Running head: Couples living with type 1 diabetes

Title: Couples living with type 1 diabetes: an integrative review of the impacts on health and wellbeing

Authors: Messina R\textsuperscript{1,2}, Due-Christensen M\textsuperscript{2,3}, Keller-Senn A\textsuperscript{2,4,5}, Polek E\textsuperscript{6}, Fantini MP\textsuperscript{1} & Sturt J\textsuperscript{2}.

Institutions: \textsuperscript{1}Department of Biomedical and Neuromotor Sciences-Unit of Hygiene and Biostatistics, University of Bologna, Italy; 
\textsuperscript{2}Florence Nightingale Faculty of Nursing, Midwifery & Palliative Care, King’s College London, United Kingdom; 
\textsuperscript{3}Steno Diabetes Centre Copenhagen, Denmark; 
\textsuperscript{4}Department of Medicine, Cantonal Hospital Winterthur, Switzerland; 
\textsuperscript{5}Zurich University of Applied Sciences, Zurich, Switzerland; 
\textsuperscript{6}Tavistock Relationships, London, United Kingdom.

Corresponding author: 
Mette Due-Christensen, PhD 
King’s College London 
Florence Nightingale Faculty of Nursing, Midwifery & Palliative Care 
Room 4.26, 
57 Waterloo Road 
LONDON SE1 8WA 
Tel: (+44) 020 78483849
Email: mette.due-christensen@kcl.ac.uk

Contribution to authorship statement
JS, EP and MDC originated the research idea. RM and MDC conducted the search and selected papers. RM, MDC, JS, AKS, EP, extracted data, assessed study quality and undertook data synthesis. RM and JS drafted the manuscript. MDC, AKS, EP, MPF reviewed, and contributed intellectual content to, the manuscript. All the authors approved the final version.

Statement of conflict of interest
The authors have no conflict of interest to declare in relation to the present work and no supporting grant to declare.

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Abstract

Impacts of type 1 diabetes and relationship factors on health and wellbeing of both persons with diabetes (PWD) and partners (T1D partners) have not been investigated. Integrative review methods evaluated the evidence. From 323 titles we included 24 studies involving 16,083 PWD and 1,020 T1D partners. Studies were quantitative (n=13), qualitative (n=9) and mixed methods (n=2). Maintaining resilient, good quality, intimate relationships optimises physical and psychological outcomes for PWD. Partners experience disturbed sleep and whilst general psychological health is maintained, distress surrounding hypoglycemia is overwhelming for over a third of partners. Nurturing quality relationships could reap significant health benefits.

Keywords: type 1 diabetes, couples, hypoglycemia, diabetes distress, psychological wellbeing
Introduction

The medical model of health is increasingly challenged and gradually replaced by a holistic approach (Handley et al., 2015) such as the biopsychosocial model of health. This sees health as a system influenced by dynamic biological, interpersonal and psychological characteristics interacting with contextual factors and changing over time (Lehman et al., 2017). In line with this approach, family can have a profound (both negative or positive) influence on people with long-term conditions and disease management (Rosland et al., 2012). Couples mutually influence each other's mental and physical health trajectories for good or ill (Kiecolt-Glaser and Wilson, 2017). A recent systematic review evaluating the effectiveness of couple interventions for adults living with long-term conditions found that combined relational and cognitive/skills based interventions were more effective for targeting both emotional resilience within the relationship and self-efficacy towards the long term condition than patient-only interventions (Berry et al., 2017).

Type 1 diabetes treatment and self-management is part of a complex and multifactorial process influenced by individual, social and environmental variables (Gonder-Frederick et al., 2002). In children with type 1 diabetes, research has continued to support the importance of familial characteristics; conversely, the role of family factors and social support in adult diabetes management has been underestimated in the literature or not differentiated between type 1 and type 2 diabetes. This family focus, and in particular intimate partner focus, has not been widely recognised in type 1 adult care. Reflecting on the evidence that couple interventions are more effective than patient-only interventions (Berry et al., 2017) it is noteworthy that the majority of Diabetes Self-Management Education (DSMES) in type 1 is provided to those with the condition alone and with limited attention paid to their intimate partners (Chatterjee et al., 2017). The impact of type 1 diabetes on those with the condition is well-researched, but the impact of the diabetes on the couple unit or the impact on the
intimate partner remains an under-studied topic. Only two previous reviews have studied this in people with diabetes (Lister et al., 2013; Rintala et al., 2013a). In these reviews less than a quarter of included studies were related to type 1 diabetes. The analyses took a clinical and social science perspective and did not consider findings related to type 1 diabetes populations separately. For couples living with type 1 diabetes, the strain on intimate relationships afforded in everyday life, is stretched with experiences of hypo- and hyperglycaemia. The aim of this study was to review the evidence to better understand the impact of type 1 diabetes on relationships and vice versa, and to better understand the impact on the health and wellbeing of partners’ of adults with type 1 diabetes (T1D partners), and, ultimately, to inform the development of couple interventions.

**Methods**

*Research Design*

To conduct the literature review and to analyse the existing literature in the field we undertook an integrative review (Souza and Silva, 2010; Whittemore and Knafl, 2005), that is a methodology that provides synthesis of knowledge and applicability of results of significant studies into practice. Integrative review is composed of six phases (Souza and Silva, 2010): preparing the guiding question; literature search; data collection; critical analysis of the studies included; discussion of results; presentation of the integrative review.

*Research questions*

Our four apriori research questions are:

Q1: What is the impact of being in an intimate relationship on diabetes outcomes and self-management?
Q2. What is the impact of type 1 diabetes on the quality/satisfaction of a couple relationship?

Q3. What is the impact of living with type 1 diabetes on T1D partners’ health and well-being?

Q4. Which patient reported outcome measures (PROMs) have been used to assess relationship quality and psychological outcomes?

The review was registered on PROSPERO (Registration number: CRD42018093796) (PNM Research Ethics Subcommittee of KCL-Study Reference: HR-17/18-5478).

