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The impact of hypoglycaemia on the quality of life of family members of adults with type 1 or type 2 diabetes – a qualitative systematic review

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Aim: To summarize and critically appraise the recent qualitative evidence regarding the impact of hypoglycaemia on quality of life of family members of adults with type 1 or type 2 diabetes.

Methods: Four databases were searched systematically (MEDLINE, PsycINFO, CINAHL and Cochrane Library) and results were screened for eligibility. Article quality was assessed using the Joanna Briggs Institute Critical Appraisal Checklist for Qualitative Research. Data were extracted, coded and analyzed using thematic analysis. The systematic review was conducted in accordance with PRISMA and ENTREQ guidelines.

Results: Eight qualitative studies were included in the final review. The majority of participants were partners or spouses of adults with type 1 diabetes. Thematic synthesis resulted in six analytical themes: “Hypoglycaemia alters everyday life, reducing freedoms and increasing disruptions”, “Hypoglycaemia has an adverse impact on sleep”, “Hypoglycaemia negatively changes the relationship with the person with diabetes”, “Hypoglycaemia negatively impacts emotional well-being”, “The detection, prevention, and treatment of hypoglycaemia consumes time and energy” and “Family members have unmet needs for informational and emotional support regarding hypoglycaemia”. Across the six analytical themes, family members described how hypoglycaemia...
has a severe negative impact on different aspects of their lives, including daily living, personal relationships and emotional well-being.

**Conclusions:** Family members experience the impact of hypoglycaemia as a major recurrent challenge in their lives. The unmet needs of family members need further attention in research and clinical practice.

**Keywords:** Diabetes mellitus, Hypoglycaemia, Quality of Life, Relatives, Systematic Review, Qualitative Research

**Introduction**

Hypoglycaemia is common and recurring for many people with type 1 or insulin-treated type 2 diabetes, which can adversely impact them both physically and psychologically (1, 2). Hypoglycaemia not only affects the lives of people with diabetes, but can also negatively impact areas of life of close family members or significant others cohabitating with them (3-5). Hypoglycaemia can lead to family members experiencing increased diabetes-related distress and fear of hypoglycaemia (FoH) (6, 7). It can also impact their general emotional well-being, disrupt daily activities and damage family relationships (3-6, 8).

Previous research on the impact of hypoglycaemia on family members’ lives has focused largely on parents and caregivers of children with type 1 diabetes (9, 10), as parents are often the persons to recognize and treat episodes of hypoglycaemia (9). Less research has been undertaken on the impact of hypoglycaemia on the lives of family members of adults with diabetes. However, these family members, particularly partners and spouses, are also closely involved in the daily management of diabetes-related tasks, and are often active in preventing and assisting with episodes of hypoglycaemia (6, 11).

A 2018 mixed-methods review (including seven qualitative and four quantitative studies) of the overall impact of type 1 diabetes on partners, identified experience with hypoglycaemia as a recurrent theme (7). Partners reported that hypoglycaemia had a negative impact on their life and relationship, describing it as a constant threat (7). However, the review had a broad focus on the impact of diabetes, rather than the impact of hypoglycaemia, and focused only on partners of adults with type 1 diabetes; that is, not on other family members or other types of diabetes. While hypoglycaemia was identified as one of three themes in the review, a detailed, in-depth account of how hypoglycaemia impacts upon family members’ quality of life is still needed.
Furthermore, family members of people with type 2 were not included in this review. While we acknowledge that the frequency, severity and impact of hypoglycaemia for persons with type 2 diabetes is different from that experienced by people with type 1 diabetes (2), the impact upon family members of persons with type 2 diabetes experiencing hypoglycaemia, may be similar to the impact experienced by family members of people with type 1 diabetes 1.

Quality of life is a subjective and dynamic construct, comprising several domains of life, including physical, psychological, and social aspects (12). A thematic synthesis of qualitative studies can provide an in-depth overview of the lived experiences of family members of adults with type 1 and type 2 diabetes in relation to hypoglycaemia and its impact on quality of life. The distinct features of a thematic synthesis can contribute with unique accounts and perspectives directly from family members, while preserving the point-of-view and complexity of the original studies (13, 14). By focusing only on the impact of hypoglycaemia on quality of life, and not on the impact of diabetes overall, this synthesis can contribute a comprehensive and nuanced understanding of how hypoglycaemia impacts upon family members, which is currently lacking, and can identify specific knowledge gaps.

The purpose of this systematic review was to provide a thematic synthesis of qualitative studies, to answer the question of how hypoglycaemia impacts on the quality of life of family members of adults with type 1 or type 2 diabetes.

