

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

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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.

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3 **Running head:** Couples living with type 1 diabetes
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12 **Abstract**
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16 diabetes (PWD) and partners (T1D partners) have not been investigated. Integrative review
17 methods evaluated the evidence. From 323 titles we included 24 studies involving 16,083 PWD
18 and 1,020 T1D partners. Studies were quantitative (n=13), qualitative (n=9) and mixed methods
19 (n=2). Maintaining resilient, good quality, intimate relationships optimises physical and
20 psychological outcomes for PWD. Partners experience disturbed sleep and whilst general
21 psychological health is maintained, distress surrounding hypoglycemia is overwhelming for over
22 a third of partners. Nurturing quality relationships could reap significant health benefits.
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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

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3 impact of type 1 diabetes on those with the condition is well-researched, but the impact of the
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5 diabetes on the couple unit or the impact on the intimate partner remains an under-studied topic.
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7 Only two previous reviews have studied this in people with diabetes (Lister et al., 2013; Rintala
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9 et al., 2013a). In these reviews less than a quarter of included studies were related to type 1
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11 diabetes. The analyses took a clinical and social science perspective and did not consider
12
13 findings related to type 1 diabetes populations separately. For couples living with type 1
14
15 diabetes, the strain on intimate relationships afforded in everyday life, is stretched with
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17 experiences of hypo- and hyperglycaemia. The aim of this study was to review the evidence to
18
19 better understand the impact of type 1 diabetes on relationships and vice versa, and to better
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21 understand the impact on the health and wellbeing of partners' of adults with type 1 diabetes
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23 (T1D partners), and, ultimately, to inform the development of couple interventions.
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31 **Methods**

32 *Research Design*

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

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55 Our four apriori research questions are:
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3 Q1: What is the impact of being in an intimate relationship on diabetes outcomes and self-
4 management?
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8 Q2. What is the impact of type 1 diabetes on the quality/satisfaction of a couple relationship?
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11 Q3. What is the impact of living with type 1 diabetes on T1D partners' health and well-being?
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14 Q4. Which patient reported outcome measures (PROMs) have been used to assess relationship
15 quality and psychological outcomes?
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19 The review was registered on PROSPERO (Registration number: CRD42018093796) (PNM
20 Research Ethics Subcommittee of KCL-Study Reference: HR-17/18-5478).
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23 24 25 *Search strategy and screening* 26

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28 A systematic search was conducted using PubMed, MEDLINE, CINAHL and PsychINFO
29 electronic databases combining keywords from the two previous literature reviews (Lister et al.,
30 2013; Rintala et al., 2013a). Keywords were: type 1 diabetes + couple, spouse, partner, husband,
31 wife, marriage, dyad, dyadic, significant other, daily activities, everyday living, self-
32 management, self-care (see Appendix 1 for search strategy). The search dates followed
33 immediately from the end date of the seminal Lister et al (2013) review from 01.01.2011 and
34 concluded on 31.12.17. Studies included in the Lister et al. (2013) and Rintala et al. (2013a)
35 reviews were searched for relevance along with the reference lists of final included studies.
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39 Where data from a single study population were published in multiple manuscripts, these were
40 combined so we report the data at the sample-level rather than publication-level. The flow
41 diagram of study selection and inclusion is presented in Figure 1. [Insert Figure 1]
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46 47 48 49 50 51 52 53 54 *Inclusion/Exclusion criteria* 55

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3 The following inclusion criteria were applied: 1) any study design reporting data from/on adults
4 18 years or older with type 1 diabetes AND/OR their partner/spouse; 2) any of the following
5 outcomes were studied: a) relationship quality/satisfaction b) partner/spouse's health and
6 wellbeing c) relationship status and diabetes outcomes; 3) papers were published in scientific
7 peer-reviewed journals. The following exclusion criteria were applied: 1) Non-peer reviewed
8 publications, e.g., reviews, dissertations, abstracts 2) Papers reporting on mixed-samples where
9 type 1 diabetes participant data was not presented separately from other conditions; 3) Papers
10 where study samples had a mix of spouses/partners and other close family members/friends
11 (however, we included studies when investigators stated that $\geq 75\%$ of the study population were
12 intimate partners).

23 24 25 26 27 *Data extraction and appraisal*

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29 All the authors contributed to data extraction using a quantitative or qualitative extraction tool,
30 and 50% of the papers were double-extracted to validate the reliability of the extracted data. The
31 Critical Appraisal Skills Program (CASP) (Public Health Resource Unit England, 2006) was
32 used to assess the quality of the study designs and reporting validity of methodology. This was
33 chosen because it enables quality assessment across study designs. The CASP tool for qualitative
34 studies is composed of 10 questions and the CASP used for quantitative studies is composed by
35 12 questions. We present the proportion in which each of the 10 or 12 criteria are met,
36 respectively, in the results column of table 1 e.g 6/12 criteria met. We did not exclude studies on
37 the basis of quality assessment (Sandelowski et al., 1997).

38 39 40 41 42 43 44 45 46 47 48 49 50 51 *Synthesizing the data*

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3 Extracted quantitative data were represented in a spreadsheet to capture variables investigated
4 and their frequency. Variables were used in the synthesis where they were reported in a
5
6 minimum of three different studies to represent perceived importance of outcomes by included
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8 study investigators. Main themes of qualitative papers were synthesized in a table of themes and
9
10 illustrative quotes. To address each research question we identified supporting data in any
11
12 included study and used the qualitative and quantitative data alongside each other to develop the
13
14 narrative findings for each question (Whittemore and Knafl, 2005).
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19 20 **Results**

21 22 *Reviewed studies*

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25 The search revealed 323 abstracts and titles of which 22 were eligible. A further 12 potential
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27 studies were identified in the Lister et al. (2013) and Rintala et al. (2013a) reviews and 6
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29 potential studies identified from the reference lists of the included studies (n=40). Sixteen of
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31 these studies were excluded at full text review and a total of 24 studies have been included in the
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33 integrative review: 13 quantitative, 9 qualitative and 2 mixed methods. Studies were published
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35 between 1985 and 2017 and were in English. Study characteristics are presented in Table 1. The
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37 sample size of the studies ranged from 5 to 8,800 and included a total of 17,103 participants
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39 (16,083 PWD; 1,020 T1D partners). No studies reported sexual orientation of the couples.
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41 Participant gender was reported in 21 studies with approximately equal gender representation in
42
43 both persons with diabetes (PWD) and T1D partners. [Insert Table 1]
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49 50 *Participants in the reviewed studies*

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52 The lowest mean age of study participants was 27 years (Gillibrand and Stevenson, 2007) and
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54 the highest was 54 years (Joensen et al., 2013), four studies did not report age. The lowest mean
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3 duration of diabetes reported in the studies was 15 years (Rajaram, 1997) and the highest 40
4 years (Ritholz et al., 2014), in six studies this was not reported. The lowest mean length of
5 relationship reported in the studies was 7 years (Gillibrand and Stevenson, 2007) and the highest
6 27 years (Ritholz et al., 2014), 11 studies did not report length of relationship.
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10 11 12 *PROMs used to measure relationship satisfaction and psychological outcomes*

