

Reference Study design	Main objectives of study/ Description of interventions	Quality of life and well-being measurement / Outcomes	Study conclusion related to the research question
6. Sassmann et al. (2012). <i>Reducing stress and supporting positive relations in families of young children with type 1 diabetes: A randomised control study for evaluating the effects of the DELFIN parenting program.</i> Randomized control trial group intervention: DELFIN program compared to control group.	This study assessed the initial efficacy and feasibility of a structured behavioural group training intervention for parents of children with type 1 diabetes to reduce parenting stress and to improve parenting skills. The DELFIN programme (DELFIN – Das Elterstraining für Eltern von Kindern mit Diabetes Typ 1 (The parenting programme for parents of children with diabetes type 1) is a structured group intervention for parents that was developed to integrate general parenting strategies and diabetes-specific conflict situations to strengthen their general and diabetes-specific education competences.	No specific measure for quality of life of parents was used. Parents' psychological distress decreased significantly in the experimental group, but no significant effects over time were observed as the control group unexpectedly also experienced a significant reduction in stress and anxiety. Biomedical data indicated that most children had good metabolic control at baseline, which remained stable after three months in the DELFIN group. However, HbA1c changed significantly in the control group. The authors state that this should be interpreted with caution as there was good metabolic control in the majority of children at onset of the study. The metabolic control of all children younger than 12 was relatively good which made it challenging to improve the metabolic and psychological outcomes.	Although quality of life was not specifically measured, the authors (Sassmann et al., 2012) used the measure of psychological distress as a reverse indicator of psychological well-being.
7. Sullivan-Bolyai et al. (2004). <i>Helping other mothers effectively work at raising young children with type 1 diabetes.</i> Randomized control trial: Mentor support programme (home visits and telephone calls) compared to control group.	The study examined the feasibility of a post-diagnosis parental mentoring intervention for mothers of young children newly diagnosed with type 1 diabetes receiving support from mothers who had successfully raised young children with the condition. This programme was refined to meet informational, affirmational and emotional support needs of mothers raising young children with type 1 diabetes. The <i>HOMEWARD</i> (Programme for Helping Other Mothers Effectively Work At Raising young children with type 1 Diabetes) includes practical, informational support and the sharing day-to-day management information.	No specific measure of parental quality of life was used or reported on. Improvements related to quality of life that were reported on included that participants in the experimental group had fewer concerns, more confidence, were able to identify more community resources to assist of support and perceived the illness as having less of a negative impact on the family than the control group mothers. No differences were found at six months between the two groups in A1c levels, number of hospitalisations or acute-care visits.	Quality of life was not recorded with quantifiable measures, but the authors argued that subtle suggestions and emotional cost-saving effects did contribute to the reduction of parental anxiety and in turn improved the quality of life of the parents.

Note. T1D = Type 1 diabetes; HbA1c = Haemoglobin A1c.

Data Analysis and Synthesis of Findings

The data, extracted from the articles and captured in the data extraction table, was analysed and synthesized in order to address the initial research question.