**Methods**

A systematic review with thematic synthesis was conducted in accordance with the methods described by Thomas and Harden (13). The systematic review is reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (15) and Enhancing transparency in reporting of qualitative research (ENTREQ) guidelines (16). The protocol was registered with the International Prospective Register of Systematic Reviews (PROSPERO, CRD42020154023).

**Search strategy**

The literature search was conducted as part of a single search strategy for five related systematic reviews on the impact of hypoglycaemia. MEDLINE, PsycINFO, CINAHL and Cochrane Library databases were systematically searched with no language restrictions. The search strategy was
developed around three concepts: population (i.e., family members), exposure (i.e., hypoglycaemia), and outcomes / experiences (i.e., quality of life and related outcomes), using both MeSH terms and free-text searching of titles and abstract. The search strategy was checked in accordance with the PRESS-Checklist, and no revisions were required (17). The search string can be seen in Appendix 1.

Selection and screening

Inclusion criteria were: 1) studies with a qualitative design; 2) participants who were family members of adults with type 1 or type 2 diabetes; 3) reported experience of hypoglycaemia in a family member with type 1 or type 2 diabetes; 4) reported quality of life outcomes / experiences of family members; and 5) reported relationships between hypoglycaemia and quality of life outcomes / experiences of family members. Exclusion criteria were: 1) systematic reviews and 2) studies conducted prior to 2009. The ten-year restriction was imposed to reflect changes in diabetes management in the past decade, where glucose sensing technologies (e.g., continuous glucose monitoring), as well as education programmes for people with type 1 diabetes have developed (18).

Articles were imported from the database search into EPPI-Reviewer 4. Titles and abstracts were initially screened by three reviewers (AS, LP and KS) according to the inclusion/exclusion criteria. Next, full-text review was completed by MVJ, and 10% of the articles were checked by a second reviewer (HC). Citation searching was carried out using the reference list of the included studies for backward chaining, and Google Scholar for forward chaining.

Data extraction and quality assessment

The following data were extracted for each included record: reference and study details, participant characteristics, methods of analysis and self-reported study limitations (AS and LP). MVJ checked 100% of the extracted data. Results (participants’ quotations and researchers’ interpretations) were extracted (MVJ) and imported into NVivo 12 for Windows. The quality of the included studies was assessed (MVJ) using the Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Qualitative Research (19). The checklist includes eight items evaluating the congruence and transparency of the methods used in the included studies, with four response options: yes, no, unclear, not applicable. The quality assessment was not used to exclude studies from the review, but rather to assess the methodological quality to inform further analysis in the review.
**Analysis and synthesis**

The three steps of thematic synthesis (i.e., coding, development of descriptive themes, and development of analytical themes) were completed by MVJ and MB. Each reviewer read through the extracted text independently to familiarise themselves with the data. Before starting the coding process, a set of a priori codes were developed to sort the data. These codes were *participants quotations, researcher statements or interpretations, and type of family member*. Studies were then coded through an inductive approach, by applying one or more codes to each section of text (ranging in length from a single sentence to a paragraph) that was relevant to the research question. Each study was coded sequentially, and as new codes were created, earlier studies were revisited to assess whether the content should be coded into newer codes as they evolved.

Following this step, the initial codes from each reviewer were discussed and compared, in order to collate codes where possible, and to reach consensus on applied codes. Descriptive themes were then created by organizing the agreed upon codes into related groups. Consistent with the approach outlined by Thomas and Harden (13) each section of text could contribute to multiple codes, and therefore, multiple themes. Descriptive themes were broad labels describing the content of related codes. See *Table 2* for an overview of descriptive themes. Descriptive themes were then translated into one or more analytical themes. The analytical themes were developed by discussing and examining similarities and relationships across and between the descriptive themes. While descriptive themes stayed close to the original data, simply describing groups of codes, the analytical themes were developed to answer the research question, “*how does hypoglycaemia impact on quality of life?*”. See *Figure 1* for an example of the development of an analytical theme.

Consistent with best practice in qualitative research (20), throughout coding and development of themes, the researchers took a reflexive approach, acknowledging and discussing their perspective as researchers in the field of diabetes, and how this may affect their analysis and interpretation of the data. For example, while all attempts were made to analyse the data inductively, the researchers’ insights and pre-existing understanding of the evidence (e.g., regarding concepts such as fear of hypoglycaemia) may have influenced the codes/themes identified and the language used to describe these, thereby inadvertently introducing some deductive analysis.
Results

Systematic search and selection

The search identified 666 studies. After initial screening, and removal of non-qualitative studies and duplicates, 49 articles were screened at abstract level, with 31 excluded as they did not meet eligibility criteria. The full text of 15 articles were screened, with 9 excluded. Two additional studies were found in the citation search; thus, the final number of eligible studies included in the review was eight. See Figure 2 for the PRISMA flow diagram.

