

Effective interventions to improve quality of life for parents of young children living with type 1 diabetes: A systematic review

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Mini-dissertation submitted in partial fulfilment of the
requirements for the degree Masters in Clinical Psychology at
the North West University

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DECLARATION BY AUTHOR

I declare that this study, *Effective interventions to improve quality of life for parents of young children living with type 1 diabetes: A systematic review*, is my own work and that I adhered to the referencing and editorial style as prescribed by the Publication Manual (6th edition) of the American Psychological Association (APA) to ensure that all sources used in this dissertation are acknowledged.

Furthermore, the co-authors, Dr Elmari Deacon (supervisor) and Prof Esme van Rensburg (co-supervisor) agree that this study does reflect the research regarding the subject matter. The co-authors of the article that forms part of this mini-dissertation, hereby give permission to the candidate, Linda Santilli, to include the article as part of a master's dissertation and that the candidate may submit the article for publication in the *Journal of Diabetes Research*.

This document has been submitted to *Turn-it-in* to provide the researchers of the North-West University with a report that stipulate the percentage of similarities detected in the mini-dissertation in relation to international databases. The content in this dissertation falls within the acceptable range (Index: 21%).



Linda Santilli

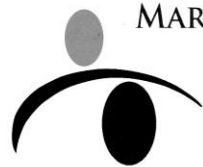
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I, Marianne (Susanna Maria) Strydom, hereby confirm that I acted as editor of the dissertation titled

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Psalm 139: “Of ek reis en of ek oorbly, U bepaal dit, U is met al my paaie goed bekend. Wat U gedoen het, vervul my met verwondering, hoe wonderlik is U gedagtes vir my.”

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SUMMARY

Many studies have shown a link between parental distress and the effect thereof on the successful adherence of the diabetes care plan, as well as the impact thereof on the quality of life for all family members. In this study, the aim was to systematically review, synthesise and integrate evidence from literature pertaining to effective interventions that improve the quality of life for parents of young children living with type 1 diabetes.

A comprehensive electronic search from 2000 to 2018 using electronic databases and citation tracking was used. The search identified 67 articles after ten duplicates and 7 review articles were removed. The reviews were cited in search of additional relevant articles of which 15 were identified. In total 82 articles were retrieved for further inclusion and exclusion procedures carried out by both reviewers, whereafter only eight (8) articles were included. After reading full-text articles, further inclusion and exclusion criteria pertaining to the quality of the articles and critical appraisals were considered with each study, and seven articles were identified for inclusion in this review. Data extraction was captured in a table format, including primary characteristics of each article.

This systematic review yielded limited yet valuable findings in terms of interventions that improve parental and family wellbeing as well as overall quality of life, despite not reaching significant differences between experimental and control groups. The most effective methods of delivery are interventions that are based on group work or telephone-based programmes that strongly emphasise the component of support regardless of content, as parents often feel isolated when dealing with this life-threatening disease. Psycho-education, cognitive behavioural therapy and coping skills training programmes that were tailored to child developmental phases, were secondary findings pertaining to the effectiveness of interventions investigated in this review. Parents reported diabetes-specific and development-specific information as informative and relevant to their circumstances, as they feel incompetent and anxious at times.

These findings hold promising ideas that can contribute to the future development of effective interventions. In order to promote healthy outcomes and improve the quality of life for the whole family living with children diagnosed with type 1 diabetes in South Africa, the limitations regarding sample size, diverse heterogeneous groups as well as steps to increase rigour and specify more specific quality of life outcomes in this review, should be taken seriously when planning future research.

Keywords: *parents, children with type 1 diabetes, effective interventions, quality of life, systematic review*

OPSOMMING

Vele studies dui daarop dat daar 'n verband is tussen ouerverwante stres en die effek daarvan op die suksesvolle nakoming van die diabetes sorgplan, asook die impak daarvan op die lewenskwaliteit vir alle lede van die gesin. Hierdie sistematiese literatuurstudie poog om literatuur wat betrekking het op effektiewe intervensies wat lewenskwaliteit bevorder vir ouers met kinders met tipe 1 diabetes te sintetiseer en bevindinge te integreer.

