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Quality of life for carers of people with type 2 diabetes: A literature review

Michele Miranda Galarraga, Sofia Llahana

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Article points

1. Many people with type 2 diabetes (T2D) are looked after by their carers and family members. It is essential that healthcare professionals are aware of carers' needs and how to support them.
2. This literature review explores the impact that T2D in adults has on carers' quality of life (QoL), and the importance of providing integrated care.
3. Understanding the impact that T2D has on carers' QoL can provide healthcare professionals with the necessary knowledge for addressing carers' needs. Further research is needed to address the current gap in this area.

Key words

- Carers
- Integrated care
- Type 2 diabetes

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This scoping literature review explores the impact of type 2 diabetes (T2D) in adults on carers' quality of life (QoL) and emphasises the importance of improving carer support in order to achieve integrated care. The review was conducted in February 2015 and included articles published in English in the past 10 years exploring carers' QoL. Five articles satisfied the inclusion criteria and were critically/thematically analysed. Evidence suggests that emotional wellbeing is the QoL domain that is most affected by T2D, with depression and anxiety being reported as the most common issues. Additional domains were social functioning and economic burden. Sociodemographic and cultural differences were identified as variables that can influence carers' QoL. This literature review suggests that T2D in adults has a significant impact on carers' QoL; however, there is limited evidence to demonstrate how healthcare professionals can support carers, so further research is needed in this area to improve the provision of integrated care.

Approximately 15 million people in England live with long-term conditions, including diabetes (Department of Health [DH], 2015a). The active involvement of carers in the management and support of people with long-term conditions is essential, and this is addressed in several current English health policies and guidelines (NICE, 2012; NICE, 2015; DH, 2015b). This article describes the impact that type 2 diabetes (T2D) in adults has on their carers' quality of life (QoL) and addresses the crucial role that healthcare professionals have in supporting carers to provide integrated care.

Background and aims

T2D is a complex long-term condition. Dunning (2014a) asserts that the management regimen should aim to minimise the effect on the person diagnosed with T2D and their lifestyle, although some modifications are necessary. The role of social

support and its influence on T2D management has been widely acknowledged, and good social support correlates with good diabetes management (Strom and Edege, 2012; Dunning, 2014b).

The NHS recognises the diversity of social support sources that people diagnosed with diabetes rely on for support, such as family, friends, and service providers. DESMOND (Diabetes Education and Self-Management for Ongoing and Newly Diagnosed; 2008a) is an education and self-management programme for people with T2D where participants are encouraged to bring a friend, family member or carer (DESMOND, 2008b). A research study found that it provides strong social support for participants, thus contributing to positive psychosocial outcomes (Khunti et al, 2012). Family members, partners or friends often take on the role of carer and are therefore a primary source of support for people with T2D.

Caregiving comes with many responsibilities;

research studies since the 1980s have contributed to the understanding of carers' experiences (Larkin, 2012). The DH (2015b), aware of the increasing number of carers and their needs, has been funding initiatives and projects to provide support for carers and healthcare professionals to address these needs. Similarly, the Queens Nursing Institute (QNI) undertook a consultation in 2013 to understand how district nurses are supporting carers, and identified a lack of knowledge regarding the needs of carers and how they can be supported to avoid mental or physical breakdown (Bradby, 2014).

Considering the relevance to healthcare systems of T2D and carers' role in the management of long-term conditions, the aims of this systematic review were:

- To explore and discuss the impact of providing care for people with T2D on carers' QoL.
- To discuss the implications for future research, education and clinical practice in order to address and improve factors that affect carers' QoL.

Methods

The methodology for this scoping review was guided by the research question:

- Does caring for adults with T2D have an impact on the carers' QoL?

The search was conducted through CINAHL (Cumulative Index to Nursing and Allied Health Literature), MEDLINE (Medical Literature Analysis and Retrieval System Online), British Nursing Index (BNI) and Applied Social Sciences Index and Abstracts (ASSIA) by utilising the following keywords combined with the Boolean operators "AND" and "OR":

- type 2 diabetes [AND]
- carer [OR]
- caregiver [OR]
- family [OR]
- next of kin [OR]
- spouse [OR]
- spousal [OR]
- partner [OR]
- proxy [AND]
- quality of life [OR]
- QoL [OR]
- health-related quality of life [OR]
- physical quality of life.