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16 Patient/Partner reported outcomes (PROs) data were extracted when used in the included studies.
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18 The PROs reported in the quantitative studies were: diabetes distress (n=4 using 4 different
19 patient reported outcome measures (PROMs), depression (n=4 using 4 PROMs), anxiety (n=3
20 using 3 PROMs), relationship satisfaction (n=6 using 5 PROMs), psychological wellbeing (n=2
21 using 2 PROMs), quality of life (n=2 using 2 PROMs), life stress (n=1 using 1 PROMs), diabetes
22 empowerment (n=2 using 2 PROMs), diabetes management (n=4 using 3 PROMs), diabetes
23 specific social support (n=2 using 2 PROMs), partner's support (n=1 using 1 PROMs) and
24 general social support (n=1 using 1 PROMs) (Table 2). The data indicates several core PROs
25 although even when limited PROMs are available, investigators choose across those available
26 and there is no consistency of PROM across the included studies. [Insert Table 2]
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43 **The impact of being in an intimate relationship on diabetes outcomes and self-management**

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45 Living with type 1 diabetes in a relationship may be expected to lighten the load for PWD and
46 indeed some research found that it did. Trief et al (2017) reported that having an engaged partner
47 was associated with better glycemic control ($\beta = 0.13, p < 0.01$) and self-care such as
48 concordance with general diet ($\beta = 0.22, p < 0.001$) and exercise ($\beta = 0.28, p < 0.01$) (Trief et al.,
49 2017). T1D partners supported self-management behaviours by reminding the PWD of blood
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3 glucose measurements (Rintala, 2017), encouraging exercise and supporting healthy eating
4 habits for the whole family (Rajaram, 1997; Rintala et al., 2013b). To further support self-
5 management, T1D partners in some cases bought the insulin and blood glucose testing materials
6 (Barnard et al., 2016; Rintala et al., 2013b). In contrast, T1D partners' overprotective behavior
7 was found to be associated with less frequent blood glucose measurement ($\beta = 0.14, p < 0.05$)
8 (Trief et al., 2017).
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11 A predominant impact of having an intimate relationship on PWD's diabetes management was
12 positive: partners assisted PWDs in preventing or managing hypoglycemic episodes (Barnard et
13 al., 2016; Johnson and Melton, 2015; King et al., 2015; Lawton et al., 2014; Morris M et al.,
14 2006; Rajaram, 1997; Rintala, 2017; Rintala et al., 2013b; Ritholz et al., 2014; Stöddberg et al.,
15 2007; Trief et al., 2013). T1D partners were in some cases better able to recognize the signs of
16 low blood glucose levels than PWD thereby preventing a severe episode of hypoglycemia: "*I do*
17 *sometimes say to him do you think you should eat something? Of course he gets very cross then*
18 *and denies (going hypoglycemic)*" (Morris et al., 2006:197). In cases where the PWD had a
19 severe episode of hypoglycemia the partner was able to prevent admission to hospital by calling
20 for the ambulance (Trief et al., 2013).
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24 In terms of psychological outcomes, PWD reported better emotional well-being when they felt
25 diabetes was a shared burden (Johnson and Melton, 2015; Peyrot et al., 1988; Rajaram, 1997).
26 For example, a woman with type 1 diabetes reported: "*Yeah, I think it's true that you're not*
27 *carrying it (diabetes) by yourself anymore. And I totally feel that. He's (spouse) much more*
28 *involved with it*" (Ritholz et al., 2014: 52). However, the level and character of support needed
29 to be negotiated between the couple otherwise it could be counterproductive for both diabetes
30 self-management and the relationship (Peyrot et al., 1988; Rajaram, 1997; Ritholz et al., 2014).
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3 Conflicting views on support was illustrated by this couple: *Spouse: "I get after him about*
4 *checking his blood sugars. They would like him to check it four times per day. Sometimes he*
5 *doesn't check it one time per day. I tell him like his mother: 'you're thirty-one years old, you can*
6 *check it.' I have to sort of keep on him.*

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12 *Patient: She's always on me, especially if I look at anything sweet, trying to get me to eat right*
13 *or something"* (Peyrot et al., 1988: 371). Similarly, Wearden et al (Wearden et al., 2000) found
14 that PWD who had a partner with high levels of "Expressed Emotion" (Leff and Vaughn, 1985)
15 had higher depression scores.
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21 Joensen and colleagues' (Joensen et al., 2013) questionnaire study on 2,419 PWD showed that
22 living without a partner (as compared to the PWD with a partner) was associated with lower
23 quality of life, lower diabetes empowerment, and poorer glycaemic control in both men and
24 women. Women appeared more susceptible to the negative impact of living without a partner in
25 terms of psychosocial outcomes and were also less likely to eat a healthy diet ($\beta = -0.24, p <$
26 0.05), exercise ($\beta = -0.29, p < 0.05$), and take prescribed medication ($\beta = -0.09, p < 0.05$) than
27 were women living with a partner. A larger proportion of men with type 1 diabetes living
28 without a partner reported poor to fair general health, compared to men with type 1 diabetes
29 living with a partner. Despite evidence from large samples, being married/partnered per se is not
30 the key to higher degrees of diabetes self-management and may depend upon the quality of that
31 relationship (Gillibrand and Stevenson, 2007; Trief et al., 2017).
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48 **The impact of type 1 diabetes on quality/satisfaction of a couple relationship**

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51 In an online survey of 317 T1D partners, their reported relationship quality was similar to that in
52 the general population (Polonsky et al., 2016). Initially, understanding the condition and
53 knowledge of the self-management required to live well with diabetes paved the way for partners
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3 to support the PWD (Johnson and Melton, 2015; Rajaram, 1997; Rintala, 2017). Lack of
4
5 understanding of, and knowledge about, diabetes causes frustration both in the partners and the
6
7 PWD (Morris et al., 2006) and consequently influences the relationship negatively (Rintala et al.,
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9 2013b; Stödberg et al., 2007). A mixed methods study of 20 T1D partners found that poor
10
11 relationship satisfaction was associated with lower diabetes knowledge and greater perception of
12
13 PWD's secretiveness, illness difficulty and severity and discrepancies with patient attitudes
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15 (Peyrot et al., 1988). The quality and satisfaction of couples' relationships appears linked to how
16
17 the spouse/partner is involved in diabetes management (Trief et al., 2013). Trief et al (2017)
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19 reported that greater relationship satisfaction ($\beta = -0.11$, $p < 0.001$), and having an engaged
20
21 partner ($\beta = 0.13$, $p < 0.01$) was associated with better glycemic control and self-care. However
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23 Gillibrand and Stevenson (2007) found that higher relationship quality predicted better self-
24
25 management in males only. The introduction of technology in diabetes care, such as the use of
26
27 insulin pump and continuous glucose monitoring, has a positive influence on marital
28
29 relationships (Ritholz et al., 2014; Trief et al., 2013). Although T1D partner involvement may
30
31 vary, the significant anxiety (especially about hypoglycemia) and fear (especially about future
32
33 complications) weighs on them and their relationships irrespective of level of engagement with it
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35 (Trief et al., 2013). In fact general marital conflict is significantly higher in couples where the
36
37 PWD has reported a recent severe episode of hypoglycaemia (Gonder-Frederick et al., 1997).
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42 T1D partners and PWD in some cases have opposing views in regard to level of partner
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44 involvement as illustrated by this partner *"She doesn't want to talk about her illness. It's almost
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46 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
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48 just there. I'd like her to tell me more, but she doesn't want to, I know that"* (Stödberg et al.,
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50 2007: 218). In describing marital satisfaction, PWD emphasise the increased emotional distance,
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3 sexual intimacy problems, and difficult decisions about if, and when, to have children, caring for
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5 young children with the constant threat of hypoglycemia, and a general increase in relationship
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7 stress (Trief et al., 2013, 2017).
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12 **The impact of living with type 1 diabetes on T1D partners' health and well-being?**