Search strategy and screening

A systematic search was conducted using PubMed, MEDLINE, CINAHL and PsychINFO electronic databases combining keywords from the two previous literature reviews (Lister et al., 2013; Rintala et al., 2013a). Keywords were: type 1 diabetes + couple, spouse, partner, husband, wife, marriage, dyad, dyadic, significant other, daily activities, everyday living, self-management, self-care (see Appendix 1 for search strategy). The search dates followed immediately from the end date of the seminal Lister et al (2013) review from 01.01.2011 and concluded on 31.12.17. Studies included in the Lister et al. (2013) and Rintala et al. (2013a) reviews were searched for relevance along with the reference lists of final included studies. Where data from a single study population were published in multiple manuscripts, these were combined so we report the data at the sample-level rather than publication-level. The flow diagram of study selection and inclusion is presented in Figure 1. [Insert Figure 1]

Inclusion/Exclusion criteria

The following inclusion criteria were applied: 1) any study design reporting data from/on adults 18 years or older with type 1 diabetes AND/OR their partner/spouse; 2) any of the following outcomes were studied: a) relationship quality/satisfaction b) partner/spouse’s
health and wellbeing c) relationship status and diabetes outcomes; 3) papers were published in scientific peer-reviewed journals. The following exclusion criteria were applied: 1) Non-peer reviewed publications, e.g., reviews, dissertations, abstracts 2) Papers reporting on mixed-samples where type 1 diabetes participant data was not presented separately from other conditions; 3) Papers where study samples had a mix of spouses/partners and other close family members/friends (however, we included studies when investigators stated that ≥75% of the study population were intimate partners).

Data extraction and appraisal

All the authors contributed to data extraction using a quantitative or qualitative extraction tool, and 50% of the papers were double-extracted to validate the reliability of the extracted data. The Critical Appraisal Skills Program (CASP) (Public Health Resource Unit England, 2006) was used to assess the quality of the study designs and reporting validity of methodology. This was chosen because it enables quality assessment across study designs. The CASP tool for qualitative studies is composed of 10 questions and the CASP used for quantitative studies is composed by 12 questions. We present the proportion in which each of the 10 or 12 criteria are met, respectively, in the results column of table 1 e.g 6/12 criteria met. We did not exclude studies on the basis of quality assessment (Sandelowski et al., 1997).

Synthesizing the data

Extracted quantitative data were represented in a spreadsheet to capture variables investigated and their frequency. Variables were used in the synthesis where they were reported in a minimum of three different studies to represent perceived importance of outcomes by included study investigators. Main themes of qualitative papers were synthesized in a table of themes and illustrative quotes. To address each research question we identified supporting
data in any included study and used the qualitative and quantitative data alongside each other to develop the narrative findings for each question (Whittemore and Knafl, 2005).

Results

Reviewed studies

The search revealed 323 abstracts and titles of which 22 were eligible. A further 12 potential studies were identified in the Lister et al. (2013) and Rintala et al. (2013a) reviews and 6 potential studies identified from the reference lists of the included studies (n=40). Sixteen of these studies were excluded at full text review and a total of 24 studies have been included in the integrative review: 13 quantitative, 9 qualitative and 2 mixed methods. Studies were published between 1985 and 2017 and were in English. Study characteristics are presented in Table 1. The sample size of the studies ranged from 5 to 8,800 and included a total of 17,103 participants (16,083 PWD; 1,020 T1D partners). No studies reported sexual orientation of the couples. Participant gender was reported in 21 studies with approximately equal gender representation in both persons with diabetes (PWD) and T1D partners. [Insert Table 1]

Participants in the reviewed studies

The lowest mean age of study participants was 27 years (Gillibrand and Stevenson, 2007) and the highest was 54 years (Joensen et al., 2013), four studies did not report age. The lowest mean duration of diabetes reported in the studies was 15 years (Rajaram, 1997) and the highest 40 years (Ritholz et al., 2014), in six studies this was not reported. The lowest mean length of relationship reported in the studies was 7 years (Gillibrand and Stevenson, 2007) and the highest 27 years (Ritholz et al., 2014), 11 studies did not report length of relationship.

PROMs used to measure relationship satisfaction and psychological outcomes
Patient/Partner reported outcomes (PROs) data were extracted when used in the included studies. The PROs reported in the quantitative studies were: diabetes distress (n=4 using 4 different patient reported outcome measures (PROMs), depression (n=4 using 4 PROMs), anxiety (n=3 using 3 PROMs), relationship satisfaction (n=6 using 5 PROMs), psychological wellbeing (n=2 using 2 PROMs), quality of life (n=2 using 2 PROMs), life stress (n=1 using 1 PROMs), diabetes empowerment (n=2 using 2 PROMs), diabetes management (n=4 using 3 PROMs), diabetes specific social support (n=2 using 2 PROMs), partner’s support (n=1 using 1 PROMs) and general social support (n=1 using 1 PROMs) (Table 2). The data indicates several core PROs although even when limited PROMs are available, investigators choose across those available and there is no consistency of PROM across the included studies. [Insert Table 2]

The impact of being in an intimate relationship on diabetes outcomes and self-management

Living with type 1 diabetes in a relationship may be expected to lighten the load for PWD and indeed some research found that it did. Trief et al (2017) reported that having an engaged partner was associated with better glycemic control ($\beta = 0.13$, $p< 0.01$) and self-care such as concordance with general diet ($\beta = 0.22$, $p< 0.001$) and exercise ($\beta = 0.28$, $p< 0.01$) (Trief et al., 2017). T1D partners supported self-management behaviours by reminding the PWD of blood glucose measurements (Rintala, 2017), encouraging exercise and supporting healthy eating habits for the whole family (Rajaram, 1997; Rintala et al., 2013b). To further support self-management, T1D partners in some cases bought the insulin and blood glucose testing materials (Barnard et al., 2016; Rintala et al., 2013b). In contrast, T1D partners’
overprotective behavior was found to be associated with less frequent blood glucose measurement ($\beta = 0.14, p < 0.05$) (Trief et al., 2017).

A predominant impact of having an intimate relationship on PWD’s diabetes management was positive: partners assisted PWDs in preventing or managing hypoglycemic episodes (Barnard et al., 2016; Johnson and Melton, 2015; King et al., 2015; Lawton et al., 2014; Morris M et al., 2006; Rajaram, 1997; Rintala, 2017; Rintala et al., 2013b; Ritholz et al., 2014; Stödberg et al., 2007; Trief et al., 2013). T1D partners were in some cases better able to recognize the signs of low blood glucose levels than PWD thereby preventing a severe episode of hypoglycemia: “I do sometimes say to him do you think you should eat something? Of course he gets very cross then and denies (going hypoglycemic)” (Morris et al., 2006:197). In cases where the PWD had a severe episode of hypoglycemia the partner was able to prevent admission to hospital by calling for the ambulance (Trief et al., 2013).