Characteristics of included studies

The eight included articles reported on eight different studies, conducted in the USA (21-24), UK (25) Finland (26) and Australia (27); and one multi-country study, involving 17 countries (28). Four studies focused specifically on experiences of family members of persons with diabetes (25-28), and four studies on both family members and persons with diabetes (21-24). In all studies, participants were recruited through a large existing study, where a person with diabetes identified a family member or nominated a significant other to participate.

The seven single-country studies included family members of a person with type 1 diabetes; in total 159 participants, of whom 149 were partners or spouses (hereafter referred to as partners) (21-27). The remaining 10 family members were seven adult children (25-27), and three parents of adults with type 1 diabetes (25). The multi-country study involved 2,057 family members, of whom three quarters were family members of people with type 2 diabetes (N=1,547) (28).

Three studies collected data through semi-structured interviews (23, 25, 26), while two studies used focus groups (21, 24). One study conducted both focus groups and semi-structured interviews (22). The multi-country study collected data online and by phone interviews applying five open-ended questions (28).

The majority of studies did not have study aims focused on hypoglycaemia. Two studies had research objectives focusing specifically on hypoglycaemia (25, 27), while two examined the use of diabetes technology and its impact on family members and relationships; including one on automated insulin delivery systems (22), and one on continuous glucose monitoring (24).
Details of the participants and methodologies in the included studies can be seen in Table 1.

**Quality assessment**
The overall quality of the included studies was good. The majority met most of the JBI tool criteria (19). In seven out of eight studies, full assessment was not possible for: 1) a statement locating the researcher culturally or theoretically; or 2) the researcher’s influence on the research, and vice-versa.
Details of the quality assessment can be seen in Table 3.

**Synthesis of findings**
Six analytical themes were identified: “Hypoglycaemia alters everyday life, reducing freedom and increasing disruptions”, “Hypoglycaemia has an adverse impact on sleep” “Hypoglycaemia negatively changes the relationship with the person with diabetes”, “Hypoglycaemia negatively impacts emotional well-being”, “The detection, prevention, and treatment of hypoglycaemia consumes time and energy” and “Family members have unmet needs for informational and emotional support regarding hypoglycaemia”.

**Hypoglycaemia alters everyday life, reducing freedom and increasing disruptions**
Across all eight studies, a central theme voiced by family members was the impact of hypoglycaemia on their everyday life. They expressed how the risk of hypoglycaemia had a negative influence on their freedom to do what they wanted, whether it be activities in their social life (25), their ability to go on holiday (23, 28), the freedom to eat when and where they wanted (23, 28), or their capacity to be spontaneous without the latent risk of hypoglycaemia (21, 26, 28).

Two studies reported on family members expressing an impact on care of their own children, in case their partner with diabetes would have hypoglycaemia (21, 22). This was described as a shift in daily responsibilities, for example, in relation to changing plans with children due to hypoglycaemia: “We’ll have to take the kids somewhere, and she’ll say ‘I can’t drive right now, I’m feeling shaky. And I’ll have to take the kids somewhere’” (22). Hypoglycaemia was reported as a disruption to family members’ lives (22, 27) who described how situations and plans needed constant adjustment (23).
Hypoglycaemia has an adverse impact on sleep

In half of the studies, family members described how fear and worries about hypoglycaemia caused interrupted sleep (21, 25, 26, 28). They reported experiencing insomnia due to their fear that their family member would have hypoglycaemia while asleep (28). Due to this worry, they regularly checked on their partner (25), with one participant describing the thought of hypoglycaemia during sleep as “totally terrifying” (21). In response, family members were hypervigilant at night, constantly looking out for signs of hypoglycaemia (25).

Family members reported that the various sounds from pumps and monitors would wake them up (23), and they would fear that these sounds meant that the person with diabetes was having hypoglycaemia (26). In contrast, one study reported that technology had made it possible for family members to rely on the monitor to wake them up during the night, and they were able to sleep without having to check on the person with diabetes (24). Authors described family members not being able to sleep a whole night through, and thus experiencing debilitating “periods of extreme exhaustion” (25).

Hypoglycaemia negatively changes the relationship with the person with diabetes

In most studies, family members described how hypoglycaemia could impact their relationship to the person with diabetes in various ways (21, 22, 24, 25, 27, 28). Two studies described how partners experienced a negative change in the dynamic of their relationship to the person with diabetes (25, 28). Family members often had to take on a “parenting” role in dealing with hypoglycaemia. They described an imbalance in the relationship and an altering view on the person with diabetes. For example, “I’m not the kind of character that finds joy in mothering another adult that I loved and respected as a male, you know, responsible being. I’m not, I want a proper partner” (25).