'n Omvattende elektroniese soektog op databasisse en vanuit aanhalings van ander studies het 67 artikels opgelewer, nadat 10 duplikaatstudies en sewe sistematiese literatuurstudies verwyder is. 'n Verdere 15 studies is geïdentifiseer en ingesluit nadat verwysingslyste van hierdie literatuurstudies ondersoek is om addisionele relevante artikels te bekom, en bring die totaal op 82 studies. Agt studies is uitgesluit op grond van titels en abstrakte wat aan die navorsingsvraag en aan die insluitingskriteria voldoen. Studiegehalte navorsingskriteria is met al agt studies gedoen, waarna sewe studies in die finale produk ingesluit is vir die sistematiese verkenning en ontleding van data. Studies wat gepubliseer is tussen die jare 2000 tot 2018, is vir die literatuurstudie oorweeg.

Die studie het beperkte maar tog waardevolle bevindinge opgelewer in terme van intervensies wat die lewenskwaliteit en welstand van ouers en die hele gesin bevorder, ten spyte daarvan dat dit geen statisties beduidende verskille tussen die eksperimentele en kontrolegroepe opgelewer het nie. Groepwerk en telefoongebaseerde programme met 'n sterk ondersteunende komponent, is as die belowendste metodes van dienslewering geïdentifiseer, aangesien ouers gereeld geïsoleerd voel in die hantering van hul kind met hierdie lewensbedreigende toestand. Programme wat opleiding in psigo-opvoeding, kognitiewe gedragsterapie en hanteringsvaardighede bied, en dit op so 'n wyse doen dat kinders se ontwikkelingsfases in ag geneem word, was sekondêre relevante bevindinge met betrekking tot hierdie studie. Ouers het gerapporteer dat diabetes-spesifieke en ouderdomspesifieke inligting relevant en informatief is omdat hulle onbevoegd en angstig voel.

Ten slotte, hoewel hierdie studies geloofwaardige idees inhou vir die ontwikkeling van effektiewe intervensies, is dit nodig om die beperkinge van die studie insluitend die steekproefgrootte, a meer diverse heterogeniese groep sowel as stappe om deursigtigheid te verbeter en meer spesifieke meetingsinstrumente vir lewenskwaliteit uitkomstes te spesifiseer, ernstig te oorweeg. Sodoende sal goeie uitkomstes en verbeterde lewenskwaliteit vir die hele familie wat leef met 'n kind wat gediagnoseer is met tipe 1 diabetes, 'n moontlikheid word.

Sleutelwoorde: ouers, kinders met tipe 1 diabetes, effektiewe intervensies, kwaliteit van lewe, sistematiewe oorsig

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OUTLINE OF STUDY

Article format

This mini-dissertation is submitted in partial fulfilment of the requirements for the completion of the Magister of Artium degree in Clinical Psychology at the Potchefstroom Campus of the North-West University. This document is written according to the NWU requirements for this method of presentation and prepared for a specific journal of which the author guidelines are provided at the beginning of the manuscript. This research involved the expertise and effort of Ms Linda Santilli and Dr Elmari Deacon. Prof Esmé van Rensburg was the co-study supervisor.

This dissertation consists of three sections:

Section 1: Background to the study

This section reflects on the development of the research proposal and includes the introduction, a brief literature review, the rationale and aim of the study, methodology and ethical considerations.

Section 2: Manuscript in Article Format

Section 2 presents a systematic review of effective interventions to improve the quality of life for parents of young children living with type 1 diabetes. This article will be submitted for publication in the *Journal of Diabetes Research*. Please take note that Section 2, comprising of the article and the reference list, is presented according to the author's guidelines and requirements set by this journal. The in-text citations, as well as the references of Sections 1 and 3, are prepared according to the APA (American Psychological Association) publication guidelines.

Section 3: Conclusion, Limitations and Reflection

In this section the conclusion will be drawn, followed by limitations. Lastly, the researcher will reflect upon the entire research process.

