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PUBLISHED

10 July 2024

CITATION

Santilli, L., Deacon, E., Van Rensburg, E., & Segal, D. (2024). A systematic review of interventions to improve quality of life and well-being for parents of young children living with type 1 diabetes. *Journal of Community Psychosocial Research* 1(1). Article #486.

Research Article

A systematic review of interventions to improve quality of life and well-being for parents of young children living with type 1 diabetes

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Abstract

Many studies have shown a link between parental distress, adherence to the diabetes care plan of their child and the impact thereof on the quality of life and well-being for family members. Still, limited studies propose quality of life interventions for parents of young children living with type 1 diabetes. This research study aimed to systematically review the scientific literature on these interventions to propose guidelines for future intervention development. A systematic review of empirical literature available in various databases, including EbscoHost, SaePublications, Academic Search Premier, ERIC, ScienceDirect, PsycArticles and PsychINFO, SocINDEX, the Cochrane Library and Google Scholar, was conducted to identify intervention studies presenting quality of life and well-being programmes to parents of children living with type 1 diabetes. Data extraction was limited to studies of parents with children of 0 – 11 years old. Seven articles representing different studies met the inclusion criteria. Findings supported the combination of behaviour modification and support interventions delivered via group work or telephone-based methods as the most effective. Furthermore, the timing of interventions varied, while interventions were mostly developmentally tailored. Although most articles reported improved aspects of quality of life or well-being of parents, only one article yielded scientific evidence of improvement. Although interventions focused on various aspects, the lack of focus on parents as the target audience for interventions was evident, emphasising the need for the development of interventions focussing more specifically on the quality of life and well-being of parents of children living with type 1 diabetes. Furthermore, incorporating positive psychology activities in interventions could further benefit the development of the quality of life and well-being of parents of children living with type 1 diabetes.

Keywords: Children with type 1 diabetes, effective interventions, parents, quality of life, systematic review, well-being.

Introduction

A growing body of literature reports on the quality of life of those living with chronic conditions (Bakas et al., 2012; Flanagan et al., 2017; Megari, 2013). This focus on quality of life stems from the positive psychology approach, which promotes a movement from disease to self-efficacy, personal empowerment and positive outcomes to overcome debilitating conditions (Ebrahimi Belil et al., 2018). Quality of life reflects an individual's perception of their position in life and their goals, expectations, standards, and concerns (Teoli & Bardway, 2023). The term is often used with phrases such as satisfaction with life and psychological well-being (Franklin, 2010), while experiencing happiness, meaning and social belonging can serve as aspects of quality of life (Megari, 2013).

Well-being of Parents Caring for Children Living with Type 1 Diabetes

The well-being of parents can be severely challenged by caring for a child living with a chronic condition, such as type 1 diabetes (Streisand & Monaghan, 2014). Diabetes management of the child, for these parents, entails adherence to diabetes care plans, including frequent blood glucose monitoring, managing insulin injections and balancing insulin doses, as well as paying attention to nutritional intake and exercise (Coghill & Hodgkins, 2016; Streisand & Monaghan, 2014). Parents of young children need to be involved in and take responsibility for the management of diabetes as these children may not understand the risks of this illness or command the skills to manage the complex tasks of diabetes independently (Wiebe et al., 2016). These challenges results in physical and psychological strain on parents (i.e. increased stress, added financial burden and lack of sleep due to blood glucose monitoring through the night), that can reach clinically significant levels (such a diagnosis of depression or anxiety disturbance), influencing the normal functioning of these parents (Streisand & Monaghan, 2014; Wiebe et al., 2016), ultimately affecting their quality of life and well-being (Vallis et al., 2016; Wiebe et al., 2016).

Interventions

To assist parents in adapting to living with children with diabetes, various interventions have been devised to reduce the adverse effects for the child (De Domenico & Mendes-Castillo, 2017). These interventions take different forms, including supportive, psycho-educational, and behavioural measures. Published review studies have focused on self-care support for young patients with type 1 diabetes (Pelicand et al., 2013), behavioural interventions to promote diabetes management in children, adolescents and families (Hilliard et al., 2016), and psycho-educational measures for children and young people (Murphy et al., 2006). However, most of these interventions focus solely on the medical aspects of diabetes management, with only a few of these interventions focusing on parental quality of life and well-being from a psychological perspective. Those that focus on the psychological aspects, mainly focus on actions to support parents of adolescents with type 1 diabetes (Eccleston et al., 2015; Hilliard et al., 2016), with very few studies reporting on the effects on the quality of life or well-being for parents of younger children (Zhang et al., 2019).