14 *Diabetes specific emotional impacts*

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18 Fear and distress related to hypoglycemia and complications are frequently experienced by T1D
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20 partners resulting in a caregiver emotional burden (Barnard et al., 2016; Johnson and Melton,
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22 2015; King et al., 2015; Lawton et al., 2014; Morris M et al., 2006; Polonsky et al., 2016;
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24 Rajaram, 1997; Rintala, 2017; Rintala et al., 2013b; Stödberg et al., 2007; Trief et al., 2013). *“It*
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26 *really bothers me to know he's home alone with M (two-year-old son) wondering if he's . . .*
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28 *wondering what would happen if he had a low blood sugar especially when M starts walking and*
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30 *gets a little bit older to where if K (husband) is sleeping, cause that's usually when his insulin*
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32 *reaction is the worst, when he's sleeping, and if M would go in there and jump in bed with him or*
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34 *something. What would K do? He gets really, he gets really combative. That scares me, scares*
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36 *me more for M than for me. . . .”* (Rajaram, 1997: 289).
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42 T1D partners regarded diabetes as a serious illness and described how the chronic illness had an
43
44 influence on their daily lives (Stödberg et al., 2007; Trief et al., 2013). Specifically acute situations
45
46 were described as traumatic (Johnson and Melton, 2015). T1D partners identified the prevention
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48 and management of hypoglycaemic events as especially distressing and frightening. T1D partners
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50 lived with an increased concern of upcoming events and felt they had to be constantly alert
51
52 (Barnard et al., 2016; King et al., 2015; Lawton et al., 2014; Polonsky et al., 2016; Rintala et al.,
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54 2013b; Stödberg et al., 2007). Quick changing tempers, moodiness and irritability of PWD in
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3 connection with high and low blood sugars were described as further situations causing distress
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5 (Stödberg et al., 2007; Trief et al., 2013). Some T1D partners struggled to keep their own
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7 frustration and emotions in control when faced with these situations and felt emotionally
8
9 vulnerable. In a few cases, additionally, T1D partners had to protect their own and their children's
10
11 physical safety during a hypoglycaemic event (Lawton et al., 2014).
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15 The fear of hypoglycaemia, long-term complications and a shortened life expectancy of their
16
17 partner made many T1D partners strive to be more involved in the direct diabetes care (Johnson
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19 and Melton, 2015; King et al., 2015; Rintala, 2017; Rintala et al., 2013b; Stödberg et al., 2007).
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21 But, being attentive to how their partner with diabetes was at any particular moment and feeling
22
23 they have to take full responsibility made many T1D partners feel exhausted (Lawton et al.,
24
25 2014; Stödberg et al., 2007). T1D partners described significant worry, stress, and anxiety about
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27 hypoglycemia and frustration in trying to prevent or manage it (e.g., the need to carry snacks, to
28
29 remind and check during lows, and prepare for potential emergencies) (Trief et al., 2013). In
30
31 order to supervise and be prepared to provide this hands on treatment, T1D partners neglected or
32
33 ignored their own health and social needs (Lawton et al., 2014) and they reported feeling
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35 uncertain, confused, lonely or even isolated (Morris M et al., 2006; Rintala et al., 2013b;
36
37 Stödberg et al., 2007). T1D partners also reported that some days they felt like they were living
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39 on an emotional roller coaster, full of worries and fears whereas other days were peaceful
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41 (Rintala, 2017; Rintala et al., 2013b). Recent hypoglycaemia experience heighten levels of
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43 distress (Gonder-frederick et al., 1997). T1D partners with no recent severe hypo experiences
44
45 reported lower scores on Hypoglycaemia Fear Survey – spouse version compared to partners
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47 with recent severe hypo experience (the mean of 32.1 ($SD=11.2$) vs 41.5 ($SD=8.2$)) on the
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49 behaviour sub-scale (the mean of 34.7 ($SD=11.5$) vs 46.3 ($SD=11.7$) on the worry sub-scale.
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3 Based on their survey of 317 US T1D partners, Polonsky and colleagues (2016) reported mean
4 diabetes distress scores, measured using the Problem Areas in Diabetes scale (PAID-5)
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6 (McGuire et al., 2010), to be in the normal range (25.4 ± 20.1), albeit with a wide standard
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8 deviation. The prevalence of elevated distress in T1D partners on the Diabetes Distress Scale for
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10 Spouses and Partners (DDS-SP) was of 38.8%. The prevalence of elevated distress was highest
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12 (64.4%) for the subscale measuring hypo-related distress. The sample had a high level of
13
14 experience of hypos with 55.5% having assisted their PWD with a hypo in the previous 6 months
15
16 which might account for the elevated hypo distress experienced by partners. The emotional strain
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18 on T1D partners extended to embarrassment for their partners, when having a hypo in public.
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20 T1D partners were worried the 'odd' behaviour may compromise their partners' personal and
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22 professional credibility and dignity (King et al., 2015; Morris et al., 2006).
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28 *General psychological morbidity*

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30 In contrast to diabetes-specific psychological distress, a survey of 74 T1D partners, found 87%
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32 completing the WHO-5 (de Wit et al., 2007) to rate their general quality of life as good over the
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34 previous 2 weeks (Barnard et al., 2016). Another population of 61 T1D partners were found to
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36 be within population-wide normal ranges on measures of depression, trait anxiety and
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38 relationship satisfaction irrespective of whether their PWD had a recent experience of a severe
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40 hypo requiring their own or another person's intervention (Gonder-Frederick et al., 1997). The
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42 above-mentioned online survey of 317 T1D partners also assessed depression and general life
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44 stress (Polonsky et al., 2016). Although the raw data were not presented, assessments were found
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46 to be "within expected average ranges" for the measures used (Polonsky et al., 2016, p294).
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51 Whilst T1D partners report living with their own significant fear of hypoglycaemia, this fear
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3 does not appear to affect their general mental health but it was related to their diabetes-related
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5 distress.
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8 *Sleep reduction and interruption* 9

