipEd

Abstract

Background: Recent research identified the issue that family carers of people with diabetes at the end of life (EOL) did not receive sufficient information to enable them to help their relative manage their diabetes at the EOL.

Aim: The aim of the current study was to undertake a literature review to identify the information needs of family carers of people with diabetes at the EOL.

Method: A comprehensive review of the literature was conducted by searching the following databases: CINAHL, PubMed, Psychinfo, Scopus, and SociNDEX. The grey literature was also searched for papers relevant to the aim. All study designs were included. A content analysis of relevant papers was undertaken to identify themes.

Results: Sixteen of the more than 300 papers identified addressed the information needs of family carers of people with diabetes at the EOL and were included in the review. Five key themes were identified from the papers reviewed: (1) performing diabetes care tasks, (2) focus of care, (3) blood glucose management, (4) EOL stage, and (5) involving patients and family carers in decisions about diabetes care. Most of the 16 papers represented the views of health professionals and focused on the need to provide information about the medical aspects of diabetes management.

Conclusions: The review suggests further research is needed to identify the information needs of family carers of people with diabetes at the EOL to enable interventions to be developed to support the family carers and meet their unique information needs.

Introduction

The important role of family carers within the context of palliative care and the importance of supporting these carers is well documented. Family carers need information about their relative's illness, how to provide comfort and care for their relative, and how to cope when they are caring for their relative. Adequate information could assist carers to solve problems and cope more effectively, which could reduce anxiety and enhance the carers' sense of control. Lack of adequate information can cause carers to feel isolated, disillusioned, frustrated, and distressed, and these feelings make it difficult to manage the caregiving burden. Support for family caregivers should be available to lessen the negative physical and mental impact of caring on carers' health.

Recent research identified the issue that family carers of people with diabetes at the end of life (EOL) do not receive sufficient information about managing diabetes. Diabetes is a complex incurable disease. Worldwide, 347 million people have diabetes. In addition, the prevalence of diabetes in people aged 65 years and above is increasing substantially. Thus, the need to provide care for people with diabetes at the EOL, and their family carers, will become increasingly important. Family members often assume diabetes care tasks such as blood glucose monitoring and administering insulin when the person with diabetes is no longer able to self-care independently. Recent research identified the issue that family members often felt overwhelmed when they assumed diabetes care tasks. Family members indicated they had not previously undertaken these tasks, lacked the necessary knowledge and skills to perform the tasks, and were concerned about managing diabetes safely and confidently, which caused them considerable stress. Further, access to diabetes educators is compromised when the person with

1Wageningen University, the Netherlands.
2Centre for Nursing and Allied Health Research, Deakin University and Barwon Health, Victoria, Australia.
Accepted August 18, 2013.
diabetes and the family carer cannot leave home due to increasing dependency/functional decline of the care recipient, which limits access to appropriate information.19

Some literature is available about the needs of family carers of people receiving palliative care, including several empirical studies and literature reviews.4,5,11-18 While the information needs identified in the palliative care literature relate to family carers of people at the EOL, it does not specify the exact needs of carers of people with diabetes.

The aims of the current study were:

1. Identifying the unique information needs of family carers of people with diabetes at the EOL by conducting a literature review.
2. Informing the development of information for family carers of people with diabetes at the EOL.

Providing information for family carers of people with diabetes at the EOL that meets their unique needs will help empower carers and enable them to manage their relatives' diabetes safely and confidently, reduce carer stress, and improve the comfort of the person they care for. Definitions of terms used in the paper are presented in Table 1.

**Methods**

**Literature search**

Papers were identified via the following:

1. Electronic searches of academic databases.
2. Searches of non-academic 'grey' literature websites.
3. The reference list of an unpublished report, which included a structured literature review about diabetes management at the EOL (see Table 2).

All searches were conducted in July 2011. Reference lists from retrieved papers were searched by hand. The search terms and combinations of terms used in the electronic searches are provided in Table 3.

**Eligibility criteria**

Literature was eligible to be included in the review if it addressed the information needs of or methods of providing information to family carers of people with diabetes at the EOL. For the purpose of the review, information needs included the needs for information, advice, explanation, education, communication, or discussion. Methods of providing information to family carers of people with diabetes at the EOL included education material specifically for these family carers.

Literature was excluded if it did not address the information needs of or methods of providing information to family carers of people with diabetes at the EOL. All study designs were included.

**Data extraction**

A data abstraction tool developed by the authors was used to record information on each study about the aim, study design, sampling population, sample size, data collected/considered, and relevant meaning units reported in the paper, which consisted of a sentence or a paragraph.