Page numbers: Pages are numbered from the title page and proceed from there onwards.

SECTION I: BACKGROUND TO THE STUDY

Introduction and Motivation

Type 1 diabetes is a chronic lifelong condition defined as an autoimmune destruction of insulin producing beta cells in the pancreas, resulting in irregular blood glucose levels which can consequently determine life or death in individuals (Erickson et al., 2015; Goldberg, Sharf, & Wiseman, 2017; Hamilton, Knudsen, Vaina, Smith, & Paul, 2017). Living with diabetes can have serious physical short- and long-term complications for children (Chiang, Kirkman, Laffel, & Peters, 2014; Hamilton et al., 2017). These complications include neurocognitive dysfunctionalities in children (Ryan, 2008; Schwartz, Axelrad, & Anderson, 2014), as well as blindness, kidney failure, amputation, cardiovascular illness (Kneck, Klang, & Fagerberg, 2011), neuropathy, seizures, loss of consciousness, with a risk of coma and early mortality (Hunter, 2016). In addition to the physical impact of living with type 1 diabetes, Delamater, De Wit, McDarby, Malik and Acerini (2014) report that psychological distress and psycho-social problems are secondary health complications in this chronic condition and include increased risks for comorbid psychiatric disorders such as anxiety and depression of the child or parents (Delamater et al., 2001; Hunter, 2016; Streisand & Monaghan, 2014), as well as difficulty with adjustments of siblings within these family systems (Wennick & Huus, 2012) and challenges in cohesion in marital relationships (Dale, 1997; Goldberg et al., 2017).

Regardless of these health risks, successful management of type 1 diabetes can result in a good quality of life for the individual and the whole family (Brown, Fouche, & Coetzee, 2010). The most important predictor of a decrease in morbidity and mortality due to diabetes complications is the basic principle of keeping glycaemic control as optimal as possible by daily insulin administration, restricted eating schedules and carbohydrate intake monitoring (Erickson et al., 2015; Hunter, 2016; Walker et al., 2016). Despite active research and developments in drugs and

technology, there are still barriers in adherence to diabetes management in order to minimise associated complications (Anderson & McKay, 2011; Murphy, Rayman, & Skinner, 2006). These complexities include the developmental age of the child, the type, quantity and timing of specific food intake, the required level of physical activity and regular monitoring of blood glucose and insulin administration (Hunter, 2016; Patton, Dolan, & Powers, 2006).

Behavioural, cognitive and psycho-social management are vital variables in the outcome of wellbeing and health for these children and their parents (Hunter, 2016), which necessitate the development and evaluation of effective interventions to guide those living with diabetes in managing these variables more effectively.

Children living with Diabetes

The American Diabetic Association (ADA, 2010) found that three-quarters of all cases of type 1 diabetes are diagnosed in individuals under the age of 18 years. According to the International Diabetes Federation (IDF, 2003), a projected 65 000 children under the age of 15 develop type 1 diabetes each year. In the UK there are an estimated 26 500 children living with type 1 diabetes (Royal College of Paediatrics and Child Health, 2016 cited in Hamilton et al., 2017), and in the United States 15 000 children are diagnosed with diabetes each year (Goldberg et al., 2017). Unfortunately no clear statistics were found for South Africa.

Children diagnosed with type 1 diabetes at any stage between infancy and approximately eleven years (middle childhood) cannot yet fully manage their condition by themselves. They depend on and require adult supervision in general and specifically in following the diabetes care plan (Hunter, 2016) that needs to be followed to successfully manage type 1 diabetes and prevent high risk conditions related to diabetes (Chiang et al., 2014). Parents play a significant role in improving diabetes management and the implementation of interventions (Delamater et al., 2001).