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11 T1D partners perceived diabetes as a burdensome illness, which affected their daily routine (e.g.,
12 eating, sleeping, and activities) (Rintala et al., 2013b; Trief et al., 2013). Sleep disturbances due
13 to diabetes technology were reported by 59% of T1D partners (Barnard et al., 2016) study of
14 which 12% reported waking at least 4 times each week. The main reason was Continuous
15 Glucose Monitoring (CGM) alarms, with 23% of T1D partners reporting frequent false alarms.
16 Partners of PWD with occurring nocturnal hypoglycaemic events suffered from poor and
17 interrupted sleep due to regular night-time checks or awakening by various sounds (Barnard et
18 al., 2016; Lawton et al., 2014; T. M. Rintala et al., 2013b). A significant severe hypo x partner
19 gender interaction for sleep disturbance is reported ($F=9.2$, $p=0.004$) (Gonder-frederick et al.,
20 1997) showing that male T1D partners, but not female T1D partners, reported more sleep
21 disturbance.
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37 *Impact on activities of daily living* 38

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40 Many T1D partners felt restricted in their lives (Stödberg et al., 2007) and grieved over the loss
41 of their 'normal' lives and their limited life choices (Johnson and Melton, 2015; Stödberg et al.,
42 2007). Together with managing a scheduled treatment of diabetes and the feeling that they
43 always have to plan ahead, partners felt a loss of spontaneity (Morris et al., 2006; Rintala, 2017;
44 Rintala et al., 2013b). The picture was not all negative, some partners felt that they lived a
45 normal live and that diabetes had become a part of it (Rintala et al., 2013b; Stödberg et al.,
46 2007). Technology afforded both negative and positive impacts: an online survey of 74 partners
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3 found insulin pumps and CGMs to both have a greater detrimental impact on T1D partners
4 compared to PWD (Barnard et al., 2016).

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

28 *Main findings*

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32 This integrative review has led to a better understanding of the value of maintaining resilient,
33 good quality, intimate relationships for people with type 1 diabetes to optimise their physical and
34 psychological health. It indicates the wellbeing risks to their partners associated with providing
35 intensified, ongoing, support. The evidence shows that PWD benefit from more optimised blood
36 glucose levels and the engagement with more self-management behaviours. The opportunities for
37 partners to maintain hypoglycaemic safety for PWD was significant and no evidence was
38 identified that attempted to quantify this. There is a strong potential for diabetes to negatively
39 affect the quality of, and satisfaction with, an intimate relationship. Whilst there was survey
40 evidence that relationship satisfaction appeared in alignment with the general population, the
41 qualitative evidence revealed the extent to which support can turn into vigilance. Partner
42 surveillance for signs of hypoglycaemia and the consequent need to protect themselves, other
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3 family members and the PWD themselves legitimised their concerns. These concerns were not
4 always welcomed by the PWD being monitored. T1D partners experience considerable amounts
5 of broken sleep alongside the PWD and whilst general psychological health appears to be largely
6 maintained, fear and distress surrounding hypoglycaemia was expressed as exhausting and
7 overwhelming for a significant majority of partners. Technology to detect hypoglycaemia
8 facilitated relationship harmony at the expense of disturbed sleep. The most assessed patient
9 reported outcomes investigated personal psychological aspects, relationship satisfaction, quality
10 of life, fear of hypoglycaemia, diabetes management and empowerment and social support.
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12 Thirty three PROMs were used, only the Summary of Diabetes Self-Care Activities Scale and
13 the Dyadic Adjustment Scale were in more than one study.
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27 Our findings concur with those of others in concluding that long-term conditions are challenging
28 and demanding for the whole family (Berry et al., 2017; Kiecolt-Glaser and Wilson, 2017). The
29 aggregated evidence in our study around preventing and managing hypoglycaemic events
30 strengthen assumption made by Berry and Colleagues (2017) that diabetes is not interpreted as a
31 shared challenge, but that PWD and their partners appraise the illness differently and
32 consequently adapt different behavior strategies. As stated by an earlier author, especially severe
33 hypoglycaemia can be a source of fear and marital distress and that T1D partners identify
34 experiencing a severe hypoglycaemic event as the scariest aspect of diabetes (King et al., 2015).
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46 In both type 1 and type 2 diabetes, across 17 countries, the DAWN study (Kovacs Burns et al.,
47 2013) demonstrated that family member burden is high and that many partners want to
48 understand better how to support their PWD. Joensen et al. (2013) recommended that in clinical
49 practice, systematically assessing cohabitation status and social support as a measure of patient
50 resources may be important when planning patient care and support. People with type 1 diabetes
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3 living without a partner may need special attention and support and may benefit from the
4 establishment of alternative social networks and specialized peer support networks. Partner
5 elevated diabetes distress prevalence, at 38%, exceeds the prevalence of elevated diabetes
6 distress in adults with type 2, and adults and adolescents with type 1 (Dennick et al., 2015;
7 Hagger et al., 2016). As occurs with PWD (Sturt et al., 2015), high levels of distress may hamper
8 partners in fully supporting the diabetes management needs of their PWD. With a newer
9 understanding of the wellbeing needs of partners as well as PWD, together with recent evidence
10 supporting interventions combining relationship and cognitive behavioral skills training for
11 couples, this offers some direction for future interventional work to support both members of
12 these relationships living with type 1 diabetes (Berry et al., 2017).
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26 *Strengths and limitations of the methods*

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

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49 Couples research is sensitive and maybe made more so with an additional daily participant in the
50 form of type 1 diabetes. More longitudinal studies are needed to investigate the direction of the
51 relation between quality of couples relationships and diabetes management; it is likely that
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3 research participation would be more welcome in the interventional space rather than
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5 observational. The findings indicate that we need to know more about what PWD and their
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7 partners would like to support resilience in their relationship with diabetes and for some
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9 relationship repair work. In clinical practice partner and co-habitation status is routinely
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11 collected. This information may be an important cue for Health Care Professionals for enquiring
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13 about the quality of support provided within that relationship and opportunities for offering
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15 support to partners and pwd to work together to manage diabetes. The vast majority of
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17 psychoeducational interventions in type 1 diabetes described in the literature (Berry et al., 2017;
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19 Sturt et al., 2015) focus exclusively on PWD with only few offering very limited support for
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21 PWD family members (Hermanns, 2013). However, the importance of partner support for PWD
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23 is increasingly recognised and its enhancement has become one of the main goals of current
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25 psychoeducational interventions (e.g., Chatterjee et al., 2017; van Puffelen et al., 2014). In line
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27 with this emerging trend, our review brought to light a burning need to improve PWD partners'
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29 empowerment through strengthening their knowledge about diabetes and its management and
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31 prevention of hypoglycaemic episodes with the aim to improve partner's self-efficacy in
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33 supporting PWD.
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41 Several themes of our qualitative analyses revealed the need to include in psychoeducational
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43 interventions a module focusing on helping patients and their partners to better manage
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45 psychological and behavioural symptoms of type 1 diabetes and improving their knowledge of
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47 how these symptoms may affect their day-to-day interactions and their relationship satisfaction.
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49 This would necessarily entail participation of both partners and application of approaches (such
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51 as specialised couple counselling) that recognise the importance of couple unit in diabetes
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53 management and the impact of intimate partners on each other.
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3 Another emerging theme in our review showed the importance of addressing the needs of T1D
4 partners to enhance their self-care skills related to their management of diabetes-related stress. In
5 particular, we propose that psychoeducational intervention should help partners to tackle 3
6 issues: how to minimize emotional impact of hypoglycaemic episodes or fear of
7 hypoglycaemia; how to refrain from over-protective or over-caring behaviours; how to minimise
8 disruptions to daily activities or night sleep (i.e., prevention and management of nocturnal
9 hypoglycaemic events).