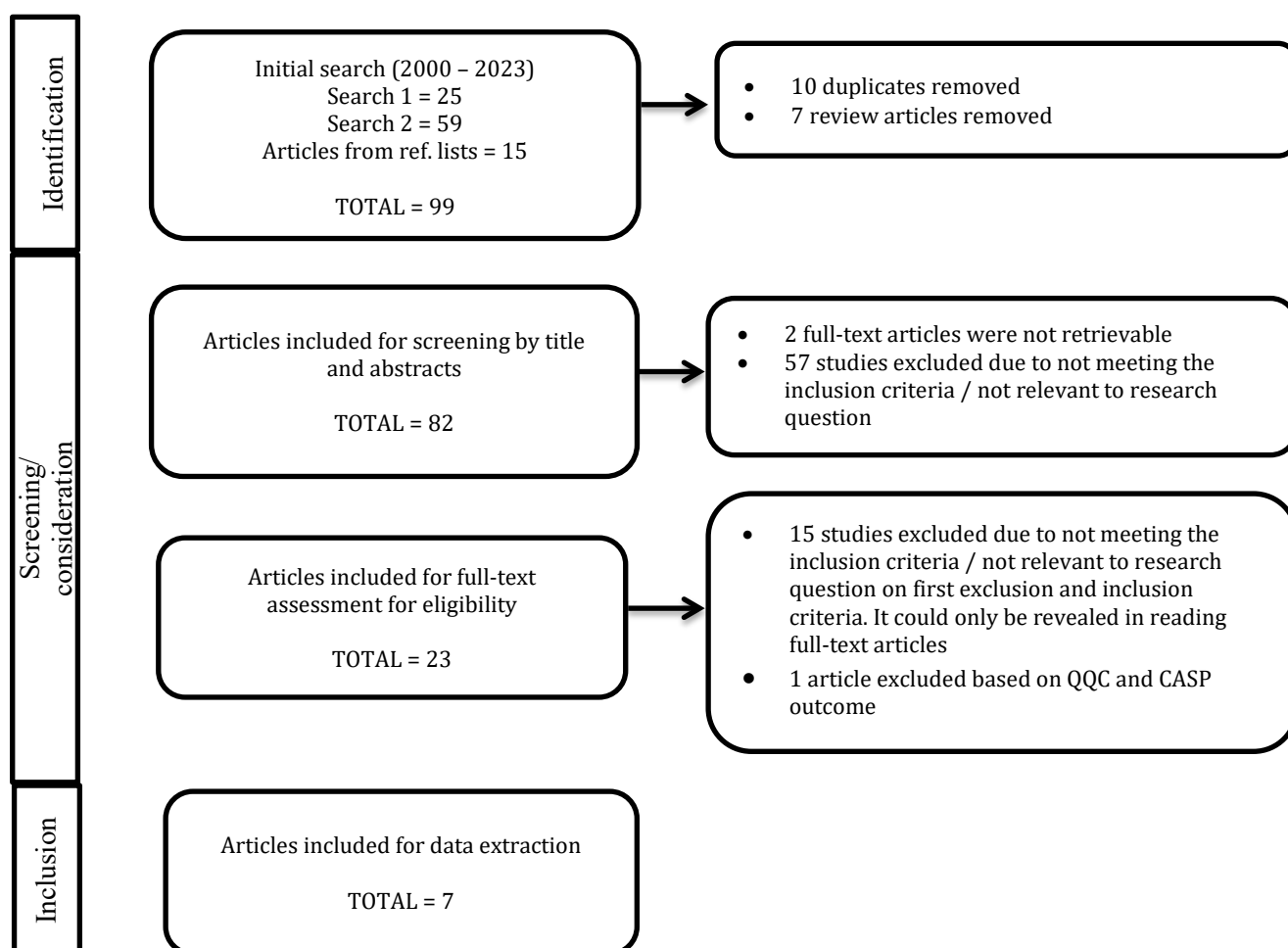
Findings

Study Selection

The initial literature search yielded 84 articles, while an additional 15 articles were identified from the review articles. After ten duplicates and seven review articles were removed, a total of 82 articles were screened for keywords in titles and abstracts. From the 82 articles, two full-text articles were not retrievable, while a further 57 articles did not meet the inclusion criteria, resulting in 23 articles being eligible for full-text assessment. 15 of these articles were excluded as they did not adhere to the inclusion criteria after assessing the full text, while one article was excluded after quality assessment. The follow-up search did not yield any new articles to consider. Hence, this review is based on seven articles identified that report on quality of life and well-being interventions for parents of children living with type 1 diabetes (see **Figure 1**, PRISMA flow diagram).

Figure 1

PRISMA Flow Diagram of Research Results



Study Characteristics

The literature reviewed reported interventions conducted with parents caring for their young child with type 1 diabetes, specifically focusing on quality of life and psychological well-being as an outcome (Ambrosino et al., 2008; Grey et al., 2011; Mackey et al., 2016; Monaghan et al., 2011; Pate et al., 2015; Sassmann et al., 2012; Sullivan-Bolyai, 2004). Five studies were conducted in the United States (Ambrosino et al., 2008; Grey et al., 2011; Mackey et al., 2016; Monaghan et al., 2011; Sullivan-Bolyai, 2004), and one each in Slovenia (Pate et al., 2015) and Germany (Sassmann et al., 2012). The studies were published between 2004 and 2016. The children's ages ranged between 1 and 12 years; the mean ages of groups in individual studies ranged between 4.10 and 9.91 years. In the reports, the study population ranged from 30 to 87 parents, whose mean ages, according to the group investigated, ranged from 33.6 to 43.3 years. The key participants were mostly mothers, who predominantly reflected a relatively high proportion of White/Caucasian middle-class individuals compared with other ethnic groups. They were mainly recruited from paediatric diabetes clinics (Sullivan-Bolyai, 2004) or hospitals (Mackey et al., 2016; Monaghan et al., 2011) and often worked in collaboration with a university-based medical centre (Ambrosino et al., 2008; Grey et al., 2011) or department of endocrinology (Pate et al., 2015).