**Data synthesis**

Units of meaning (sentences or paragraphs about the information needs of family caregivers of people with diabetes at the EOL) were synthesized by undertaking a content analysis to identify themes. The first author developed descriptive codes from repeated readings of the meaning units, then identified emerging themes on the basis of coding and categorizing. This process resulted in preliminary themes being discussed among all the authors. Disagreements about coding and categorizing were rare; when they did occur, they were discussed until consensus was reached.

**Search outcome**

In total, more than 300 papers were identified in the search. After reviewing the titles and abstracts identified in the search, 23 papers appeared to meet the inclusion criteria and their full text was retrieved. Following full text review, 16 papers met the inclusion criteria. Five papers did not address family carers and/or diabetics. Two documents were sections of Dunning and colleagues' report. Sixteen papers that addressed the information needs of family carers of people with diabetes were included.

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information needs for family carers of people with diabetes</td>
<td>Perceived requirement or wish for information from health professionals. Family members and significant others who provide any physical, emotional, and practical support and assistance to people with diabetes. These family members and significant others &quot;are not acting in a professional or occupational capacity. They may or may not be co-residing with the care recipient, and the care recipient may be in either a home or institutional setting.&quot;17</td>
</tr>
<tr>
<td>Caregiving</td>
<td>Assistance provided to individuals who need support because of &quot;a disability, mental illness, chronic condition, terminal illness, or who are frail.&quot;12 The assistance can include attention to any of the needs of the person being cared for, including emotional support, domestic assistance, personal care, nursing care, supervision, collecting medications, transporting to appointments, and shopping.9,10 &quot;Caregiving is distinguished from 'normal helping' that occurs in the context of family relationships; rather, caregiving emerges because of particular needs for assistance.&quot;17</td>
</tr>
<tr>
<td>End of life (EOL)</td>
<td>Refers to people with diabetes in the end stages of life. The end stages of life are the Palliative Care Outcomes Collaboration (PCOC) palliative care phases: stable, unstable, deteriorating, and terminal.20</td>
</tr>
</tbody>
</table>
diabetes at the EOL were included in the review (see Table 4). No education material specifically for family carers of people with diabetes generally or at the EOL was identified.

Study perspective

All the papers included addressed the information needs of family carers of people with diabetes at the EOL. However, the majority of the papers included in the review aimed primarily to provide clinical guidelines or recommendations for managing diabetes at the EOL, and the information needs of carers received limited attention (see Table 4). Thus, very little information about family carers’ information needs was provided in any of the papers reviewed.

Study design

The key characteristics of the 16 papers included in the review are summarized in Table 4. Some papers reported research data about the information needs of family carers, but frequently, papers only addressed the information needs in the discussion section. Most of the information was derived from expert opinion and clinical experience rather than actual research data.

Results

There was general consensus that family carers need information about managing diabetes at the EOL. Five key themes about the information needs of family carers of people with diabetes at the EOL were identified from the literature:

- Performing diabetes care tasks
- Focus of care
- Blood glucose management
- EOL stages
- Involving patients and family carers in decisions about diabetes care

Performing diabetes care tasks

Most of the 10 family members interviewed indicated they needed more information about managing diabetes as their relative’s health deteriorated and the family member began to take responsibility for diabetes care tasks such as blood glucose testing, making care decisions based on the results, administering insulin, and interpreting symptoms such as hypo- and hyperglycemia. In most cases the family members had not performed these tasks before. Dunning and colleagues interviewed family members providing information to enable family carers to help their relative manage diabetes at the EOL.

Focus of care

Several authors addressed the need to provide information about the focus of care, which can be defined as preventing symptoms of hypo- and hyperglycemia and their consequences, maximizing quality of life, and achieving a peaceful death. Family carers need to be reassured that changes in diabetes management do not reflect a lower standard of care or a diminished interest in the patient’s wellbeing, but a change in focus from preventing the long-term complications of diabetes to promoting quality of life and comfort. For example, some authors indicated family carers need to understand that withdrawing some diabetes treatment in the terminal phase of life is not a sign that the medical team has ‘given up’ on the patient, rather it is a measure to aid comfort. The need to maintain blood glucose levels within a narrow range using diet and glucose lowering medicines may not be the goal in the end stages of life. A move away from the tight blood glucose control that had been the patient’s diabetes management focus in the past could concern family members. Some authors suggested