In terms of psychological outcomes, PWD reported better emotional well-being when they felt diabetes was a shared burden (Johnson and Melton, 2015; Peyrot et al., 1988; Rajaram, 1997). For example, a woman with type 1 diabetes reported: ‘Yeah, I think it’s true that you’re not carrying it (diabetes) by yourself anymore. And I totally feel that. He’s (spouse) much more involved with it” (Ritholz et al., 2014: 52). However, the level and character of support needed to be negotiated between the couple otherwise it could be counterproductive for both diabetes self-management and the relationship (Peyrot et al., 1988; Rajaram, 1997; Ritholz et al., 2014). Conflicting views on support was illustrated by this couple: Spouse: “I get after him about checking his blood sugars. They would like him to check it four times per day. Sometimes he doesn’t check it one time per day. I tell him like his mother: ‘you’re thirty-one years old, you can check it.’ I have to sort of keep on him.

Patient: She’s always on me, especially if I look at anything sweet, trying to get me to eat right or something” (Peyrot et al., 1988: 371). Similarly, Wearden et al (Wearden et al.,
2000) found that PWD who had a partner with high levels of “Expressed Emotion” (Leff and Vaughn, 1985) had higher depression scores. Joensen and colleagues’ (Joensen et al., 2013) questionnaire study on 2,419 PWD showed that living without a partner (as compared to the PWD with a partner) was associated with lower quality of life, lower diabetes empowerment, and poorer glycaemic control in both men and women. Women appeared more susceptible to the negative impact of living without a partner in terms of psychosocial outcomes and were also less likely to eat a healthy diet ($\beta = -0.24$, $p < 0.05$), exercise ($\beta = -0.29$, $p < 0.05$), and take prescribed medication ($\beta = -0.09$, $p < 0.05$) than were women living with a partner. A larger proportion of men with type 1 diabetes living without a partner reported poor to fair general health, compared to men with type 1 diabetes living with a partner. Despite evidence from large samples, being married/partnered per se is not the key to higher degrees of diabetes self-management and may depend upon the quality of that relationship (Gillibrand and Stevenson, 2007; Trief et al., 2017).

The impact of type 1 diabetes on quality/satisfaction of a couple relationship

In an online survey of 317 T1D partners, their reported relationship quality was similar to that in the general population (Polonsky et al., 2016). Initially, understanding the condition and knowledge of the self-management required to live well with diabetes paved the way for partners to support the PWD (Johnson and Melton, 2015; Rajaram, 1997; Rintala, 2017). Lack of understanding of, and knowledge about, diabetes causes frustration both in the partners and the PWD (Morris et al., 2006) and consequently influences the relationship negatively (Rintala et al., 2013b; Stödberg et al., 2007). A mixed methods study of 20 T1D partners found that poor relationship satisfaction was associated with lower diabetes knowledge and greater perception of PWD’s secretiveness, illness difficulty and severity and discrepancies with patient attitudes (Peyrot et al., 1988). The quality and satisfaction of
couples’ relationships appears linked to how the spouse/partner is involved in diabetes management (Trief et al., 2013). Trief et al (2017) reported that greater relationship satisfaction ($\beta = -0.11$, $p< 0.001$), and having an engaged partner ($\beta = 0.13$, $p< 0.01$) was associated with better glycemic control and self-care. However Gillibrand and Stevenson (2007) found that higher relationship quality predicted better self-management in males only. The introduction of technology in diabetes care, such as the use of insulin pump and continuous glucose monitoring, has a positive influence on marital relationships (Ritholz et al., 2014; Trief et al., 2013). Although T1D partner involvement may vary, the significant anxiety (especially about hypoglycemia) and fear (especially about future complications) weighs on them and their relationships irrespective of level of engagement with it (Trief et al., 2013). In fact general marital conflict is significantly higher in couples where the PWD has reported a recent severe episode of hypoglycaemia (Gonder-Frederick et al., 1997).

T1D partners and PWD in some cases have opposing views in regard to level of partner involvement as illustrated by this partner “She doesn’t want to talk about her illness. It’s almost taboo. It’s not that it’s a secret, it’s not like that. It’s just that she feels it’s nothing to discuss. It’s just there. I’d like her to tell me more, but she doesn’t want to, I know that” (Stödberg et al., 2007: 218). In describing marital satisfaction, PWD emphasise the increased emotional distance, sexual intimacy problems, and difficult decisions about if, and when, to have children, caring for young children with the constant threat of hypoglycemia, and a general increase in relationship stress (Trief et al., 2013, 2017).

The impact of living with type 1 diabetes on T1D partners’ health and well-being?

Diabetes specific emotional impacts

Fear and distress related to hypoglycemia and complications are frequently experienced by T1D partners resulting in a caregiver emotional burden (Barnard et al., 2016; Johnson and
T1D partners regarded diabetes as a serious illness and described how the chronic illness had an influence on their daily lives (Stödberg et al., 2007; Trief et al., 2013). Specifically acute situations were described as traumatic (Johnson and Melton, 2015). T1D partners identified the prevention and management of hypoglycaemic events as especially distressing and frightening. T1D partners lived with an increased concern of upcoming events and felt they had to be constantly alert (Barnard et al., 2016; King et al., 2015; Lawton et al., 2014; Polonsky et al., 2016; Rintala et al., 2013b; Stödberg et al., 2007). Quick changing tempers, moodiness and irritability of PWD in connection with high and low blood sugars were described as further situations causing distress (Stödberg et al., 2007; Trief et al., 2013). Some T1D partners struggled to keep their own frustration and emotions in control when faced with these situations and felt emotionally vulnerable. In a few cases, additionally, T1D partners had to protect their own and their children’s physical safety during a hypoglycaemic event (Lawton et al., 2014).