Six studies used a randomised control group design for the purpose of implementing a trial for an intervention and compared it to a control group (Ambrosino et al., 2008; Grey et al., 2011; Mackey et al., 2016; Monaghan et al., 2011; Sassmann et al., 2012; Sullivan-Bolyai, 2004). Participants in these six studies reported on the baseline and post-intervention follow-up using quantifiable measures with questionnaires and scales. Two of the six studies (Sassmann et al., 2012; Sullivan-Bolyai, 2004) used a mixed-method approach, as they used questionnaires and scales, as well as semi-structured qualitative interviews. The seventh study (Pate et al., 2015) used a mixed-method group intervention, not as part of a randomized control trial. Interventions were delivered in one of two methods, namely, group interventions (Ambrosino et al., 2008; Grey et al., 2011; Pate et al., 2015; Sassmann et al., 2012) and telephone-based interventions (Mackey et al., 2016; Monaghan et al., 2011; Sullivan-Bolyai, 2004).

Although metabolic management (using HbA1c, glycated haemoglobin, as a reference) was not an eligible criterion, it is an important outcome in measuring the effectiveness of diabetes interventions. Information on this outcome was found in six of the studies and captured in the data extraction table (**Table 1**) (Ambrosino et al., 2008; Grey et al., 2011; Mackey et al., 2016; Monaghan et al., 2011; Sassmann et al., 2012; Sullivan-Bolyai, 2004).

Focus of Interventions

The interventions can be categorised as behaviour modification interventions – comprising coping skills training (Ambrosino et al., 2008; Grey et al., 2011), psycho-education (Ambrosino et al., 2008; Grey et al., 2011; Mackey et al., 2016) and cognitive-behaviour strategy training (Mackey et al., 2016; Monaghan et al., 2011; Sassmann et al., 2012) – and support interventions such as mentoring or support from peer parents via telephone sessions (Monaghan et al., 2011; Pate et al., 2015; Sullivan-Bolyai, 2004). Facilitators involved in the interventions included experienced clinical psychologists (Grey et al., 2011; Sassmann et al., 2012), therapists who used group and psychotherapeutic intervention techniques (Pate et al., 2015), and other health professionals such as marriage and/or family therapists (Ambrosino et al., 2008; Grey et al., 2011). The mentors and peer parents were lay mothers who had successfully met their child's diabetes challenges (Sullivan-Bolyai, 2004).

Effectiveness of Interventions

Only one study (Grey et al., 2011) reported a statistically significant difference between groups as evidence of the improvement in the quality of life and well-being of the parents that took part in the intervention. The other articles hinted at the improvement of the quality of life and well-being of parents, but without statistically significant differences for four important reasons: A summary of aspects related to quality of life of parents found in review articles includes positive changes in adaptation in coping skills interventions (Ambrosino et al., 2008), a more positive perception of the child's quality of life (Mackey et al., 2016), a decrease in parental stress (Monaghan et al., 2011; Sassmann et al., 2012; Sullivan-Bolyai, 2004) and an increase in social support experienced by parents (Monaghan et al., 2011).

Timing of Interventions

Some studies intervened following a relatively longer period (at least six months) after the child had been diagnosed with type 1 diabetes (Ambrosino et al., 2008; Grey et al., 2011). Other studies proposed that parents of newly diagnosed children (in the first 6 months after diagnosis) should receive interventions immediately after diagnosis (Mackey et al., 2016; Monaghan et al., 2011; Sullivan-Bolyai, 2004), as this period presents a unique opportunity to provide additional support to counter negative effects (Mackey et al., 2016). During this early phase, parents may need more regular contact with a professional and may appreciate additional support from their clinical team (Mackey et al., 2016), as these parents are at risk of experiencing anxiety, depression and parenting stress (Monaghan et al., 2011).