The search was conducted in February 2015, and was limited to adults with T2D and articles published

in English between 2005 and 2015. The method for selecting articles can be seen in *Figure 1*.

The critical appraisal and thematic analysis approach was adopted for data analysis. The appraisal tools used to guide the relevance and quality assessment process via a checklist were the Critical Appraisal Skills Programme (CASP) qualitative research appraisal tool and the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) tool (Booth et al, 2016). The thematic analysis guided the selection of key themes that emerged from this literature review, which were named and compared between the studies.

Results and discussion

Five articles were selected from the scoping review. Findings were reported as main findings, thematic analysis themes, and factors that influence carers'

Aims of the systematic review

1. To explore and discuss the impact of providing care for people with type 2 diabetes on carers' QoL (quality of life).
2. To discuss the implications for future research, education and clinical practice in order to address and improve factors that affect carers' QoL.

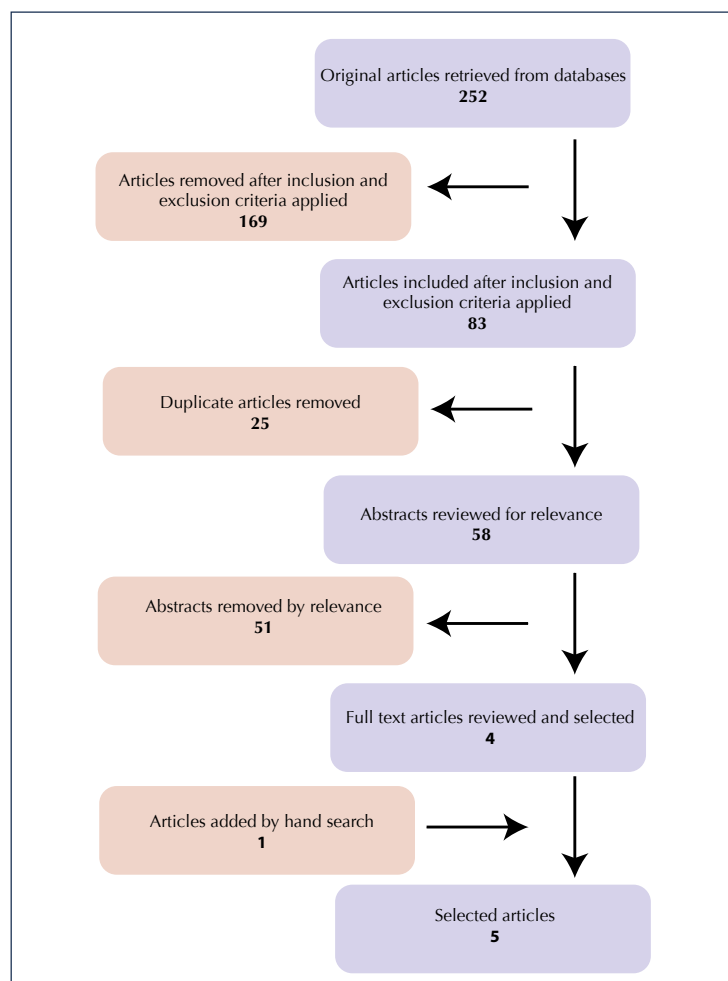


Figure 1. Literature search process and findings.

Page points

1. Three common themes were derived from the thematic analysis: The overall impact on carers' quality of life (QoL); the domains or components of QoL affected; the economic burden placed on carers and families due to providing care to adults with type 2 diabetes.
2. Domains of QoL affected by caregiving were predominantly related to emotional wellbeing, in particular, anxiety and depression, and social functioning.
3. The factor that was identified in three of the studies was the economic burden that caregiving placed on the carers.

QoL. In all five studies (*Table 1*), the carers were family members and the majority were female (Adawalla et al, 2006; Orvik et al, 2006; Anaforoğlu et al, 2011; Kovacs Burns et al, 2013; Scarton et al, 2014). Findings from the scoping review, the measurement tools used in the studies and their key findings are presented in *Table 1*.

Overall impact of T2D on carers' QoL

Three common themes were derived from the thematic analysis:

- 1) The overall impact on carers' QoL.
- 2) The domains or components of QoL affected.
- 3) The economic burden placed on carers and families due to providing care to adults with T2D.