Two studies further described how the actions taken to prevent hypoglycaemia (e.g. urging the person with diabetes to monitor their blood glucose) could result in conflicts (22, 28). In relation to this, family members experienced an increasing bitterness or “an outward and growing sense of resentment” (25, 27) towards the person with diabetes. Family members felt angry and frustrated
when they believed that the person with diabetes could have avoided hypoglycaemia. This perception could have a direct impact on their relationship, “I’m ashamed to say that I got to the stage where I said to her ‘I’ve had enough. I’m off. See you later.’ It was the fact that she wouldn’t look after herself and wouldn’t stop [the hypos]” (27).

Family members described how the sudden changes that hypoglycaemia could inflict on the behaviour of the person with diabetes could impact on the way family members related to and communicated with their partner. In three studies, family members described how hypoglycaemia could be accompanied by aggressive and unpleasant behavior (21, 25, 27). Verbally abusive behaviour towards the family member during episodes of hypoglycaemia was also described (27). These experiences of violent and verbally abusive behavior would leave family members feeling “constantly on alert, frightened, and apprehensive” (25). Family members tried to appease these instances of aggressive behaviors by upholding “a non-threatening environment” (27).

One study reported on family members expressing a sense of control, empowerment and importance about the responsibility that they took on as carers in their relationship, stating “I can do something about it. I’m the one who can fix it. She’s relying on me.” (27). Likewise, the authors of another paper reported that some family members “were keen to present themselves as having taken on their caring roles willingly and knowingly” (25).

Worries about hypoglycaemia when the family member was not around the person with diabetes was reported in five studies (22, 23, 25, 27, 28). Family members described being “perpetually worried” (25) when they were away from the person with diabetes, and that the worry was present at any stage of physical remoteness, whether the family member was going to work or on holiday (21, 23). In two studies, authors noted that “…even when they were physically remote from the person with HU [hypoglycaemia unawareness], family members reported little respite from their supervisory roles and responsibilities” (25), and that the worry of leaving the person with diabetes alone was related to the family member not being “able or available to help” (28).

In two studies focused on continuous glucose monitoring (24) and automated insulin delivery systems (22), respectively, family members expressed hope and positivity in terms of how technology could possibly reduce the negative impact of hypoglycaemia on their relationship.
Family members described how technology could reduce conflicts around daily glucose checking (22) and could shift the responsibility from the family member to the device. Family members anticipated that if they no longer had to deal with hypoglycaemia, it could have a positive impact on their relationship with the person with diabetes, and relief from their constant worry (24).

**Hypoglycaemia negatively impacts emotional well-being**

Across all eight studies, family members expressed emotional distress about hypoglycaemia. This related to the family member assisting during hypoglycaemia episodes (21, 26, 27), the family members’ daily life being impacted by hypoglycaemia (22, 23, 25), and the negative emotions accompanying the experience of seeing the person with diabetes having a hypoglycaemic episode (25, 28). The negative emotions expressed ranged from feeling “…inadequate, unprepared, or a degree of panic” (27), in relation to dealing with hypoglycaemic episodes, to feeling “…a bit angry at times” (25). Family members described feelings in relation to hypoglycaemia with words like, “distressing” (27), “annoyed” (22), “frightened” (25) “uncomfortable” (28) and “scary” (24).

Worries of various kinds were described by family members across studies. These related to episodes of hypoglycaemia while asleep (21, 25, 28), leaving the person with diabetes alone (21-23, 25, 27, 28), other people’s perception of hypoglycaemia (27), and worries about the violent or aggressive behavior that sometimes accompanied the episodes (25, 27, 28). Fear of hypoglycaemia was mentioned specifically in three of the eight studies (22, 26, 28). Five studies reported family members’ worries and concerns about hypoglycaemia, but did not refer to fear of hypoglycaemia (22, 23, 25-27). Family members described worries about hypoglycaemia as an ongoing theme in their lives, impacting on their sleep (25, 28) and their freedom to plan activities (25, 28). Four studies reported that fear or worries about hypoglycaemia were often present in relation to previous traumatic events, where the family member had been unable to help the person with diabetes (21, 25, 26, 28), either due to “…their inability to know what to do, how to react, or to understand what is happening” (28), or because the person with diabetes had been alone when the incident occurred (21, 25, 26).