Eccleston et al. (2015) report that psychological interventions for parents can benefit parents of children with chronic illness in general. Hilliard et al. (2016) report that there were only a few well-developed theory-based behavioural strategies (such as Family Teamwork and Behavioural Family Systems Therapy) that had the potential to promote the well-being of the family, as well as optimal glycaemic management in middle school age and

adolescent age groups, but that these approaches were not adapted to younger children. Although it can be anticipated that parents of younger children might also benefit from some of the above interventions, it should be noted that they face different management needs that can be very challenging (Streisand & Monaghan, 2014). Physiological factors further complicate daily management of diabetes for younger children with type 1 diabetes, as well as their cognitive, behavioural and socio-emotional developmental capacities (Streisand & Monaghan, 2014).

Problem Statement

Several studies emphasise that parents' well-being, positive family functioning and coping with the challenges of type 1 diabetes are associated with metabolic management (that is, of HbA1c/blood glucose levels) of their children and adolescents (Delamater et al., 2018), which is the outcome of diabetes management. Good metabolic management is linked to less harmful, short- and long-term physical complications and an enhanced quality of life and well-being for the patient with diabetes. As parents often judge their competence to manage the requirements of the child's diabetes (as measured by HbA1C) – and this influences their quality of life and well-being (Streisand & Monaghan, 2014) – it is essential to implement interventions designed to reduce stress and improve coping to promote the parent's and child's well-being and enhance the quality of life of the parents as metabolic management can be an ongoing challenge (Streisand & Monaghan, 2014). Furthermore, providing social support for children and their parents managing their child's diabetes care plan can reduce the emotional distress for the family, assist them in managing the condition, offer a sense of cohesion and enhance their quality of life and well-being (De Domenico & Mendes-Castillo, 2017).

Goal of Research Study

This research study aimed to report on scientific literature focusing on interventions that impact the quality of life and well-being for parents of young children with type 1 diabetes. The outcome can further be used to set guidelines for these parents' interventions. A greater understanding of the focus, content and method of delivery of these measures – those that improved quality of life and well-being and those that did not – will assist in developing more effective interventions to improve the conditions at home where a child is living with type 1 diabetes. Therefore, the specific review question was as follow: According to scientific literature, what does effective interventions to improve the quality of life and well-being of parents of young children living with type 1 diabetes entail?

Method of Investigation

Approach

This systematic review followed the Preferred Reporting Items for Systematic Review and Meta-analysis (PRISMA) statement (Moher et al., 2009). Ethical clearance was obtained from the North-West University Research Regulatory Committee (NWU-RERC - ethics number NWU-HS-2018-0092).

Search Strategy

The research team developed the search terms in collaboration with the faculty librarian (North-West University). The predefined search terms used to search for relevant scientific literature included parent or caregiver or family or mother or father AND child or children or paediatric or young person AND program or intervention or training or strategy or plan or regiment AND type 1 diabetes or diabetes mellitus AND well-being or wellbeing or well-being or quality of life. The following databases were searched: EbscoHost, SaePublications, Academic Search Premier, ERIC, ScienceDirect, PsycArticles and PsychINFO, SocINDEX, the Cochrane Library and Google Scholar. The initial search was conducted in October 2018 and was updated with the final search in December 2023. The reference lists of all potentially relevant review studies that the electronic database searches on specific keywords may not have captured were also searched and included to locate all appropriate published literature.

Inclusion and Exclusion Criteria

Titles and abstracts of scientific literature were independently screened by two researchers according to the following criteria: (a) parents who manage type 1 diabetes of their young child; (b) babies, toddlers and primary-school children between 0 and 11 years of age (pre-adolescents/ before puberty); (c) any types of interventions for parents that has a child/children with type 1 diabetes; (d) outcomes related to quality of life and well-being; (e) English language articles; (f) full-text articles and PhD dissertations; and (g) searched within the period from 2000 up to 2023. All kinds of designs were included in the research study. Studies focusing on type 2 diabetes were excluded. No specific measure was used in this review to assess the quality of life or well-being outcomes, but all results related to quality of life and well-being were included as outcomes for this research study. The reader should note that it was decided not to include metabolic management as an eligible criterion for this study despite the research's inter-correlation as this would limit available articles even more. Secondly, assessing the findings of metabolic management outcomes post-intervention may be viewed as another independent study due to its complexity. Furthermore, interventions developed by psychologists derive from psychologically rooted methodologies and not from medical models, as this may act beyond the scope of practice for the psychologist.