The fear of hypoglycaemia, long-term complications and a shortened life expectancy of their partner made many T1D partners strive to be more involved in the direct diabetes care (Johnson and Melton, 2015; King et al., 2015; Rintala, 2017; Rintala et al., 2013b; Stödberg et al., 2007). But, being attentive to how their partner with diabetes was at any particular moment and feeling they have to take full responsibility made many T1D partners feel
exhausted (Lawton et al., 2014; Stödberg et al., 2007). T1D partners described significant worry, stress, and anxiety about hypoglycemia and frustration in trying to prevent or manage it (e.g., the need to carry snacks, to remind and check during lows, and prepare for potential emergencies) (Trief et al., 2013). In order to supervise and be prepared to provide this hands on treatment, T1D partners neglected or ignored their own health and social needs (Lawton et al., 2014) and they reported feeling uncertain, confused, lonely or even isolated (Morris M et al., 2006; Rintala et al., 2013b; Stödberg et al., 2007). T1D partners also reported that some days they felt like they were living on an emotional roller coaster, full of worries and fears whereas other days were peaceful (Rintala, 2017; Rintala et al., 2013b). Recent hypoglycaemia experience heighten levels of distress (Gonder-frederick et al., 1997). T1D partners with no recent severe hypo experiences reported lower scores on Hypoglycaemia Fear Survey – spouse version compared to partners with recent severe hypo experience (the mean of 32.1 (SD=11.2) vs 41.5 (SD=8.2)) on the behaviour sub-scale (the mean of 34.7 (SD=11.5) vs 46.3 (SD=11.7) on the worry sub-scale. Based on their survey of 317 US T1D partners, Polonsky and colleagues (2016) reported mean diabetes distress scores, measured using the Problem Areas in Diabetes scale (PAID-5) (McGuire et al., 2010), to be in the normal range (25.4 ±20.1), albeit with a wide standard deviation. The prevalence of elevated distress in T1D partners on the Diabetes Distress Scale for Spouses and Partners (DDS-SP) was of 38.8%. The prevalence of elevated distress was highest (64.4%) for the subscale measuring hypo-related distress. The sample had a high level of experience of hypos with 55.5% having assisted their PWD with a hypo in the previous 6 months which might account for the elevated hypo distress experienced by partners. The emotional strain on T1D partners extended to embarrassment for their partners, when having a hypo in public. T1D partners were worried the ‘odd’ behaviour may compromise their partners' personal and professional credibility and dignity (King et al., 2015; Morris et al., 2006).
General psychological morbidity

In contrast to diabetes-specific psychological distress, a survey of 74 T1D partners, found 87% completing the WHO-5 (de Wit et al., 2007) to rate their general quality of life as good over the previous 2 weeks (Barnard et al., 2016). Another population of 61 T1D partners were found to be within population-wide normal ranges on measures of depression, trait anxiety and relationship satisfaction irrespective of whether their PWD had a recent experience of a severe hypo requiring their own or another person’s intervention (Gonder-Frederick et al., 1997). The above-mentioned online survey of 317 T1D partners also assessed depression and general life stress (Polonsky et al., 2016). Although the raw data were not presented, assessments were found to be “within expected average ranges” for the measures used (Polonsky et al., 2016, p294). Whilst T1D partners report living with their own significant fear of hypoglycaemia, this fear does not appear to affect their general mental health but it was related to their diabetes-related distress.

Sleep reduction and interruption

T1D partners perceived diabetes as a burdensome illness, which affected their daily routine (e.g., eating, sleeping, and activities) (Rintala et al., 2013b; Trief et al., 2013). Sleep disturbances due to diabetes technology were reported by 59% of T1D partners (Barnard et al., 2016) study of which 12% reported waking at least 4 times each week. The main reason was Continuous Glucose Monitoring (CGM) alarms, with 23% of T1D partners reporting frequent false alarms. Partners of PWD with occurring nocturnal hypoglycaemic events suffered from poor and interrupted sleep due to regular night-time checks or awakening by various sounds (Barnard et al., 2016; Lawton et al., 2014; T. M. Rintala et al., 2013b). A significant severe hypo x partner gender interaction for sleep disturbance is reported (F=9.2, p=0.004) (Gonder-frederick et al., 1997) showing that male T1D partners, but not female T1D partners, reported more sleep disturbance.
Impact on activities of daily living

Many T1D partners felt restricted in their lives (Stödberg et al., 2007) and grieved over the loss of their ‘normal’ lives and their limited life choices (Johnson and Melton, 2015; Stödberg et al., 2007). Together with managing a scheduled treatment of diabetes and the feeling that they always have to plan ahead, partners felt a loss of spontaneity (Morris et al., 2006; Rintala, 2017; Rintala et al., 2013b). The picture was not all negative, some partners felt that they lived a normal live and that diabetes had become a part of it (Rintala et al., 2013b; Stödberg et al., 2007). Technology afforded both negative and positive impacts: an online survey of 74 partners found insulin pumps and CGMs to both have a greater detrimental impact on T1D partners compared to PWD (Barnard et al., 2016).

Greater diabetes-related distress was significantly associated with more frequent episodes of recent severe hypoglycemia, poorer PWD glycemic control (as perceived by the partner), greater involvement in their PWD’s diabetes management, lower levels of overall relationship satisfaction, and with the partner feeling less trusting and confident about his or her PWD’s physician (Polonsky et al., 2016). Less distressed T1D partners reported higher levels of at least moderate satisfaction with the self-care of their PWD (81%), their personal diabetes knowledge levels (71%) and the health care that their PWD received (59%) (Polonsky et al., 2016).

Discussion

Main findings

This integrative review has led to a better understanding of the value of maintaining resilient, good quality, intimate relationships for people with type 1 diabetes to optimise their physical and psychological health. It indicates the wellbeing risks to their partners associated with
providing intensified, ongoing, support. The evidence shows that PWD benefit from more optimised blood glucose levels and the engagement with more self-management behaviours. The opportunities for partners to maintain hypoglycaemic safety for PWD was significant and no evidence was identified that attempted to quantify this. There is a strong potential for diabetes to negatively affect the quality of, and satisfaction with, an intimate relationship. Whilst there was survey evidence that relationship satisfaction appeared in alignment with the general population, the qualitative evidence revealed the extent to which support can turn into vigilance. Partner surveillance for signs of hypoglycaemia and the consequent need to protect themselves, other family members and the PWD themselves legitimised their concerns. These concerns were not always welcomed by the PWD being monitored. T1D partners experience considerable amounts of broken sleep alongside the PWD and whilst general psychological health appears to be largely maintained, fear and distress surrounding hypoglycaemia was expressed as exhausting and overwhelming for a significant majority of partners. Technology to detect hypoglycaemia facilitated relationship harmony at the expense of disturbed sleep. The most assessed patient reported outcomes investigated personal psychological aspects, relationship satisfaction, quality of life, fear of hypoglycaemia, diabetes management and empowerment and social support. Thirty three PROMs were used, only the Summary of Diabetes Self-Care Activities Scale and the Dyadic Adjustment Scale were in more than one study.