Participants in these studies reported that the overall impact on their QoL was neutral (Orvik et al, 2006; Kovacs Burns et al, 2013), negative (Anaforoğlu et al, 2011; Kovacs Burns et al, 2013; Scarton et al, 2014) or positive (Adawalla et al, 2006; Kovacs Burns et al, 2013).

Domains or components of QoL affecting carers due to providing care to adults with T2D

Emotional wellbeing

Domains of QoL affected by caregiving were predominantly related to emotional wellbeing, in particular, anxiety and depression, and social functioning. Almost half of the participants ($n=893$, 44.6%) in the study by Kovacs Burns et al (2013) reported that caregiving had a negative impact on their lives, specifically their emotional wellbeing, which was measured using the DIDP-FM (DAWN Impact Diabetes Profile Family Members) measurement tool. Similarly, this impact on emotional wellbeing was a common outcome found in a study by Scarton et al (2014).

Anxiety was considerable in female carers in the study by Anaforoğlu et al (2011). They reported significantly lower scores than their male counterparts on the mental health assessment tool 36-Item Short Form Health Survey (SF-36; $P=0.001$) and the Trait Anxiety Inventory (STAI-TX2; $P=0.041$). Kovacs Burns et al (2013) reported that the possibility of hypoglycaemic events was a worry for 61.3% ($n=1197$) of carers. In contrast, Adawalla et al (2006) reported that the presence of complications related to diabetes had no significant impact on carers' QoL.

Depression was a significant finding in the study by Anaforoğlu et al (2011), with 64% ($n=32$) of carers reporting significantly higher Beck Depression Inventory (BDI) scores compared to 27.8% ($n=15$) in the control group ($P=0.001$). Conversely, only 11.6% ($n=239$) of carers in Kovacs Burns et al (2013) reported symptoms of depression on the World Health Organisation (WHO) 5-Item Well-Being Index.

Social functioning

The second QoL domain that was affected was social functioning. Participants in the study by Anaforoğlu et al (2011) had significantly lower social functioning scores compared to the control group ($P<0.005$); however, only 19.8% ($n=461$) of participants in Kovacs Burns et al (2013) reported that caregiving impacted on their relationships.

Economic burden

The factor that was identified in three of the studies was the economic burden that caregiving placed on the carers (Orvik et al, 2006; Kovacs Burns et al, 2013; Scarton et al, 2014). A third ($n=700$, 35.2%) of the participants in Kovacs Burns et al (2013) reported that caregiving impacted negatively on their financial situation, as measured by the DIDP-FM. Orvik et al (2006) reported that 41% ($n=31$) of participants found the economic burden to be a consequence of their partner having diabetes. All participants ($n=32$) in Scarton et al (2014) expressed financial concerns; this was more profound for the majority of African-American caregivers ($n=8$, 81.8%).

Validated QoL tools used

Four of the studies used validated QoL tools. The SF-36 was used by Orvik et al (2006) and Anaforoğlu et al (2011), and the WHO QoL-BREF by Adawalla et al (2006) and Kovacs Burns et al (2013). These QoL scales have been tested, and show reliability and convergent validity in the assessment of QoL domains (Castro et al, 2014). Therefore, data from the studies discussed in this review present significant evidence regarding the impact on the QoL for carers of people with T2D.

Validated scales were also used to measure additional QoL domains and emotional wellbeing issues such as depression and anxiety. Anaforoğlu et al (2011) used the BDI to assess carers' depression, and the State-Trait Anxiety Inventory (STAI-TX1

Table 1. Summary of the research included in the analysis.