Table 3. Search terms and combinations used in the electronic searches

AND (carer OR caregiver OR informal carer OR informal caregiver OR family OR relatives OR spouse OR next of kin)
AND (end-of-life OR palliative care OR terminal care OR palliative OR terminal OR hospice OR last days of life OR advanced disease OR advanced illness OR life-limiting illness OR life-limiting disease OR life-threatening illness OR life-threatening disease)
AND (support OR needs OR information OR education)
<table>
<thead>
<tr>
<th>Source type</th>
<th>Paper (n = 16)</th>
<th>Country</th>
<th>Study design, sampling population, sample size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research data</td>
<td>Ford-Dunn et al. (2006)</td>
<td>U.K.</td>
<td>To form consensus expert opinion about the management of diabetes during the terminal phase of life.</td>
</tr>
<tr>
<td></td>
<td>Quinn et al. (2006)</td>
<td>Australia</td>
<td>To describe the current practices of doctors and nurses caring for patients with diabetes and advanced disease.</td>
</tr>
<tr>
<td></td>
<td>Dunning et al. (2010)</td>
<td>Australia</td>
<td>To develop guidelines for managing diabetes at the end of life to enhance the quality of palliative care delivered to people with diabetes in the end stages of life.</td>
</tr>
<tr>
<td>Case history</td>
<td>Boyd (1993)</td>
<td>U.K.</td>
<td>To provide guidelines for managing diabetes in hospice patients.</td>
</tr>
<tr>
<td></td>
<td>Tice (2006)</td>
<td>U.S.</td>
<td>To explore the appropriateness of shifting the goal of diabetes therapy from tight control of blood glucose to maintaining comfort and enhancing quality of life at the end of life.</td>
</tr>
<tr>
<td></td>
<td>McCoubrie et al. (2005)</td>
<td>U.K.</td>
<td>To establish how diabetes is managed in patients with advanced cancer and diabetes mellitus.</td>
</tr>
<tr>
<td></td>
<td>Smyth &amp; Smyth (2005)</td>
<td>U.K.</td>
<td>To address some of the problems that can arise due to diabetes treatment in the later stages of terminal illness and their management.</td>
</tr>
<tr>
<td></td>
<td>Knox (2007)</td>
<td>U.K.</td>
<td>To consider the management of blood glucose for patients with diabetes who entered the Liverpool Integrated Care Pathway for the Dying Patient in a specialist palliative care unit.</td>
</tr>
<tr>
<td></td>
<td>Lim (2009)</td>
<td>U.S.</td>
<td>To establish how diabetes is currently managed in terminally ill medical patients.</td>
</tr>
<tr>
<td></td>
<td>Budge (2010)</td>
<td>U.K.</td>
<td>To explore the need for better communication and national guidelines to improve the quality of end-of-life care for patients with diabetes.</td>
</tr>
<tr>
<td></td>
<td>Angelo et al. (2011)</td>
<td>U.S.</td>
<td>To propose a specific framework to guide management in patients with diabetes and advanced disease to address individual patient needs, provide guidance for patients and caregivers, and ultimately maximize outcomes for patients with diabetes in the palliative care setting.</td>
</tr>
<tr>
<td></td>
<td>Rowles et al. (2011)</td>
<td>U.K.</td>
<td>To offer guidelines for managing diabetes during the end stages of life and trigger discussion within multidisciplinary diabetes teams relating to their role in end-of-life care.</td>
</tr>
</tbody>
</table>
family carers may need help accepting a 'less tight' blood glucose control.26,30,31

**Blood glucose management**

Next to the need to explain measures such as accepting a higher blood glucose range and permitting a more liberal diet, authors suggested explaining the role of blood glucose monitoring and the need for diabetes medicines.22,35,39,41,45 Some authors recommended health professionals should discuss the risk of hypo- and hyperglycaemia at the EOL in their explanations about blood glucose management.25,41 For example, McPherson recommended explaining that people with advanced illness often have reduced appetite, and continuing glucose lowering medications can increase the risk of hypoglycaemia, which is uncomfortable and can be fatal.33 Hyperglycaemia can also be fatal and is uncomfortable. Poulton suggested explaining that corticosteroid medicines are likely to cause hyperglycaemia, and therefore insulin therapy or oral glucose lowering medicines are likely to be needed.21

**End-of-life stages**

Two authors referred to the different EOL stages in their recommendations about the information family carers need.7,34 For example, Angelo and colleagues34 suggested providing information about the signs of hypoglycaemia and an appropriate action plan for family carers of a patient with underlying disease and organ failure if hypoglycaemia develops. Further, two authors recommended providing information to prepare patients and families for the future.22,29 For example, McCoubrie and colleagues29 stressed that patients and their families should be informed about the likely diabetes management approach for people with a prognosis of weeks to months to live, in an earlier stage in the patient’s life-limiting illness. By providing patients and their families such information in an earlier stage, they can be actively involved in making informed decisions about their care.

**Involving patients and family carers in decisions about diabetes**

Several authors addressed the importance of involving patients and their family carers in decisions about diabetes care.22,30,33,35 particularly when the patient is in the terminal phase of life.7,23,25,26,30,35 They recommended health professionals should respect and explore patients’ and family carers’ diabetes management preferences and their views on continuing treatment. Adequate information could help patients and their family carers to make informed decisions about diabetes EOL care.