While negative emotions in relation to hypoglycaemia were often reported, half of the studies also reported on family members expressing ambivalent emotions. These related to their satisfaction...
with learning and developing the ability to recognize and treat hypoglycaemia, as well as playing an important role in the life of the person with diabetes (23, 25-27). Four studies described how family members assumed ‘control’ over factors relating to hypoglycaemia, and developed confidence and expertise in detecting and managing hypoglycaemia (23, 25-27).

**The prevention, detection and treatment of hypoglycaemia consumes time and energy**

Six studies described family members’ actions to prevent and detect hypoglycaemia (21, 23, 25-28). It was clear that considerable time and (physical and emotional) energy was devoted by family members to these tasks.

In most studies, family members described specific incidents of hypoglycaemia where they had assisted the person with diabetes with treatment (21, 25-28). Family members reported being constantly mentally prepared for incidences of hypoglycaemia. They expressed being “vigilant” (27), noticing signs of hypoglycaemia before the person with diabetes (21, 25, 27). These signs could be “...glazed look in the eyes, the changes in speech” (27), or “rapid change in mood” (23).

In half of the studies, family members described how they gained more knowledge about hypoglycaemia symptoms, and became able to detect even the slightest changes in behavior and subtle physical signs of hypoglycaemia commencing (23, 25-27).

Three studies reported on family members employing a range of “checking-up” strategies in order to monitor the person with diabetes. These strategies could be “having neighbours and other people checking on the person with diabetes” or “calling and texting regularly”, as well as being prepared for possible hypoglycaemia by carrying around snacks, sugar and “hypo-kits” at all times (23, 25, 27). They also reported carefully planning their daily schedule or outings in order to avoid situations where hypoglycaemia could occur (26).

Three studies reported on family members administering glucagon injections during hypoglycaemic events (21, 27, 28), with the majority expressing concern and insecurities about their ability to do it swiftly and correctly (27). Others had helped the person with diabetes managing hypoglycaemia by
urging them to check their blood glucose, and in some cases actively helping them to eat if they were not able to do so themselves (26, 27), or calling the emergency services (21).

**Family members’ unmet needs for informational and emotional support regarding hypoglycaemia**

Two studies reported on the expressed needs of family members in relation to knowledge and education about hypoglycaemia and support from their social surroundings (25, 27). Family members described a need for further education on hypoglycaemia (27) and advice from health care professionals, especially in relation to feeling confident giving glucagon injections (25). Family members also reported that they were not prepared for or informed of the physical and behavioral changes that came with hypoglycaemia, with one stating: “if someone could just put a couple of lines in to say that these things may happen!” (27). Family members further expressed a wish to accompany the person with diabetes to consultations, as they did not always feel confident that they could rely on the information passed on to them by the person with diabetes (25).

The same two studies further reported on the emotional and social needs expressed by family members. They “felt emotionally ill-prepared for the behavioral and personality changes that could accompany hypoglycaemia”, and expressed a lack of support from health care professionals, friends and other relatives (25). Family members reported needing reassurance from people in the same situation, missing a dedicated forum to talk about their experiences and concerns, and indicated that they were rarely asked about their needs or experiences by anyone (25, 27).

In contrast to this, authors described a discrepancy between family members’ expressed need for support from their social surroundings, and a struggle to recognize their own right for support independent of the person with diabetes. Participants expressed the following: “I still feel very much like the person who has the illness is the person who needs the most support” (25), and “it’s just part and parcel of the give and take in a relationship. . . . Every partner comes with some sort of baggage and I have my baggage too . . . and he supports that” (27).

**Discussion**

This thematic synthesis of eight qualitative studies clearly shows that the quality of life of family members of adults with diabetes is severely affected by hypoglycaemia. Across the included
studies, partners (predominantly), parents and adult children of adults with type 1 diabetes or type 2 diabetes consistently described how hypoglycaemia negatively impacts their everyday life, their relationship with the person with diabetes and their emotional well-being. However, conclusions drawn about the experiences of family members of people with type 2 diabetes should be regarded as tentative, as this group was only represented in a single study in the synthesis The synthesis revealed further how the majority of family members are required to play a significant role in detecting and treating hypoglycaemia, resulting in worries and reduced freedom, sleep, time and energy. Finally, the synthesis shed light on family members’ unmet informational and support needs in relation to hypoglycaemia. Overall, the synthesis highlights the relentless presence of hypoglycaemia in the lives of family members, and the clear link between this and their overall quality of life.