Developmentally Tailored Interventions

The literature reviewed reported evidence of interventions mostly targeting parents, except for two studies which targeted both parents and children (Ambrosino et al., 2008; Grey et al., 2011). These interventions were tailored to their child's developmental level and included these parents in some programmes. Although similar to the study of Monaghan et al. (2011), the intervention programme of Mackey et al. (2016) proved more effective, as it made additional provision for integrating developmentally tailored education, cognitive behavioural strategies to support parents in their daily management of diabetes, and parenting strategies relating to the young child. In this intervention for parents, the authors incorporated age-appropriate levels of development and related expectations into all the sessions of the intervention. Data was reported at baseline, one, six and 12 months post-intervention, whereas Monaghan et al. (2011) only reported on data pre- and post-intervention three weeks after the intervention. In the study by Grey et al. (2011), the content was tailored to the child's developmental level for each group of parents in the intervention by using different examples in group sessions. The programme Sullivan-Bolyai (2004) reported comprised characteristics including knowledge of managing the illness and child development. This approach is supported by literature emphasizing the parental need for guidance about their child's specific developmental phase in managing diabetes (Chiang et al., 2014; Hilliard et al., 2016; Streisand & Monaghan, 2014).

Discussion

The aim of this research study was to investigate effective interventions to improve the quality of life and well-being for parents of young children living with type 1 diabetes. Few studies that investigated interventions to improve the quality of life and well-being of parents of young children living with type 1 diabetes were found, and results from these studies were not conclusive. Only one investigation reported scientific evidence of improvement in the quality of life of the parents, while the other articles mentioned aspects related to such quality of life and well-being with the decrease of psychological distress and anxiety, as well as a decrease in symptoms of depression and an increase in psychological well-being and parental skills. A major challenge in the review was the conceptualisation of quality of life (or lack thereof) in articles. Firstly, not all the studies had improvement of quality of life as a goal, and the measurement of quality of life of parents was not included in their protocols, but when looking at the study findings, aspects of quality of life and well-being could be identified and reported on. Secondly, as various definitions of quality of life are argued by theorists, a broader description of the term was used in most articles to describe how it was used. We also included the reduction of parental stress and improvement of coping as important elements in the improvement of quality of life and thus also acknowledge findings related to those outcomes. Furthermore, findings related to parents' subjective experience of feeling supported were also included as it has been linked to improved quality of life.

Despite this challenge, the findings of this review suggests that a combination of both group-based and telephone-based interventions should be considered in the development of an intervention to improve quality of life and well-being for parents of children living with diabetes. However, very few studies have been conducted in the area. Participants represented in the studies reviewed recommended more social support and group-based interventions incorporating diabetes resources and opportunities to connect with others and to improve family functioning (Ambrosino et al., 2008; Grey et al., 2011; Mackey et al., 2016; Monaghan et al., 2011; Pate et al., 2015; Sassmann et al., 2012). Children's groups may also facilitate peer social support (Grey et al., 2011). This conclusion relates to Streisand and Monaghan (2014), who reported that parents living with children with type 1 diabetes often deal with social isolation and feelings of loss that is not understood by those who do not share similar challenges.

The developmental stage of the child was an important variable to consider in the development of interventions, which was tailor-made for the different developmental stages. One such developmental challenge is the transfer of responsibility to the child as the child ages. Some of these studies reflect on the parents' level of responsibility for their child's metabolic management (Grey et al., 2011; Sassmann et al., 2012; Sullivan-Bolyai, 2004). The reader may assume that the improvement in the quality of life and well-being of parents post-intervention was associated with their taking less responsibility for their child's metabolic management, and this can be a dangerous message. There may be multiple reasons why parents become less involved or take less responsibility for their child's metabolic management, which can become a complicated dynamic of various mediating factors interacting with one another. For example, Sassmann et al. (2012) refer to the diffusion of responsibilities. Many of these intervention programmes within the studies promoted practical self-management skills and new strategies between parent and child to empower the parent and to promote the child with an experience of mastery when taking over more age-appropriate responsibility for metabolic management. Furthermore, this diffusion also refers to a better distribution of role responsibilities within families (e.g. involving

fathers) and more extensive support systems (teachers, grandparents, etc.) (Grey et al., 2011; Sassmann et al., 2012; Sullivan-Bolyai, 2004). Grey et al. (2011) reason that the finding of less parental responsibility over time with diabetes management might also be developmentally appropriate, typically occurring with preteens and that metabolic management by the parent is expected to lessen as children reach puberty and take on more of their own management. Some intervention programmes within the studies promoted practical self-management skills and strategies between parent and child to clarify parental responsibilities and developmentally appropriate tasks for children to master in terms of their metabolic management (Grey et al., 2011; Sassmann et al., 2012; Sullivan-Bolyai, 2004), especially occurring in pre-adolescents.