**Discussion**

The aim of the study was to identify through a literature review the information needs of family carers of people with diabetes at the EOL to inform the development of information for these family carers. The results of the literature review suggest that when developing information for these family carers it is important to consider:

- The changing information needs as the person with diabetes approaches the EOL.
- Providing practical information about how to undertake tasks the family carers may need to perform.
- Explaining the changing approach to managing diabetes as the person with diabetes becomes increasingly unwell.

There was a paucity of literature about the information needs of family carers of people with diabetes at the EOL. The majority of the information was derived from expert opinion and clinical experience rather than from carers of people with diabetes or actual research data. Frequently, authors only discussed the need to provide information about the required changes to diabetes medical management. Significantly, the small amount of information about the information family carers of people with diabetes at the EOL require was obtained from health professionals rather than from family carers.

Thus, the literature may not reflect actual information needs or address key concerns of family carers. One exception, Dunning and colleagues’ paper,7 was based on interviews of family members caring for their dying relatives as part of the process used to develop guidelines for EOL care for people with diabetes. During in-depth interviews with family carers of people with diabetes at the EOL, the lack of knowledge and skills to undertake key diabetes management tasks emerged. The family carers reported they needed information about performing diabetes care tasks such as blood glucose testing, making care decisions based on the results and administering insulin.

Although some authors recommended providing diabetes management plans to family carers, most authors who presented the health professionals’ perspective recommended including topics the family carers did not mention, such as the change in the focus of diabetes management and the need for less tight blood glucose control. However, the interviews with family carers did not focus on their information needs.7 Perhaps the topics recommended by health professionals will emerge in interviews focusing on the information needs of family carers of people with diabetes at the EOL. Generally, family carers indicate they need information about the patient’s medical condition and treatment plan.13,16,18

Family carers also need information about other topics such as preparatory information regarding typical aspects of the caregiving role.4,5 For example, carers indicated they needed information about carer rights with regard to the level and type of care they provide, psychosocial issues, managing pain and medicines, and how to access professional/local support. However, most authors did not go beyond the topic ‘patient’s disease,’ with information about the patient’s medical condition and treatment plan. In accordance with the literature about carers’ needs,12,18,35 some authors recommended information should be tailored to the different EOL stages.

Further research is needed to identify the particular information needs of family carers of people with diabetes at the EOL. Next to this, it is important to consider the capacity of different carers to utilize information.30 We suggest further research could include exploratory qualitative methods investigating what carers (current and past) what they regard as the most relevant issues and when and how they would like to be informed about these issues.
Strengths and limitations

A strength of the current study was that it addressed a topic that has received little attention and integrated the various small amounts of information in the literature about the information needs of family carers of people with diabetes at the EOL. Notably, the literature study did not identify every paper that could address family carers’ information needs. Grey literature searches were restricted to credible international and Australian websites. Further, when published papers addressed family carers’ needs, but terms such as ‘family’ or ‘caregiver’ were not included in their abstracts or key words, these papers were not likely to be identified during searches in academic databases. Lastly, the search was completed in 2011; more information about the subject may have been published since then.

The literature search indicated that the information needs of family caregivers of people with diabetes at the EOL is an understudied topic. The limited availability of literature addressing the topic and the aim of the study to inform the development of information for family carers required an exploratory approach in reviewing the current literature. The findings of this study are useful for systematically collecting data about this issue.

Conclusion

Very little evidence was available to identify the information needs of family carers of people with diabetes at the EOL to inform the development of information for these family carers. However, the literature suggested that family carers need information about managing diabetes at the EOL. Furthermore, authors stressed that the information could be tailored to the different EOL stages and should prepare family carers for the future. Family carers should have a key role in developing user-friendly information for family carers of people with diabetes at the EOL that reflect their needs.

Acknowledgments

The authors acknowledge Wageningen University for providing Marjole Dikkers the opportunity to visit the Centre for Nursing and Allied Health Research of Deakin University and Barwon Health. Further, the authors thank Dr. Lennice Vaandrager for her useful comments in the earlier phases of the literature review.

Author Disclosure Statement

The authors have no competing financial interests or other conflicts to declare.

References

2. Palliative Care Australia: The hardest thing we have ever done – The social impact of caring for terminally ill people in Australia: The hardest thing we have ever done: Full report of the national inquiry into the social impact of caring for terminally ill people. Canberra: Palliative Care Australia, 2004.

Address correspondence to:
Sally Savage, PhD, BA(Health), DipEd
Kitchener House
The Geelong Hospital
PO Box 281
Geelong
Victoria 3220 Australia

E-mail: sally.savage@deakin.edu.au