Consistent with the 2018 mixed review (7) the current review found that hypoglycaemia was a central and prevalent theme in these qualitative studies, even though the majority of the included studies were not specifically aiming to explore the impact of hypoglycaemia. However, unlike previous quantitative and mixed method studies, the present review focused exclusively on the impact on quality of life. In doing so, the review provides an in-depth summary of the current evidence of the specific impacts of hypoglycaemia on areas of life that are important and meaningful to family members, bringing us closer to understanding its impact on their quality of life. This includes how the impact of hypoglycaemia goes beyond worries and fears, but also has a complex effect on the relationship between the family member and the person with diabetes; and further, how dealing with hypoglycaemia (both physically and emotionally) can be associated with extreme emotional distress in family members. The complexity of the impact of hypoglycaemia is highlighted with the findings of ambivalence in the family members. This involved family members feeling concurrent resentment and sympathy towards the person with diabetes, as well as family members expressing a need for support, yet feeling guilty about asking for help.

Although the included studies did not explicitly report on quality of life, the synthesis of these studies show that family members’ time and energy is consumed with hypoglycaemia-related thoughts and actions that can have a detrimental and damaging impact on their quality of life and related outcomes, such as relationships, general well-being, emotional well-being and freedom to plan or be spontaneous.
Strengths and limitations

The synthesis of qualitative data and the use of thematic synthesis in systematic reviews is still a developing area (29). The criticism of the method is usually related to the subjective nature of the creation of themes and analysis, and the reproducibility of the results (30). However, by adopting recognized methods for thematic synthesis (13), we sought to ensure rigour to the identification and analysis of themes in the included articles. While recognizing the independent preconceptions as researchers analyzing the data, we sought to limit this by two independent reviewers with different backgrounds (nursing and psychology, respectively) completing coding separately. Furthermore, well-established guidelines were used to ensure a transparent reporting of the findings of the synthesis with detailed description of the process of extraction and the development of both descriptive and analytical themes (16).

The studies by Lawton et al (2014) (25), and King et al (2015) (27) contributed more to the synthesis than other studies, as their study aims focused on hypoglycaemia specifically. The limited detail in some of the included studies may have reduced the comprehensiveness of the synthesis, such that we cannot exclude that some aspects of the impact of hypoglycaemia on quality of life may have been missed. However, irrespective of study objectives, all included studies had several valuable extractions related to our research question, and therefore all studies are represented across the synthesis.

Although our literature search sought to identify studies reporting on all types of family members, partners were over-represented in the included studies. However, in four of the eight studies (24, 25, 27, 28) parents and children of adults with diabetes were included and the findings of the thematic synthesis were similar across these three family member types. The recurrent themes show that the impact of hypoglycaemia on partners can be similar for parents and (adult) children of a person with diabetes, however, their experiences are understudied. Thus, it is important that future qualitative research focuses specifically on the impact of hypoglycaemia on quality of life among different types of family members.

The large, multi-country study (28), used a different design (i.e. online survey using open-ended questions), had a much larger sample size, and included participants who were family members of people with type 1 or type 2 diabetes, when compared to other included studies that reported only...
on family members to adults with type 1 diabetes. However, inspection of the data showed similar
depth and topic relevance compared to other studies included in the review.

**Recommendations and implications**
These findings show that family members play a crucial role in preventing and managing all aspects
of hypoglycaemia, and that their lives are deeply impacted by hypoglycaemia on a daily basis. The
findings of this review indicate that family members could benefit from tailored support (from both
peers and healthcare professionals) and specific education in relation to detection, prevention and
treatment of hypoglycaemia. With family members reporting a significant negative impact of
hypoglycaemia on their relationship to the person with diabetes, a greater involvement of family
members in clinical care might help to prevent or reduce conflicts and enable health care
professionals to identify areas where there are challenges. Finally, further research is needed on
whether the impact of hypoglycaemia differs for various types of family members, and whether the
impact of hypoglycaemia on the family member differs when a person has type 1 diabetes versus
type 2 diabetes.

**Conclusion**
This review has shown the complex impact of hypoglycaemia on family members of adults with
diabetes. Their central role in many aspects of hypoglycaemia (such as prevention, detection and
management, and general support and concern for the person with diabetes) results in family
members being greatly impacted by hypoglycaemia in various areas of their lives. The unmet needs
of family members need to be considered in future research and clinical care.