Study reference and location	Number of participants	Type of diabetes	Time since diabetes diagnosis	Measurement tools used	Key findings
Anafroglu et al (2012) Tarbzon, Turkey.	<ul style="list-style-type: none"> ● 104 participants: - 50 carers of people with T2D. - 54 participants in the control group (healthy relatives of the hospital staff). 	Type 2 diabetes	At least 6 months	<ul style="list-style-type: none"> ● SF-36 ● BDI ● State anxiety (STAI-TX1) and trait anxiety (STAI-TX2). 	<ul style="list-style-type: none"> ● Female carers reported significantly lower scores than their male counterparts on the mental health component of the SF-36 ($P=0.001$) and the STAI-TX2 ($P=0.041$). ● 64% ($n=32$) of carers reported significantly higher BDI scores compared to 27.8% ($n=15$) in the control group ($P=0.001$). ● Carers had significantly lower social functioning scores compared to the control group ($P<0.005$).
Awadalla et al (2006) Khartoum, Wad Medani, Atbara, Sudan.	<ul style="list-style-type: none"> ● 379 participants: - 105 carers of people with T1D - 135 carers of people with T2D - 139 people from the general population 	Type 1 and type 2 diabetes	At least one year	<ul style="list-style-type: none"> ● WHOQOL-BREF instrument ● Modified version of the WHOQOL-BREF 	<p>Complications related to diabetes had no significant impact on carers' QoL.</p>
Kovacs Burns et al (2013) 17 countries (Algeria, Canada, China, Denmark, France, Germany, India, Italy, Japan, Mexico, the Netherlands, Poland, Russian Federation, Spain, Turkey, the UK and the USA).	<ul style="list-style-type: none"> ● 2055 carers: - 510 carers of people with T1D - 1268 carers of people with T2D - 277 carers were unsure about the diabetes type 	Type 1 and type 2 diabetes	At least 12 months	<ul style="list-style-type: none"> ● PAID-5 ● DFEPI ● DIDP-FM ● WHO 5 item-measure of well-being ● WHOQOL-BREF 	<ul style="list-style-type: none"> ● 44.6% ($n=893$) reported that caregiving had a negative impact on their lives, specifically on emotional wellbeing. ● 61.3% ($n=1197$) of carers reported worry about hypoglycaemic events. ● 11.6% ($n=239$) of carers reported symptoms of depression. ● 19.8% ($n=461$) of participants reported that caregiving impacted on their relationships. ● 35.2% ($n=700$) of the carers reported that caregiving impacted negatively on their financial situation.
Orvik E et al (2006) Oslo, Norway.	75 carers	Type 2 diabetes	Up to 14 years	<ol style="list-style-type: none"> 1. SF-36 2. Additional questions (five related to diabetes and one question about their own health compared to their partners). 	<ul style="list-style-type: none"> ● 41% ($n=31$) of participants found the economic burden to be a consequence of their partner having diabetes.
Scarton et al (2014) Midwestern USA.	32 carers	Type 2 diabetes	Average of 8 years	Telephone semi-structured interviews (12 open-ended questions)	<ul style="list-style-type: none"> ● All participants ($n=32$) expressed financial concerns; this was more profound for the majority of African-American caregivers ($n=8$, 81.8%).

BDI=Beck Depression Inventory; DFEPI=DAWN Family Experiences of Patient Involvement; DIDP-FM=DAWN Impact of Diabetes Profile-Family Members; PAID-5=Problem Areas in Diabetes; SF-36=Short-form quality of life questionnaire; STAI=State-Trait Anxiety Inventory; QoL=Quality of life; WHO=World Health Organisation; WHOQOL-BREF= WHO Quality of Life-BREF.

Page points

1. The time from diagnosis for people with type 2 diabetes (T2D) in these studies ranged from 6 months to 14 years, and the cumulative period that their carers and family members provided care for is worth noting as a QoL (quality of life)-influencing factor. The total amount of time devoted to caring influenced the QoL scores.
2. The overall impact on carers' QoL was reported as neutral or positive, but many carers also reported a negative impact in relation to their experience.
3. The existing evidence suggests that carers have impaired emotional wellbeing, particularly in terms of depression and anxiety. In addition, carers reported that caregiving has a negative impact on their social functioning and that they are faced with a financial burden and constraints as a result of providing care to adults with T2D.

and STAI-TX2) to assess anxiety. Kovacs Burns et al (2013) used the WHO 5-Item Well-Being Index (Topp et al, 2015) and a number of questions developed by the authors to measure problem areas in diabetes, family experience of patient involvement, and the impact of diabetes in diverse aspects of family members' lives. The fact that different scales and non-validated measures were used in the aforementioned studies presents difficulties in determining the most suitable tool to assess the QoL of carers of adults with T2D.