Although this research study does not focus on metabolic management or glycaemic goals of children with type 1 diabetes, this aspect of health remains a major factor in caring for these children and will be reported on briefly. No studies reported any effect of the intervention on the metabolic management of children with type 1 diabetes. Some revealed an increase in metabolic management in both the intervention group and the parental control groups (Ambrosino et al., 2008; Grey et al., 2011). Mackey et al. (2016) claimed that there was no change in the metabolic management of the children, which demonstrated that although parental perception is important, metabolic management of the child may be much more complicated and significantly harder to influence. Monaghan et al. (2011) did not consider metabolic management outcomes despite reporting on these levels at baseline; Pate et al. (2015) postulated that good family functioning and coping with the challenges of type 1 diabetes leads to better metabolic management. Although the subjective experiences of the parents made them believe that the interventions helped them to improve their family dynamics, no measures were recorded to evaluate blood glucose levels before or after the intervention. Sassmann et al. (2012) reported that their biomedical data indicated that most children had stable blood glucose levels at baseline, which remained stable after three months in the DEFIN group; moreover, metabolic management increased significantly in the control group. Sullivan-Bolyai (2004) also reported no differences at six months between the two groups compared with respect to metabolic management and the number of emergency room or acute-care visits.

Limitations

A major limitation of this research study was conceptualizing quality of life. This concept has been defined by many theorists, and several related concepts were found in this review. As improvement in quality of life was very broadly defined by some authors of the studies, those findings were included despite not reaching significant differences in the studies reviewed. Furthermore, only articles available in English were included in the review, and the concept of “quality of life” may be presented differently in other languages and cultural groups. This further links to the lack of literature on ethnic minority groups and the interventions available and needs for parents of children living with diabetes in such groups. Lastly, no specific measure was used to evaluate the outcomes of quality of life. Thus, different ways of assessing this criterion were acceptable. The measure considered required only an improvement in the quality of life and well-being of the parents and did not, for example, value the level of blood glucose of the children as an additional primary outcome – future research may consider a more specific evaluation of interventions.

Conclusion and Recommendations

Despite these limitations, the main contribution of this research study lies in the focus of interventions of the review articles. These studies focused mainly on mastering the management of the young child living with type 1 diabetes in respect of its condition while missing the parent as the focus of the intervention. In these studies, it is suggested that interventions should be tailored with the developmental stage of the child in mind, as well as time intervals since diagnosis, but the strengths and developmental areas of the parent are missed in these interventions. It is unclear how parents were functioning before the interventions or diagnosis, which is important to consider as the baseline for improvement. It would be worth investigating the outcomes if the target group of the intervention is considered at every stage of its development.

More research is needed to explore the development of interventions that take a combination of methods of delivery and different objectives in a programme into account. For example, to explore developmentally tailored programmes in support groups via telephone or online platforms. This would aid in contributing to the more specific needs of parents whilst providing support in a way that will be less time-consuming. In addition, Mackey et al. (2016) also support the rethinking of the delivery of mental health services by training lay community members to deliver a relevant service to reduce healthcare users' costs.

From this review, more research is also suggested, focussing on the development of interventions to improve the quality of life and well-being for parents who have to deal with the challenges of living with a young child with type 1 diabetes. Parents play an important role not only in the immediate management of diabetes but also in how the child will perceive diabetes in future and how the child will think about his/her ability to manage the condition. If parents experience well-being, it will model positive psychological attributes for the child, or even hint at the possibility to live a quality life with diabetes. Future studies on the lived experience of quality of life and well-being for a parent living with type 1 diabetes in a child should be considered, to create a better understanding of what quality of life and well-being actually entails for this group.

Conflict of Interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest. Also, the authors did not receive any funding for this research project.

Author Contributions

All authors contributed to the conceptualisation and writing-up of the article. The first and second author gathered the data and analysed it independently. The third and fourth authors reviewed the final drafts with the first two authors.

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