Study Selection Process

Studies identified in the searches were combined into a single list, and duplicates were removed. The first and second researchers independently screened these studies based on the title and abstract. After completing the screening, the researchers met to compare which studies should be included and to discuss those on which they disagreed. After the researchers agreed on the studies to be included, the full-text documents were downloaded onto an electronic platform that both researchers could access. Both researchers reviewed these full texts to determine which studies are eligible for quality assessment and data extraction. A third researcher was available for consultation should the first and second researchers not agree on the status of a study, but it was optional to involve the researcher.

Quality Review

Quality Assessment and Critical Appraisal were done before the data extraction to ensure that the review had the best research available. The two independent researchers screened and scored the full-text articles using the Quality Criteria Checklist (QCC, ADA, 2008) for quantitative studies and the Critical Appraisal Skills Programme (CASP, 2006) for qualitative studies to identify methodological weaknesses. These assessment tools provided relevant questions about specific criteria that had to be met to qualify as good-quality research. Some examples of the quantitative assessment tool were whether the research question was clearly stated and if the selection of participants was free from bias; whether the study groups were comparable; was blinding used to prevent bias; whether the studies provided information on biases and limitations in the conclusions etcetera (QCC: ADA, 2008). The assessment tools that measured the quality of qualitative articles included questions about the validity of the research results, how the recruitment strategy was conducted, the relationship between the researcher and participants if ethical aspects were considered, etcetera (CASP, 2006).

The first and second researchers conducted their quality assessment using these checklists to identify methodological weaknesses in studies. A grid with Yes (Y), No (N), Can't tell (U), and N/A for each item on the checklist was designed in which inclusion and exclusion were condensed by the two reviewers to ensure transparency in checking whether the articles were of good research quality. Articles that scored an overall "Yes" in the agreement were included, and those that scored an overall "No" in the agreement were excluded. A mutual agreement on which studies adhere to the quality stipulated in the checklists followed. The third researcher was available for an additional opinion on studies if not agreed upon by the researchers, but this was unnecessary.

Data Extraction

The first and second researchers agreed upon the data to be extracted from the articles before the first researcher did data extraction. The second researcher checked and revised the extracted data until a consensus was reached. The main findings as related to the inclusion criteria were extracted from the articles in electronic form into a table format (see **Table 1**) under the following headings: Reference and study design; Main objectives of the study and description of the intervention; Quality of life and well-being measurement and outcomes; Study conclusion related to the research question.

Table 1

Data Extracted from Literature Search

	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
1.	Ambrosino et al. (2008). <i>Short-term effects of coping skills training in school-age children with type 1 diabetes.</i> Randomised control trial group intervention: Coping skills training compared with group education.	This study evaluated the short-term efficacy and feasibility of a coping skills training intervention for school-aged children with T1D and their parents compared with an educational group intervention. The coping skills training intervention aimed to increase the children's and parents' sense of competence and mastery by retraining inappropriate or non-constructive coping styles and forming more positive styles and patterns of behaviour. The group education intervention covered age-appropriate topics such as intensive insulin regimens (multiple daily injections or use of a pump), carbohydrate counting, sports, and sick days.	The quality of life of the child was measured by the Diabetes Quality of Life Scale for Youth (DQOL), but no measures of the parents' quality of life were reported in the study. Parents completed the Family Adaptability and Cohesion Scale (FACES) and showed modest positive changes in many areas of psychosocial adaptation in both groups. HbA1c measures indicated an increase in metabolic control in both groups. Researchers averred that these findings should be interpreted with caution as sample sizes were small, group sizes were unequal, variables at baseline were different, and many participants used pump therapy, which has been linked to better quality of life in general.	Although the quality of life of parents was not measured, positive changes in adaptation could be argued to increase their quality of life. This was evident for both intervention groups. Continuing longer-term follow-up of this cohort will help determine whether being introduced earlier to coping skills training would enhance outcomes and help prevent the deterioration in glycaemic control and increased family conflict.
2.	Grey et al. (2011). <i>Coping skills training for parents of children with type 1 diabetes.</i> Randomized control trail group intervention: coping skills training compared with group education	In this study the effectiveness of a group educational intervention for parents of children with T1D was compared to that of a coping skills training intervention. The interventions in this study were similar to those in that of Ambrosino et al (2008), including coping skills training and a group education intervention.	The Parents Diabetes Quality of Life Questionnaire was completed by parents. This measure was adapted by Vandagriff, and colleagues in 1992 to assess parents' perception of the impact of diabetes treatment on their general satisfaction with life. Although there was no significant improvement reported in any of the intervention groups, parents receiving any of the intervention reported significantly better parental quality of life with time. Although children's metabolic control worsened over time, mean values at 12 months were still within the recommended levels in this well-controlled sample.	In this study parents in both intervention groups reported significant improvement in parental quality of life over time.