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

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

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

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29 [Insert, from the title page: contribution authorship statement; conflict of interest;
30 acknowledgments]

31 32 33 **Data availability statements**

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3 Data generated during and/or analyzed during the current study are available from the
4 corresponding author on reasonable request.
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For Peer Review

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Author Year Country	Study design/methods	Aim	Sample	Main results/themes and CASP quality assessments (QA)
Quantitative studies				
Gillibrand and Stevenson (2007) UK	Cross-sectional	To explore the role of partner support in self-care for young people with type 1 diabetes.	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	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 ($r=.674, p<0.01$). Relationship quality did not predict a better diabetes management unless person with diabetes was male (path value = 1.461). QA: 8/12
Gonder-Frederick et al. (1997) USA	Cross-sectional	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.	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 ±9.5 years Length of relationship (mean, SD): N/D	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 vs. 1.9; $t = 9.52, P= 0.0001$). QA: 5/12
Hagedoorn et al. (2006) Netherlands	Longitudinal	To examine the role of overprotection by the partner in changes in patient self-management in the context of diabetes education.	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	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
Imayama et al. (2011) Canada	Longitudinal	To examine the determinants QOL in adults with type 1 diabetes.	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	Having a partner ($\beta = 0.11, p< 0.05$), high annual income ($\beta = 0.16, p < 0.01$), and high activity trait (personality) score ($\beta = 0.27, p < 0.01$) were significantly associated with higher life satisfaction QA: 8/12
Jensen (1985 b) Denmark	Longitudinal	To explore the emotional aspects in having a chronic disease seen from both PWD and T1D partners' point of view.	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)	Reactions of PWD compared to T1D partners: PWD had more fear and anxiety about the future than their spouses (57% vs 33% $p <0.05$); PWD found daily life more troublesome and difficult than their partners did (40% vs 14% $p <0.05$); PWD were more often tired than their partners (47% vs 25% $p <0.05$); PWD feared more often to be left by their healthy partner (26% VS 8% $p <0.05$); PWD more often had sexual concerns than their partners (39% vs 7% $p <0.05$) 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

1 2 3 4 5 6 7 8	Joensen et al. (2013) Denmark	Cross-sectional	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.	Population: PWD Sample size: 2419 Gender (M/F): 1259/1160 Age (mean, SD): living with a partner, M 53.7 ±13.5 years; F 50.8 ±13.9 years Diabetes duration (mean, SD): living with a partner, M 26.9 years±14.7; F 27.5 ±14.9 Length of relationship (mean, SD): ND	Significant associations were found between living without a partner and low quality of life, low diabetes empowerment and HbA1c for both men ($\beta = -3.68, p < 0.001$; $\beta = -0.13, p = 0.004$; $\beta = 0.27, p < 0.001$) and women ($\beta = -2.16, p < 0.001$; $\beta = -0.16, p = 0.002$; $\beta = 0.39, p < 0.001$). QA: 7/12
9 10 11 12 13 14 15	JØrgensen et al. (2003) Denmark	Cross-sectional	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.	Population: PWD and their closest cohabitants Sample size: 284 Gender (M/F): 54%/46% Age (mean, SD): 44 ±12 years Diabetes duration (mean, SD): 24 ±12 years Length of relationship (mean, SD): 18 years	Cohabitants recalled more episodes of severe hypoglycemia than patients (2.7 vs 1.6 episodes/patient-year; $p < 0.001$). Degree of involvement was positively related to the rate of severe hypoglycemia ($P = 0.002$) and negatively related to the state of awareness ($P = 0.007$) but not to level of HbA1c, duration of diabetes, or presence of late complications, except for peripheral neuropathy ($p = 0.01$). QA: 8/12
16 17 18 19	Nefs et al. (2015) Netherlands	Cross-sectional	To examine sociodemographic, clinical and psychological factors associated with fear of hypoglycaemia in adults with type 1 diabetes.	Population: PWD Sample size: 232 Gender (M/F): 80/152 Age (mean, SD): 45 ±14 years Diabetes duration (mean, SD): 22± 14 years Length of relationship (mean, SD): ND	Fear of hypoglycaemia was associated with depressive symptoms ($\beta = 0.38, p < 0.001$) and history of hypoglycaemia (1–2 events: $\beta = 0.30, p < 0.001$; ≥ 3 events: $\beta = 0.19, p = 0.002$). QA: 8/12
20 21 22 23 24 25 26 27	Polonsky et al. (2016) USA	Cross-sectional	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.	Population: T1D partners Sample size: 317 Gender (M/F): 161/156 Age (mean, SD): 43.4± 13.7 Diabetes duration (mean, SD): 24.1± 15.0 Length of relationship (mean, SD): 13.6 ±9.0 years	High DD was most common for Hypoglycemic Distress (64.4% of the sample) and least for Management Distress (28.4%). Greater DD was significantly and independently linked with: being younger, female, greater involvement in the PWD's diabetes management, lower levels of relationship satisfaction, less trusting of the PWD's physician, poorer PWD glycemic control, and more frequent hypoglycemic episodes. T1D partners also reported low levels of diabetes-related support from all sources. QA: 7/12
28 29 30 31 32	Rawshani et al. (2015) Sweden	Cohort study	To investigate how income, education, marital status, immigrant status, and sex relate to CVD and death in a population of type 1 diabetes patients.	Population: PWD Sample size: 24,947 Gender (M/F): 4,411/4,389 in married/cohabiting group Age (mean, SD): 46.81±12.11 in married/cohabiting group Diabetes duration (mean, SD): ND Length of relationship (mean, SD): ND	Being married/cohabiting was associated with 50–64% lower risk of all-cause death, CV death, and diabetes-related death. Being male, divorced, single, or widowed was also associated with substantially higher risk of poor outcomes. QA: 5/12
33 34 35 36 37 38	Simmons et al. (2013) USA	Cross-sectional	To identify characteristics and diabetes management techniques in adults with type 1 diabetes, differentiating those under excellent glycemic control from those with poorer control.	Population: PWD Sample size: 1894 Gender (M/F): 866/1028 Age (mean, SD): 47.6±14.2 in excellent control group; 45.0 ±12.6 in fair control Diabetes duration (mean, SD): 22.9 ±14.7 in excellent control; 22.7±12.1 in fair/poor control group Length of relationship (mean, SD): ND	Compared with the fair/poor control group, participants in the excellent control group had higher socioeconomic status, were more likely to be older and married, were less likely to be overweight, were more likely to exercise frequently, and had lower total daily insulin dose per kilogram ($p < 0.0001$ for each). QA: 6/12
39 40 41 42 43 44 45 46 47	Trief et al. (2017) USA	Cross-sectional	To examine the association of relationship status with diabetes outcomes; To examine in those who	Population: PWD Sample size: 1660 Gender (M/F): 619/1041 Age (mean, SD): 40±14 years	Differences in glycaemia and concordance between married/partnered and not married/not partnered not were non-significant. Higher relationship satisfaction, and having an engaged, not over-protective, partner was associated with optimal blood