**Conflict of interest statement**
The authors have no disclosures.

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References


*indicate studies included in the review
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<td>King et al (2015), Australia (27)</td>
<td>n= 7</td>
<td>Age range, 34-60 years</td>
<td>Female n=4 Male n=3</td>
<td>Spouses: n=4Boyfriend: n=1Daughter: n=1Partner: n=1</td>
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<tr>
<td>Lawton et al (2014), UK (25)</td>
<td>n= 24</td>
<td>Spouse/partner: 51.4(11.2), 26-72 Parents: 60.7 (10.1), 49-66 Adult child: 25.7 (6.0), 20-32</td>
<td>Female n=17 Male n=7</td>
<td>Spouse/partner: n=18Parent: n=3Adult child: n=3</td>
<td>T1D</td>
<td>Semi-structured interview</td>
<td>Thematic analysis</td>
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<tr>
<td>Litchman et al (2019), US (23)</td>
<td>n= 26</td>
<td>68 (5.11)</td>
<td>Female n=16 Male n=10</td>
<td>Spouse/partner: n=26</td>
<td>T1D</td>
<td>Semi-structured interview</td>
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<td>Sample Size</td>
<td>Age Distribution</td>
<td>With Diabetes</td>
<td>Diagnosis</td>
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<td>Analysis Method</td>
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<tr>
<td>Rintala et al (2013), Finland (26)</td>
<td>n=19</td>
<td>Under 30 n=3, 30-40 n=6, 41-50 n=5, 51-60 n=2, Over 60 n=3</td>
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<td>Semi-structured interview</td>
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<td>Ritholz et al (2013), US (24)</td>
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<td>Young male: 38 (4), Young female: 35 (2), Older male: 66(5), Older female: 56(5)</td>
<td>Female n=7, Male n=7</td>
<td>Spouses</td>
<td>T1D</td>
<td>Focus groups</td>
<td>Thematic analysis</td>
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<td>Stuckey et al (2016), Multi-country (28)</td>
<td>n=2057</td>
<td>Median age (interquartile range) was 46 (31-57)</td>
<td>Female n=1337, Male n=720</td>
<td>Caring for (%): Spouse/partner (40.7), Child aged 18 years or above (2.9), Parent (36.6), Other adult relative (18.5)</td>
<td>T2D (61.6%), T1D (24.8%)</td>
<td>Five open ended questions in online survey</td>
<td>Thematic analysis</td>
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<td>45.6 (13.5)</td>
<td>Female n=5, Male n=9</td>
<td>Partners</td>
<td>T1D</td>
<td>Focus groups</td>
<td>Thematic analysis</td>
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<td>Codes</td>
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<td>Analytical Themes</td>
<td>Studies contributing to analytical theme</td>
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<td>• Worries about nighttime hypoglycaemia</td>
<td>Theme 2: Social and behavioural impact of hypoglycaemia</td>
<td>Hypoglycaemia has an adverse impact on sleep</td>
<td>Trief et al, Lawton et al, Rintala et al, Stuckey et al (21, 25, 26, 28).</td>
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<td>• Worries about other people’s interpretation of hypoglycaemia</td>
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<td>Hypoglycaemia negatively changes the family member’s relationship to the person with diabetes</td>
<td>Trief et al, Garza et al, Ritholz et al, Lawton et al, King et al, Stuckey et al (21, 22, 24, 25, 27, 28).</td>
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<tr>
<td>• Ambivalent emotions</td>
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<td>• Impact of hypoglycaemia on lifestyle and daily activities</td>
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<td>• Impact of hypoglycaemia on travel and leisure time</td>
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<tr>
<td>• Excessive planning</td>
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<tr>
<td>• Impact of hypoglycaemia on sleep</td>
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<tr>
<td>• Impact of hypoglycaemia on relationship</td>
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<td>• Aggressive and verbally abusive behavior</td>
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<td>• Protective role of technology</td>
<td></td>
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<tr>
<td>• Worries about leaving person with diabetes alone</td>
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<tr>
<td>• Conflicts and parenting role</td>
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</table>
- Preventing and detecting hypo
- Developing skills
- Changes in the behaviour and mood of the person with diabetes
- Assistance during hypoglycaemia
- Excessive planning

**Theme 3:** Hypoglycaemia management  
The prevention, detection and treatment of hypoglycaemia consumes time and energy  

- Peer support
- Need for education and knowledge
- Involvement in consultations
- Practical skills

**Theme 4:** Expressed needs of family members  
Family members need informational and emotional support regarding hypoglycaemia  
Lawton et al, King et al (25, 27).
<table>
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<tr>
<td>Are participants, and their voices, adequately represented?</td>
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<td>Is the research ethical according to current criteria or, for recent studies, is there evidence of ethical approval by an appropriate body?</td>
<td>Yes</td>
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<td>Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data</td>
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</table>