Our findings concur with those of others in concluding that long-term conditions are challenging and demanding for the whole family (Berry et al., 2017; Kiecolt-Glaser and Wilson, 2017). The aggregated evidence in our study around preventing and managing hypoglycaemic events strengthen assumption made by Berry and Colleagues (2017) that diabetes is not interpreted as a shared challenge, but that PWD and their partners appraise the illness differently and consequently adapt different behavior strategies. As stated by an earlier
author, especially severe hypoglycaemia can be a source of fear and marital distress and that T1D partners identify experiencing a severe hypoglycaemic event as the scariest aspect of diabetes (King et al., 2015).

In both type 1 and type 2 diabetes, across 17 countries, the DAWN study (Kovacs Burns et al., 2013) demonstrated that family member burden is high and that many partners want to understand better how to support their PWD. Joensen et al. (2013) recommended that in clinical practice, systematically assessing cohabitation status and social support as a measure of patient resources may be important when planning patient care and support. People with type 1 diabetes living without a partner may need special attention and support and may benefit from the establishment of alternative social networks and specialized peer support networks. Partner elevated diabetes distress prevalence, at 38%, exceeds the prevalence of elevated diabetes distress in adults with type 2, and adults and adolescents with type 1 (Dennick et al., 2015; Hagger et al., 2016). As occurs with PWD (Sturt et al., 2015), high levels of distress may hamper partners in fully supporting the diabetes management needs of their PWD. With a newer understanding of the wellbeing needs of partners as well as PWD, together with recent evidence supporting interventions combining relationship and cognitive behavioral skills training for couples, this offers some direction for future interventional work to support both members of these relationships living with type 1 diabetes (Berry et al., 2017).

**Strengths and limitations of the methods**

We developed a search strategy based on those of earlier reviews (Lister et al., 2013; Rintala et al., 2013a) and amended it for our population of interest. Our protocol was published on Prospero. Only one member of the team was a native English speaker and this added both challenge and opportunity for conducting a mixed methods review. When we developed our
search strategy we were hoping to find intervention studies but did not. The subsequently published review across long-term conditions (Berry et al., 2017) validated our strategy as neither review identified any couples interventions in type 1 diabetes.

**Recommendations for research and practice**

Couples research is sensitive and maybe made more so with an additional daily participant in the form of type 1 diabetes. More longitudinal studies are needed to investigate the direction of the relation between quality of couples relationships and diabetes management; it is likely that research participation would be more welcome in the interventional space rather than observational. The findings indicate that we need to know more about what PWD and their partners would like to support resilience in their relationship with diabetes and for some relationship repair work. In clinical practice partner and co-habitation status is routinely collected. This information may be an important cue for Health Care Professionals for enquiring about the quality of support provided within that relationship and opportunities for offering support to partners and pwd to work together to manage diabetes. As pointed out by Berry et al. (2017) and Sturt et al. (2015), the vast majority of psychoeducational interventions in type 1 diabetes described in the literature focus exclusively on PWD with only few (e.g., Hermanns et al., 2013) offering very limited support for PWD family members. However, the importance of partner support for PWD is increasingly recognised and its enhancement has become one of the main goals of current psychoeducational interventions (e.g., Chatterjee et al., 2017; van Puffelen et al., 2014). In line with this emerging trend, our review brought to light a burning need to improve PWD partners’ empowerment through strengthening their knowledge about diabetes and its management and prevention of hypoglycaemic episodes with the aim to improve partner’s self-efficacy in supporting PWD.
Several themes of our qualitative analyses revealed the need to include in psychoeducational interventions a module focusing on helping patients and their partners to better manage psychological and behavioural symptoms of type 1 diabetes and improving their knowledge of how these symptoms may affect their day-to-day interactions and their relationship satisfaction. This would necessarily entail participation of both partners and application of approaches (such as specialised couple counselling) that recognise the importance of couple unit in diabetes management and the impact of intimate partners on each other.

Another emerging theme in our review showed the importance of addressing the needs of T1D partners to enhance their self-care skills related to their management of diabetes-related stress. In particular, we propose that psychoeducational intervention should help partners to tackle 3 issues: how to minimalize emotional impact of hypoglycaemic episodes or fear of hypoglycaemia; how to refrain from over-protective or over-caring behaviours; how to minimise disruptions to daily activities or night sleep (i.e., prevention and management of nocturnal hypoglycaemic events).

Our results also point to the necessity to extend instructions about diabetes technologies to T1D partners (beyond instructions offered to patients themselves). These instructions should inform on how to enhance benefits of diabetes technologies and how to minimise possible negative effects on daily life of patients and partners.

Finally, offering support of a trained medical professional as well as peer support to PWD partners would be beneficial, especially for those who recently experienced hypoglycaemic episodes of their partners.

Delivery systems of those psychoeducational interventions and support for patients and their partners might include face-to-face couple interventions in individual or group settings, with
some aspects of the intervention (e.g., educational modules) being delivered through digital platforms.

Data availability statements
Data generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.
References