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		were married/partnered, the association of perceived partner support style with relationship satisfaction and glycemic control, BMI and self-care adherence.	Diabetes duration (mean, SD): 22±13 years Length of relationship (mean, SD): ND	glucose levels and self-care. QA:6/12
Wearden et al. (2000, 2006) UK	Cross-sectional	1) Hypothesis: high EE in T1D partners would be associated with poorer glucose control, management of and adaptation to diabetes; 2) To perform the first test of the attributional model of EE in a population spouses or partners of patients with a physical illness with a clearly understood cause (i.e. type 1 diabetes).	Population: Couples 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	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. QA:9/12
Qualitative studies				
Johnson and Melton (2015) USA	Interviews	To determine the challenges and needs of partners of people with type 1 diabetes.	Population: T1D partners 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	Emotional strain of loving a person with diabetes; Managing the caregiver role; Coping strategies. QA: 9/10
King et al. (2015) Australia	Interviews	To gain a better understanding of what severe hypoglycemia means to significant others.	Population: T1D partners 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)	Managing disruption. QA: 7/10
Lawton et al. (2014) UK	Interviews	To explore the impact of HU on family members' lives, their involvement in preventing and managing hypoglycaemia, and their information and support needs.	Population: T1D partners 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	Monitoring and Supervision: Restricting One's Own Lifestyle; Dealing with hypoglycemia: 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. QA: 9/10
Morris et al. (2006) UK	Interviews	To explore the experience of living with an adult with type 1 diabetes and the impact that has on the partner.	Population: T1D partners 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	Emotional issues; Control; Knowledge. QA: 7/10
Rajaram (1997)	Interviews	To explore the dynamic process by which patients	Population: PWD Sample size: 23	Patient's experience of hypoglycemia; Spouse's reaction to the illness.

USA		and their spouses manage hypoglycemia in their daily lives.	Gender (M/F): 12/11 Age (mean, SD): PWD 36±7.26; T1D partners 32 ±5.17 Diabetes duration (mean, SD): 15 ±8.43 Length of relationship (mean, SD): 12 ±8.31	QA:5/10
Rintala (2013, 2017) Finland	Interviews	1) To explore family members' experiences of everyday life in families with adult people living with type 1 diabetes; 2) To explore the experiences of everyday life in families from the point of view of adult people with type 1 diabetes.	Population: Couples Sample size: PWD 19, T1D partners 16 Gender (M/F): 1/18 Age (mean, SD): range 28-65 years Diabetes duration (mean, SD): range 2-58 years Length of relationship (mean, SD): ND	Intertwining with hypoglycaemia; Becoming acquainted with diabetes; Being involved in the management of diabetes; Integrating Diabetes into Everyday Life; Watching Self-Management from the sidelines; Living on an emotional roller-coaster; Diabetes is visible and invisible present in family's everyday life; Keeping the balance with self-management; The managing with hypoglycemia; Living with changing feelings; The family's contribution to self-management; Learning to live with diabetes. 2013 QA: 8/10 2017 QA: 3/10
Ritholz et al. (2014) USA	Focus groups	To examine the impact of continuous glucose monitoring on diabetes management and marital relationships of adults with type 1 diabetes and their spouses.	Population: Couples Sample size: PWD 20, T1D partners 14 Gender (M/F): PWD 10/10; T1D partners 7/7 Age (mean, SD): PWD range 30-70 years Diabetes duration (mean, SD): Young male 21 ±12, young female 18 ±84 Older male 40 ±15, older female 33 ±94 Length of relationship (mean, SD): Young male 8 ±5, young female 8 ±5 Older male 27 ±9, older female 28 ±7	Continuous glucose monitoring and diabetes management: coping with hypoglycaemia; Continuous glucose monitoring and the marital relationship. QA: 9/10
Stodberg et al. (2007) Sweden	Interviews	To elucidate the lived experience of being a significant other of a person with diabetes.	Population: T1D partners Sample size: 11 Gender (M/F): 5/6 Age (mean, SD): ND Diabetes duration (mean, SD): range 7months-37 years Length of relationship (mean, SD): range 4-36 years	Living in concern about the other's health; Striving to be involved; Experiencing confidence; Handling the illness. QA: 7/10
Trief et al. (2013) USA	Focus groups	To better understand the unique psychosocial challenges of adults with type 1 diabetes, and patient/partner perspectives on how diabetes impacts their relationships.	Population: PWD, T1D partners Sample size: 16, 14 Gender (M/F): PWD 5 /11, T1D partners 9/5 Age (mean, SD): PWD 51.3 ±17.7; T1D partners 45.6±13.5 Diabetes duration (mean, SD): ND Length of relationship (mean, SD): PWD 19.3±17.4; T1D partners 14.1±13.3	Impact of diabetes on the relationship; Understanding the impact of hypoglycemia; Stress of potential complications; Benefits of technology. QA:5/10
Mixed methodology				
Barnard et al. (2016) USA	Survey and open-ended questions	To explore the impact of technological devices on the life, mood and well-being of the T1D partners.	Population: T1D partners Sample size: 74 Gender (M/F): 42/32 Age (mean, SD): 42.7±14.9 years Diabetes duration (mean, SD): ND Length of relationship (mean, SD): 16±14.9 years	Reminders and monitoring; Practical support; Nocturnal BG testing; Treating hypoglycemic events; Team work; Providing moral support. Quantitative QA: 7/12 Qualitative QA: 2/10
Peyrot et al.	Survey and	To investigate the	Population: couples	Interpersonal Congruence and Self-disclosure

(1988) USA	Inerview	adjustment of adult patients and their spouses to insulin-treated diabetes mellitus.	Sample size: 20 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	Quantitative QA: 5/12 Qualitative QA: 7/10
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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;