**Figure legends**

*Appendix 1: Search string*

*Figure 1: Development of an analytical theme*

*Figure 2: PRISMA flow diagram*
Appendix 1: Search string.

```
1  exp Diabetes Mellitus, Type 1/
2  (("typ* 1" or "typ* I") adj2 diabet*).tw.
3  (IDDM or T1DM or T1D).tw.
4  ("insulin* depend*" or "insulin depend**") not ("non-insulin* depend**" or "noninsulin depend**") .tw.
5  1 or 2 or 3 or 4

11 exp Hypoglycemia/ or Blood Glucose Self-Monitoring/
12  (hypoglycemi* or hypoglycaemi* or hypo-glycemi* or hypo-glycaemi* or low blood sugar or low blood glucose or blood glucose monitor*).mp.
13  11 or 12
14  5 and 13 [T1DM + hypo]
15  10 and 13 [T2DM + hypo]
16  ((psychological or psychosocial or psycho-social) adj3 outcome*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
17  ("level of independence" or self-efficacy or self-esteem or resilien* or ((social or friend* or marital or partner* or husband* or wife* or spous* or family or familial or families) adj3 relationship*)) or social* isolat* or finances or sleep or "daytime functioning" or "cognitive function*" or productivity or (work adj2 absen*) or absenteeism or presenteeism or memory or mood or depress* or anxi* or ((fear or afraid or worr* or distress* or stigma* or impact*) adj3 (hypoglycaemi* or hypoglycemi*)) or "diabetes distress" or "diabetes stigma" or "diabetes burnout" or "psychological conflict").mp.
18  ("care needs" adj3 (express* or perception* or perspective* or judge* or (patient* adj2 view*)) or "own assessment**").mp.
19  Quality of Life/
20  quality of life.mp.
```
<table>
<thead>
<tr>
<th>21</th>
<th>(hql or hqol or h qol or hrqol or hr qol).ti,ab,kf.</th>
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<td>22</td>
<td>(life satisfaction or wellbeing or well-being).mp.</td>
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<tr>
<td>23</td>
<td>16 or 17 or 18 or 19 or 20 or 21 or 22 <strong>[outcome / QoL terms]</strong></td>
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<tr>
<td>24</td>
<td>randomized controlled trial.pt. or randomized.mp. or placebo.mp.</td>
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<tr>
<td><strong>[McMaster therapy filter]</strong></td>
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<td>25</td>
<td>meta analysis.mp,pt. or review.pt. or search:.tw. <strong>[McMaster SR filter]</strong></td>
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<tr>
<td>26</td>
<td>(((&quot;semi-structured&quot; or semistructured or unstructured or informal or &quot;in-depth&quot; or indepth or &quot;face-to-face&quot; or structured or guide) adj3 (interview* or discussion* or questionnaire*)) or (focus group* or qualitative or ethnograph* or fieldwork or &quot;field work&quot; or &quot;key informant&quot;))).ti,ab. or interviews as topic/ or focus groups/ or narration/ or qualitative research/</td>
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<tr>
<td><strong>[University of Texas qualitative filter]</strong></td>
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<tr>
<td>27</td>
<td>Epidemiologic studies/ or exp case control studies/ or exp cohort studies/ or Cross-sectional studies/</td>
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</table>

| 28 | (Case control or cohort analysis).tw. |
| 29 | (longitudinal or retrospective or cross sectional).tw. |
| 30 | (cohort adj (study or studies)).tw. |
| 31 | (Follow up adj (study or studies)).tw. |
| 32 | (observational adj (study or studies)).tw. |
| 35 | or/24-32 **[ALL eligible study types]** |
| 42 | ((14 or 15) and 23 and 35) not 34 |
| 43 | (family or families or spous* or husband* or wife or wives or partner* or son or sons or daughter* or children).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] |
| 44 | 42 and 43 **[Rev 5: families of adults with T1DM or T2DM]** |
**Figure 1:** Development of an analytical theme

Extracts:

“Then I started to pick up lumps of sugar from restaurants and kept them in my pockets all the time during my adolescence... just in case mother would need help”, Rintala et al (2013)

“I expected that] somebody gets maybe a bit drowsy and dizzy or they may faint and then you have to give them the injection. So that was my expectation. [I didn't expect] to see him acting like Donald Duck jumping around... They never said for instance this could happen”, King et al (2015).

One evening my husband had hypoglycaemia and woke me up to give him a Glucagon injection, and I was unsuccessful. It was horrible, because he was barely conscious. I panicked, I didn't succeed in injecting him with the needle, and I went to get him a soda right away. Since then I've been anxious about nighttime hypoglycaemia attacks”, Stuckey et al (2016).

Codes:

- Preventing and detecting hypoglycaemia
- Changes in PwD behaviour and mood
- Providing assistance during hypoglycaemia

Descriptive theme:

Hypoglycaemia management

Analytical theme:

The prevention, detection and treatment of hypoglycaemia consumes time and energy.

PwD: Person with diabetes
Figure 2: PRISMA flow diagram

Records identified through database searching
(n = 666)

Records after initial study selection process (and duplicates and non-qualitative studies removed)
(n = 49)