Supervising a child living with diabetes includes an extensive amount of planning, organising, effort, trust in others and general alertness, and this can be challenging and disrupt normal parenting (Chiang et al., 2014; Hunter, 2016; Streisand & Monaghan, 2014). These

complex management demands leave parents worried about interpreting and following sufficient glycaemic control levels, which increases the risk of anxiety and feelings of stress, depression and frustration about all the responsibilities (Erickson et al., 2015). Self-doubt and isolation are also common for parents managing their child's health (Streisand & Monaghan, 2014). Younger children are even more at risk for hypoglycaemic inconsistency, particularly at night time, which consequently impacts on parents' sleeping patterns (Hunter, 2016; Streisand & Monaghan, 2014). The high degree of stress experienced by parents has repercussions on the parents' adjustments, their children's adjustments, the glycaemic control, adherence to treatment and psychological wellbeing of the family (Eccleston, Fisher, Law, Bartlett, & Palermo, 2015; Moreira & Canavarro, 2016). Interventions are needed to help parents cope with these challenges.

Interventions

Different intervention categories, which include educational interventions, psycho-social interventions and behavioural interventions, can be identified. *Educational interventions* focus on developing or enhancing learning methods to improve self-management of type 1 diabetes by providing knowledge of the condition (Winkley, Landau, Eisler, & Ismail, 2006). The 2011 Guidelines of the International Diabetes Federation/International Society of Paediatric and Adolescent Diabetes (IDF/ISPAD) state that on the most basic level of intervention, childhood-onset diabetes management requires that children and their caregivers have access to effective basic education and practical skills in order to manage the onset, course and long-term concerns of diabetes from the phase of initial adjustment of the condition to life-long management (Dhada & Blackbeard, 2014).

Psycho-social interventions focus on psychological and social factors within the child, parent or families (Delamater et al., 2001; Harkness et al., 2010; Hunter, 2016). More age appropriate biomedical and psycho-social interventions are of utmost importance, as well as interventions focusing on the dynamics between the above mentioned, as this could be important when motivating for the quality of life and adherence to the diabetes care plan of parents of children

diagnosed with type 1 diabetes (Dhada & Blackbeard, 2014; Murphy et al., 2006). Delamater, Anderson, Skinner, Wysocki and Swift (2011), as well as Hilliard, Powell and Anderson (2016) report that psycho-social interventions can be effective in improving biomedical glycaemic control and healthy behaviour. Aspects such as family inclusion, family teamwork, goal-settings, self-management, defining responsibilities in the form of behavioural contracts and enriching communication skills of caregivers and children can enhance adherence to the diabetes care plan, collaboration and conflict prevention or resolution (Delamater et al., 2011; Hilliard et al., 2016). Furthermore parents may need specific guidance about their child's developmental phase and best practice for negotiating, for example, eating habits or managing the young child's activity levels with regards to glycaemic control (Streisand & Monaghan, 2014). Hunter (2016) emphasises the importance of a bio-psycho-social approach in managing the totality of the condition.

Behavioural interventions refer to psychological principles applied to facilitate children in making desirable changes to their behavioural patterns and their lifestyle (Hampson et al., 2000). There is evidence for behavioural interventions to improve physical, psychological and social outcomes, including problem-solving, cognitive-behavioural therapy, motivational interviewing, patient empowerment, family-based approaches, technology-assisted behavioural approaches and family teamwork (Hunter, 2016). Many younger children under the age of seven often find it difficult to comply with the discipline of their parents and present, with age, developmental behavioural problems (Patton et al., 2006). It is difficult for parents to understand and facilitate this behaviour, even in children without type 1 diabetes. Patton et al. (2006) reports a significant correlation between parents' use of an ineffective or coercive parenting style, especially with children's dietary deviations and glycaemic control (Patton et al., 2006).

Interventions should not only include parents, but the whole family, as Delamater et al. (2001) argue. The family should be a central part of an intervention. There is a need to improve problem-solving, communication and behavioural skills management in relation to optimise diabetes management and better the quality of life outcomes for the whole family (Hunter, 2016).

Streisand and Monaghan (2014) reported that there are limited tailored interventions, specifically developed to assist families in facilitating parents to the psychological adjustment and better management of the demands of the diabetes care plan for their children. This type of support might improve the quality of life for both child and parent. Harris and Mertlich (2003) also come to the conclusion that positive outcomes have shown to be effective from family-based psycho-social treatment plans in managing this condition and all its facets.