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<th>Author Year Country</th>
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<th>Sample</th>
<th>Main results/themes and CASP quality assessments (QA)</th>
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<tr>
<td>Gillibrand and Stevenson (2007) UK</td>
<td>Cross-sectional</td>
<td>To explore the role of partner support in self-care for young people with type 1 diabetes.</td>
<td>Population: Couples  Sample size: 50  Gender (M/F): PWD 24/26  Age (mean, SD): PWD 26.6±4.08 years; T1D partners 28.1±3.43 years  Diabetes duration (mean, SD): ND  Length of relationship (mean, SD): 6.58 years ±3.15</td>
<td>For PWD, social support does not correlate with relationship quality or diabetes self-care behavior. However, for T1D partners, social support is highly correlated with their report of the person with diabetes' self-care behavior (r = 0.674, p &lt; 0.01). Relationship quality did not predict a better diabetes management unless person with diabetes was male (path value = 1.461). QA: 8/12</td>
</tr>
<tr>
<td>Gonder-Frederick et al. (1997) USA</td>
<td>Cross-sectional</td>
<td>To examine the impact of SH in PWD and their partners; To compare SH vs NoSH T1D partners on psychosocial status, marital conflict and diabetes measures.</td>
<td>Population: Couples  Sample size: 61  Gender (M/F): PWD 38/23  Age (mean, SD): PWD 39.3±8.3 years; T1D partners 40.3 ± 10.2 years  Diabetes duration (mean, SD): 20.3 ±9.3 years  Length of relationship (mean, SD): ND</td>
<td>T1D partners of SH patients in comparison to NoSH patients showed significantly more fear of hypoglycemia, marital conflict about diabetes management, and sleep disturbances (HFS behavior=41.5±8.2 vs 32.1±11.2; HFS worry= 46.3±11.7 vs 34.7 ± 11.5; DAS=22.3 ±5.7 vs 19.3 ± 5.7; Sleep disturbance survey=4.8 ± 3.4 vs 3.2 ± 3.0). In comparison to wives, husbands of SH patients reported more sleep disturbances (F= 9.2, P= 0.004). T1D partners showed on average greater fear of hypoglycemia than PWD (2.8 ± 1.9; t= 9.52, P= 0.0001). QA: 6/12</td>
</tr>
<tr>
<td>Hagedoorn et al. (2006) Netherlands</td>
<td>Longitudinal</td>
<td>To examine the role of overprotection by the partner in changes in patient self-management in the context of diabetes education.</td>
<td>Population: PWD  Sample size: 45  Gender (M/F): ND  Age (mean, SD): 42.2 ± 10.5 years  Diabetes duration (mean, SD): 18.5 ± 13.2 years  Length of relationship (mean, SD): ND</td>
<td>The increase in internal locus of control and decrease in HbA1c were both significantly less for female patients who perceived their partner to be rather overprotective than for female patients who did not perceive their partner to be overprotective. The more patients, both male and female, perceived their partner to be overprotective, the less their diabetes-related distress decreased. QA: 7/12</td>
</tr>
<tr>
<td>Imayama et al. (2011) Canada</td>
<td>Longitudinal</td>
<td>To examine the determinants of QOL in adults with type 1 diabetes.</td>
<td>Population: PWD  Sample size: 490  Gender (M/F): 230/260  Age (mean, SD): 51.5±16.4 years  Diabetes duration (mean, SD): 21.6±12.8 years  Length of relationship (mean, SD): ND</td>
<td>Having a partner (β= 0.11, p&lt; 0.05), high annual income (β= 0.16, p&lt; 0.01), and high activity trait (personality) score (β= 0.27, p &lt; 0.01) were significantly associated with higher life satisfaction QA: 8/12</td>
</tr>
<tr>
<td>Jensen (1985 b) Denmark</td>
<td>Longitudinal</td>
<td>To explore the emotional aspects in having a chronic disease seen from both PWD and T1D partners' point of view.</td>
<td>Population: Couples  Sample size: 51  Gender (M/F): PWD 23/28  Age (mean, SD): PWD M=43 years, F=41 years  Diabetes duration (mean, SD): M=17 years (8-37), F=21 years (7-38)  Length of relationship (mean, SD): M=13 years (1/4-28), F= 16 years (2-30)</td>
<td>Reactions of PWD compared to T1D partners: PWD had more fear and anxiety about the future than their spouses (57% vs 33% p &lt;0.05); PWD found daily life more troublesome and difficult than their partners did (40% vs 14% p &lt;0.05); PWD were more often tired than their partners (47% vs 25% p &lt;0.05); PWD feared more often to be left by their healthy partner (26% VS 8% p &lt;0.05); PWD more often had sexual concerns than their partners (39% vs 7% p &lt;0.05) and the finding was significant for males but not for females PWD. The answers from each couple illustrated their individual needs for a better communication and counselling. QA: 3/12</td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>Study Aim</td>
<td>Population</td>
<td>Sample Size</td>
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</tr>
<tr>
<td>Joensen et al. (2013)</td>
<td>Cross-sectional</td>
<td>To investigate the association between cohabitation status and psychological aspects of living with diabetes and to explore whether potential associations are mediated by social support.</td>
<td>PWD</td>
<td>2419</td>
</tr>
<tr>
<td>Jørgensen et al. (2003)</td>
<td>Cross-sectional</td>
<td>To compare patients’ and relatives’ assessments of rates of severe hypoglycemia and state of awareness and to explore the influence on involvement and concern of relatives.</td>
<td>PWD and their closest cohabitants</td>
<td>284</td>
</tr>
<tr>
<td>Nefs et al. (2015)</td>
<td>Cross-sectional</td>
<td>To examine sociodemographic, clinical and psychological factors associated with fear of hypoglycemia in adults with type 1 diabetes.</td>
<td>PWD</td>
<td>232</td>
</tr>
<tr>
<td>Polonsky et al. (2016)</td>
<td>Cross-sectional</td>
<td>To investigate the prevalence and sources of DD in T1D partners and to examine the associations of DD in this population with key demographic and contextual factors.</td>
<td>T1D partners</td>
<td>317</td>
</tr>
<tr>
<td>Rawshani et al. (2015)</td>
<td>Cohort study</td>
<td>To investigate how income, education, marital status, immigrant status, and sex relate to CVD and death in a population of type 1 diabetes patients.</td>
<td>PWD</td>
<td>24,947</td>
</tr>
<tr>
<td>Simmons et al. (2013)</td>
<td>Cross-sectional</td>
<td>To identify characteristics and diabetes management techniques in adults with type 1 diabetes, differentiating those under excellent glycemic control from those with poorer control.</td>
<td>PWD</td>
<td>1804</td>
</tr>
<tr>
<td>Trief et al. (2017)</td>
<td>Cross-sectional</td>
<td>To examine the association of relationship status with diabetes outcomes; To examine in those who were married/partnered, the</td>
<td>PWD</td>
<td>1660</td>
</tr>
</tbody>
</table>
Table 1. Scientific literature on couples living with type 1 diabetes, from 1980 to 2017: n.24 studies included (n.13 quantitative, n.9 qualitative, n.2 mixed methodology).