3.	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
3.	Mackey et al. (2016). <i>The feasibility of a pilot intervention for parents of young children newly diagnosed with type 1 diabetes.</i> Randomized control trial: Phone-based intervention compared with education programme.	This study investigated the feasibility and acceptability of a phone-based intervention for parents of children newly diagnosed with diabetes. The Young Child–Newly Diagnosed intervention consisted of five sessions with a telephone counsellor (content adapted from Young Child Project of Monaghan et al., 2011) and four calls from a trained peer parent for support. The content of the first session was based on developmentally tailored education, cognitive-behavioural strategies to support parents in their daily management of their child’s diabetes, and parenting strategies related to young children with T1D.	The Pediatric Quality of Life Inventory (PedsQL) was used to obtain the parent’s report of their child’s health-related quality of life. Despite the intervention being well-received, there were no changes in HbA1c, demonstrating that although parental perception is important, changes to metabolic control may be significantly harder to achieve.	Although the parents’ perception of their child’s quality of life was important and might influence his/her own well-being, no other measures of positive adjustment or well-being were reported on. This intervention had a very strong educational and support focus, but parents did not experience an increase in support after completion of the intervention.
4.	Monaghan et al. (2011). <i>Supporting parents of very young children with type 1 diabetes: Results from a pilot study.</i> Randomised control trial: Phone-based support intervention compared to control group.	The objective of this study was to assess the initial efficacy and feasibility of a telephone-based supportive intervention for parents of young children with type 1 diabetes. The intervention was designed to enhance parental quality of life through the reduced parental stress and increased social support, and to improve daily management of their child’s diabetes. The Supporting Parents programme was outlined in social cognitive theory, including increasing support and efficacy for diabetes management tasks, promoting mastery, learning through skills training (e.g. problem-solving), and encouraging the use of cognitive-behavioural coping strategies.	No specific measure of quality of life was used. Although a decrease in parenting stress and increase in social support were reported from baseline to first follow-up measurement, there were no significant group differences at follow-up. Participants further indicated high satisfaction with the intervention’s content and telephone-delivery format, which were not present in the control group. This study did not take into consideration the effect of the intervention on metabolic control, although measured at baseline.	No specific measure of quality of life was used or reported on, but the authors (Monaghan et al., 2011) argued that results from this intervention is promising to enhance parents’ emotional functioning and quality of life.
5.	Pate et al. (2015). <i>Support group for parents coping with children with type 1 diabetes.</i> Mixed-method group intervention including quantitative and qualitative methods.	The purpose of this study was to assess parental satisfaction with participation in the support group and to gather their perceptions of the impact of the intervention on living and coping with their children’s T1D. The key objective of the intervention was to help parents reflect on their roles as parents, to enhance “attunement” to children’s needs, connection and more profound understanding between a parent and child, as well as to improve their coping and ability for practical and functional living with the child’s diabetes.	Data were gathered using a self-evaluation questionnaire consisting of 2 parts: The first part was related to parents’ well-being in the group, whereas the second part consisted of open-ended questions regarding, in part, the effect of changes that the group might have brought to the participant. Two themes from the data gathered that related to the quality of life of parents were: As a parent, which related to how participants served each other as models of emotional regulation; and Transformation of the family dynamics, indicating that parents believed the intervention helped to improve family dynamics.	The results in this study did not specifically relate to the parents’ quality of life, but rather to the well-being of the group of parents involved in the intervention.