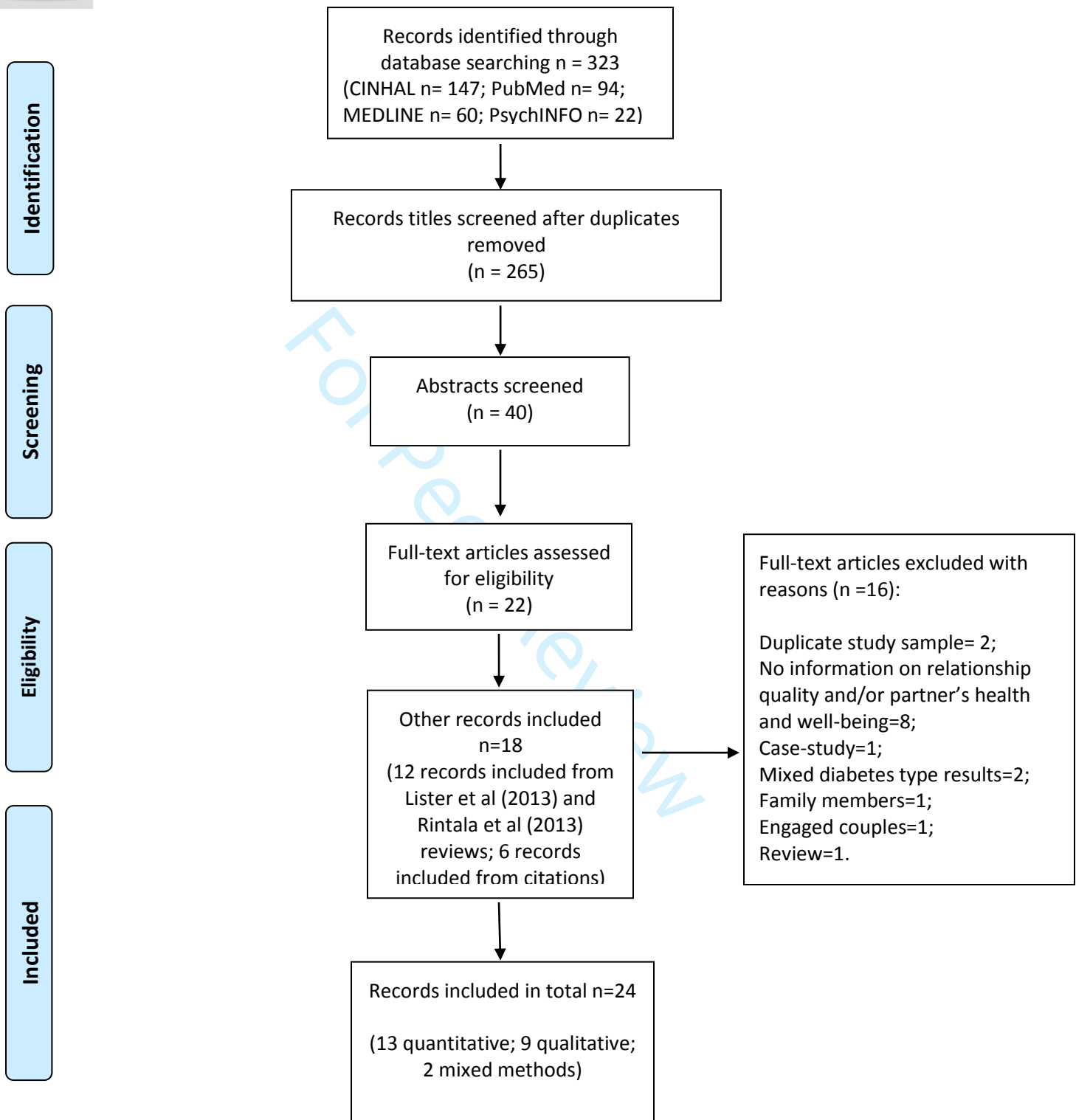
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Table 2. Patient/Partner Reported Outcomes Measures (PROMs) investigated in quantitative studies

Variable investigated	PROMs used to investigate	Papers
<i>Diabetes specific</i>		
Diabetes Distress	Diabetes Distress Scale (DDS) Diabetes Distress Scale for Spouses (DDS-SP) Problem Areas In Diabetes (PAID) Problem Areas In Diabetes-5 (PAID-5)	Joensen et al. 2013 Polonsky et al. 2016 Hagedoorn et al. 2006 Barnard et al. 2016
Diabetes Empowerment	Appraisal of Diabetes Scale (ADS) Diabetes Empowerment Scale-Short Form (DES-SF)	Wearden et al. 2000; 2006 Joensen et al. 2013
Diabetes Management	Psychosocial Aspects of Diabetes Schedule short-version Summary of Diabetes Self-Care Activities Scale (SDSCA) Summary of Diabetes Self-Care Activities Scale Revised Version (SDSCA-R)	Wearden et al. 2000; 2006 Gillibrand and Stevenson 2007; Trief et al. 2017 Joensen et al. 2013
Diabetes specific social support	Diabetes Care Profile (DCP) Diabetes Family Behavior Checklist (DFBC)	Joensen et al. 2013 Gillibrand and Stevenson 2007
Fear of Hypoglycaemia	Hypoglycaemia Fear Survey (HFS) Hypoglycaemia Fear Survey – Second Version Worry subscale (HFS-II-W)	Gonder-Frederick et al. 1997 Nefs et al. 2015
<i>Generic</i>		
Anxiety	Generalized Anxiety Disorder 7-item scale (GAD-7) Hospital Anxiety and Depression Scale (HAD) Spielberg Trait Anxiety Inventory	Nefs et al. 2015 Wearden et al. 2000; 2006 Gonder-Frederick et al. 1997
Depression	Beck Depression Inventory (BDI) Hospital Anxiety and Depression Scale (HAD) Patient Health Questionnaire-8 items (PHQ-8) Patient Health Questionnaire-9 items (PHQ-9)	Gonder-Frederick et al. 1997 Wearden et al. 2000; 2006 Polonsky et al. 2016 Nefs et al. 2015
General social support	Items from the Danish Population Health Profile	Joensen et al. 2013
Internal locus of control	Multidimensional Health Locus of Control (MHLC) Form C	Hagedoorn et al. 2006
Life stress	General Life Stress	Polonsky et al. 2016
Partner's support	Active Engagement (AE), Protective-Buffering (PB), Over-Protection (OP): APO measures	Trief et al. 2017
Psychological well-being	General Health Questionnaire-28 items (GHQ-28) World Health Organization Well-Being Index (WHO-5)	Wearden et al. 2000; 2006 Barnard et al. 2016
Quality of life	Satisfaction with Life Scale-5 items Mental Component score of the 12-Item Short Form Health Survey (MCS of the SF12)	Imayama et al. 2011 Joensen et al. 2013
Relationship satisfaction	Dyadic Adjustment Scale (DAS) Revised Dyadic Adjustment Scale (RSDAS) General Relationship Satisfaction-3 items Marital Satisfaction Instrument (MARSAT) Relationship Assessment Scale (RAS)	Wearden et al. 2000; 2006; Gonder-Frederick et al. 1997 Trief et al. 2017 Polonsky et al. 2016 Peyrot et al. 1988 Gillibrand and Stevenson 2007