Critical and thematic analyses overview

The time from diagnosis for people with T2D in these studies ranged from 6 months to 14 years, and the cumulative period that their carers and family members provided care for is worth noting as a QoL-influencing factor. The total amount of time devoted to caring influenced the QoL scores. This was supported in a study by Hirst (2005), in which rates of onset and recurrence of psychological distress were higher in carers who provided longer periods of care per week (over 20 hours), compared to their counterparts who were providing 10–19 hours and less than 10 hours of care, respectively.

The thematic analyses provided an overview of the QoL domains that were affected by providing care to adults with T2D. The overall impact on carers' QoL was reported as neutral or positive, but many carers also reported a negative impact in relation to their experience. Three of the studies highlighted carer's emotional wellbeing as an important factor (Anaforoğlu et al, 2011; Kovacs Burns et al, 2013; Scarton et al, 2014). These findings are supported by Golics et al (2013), who reported that 92% ($n=122$) of carers of people with long-term conditions found that caregiving had a negative impact on their emotional wellbeing.

The financial demands and constraints of caring for people with T2D were identified as issues by Scarton et al (2014) and Orvik et al (2006). This is supported by findings from a survey of carers in the UK, where almost three quarters of respondents were worried that financial difficulties were affecting their health (Carers UK, 2016).

The impact on the social functioning component was less prominent than on emotional wellbeing and may have been influenced by sociodemographic differences, carers' needs and knowledge regarding

T2D care, and cultural differences (Adawalla et al, 2006; Orvik et al, 2006; Anaforoğlu et al, 2011; Kovacs Burns et al, 2013; Scarton et al, 2014). A variety of factors related to poor social functioning were identified in the studies including: impaired social life (Scarton et al, 2014); the frustration of not knowing how to provide excellent care for the person with T2D (Kovacs Burns et al, 2013); and a general negative impact on social function (Orvik et al, 2006; Anaforoğlu et al, 2011). Although a detailed investigation and discussion into this is beyond the scope of this review, it is an area that warrants further research.

Study limitations

This scoping review has discussed existing evidence on the impact that caring for adults with T2D has on the QoL of carers, partners and family members. There are a few limitations, however, including: the small number of studies analysed; the use of different measurement tools in each study; and the variable amount of time devoted by carers to caregiving. With these limitations, we are unable to generalise findings and draw concrete conclusions for recommendations. In addition, only Kovacs Burns et al (2013) included participants from the UK, although one can argue that geographical parameters are not a limitation to generalising findings, especially as participants from all 16 countries in this study reported similar experiences.

Despite this limitation, the existing evidence suggests that carers have impaired emotional wellbeing, particularly in terms of depression and anxiety. In addition, carers reported that caregiving has a negative impact on their social functioning and that they are faced with a financial burden and constraints as a result of providing care to adults with T2D.

Conclusion

In the NHS outcomes framework, the carers' health-related quality of life is an important factor (DH, 2016), and addressing this is of paramount importance for integrated care. The assessment of carers' QoL is a recommended component in the training pathway for district/community nursing in order to empower carers and meet their needs (DH, 2015b). This component is important in district nursing with regard to working collaboratively with

people with diabetes, and the carers and families who provide care within homes (NHS England, 2015). The DH is providing funding to the Royal College of Nursing and the QNI to offer training and support to community and school nurses (DH, 2015b), and the QNI resources can be accessed online (QNI, 2016). Furthermore, healthcare professionals can advise carers to access available support networks, such as Carers UK (2014) and Diabetes UK (2018).

The reliance of the current healthcare system on carers' engagement in the management of long-term conditions supports the need to understand carers' needs and the impact on their QoL. This is paramount to maintaining the efficiency of the health system and to delivering care that is fair and considerate of individuals' needs. Therefore, further research is required regarding the carers of people with T2D; future studies should consider the influence of sociodemographic variables and cultural differences in community and secondary care.

In clinical practice, there is a need to invest in the training of healthcare professionals to enable them to address the possible psychosocial impact that caregiving can have on carers and available resources should be used to support carers to manage their needs and concerns. This could include screening carers for depression and anxiety, with community nurses ideally placed to take on this task. In addition, the new nursing workforce would benefit from changes to the pre-registration nursing programme, which could focus on increasing nurses' awareness of the role that carers play in the provision of person-centred care, self-management and integrated care. ■

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“In clinical practice, there is a need to invest in the training of healthcare professionals to enable them to address the possible psychosocial impact that caregiving can have on carers.”