	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 Elterntraining 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.

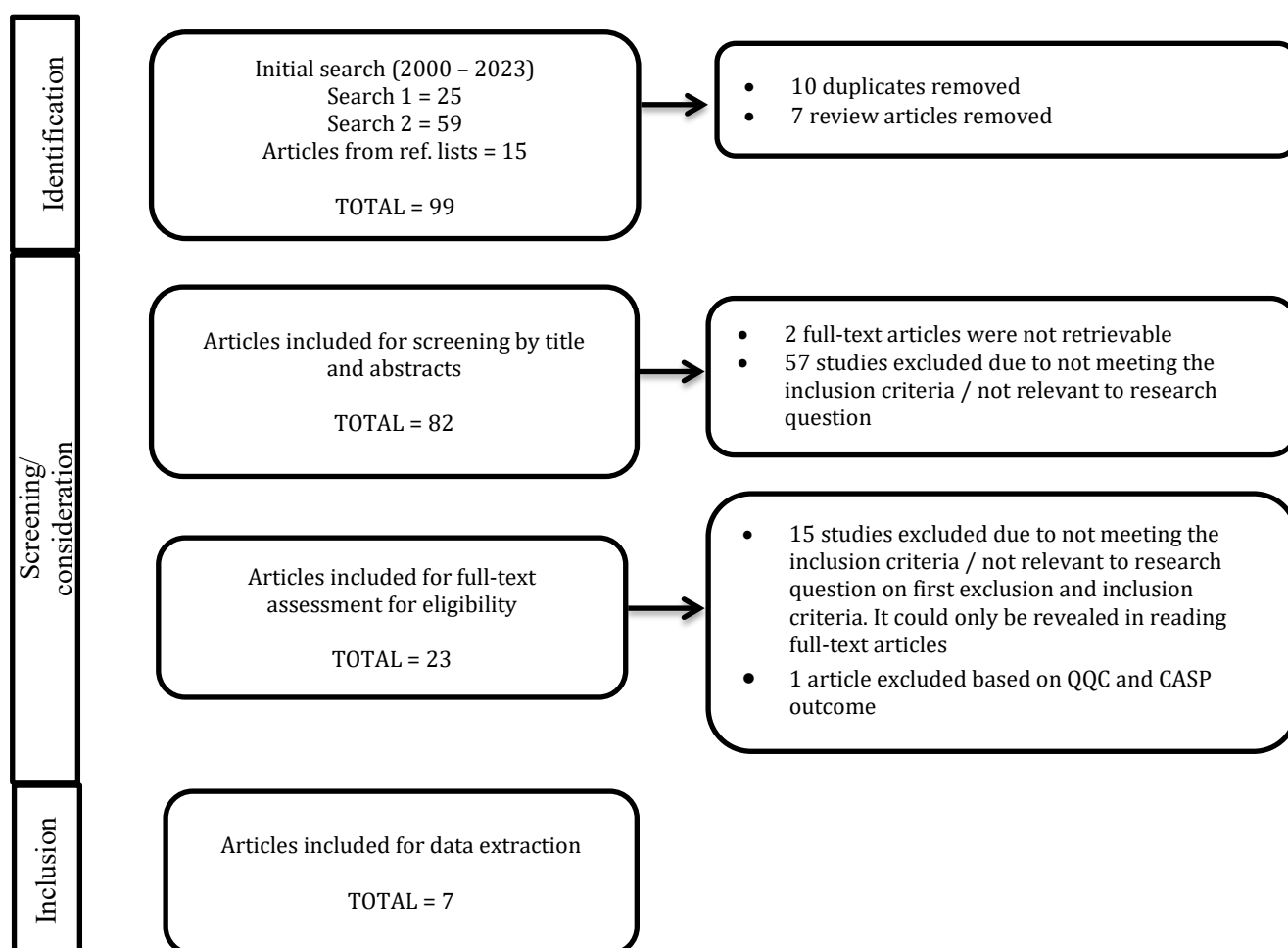
Findings

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.

Acknowledgements

The authors want to thank all parents who took part in the reviewed articles – your inputs are invaluable in the development of appropriate interventions for parents of children living with type 1 diabetes.

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