PRISMA 2009 Flow Diagram



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

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

<http://mc.manuscriptcentral.com/jhealthpsychology>

PubMed, search strategy at 12.12.17

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((((((("diabetes mellitus, type 1"[MeSH Terms] OR "type 1 diabetes mellitus"[All Fields] OR "type 1 diabetes"[All Fields]) AND ("family characteristics"[MeSH Terms] OR ("family"[All Fields] AND "characteristics"[All Fields]) OR "family characteristics"[All Fields] OR "couple"[All Fields]) OR ("diabetes mellitus, type 1"[MeSH Terms] OR "type 1 diabetes mellitus"[All Fields] OR "type 1 diabetes"[All Fields]) AND ("spouses"[MeSH Terms] OR "spouses"[All Fields] OR "spouse"[All Fields])) AND ("2011/01/01"[PDAT] : "2017/12/31"[PDAT]) AND English[lang]) OR (((("diabetes mellitus, type 1"[MeSH Terms] OR "type 1 diabetes mellitus"[All Fields] OR "type 1 diabetes"[All Fields]) AND partner[All Fields] OR ("diabetes mellitus, type 1"[MeSH Terms] OR "type 1 diabetes mellitus"[All Fields] OR "type 1 diabetes"[All Fields]) AND ("spouses"[MeSH Terms] OR "spouses"[All Fields] OR "husband"[All Fields]) OR ("diabetes mellitus, type 1"[MeSH Terms] OR "type 1 diabetes mellitus"[All Fields] OR "type 1 diabetes"[All Fields]) AND ("spouses"[MeSH Terms] OR "spouses"[All Fields] OR "wife"[All Fields])) AND ("2011/01/01"[PDAT] : "2017/12/31"[PDAT]) AND English[lang])) OR (((("diabetes mellitus, type 1"[MeSH Terms] OR "type 1 diabetes mellitus"[All Fields] OR "type 1 diabetes"[All Fields]) AND ("marriage"[MeSH Terms] OR "marriage"[All Fields]) OR ("diabetes mellitus, type 1"[MeSH Terms] OR "type 1 diabetes mellitus"[All Fields] OR "type 1 diabetes"[All Fields]) AND ("marriage"[MeSH Terms] OR "marriage"[All Fields] OR "marital"[All Fields])) AND ("2011/01/01"[PDAT] : "2017/12/31"[PDAT]) AND English[lang])) OR (((("diabetes mellitus, type 1"[MeSH Terms] OR "type 1 diabetes mellitus"[All Fields] OR "type 1 diabetes"[All Fields]) AND dyad[All Fields] OR ("diabetes mellitus, type 1"[MeSH Terms] OR "type 1 diabetes mellitus"[All Fields] OR "type 1 diabetes"[All Fields]) AND dyadic[All Fields]) AND ("2011/01/01"[PDAT] : "2017/12/31"[PDAT]) AND English[lang])) OR (type 1 diabetes[Title/Abstract] AND "significant other"[Title/Abstract] OR type 1 diabetes[Title/Abstract] AND "daily activities"[Title/Abstract] OR type 1 diabetes[Title/Abstract] AND "everyday living"[Title/Abstract] OR type 1 diabetes[Title/Abstract] AND self-management[Title/Abstract] OR type 1 diabetes[Title/Abstract] AND self-care[Title/Abstract])) AND ("2011/01/01"[PDAT] : "2017/12/31"[PDAT]) AND "humans"[MeSH Terms] AND English[lang]) NOT child$[Title/Abstract]) AND ("2011/01/01"[PDAT] : "2017/12/31"[PDAT]) AND "humans"[MeSH Terms] AND English[lang]) NOT adolescents[Title/Abstract] AND ("2011/01/01"[PDAT] : "2017/12/31"[PDAT]) AND "humans"[MeSH Terms] AND English[lang])
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MEDLINE, search strategy at 12.12.17

1. type 1 diabetes.mp.
2. couple.mp.
3. spouse.mp.
4. partner.mp.
5. husband.mp.
6. wife.mp.
7. marriage.mp.
8. marital.mp.
9. dyad.mp.
10. dyadic.mp.
11. 1 and 2
12. 1 and 3
13. 1 and 4
14. 1 and 5
15. 1 and 6
16. 1 and 7
17. 1 and 8
18. 1 and 9
19. 1 and 10
20. 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19
21. limit 20 to yr="2011 - 2017"
22. limit 21 to english
23. "significant other".mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
24. 1 and 23
25. "daily activities".mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
26. 1 and 25
27. "everyday living".mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
28. 1 and 27
29. self-management.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
30. 1 and 29
31. self-care.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
32. 1 and 31
33. 22 or 24 or 26 or 28 or 30 or 32
34. 21 and 33
35. limit 34 to (english and humans)
36. 22 or 35

PsychINFO, search strategy at 12.12.17

1. type 1 diabetes.mp.
2. couple.mp.
3. spouse.mp.
4. partner.mp.
5. husband.mp.
6. wife.mp.
7. marriage.mp.
8. marital.mp.
9. dyad.mp.
10. dyadic.mp.
11. 1 and 2
12. 1 and 3
13. 1 and 4
14. 1 and 5
15. 1 and 6
16. 1 and 7
17. 1 and 8
18. 1 and 9
19. 1 and 10
20. 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19
21. limit 20 to yr="2011 - 2017"
22. limit 21 to english
23. "significant other".mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
24. 1 and 23
25. "daily activities".mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
26. 1 and 25
27. "everyday living".mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
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31. self-care.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
32. 1 and 31
33. 22 or 24 or 26 or 28 or 30 or 32
34. 21 and 33
35. 22 or 34

CINAHL, search strategy at 12.12.17

1		
2		
3		
4	S32	S30 NOT adolescen\$
5		
6	S31	S30 NOT child\$
7		
8	S30	S18 OR S27
9		
10	S29	S18 OR S27
11		
12	S28	S18 AND S27
13		
14	S27	S23 OR S24 OR S25 OR S26
15		
16	S26	S1 AND S22
17		
18	S25	S1 AND S21
19		
20	S24	S1 AND S20
21		
22	S23	S1 AND S19
23		
24	S22	"self-care"
25		
26	S21	"self-management"
27		
28	S20	""daily activities""
29		
30	S19	""significant other""
31		
32	S18	S3 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17
33		
34	S17	S1 AND S10
35		
36	S16	S1 AND S9
37		
38	S15	S1 AND S8
39		
40	S14	S1 AND S7
41		
42	S13	S1 AND S6
43		
44	S12	S1 AND S5
45		
46	S11	S1 AND S4
47		
48	S10	"dyadic"
49		
50	S9	"dyad"
51		
52	S8	"marital"
53		
54	S7	"wife"
55		
56	S7	"husband"
57		
58	S6	"partner"
59		
60	S5	"marriage"
	S4	"spouse"

S3	S1 AND S2
S2	"couple"
S1	"type 1 diabetes"

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