<table>
<thead>
<tr>
<th>Study Authors</th>
<th>Year(s)</th>
<th>Design</th>
<th>Population</th>
<th>Methodology</th>
<th>Population characteristics</th>
<th>Findings/Implications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wearden et al. (2000, 2006)</td>
<td>UK</td>
<td>Cross-sectional</td>
<td>Couples</td>
<td>Quantitative</td>
<td>Sample size: 60, Gender (M/F): 30/30, Age (mean, SD): T1D partners 42.7± 11.5 years, PWD 42.3± 10.9 years, Diabetes duration (mean, SD): 19.9± 9.9 years, Length of relationship (mean, SD): 17.8 ±12.0 years</td>
<td>High-EE partners were more anxious than low-EE partners, and attributed proportionally more negative diabetes and non-diabetes events to factors controlled by the PWD.</td>
</tr>
<tr>
<td>Johnson and Melton (2015)</td>
<td>USA</td>
<td>Interviews</td>
<td>T1D partners</td>
<td>Qualitative</td>
<td>Sample size: 19, Gender (M/F): 11/8, Age (mean, SD): 35 years, Diabetes duration (mean, SD): 17.9 years, Length of relationship (mean, SD): 9.4 years</td>
<td>Emotional strain of loving a person with diabetes; Coping strategies.</td>
</tr>
<tr>
<td>King et al. (2015)</td>
<td>Australia</td>
<td>Interviews</td>
<td>T1D partners</td>
<td>Qualitative</td>
<td>Sample size: 5, Gender (M/F): 2/3, Age (mean, SD): 42.4 years (34-57), Diabetes duration (mean, SD): ND, Length of relationship (mean, SD): 16.6 years (6-33)</td>
<td>Managing disruption.</td>
</tr>
<tr>
<td>Lawton et al. (2014)</td>
<td>UK</td>
<td>Interviews</td>
<td>T1D partners</td>
<td>Qualitative</td>
<td>Sample size: 18, Gender (M/F): 6/12, Age (mean, SD): 51.4±11.2 years, Diabetes duration (mean, SD): ND, Length of relationship (mean, SD): 24.7±11.1 years</td>
<td>Monitoring and Supervision: Restricting One’s Own Lifestyle; Dealing with hypoglycaemia: Fear and worries about safety; Physical and emotional impact of caring for a person with HU: Exhaustion, Neglecting One’s Own Health and Social Needs, Resentment and Ambivalence; Education, information and support needs.</td>
</tr>
<tr>
<td>Morris et al. (2006)</td>
<td>UK</td>
<td>Interviews</td>
<td>T1D partners</td>
<td>Qualitative</td>
<td>Sample size: 15, Gender (M/F): ND, Age (mean, SD): range 37-71 years, Diabetes duration (mean, SD): range 7-41 years, Length of relationship (mean, SD): range 4-50 years</td>
<td>Emotional issues; Control; Knowledge.</td>
</tr>
<tr>
<td>Rajaram (1997)</td>
<td>USA</td>
<td>Interviews</td>
<td>PWD</td>
<td>Qualitative</td>
<td>Sample size: 23, Gender (M/F): 12/11, Age (mean, SD): PWD 36±7.26, T1D partners 32 ±5.17</td>
<td>Patient's experience of hypoglycaemia; Spouse's reaction to the illness.</td>
</tr>
</tbody>
</table>
Table 1. Scientific literature on couples living with type 1 diabetes, from 1980 to 2017: n.24 studies included (n.13 quantitative, n.9 qualitative, n.2 mixed methodology).

<table>
<thead>
<tr>
<th>Study</th>
<th>Year(s)</th>
<th>Country</th>
<th>Study Design</th>
<th>Population</th>
<th>Sample size</th>
<th>Gender (M/F)</th>
<th>Age (mean, SD)</th>
<th>Diabetes duration (mean, SD)</th>
<th>Length of relationship (mean, SD)</th>
<th>Methods and Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rintala et al.</td>
<td>2013-2017</td>
<td>Finland</td>
<td>Interviews</td>
<td>Couples</td>
<td>PWD 19, T1D partners 16</td>
<td>M/F: 1/18</td>
<td>Young male 21±12, young female 18±84</td>
<td>28-65 years</td>
<td>2-58 years</td>
<td>ND</td>
</tr>
<tr>
<td>Rintala et al.</td>
<td>2013-2017</td>
<td>Finland</td>
<td>Focus groups</td>
<td>Couples</td>
<td>PWD 20, T1D partners 14</td>
<td>M/F: 5/6</td>
<td>Young male 21±12, young female 18±84</td>
<td>7/10</td>
<td>Continuous glucose monitoring and diabetes management: coping with hypoglycaemia; Continuous glucose monitoring and the marital relationship. QA: 9/10</td>
<td></td>
</tr>
<tr>
<td>Stodberg et al.</td>
<td>2007</td>
<td>Sweden</td>
<td>Interviews</td>
<td>T1D partners</td>
<td>PWD 11, T1D partners 9/5</td>
<td>Female: 5/6</td>
<td>T1D partners 45.6±13.5</td>
<td>Range 7 months-37 years</td>
<td>Range 4-36 years</td>
<td>Nocturnal BG testing; Stress on the relationship; Impact of diabetes on the relationship; Understanding the impact of hypoglycaemia; Stress of potential complications; Benefits of technology. QA: 5/10</td>
</tr>
<tr>
<td>Frei et al.</td>
<td>2016</td>
<td>USA</td>
<td>Focus groups</td>
<td>Couples</td>
<td>PWD, T1D partners 16, 14</td>
<td>M/F: 2/3</td>
<td>T1D partners 45.6±13.5</td>
<td>Range 7 months-37 years</td>
<td>Range 4-36 years</td>
<td>Being involved in the management of diabetes; Preventing hypoglycaemic events; Team work; Providing moral support.</td>
</tr>
<tr>
<td>Barnard et al.</td>
<td>2016</td>
<td>USA</td>
<td>Survey and open-ended questions</td>
<td>Couples</td>
<td>PWD, T1D partners 74</td>
<td>M/F: 42/32</td>
<td>T1D partners 45.6±13.5</td>
<td>Range 7 months-37 years</td>
<td>Range 4-36 years</td>
<td>Nocturnal BG testing; Stress on the relationship; Impact of diabetes on the relationship; Understanding the impact of hypoglycaemia; Stress of potential complications; Benefits of technology. QA: 5/10</td>
</tr>
<tr>
<td>Peyrot et al.</td>
<td>1988</td>
<td>USA</td>
<td>Survey and interview</td>
<td>Couples</td>
<td>Couples</td>
<td>M/F: 20</td>
<td>Couples</td>
<td>Range 7 months-37 years</td>
<td>Range 4-36 years</td>
<td>Nocturnal BG testing; Stress on the relationship; Impact of diabetes on the relationship; Understanding the impact of hypoglycaemia; Stress of potential complications; Benefits of technology. QA: 5/10</td>
</tr>
</tbody>
</table>
Table 1. Scientific literature on couples living with type 1 diabetes, from 1980 to 2017: n.24 studies included (n.13 quantitative, n.9 qualitative, n.2 mixed methodology).

<table>
<thead>
<tr>
<th>Gender (M/F)</th>
<th>Age (mean, SD) PWD 41.7 years; T1D partners 42.8 years</th>
<th>Diabetes duration (mean, SD): ND</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Length of relationship (mean, SD): 13.5 years</td>
<td>Qualitative QA: 7/10</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Spouses to insulin-treated diabetes mellitus.</th>
</tr>
</thead>
</table>

| Gender (M/F): 42/32 |
| Age (mean, SD): PWD 41.7 years; T1D partners 42.8 years |
| Diabetes duration (mean, SD): ND |
| Length of relationship (mean, SD): 13.5 years |

Abbreviations

- CVD: Cardio vascular disease;
- Couples: PWD and their T1D partners;
- DD: Diabetes Distress;
- EE: Expressed Emotion;
- HRQL: Health-Related Quality of Life;
- HU: Hypoglycaemia Unawareness;
- NA: not available data;
- ND: not detected;
- NoSH: Patients who have not experienced recent severe hypoglycaemia;
- PWD: person with type 1 diabetes;
- QOL: Quality Of Life/life satisfaction;
- RS: Relationship Satisfaction;
- SH: Patients who have experienced recent severe hypoglycaemia;
- T1D: type 1 diabetes;
- T1D partner: partner/spouse of the person that has type 1 diabetes;
**Table 2. Patient/Partner Reported Outcomes Measures (PROMs) investigated in quantitative studies**

<table>
<thead>
<tr>
<th>Variable investigated</th>
<th>PROMs used to investigate</th>
<th>Papers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Diabetes specific</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes Distress</td>
<td>Diabetes Distress Scale (DDS)</td>
<td>Joensen et al. 2013</td>
</tr>
<tr>
<td></td>
<td>Diabetes Distress Scale for Spouses (DDS-SP)</td>
<td>Polonsky et al. 2016</td>
</tr>
<tr>
<td></td>
<td>Problem Areas In Diabetes (PAID)</td>
<td>Hagedoorn et al. 2006</td>
</tr>
<tr>
<td></td>
<td>Diabetes Empowerment Scale-Short Form (DES-SF)</td>
<td>Joensen et al. 2013</td>
</tr>
<tr>
<td></td>
<td>Summary of Diabetes Self-Care Activities Scale (SDSCA)</td>
<td>Gillibrand and Stevenson 2007; Trief et al. 2017</td>
</tr>
<tr>
<td></td>
<td>Summary of Diabetes Self-Care Activities Scale Revised Version (SDSCA-R)</td>
<td>Joensen et al. 2013</td>
</tr>
<tr>
<td>Diabetes specific social support</td>
<td>Diabetes Care Profile (DCP)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Diabetes Family Behavior Checklist (DFBC)</td>
<td></td>
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<tr>
<td>Fear of Hypoglycaemia</td>
<td>Hypoglycaemia Fear Survey (HFS)</td>
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<tr>
<td></td>
<td>Hypoglycaemia Fear Survey – Second Version Worry subscale (HFS-II-W)</td>
<td></td>
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<tr>
<td><strong>Generic</strong></td>
<td></td>
<td></td>
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<tr>
<td>Anxiety</td>
<td>Generalized Anxiety Disorder 7–item scale (GAD-7)</td>
<td>Nefs et al. 2015</td>
</tr>
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<td></td>
<td>Hospital Anxiety and Depression Scale (HAD)</td>
<td>Wearden et al. 2000; 2006</td>
</tr>
<tr>
<td></td>
<td>Spielberg Trait Anxiety Inventory</td>
<td>Gonder-Frederick et al. 1997</td>
</tr>
<tr>
<td>Depression</td>
<td>Beck Depression Inventory (BDI)</td>
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<tr>
<td></td>
<td>Hospital Anxiety and Depression Scale (HAD)</td>
<td>Gonder-Friederick et al. 1997</td>
</tr>
<tr>
<td></td>
<td>Patient Health Questionnaire-8 items (PHQ-8)</td>
<td>Wearden et al. 2000; 2006</td>
</tr>
<tr>
<td></td>
<td>Patient Health Questionnaire-9 items (PHQ-9)</td>
<td>Polonsky et al. 2016</td>
</tr>
<tr>
<td>General social support</td>
<td>Items from the Danish Population Health Profile</td>
<td></td>
</tr>
<tr>
<td>Internal locus of control</td>
<td>Multidimensional Health Locus of Control (MHLC) Form C</td>
<td></td>
</tr>
<tr>
<td>Life stress</td>
<td>General Life Stress</td>
<td></td>
</tr>
<tr>
<td>Partner's support</td>
<td>Active Engagement (AE), Protective-Buffering (PB), Over-Protection (OP): APO measures</td>
<td>Trief et al. 2017</td>
</tr>
<tr>
<td>Psychological well-being</td>
<td>General Health Questionnaire-28 items (GHQ-28)</td>
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<td>World Health Organization Well-Being Index (WHO-5)</td>
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<tr>
<td>Quality of life</td>
<td>Satisfaction with Life Scale-5 items</td>
<td></td>
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<td></td>
<td>Mental Component score of the 12-Item Short Form Health Survey (MCS of the SF12)</td>
<td></td>
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<tr>
<td>Relationship satisfaction</td>
<td>Dyadic Adjustment Scale (DAS)</td>
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<tr>
<td></td>
<td>Revised Dyadic Adjustment Scale (RSDAS)</td>
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<td></td>
<td>General Relationship Satisfaction-3 items</td>
<td></td>
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<td></td>
<td>Marital Satisfaction Instrument (MARSAT)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Relationship Assessment Scale (RAS)</td>
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<td></td>
<td>Imayama et al. 2011</td>
<td></td>
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<tr>
<td></td>
<td>Joensen et al. 2013</td>
<td></td>
</tr>
</tbody>
</table>
Records identified through database searching n = 323 (CINHAL n= 147; PubMed n= 94; MEDLINE n= 60; PsychINFO n= 22)

Records titles screened after duplicates removed (n = 265)

Abstracts screened (n = 40)

Full-text articles assessed for eligibility (n = 22)

Full-text articles excluded with reasons (n =16):
Duplicate study sample= 2;
No information on relationship quality and/or partner’s health and well-being=8;
Case-study=1;
Mixed diabetes type results=2;
Family members=1;
Engaged couples=1;
Review=1.

Other records included n=18
(12 records included from Lister et al (2013) and Rintala et al (2013) reviews; 6 records included from citations)

Included

Eligibility

Screening

Identification


For more information, visit www.prisma-statement.org.