Interventions could be tailored for the individuals or presented in groups. Individualised treatment might include psychological therapies to acknowledge problems experienced by a person living with type 1 diabetes and to reduce psychological distress and improve adherence (Winkley et al., 2006). Studies emphasised the possibility for more individualised or tailored interventions and continuing education for parents of children to adapt to the needs of each child as they develop, and require adequate support in adherence to diabetes management as well as personal and family psychological wellbeing (Chiang et al., 2014; Hilliard et al., 2016). Studies also indicate that having professional group involvement in the form of training programmes for parents in managing their child's diabetes care plan, has favourable outcomes for glycaemic control and the quality of life for all members, as it enhances parents' responsibility (Murphy et al., 2007). A number of studies (Hilliard et al., 2016; Hunter, 2016; Streisand & Monaghan, 2014) emphasise a gap between guidelines for the clinical care of young children diagnosed with type 1 diabetes and effective mental health interventions that can integrate the guidelines and psycho-social aspects for successful adherence to the diabetes care plan and psychological wellbeing.

Interventions focus on treatment adherence, the quality of life of parents and their children, or a combination of the two. For the purpose of this study, effective interventions will be seen as those interventions showing improvement in the quality of life of parents. Quality of life refers to the quality of health and includes the subjective experience of an individual's physical, mental and social health (Wright, 2013). Parents of children with type 1 diabetes are more vulnerable to concerns about childrearing and their child's wellbeing, which can have an impact on the quality of

life for both parent and child (Eccleston et al., 2015; Moreira & Canavarro, 2016; Moreira & Frontini, 2014). Literature identified the need for more robust trials focussing on parenting interventions for parents of children with type 1 diabetes (Lohan, Morawska & Michell, 2015). It appears that basic educational intervention programmes that are included in routine paediatric diabetes care, seem to be effective in some settings, but not as effective in other settings and the need for individualised interventions to target different stages, ages, risks and needs in individuals, developed (Hilliard et al., 2016; Murphy et al., 2006). According to Lohan et al. (2015), the role of psychologists is to integrate behavioural interventions and practical guidance into health care systems by translating research to practice. A further role would be to investigate how to implement effective interventions in routine paediatric diabetes care systems and to train mental health providers or lay community members to assist with interventions (Hilliard et al., 2016). This study aims to investigate effective interventions to improve the quality of life for parents of young children living with type 1 diabetes. The research question for this study is:

What does effective interventions to improve the quality of life of parents of young children living with diabetes entail?

Objectives

The objective of this study is to describe effective interventions available to improve the quality of life of parents of young children living with type 1 diabetes. Within this objective the researcher aims to identify and describe current research on effective intervention programmes to improve the quality of life that have been developed and implemented for parents of young children. This is an individual study, although it will contribute to further diabetes and wellness research done at the North-West University. Once an overview of which interventions improve the quality of life for parents of these young children is established, research can be directed to developing interventions in order to promote healthy outcomes and promote wellbeing in families with children diagnosed with type 1 diabetes in South Africa.

Research Approach and Design

Systematic reviews are quoted a '*gold standard*' research approach in order to synthesise literature findings on related studies exploring the same question (Booth, Papaioannou, & Sutton, 2012; Dickson, Cherry, & Boland, 2014). This type of review provides clear informative answers to the specific research question (Dickson et al., 2014), and provides researchers with up-to-date growing literature in digestible formats (Gough, Oliver, & Thomas, 2012).

This study shall adhere to the methodology of a systematic review. Systematic research reviews are transparent and promote rigour, reliability and relevance which are central themes in good quality research (Grant & Booth, 2009). This type of review is different from a rapid review in terms of the quality of appraisal that is implemented and that it seeks to draw together all known knowledge on a topic area using more time to conduct the search and synthesise the data (Grant & Booth, 2009). Gough et al. (2012) emphasise that it is often ethically necessary to review what has been done on a specific topic of interest (Gough et al., 2012) such as interventions on the quality of life for parents of children with type 1 diabetes, before one can intervene. The benefit of a systematic review is to inform the researcher and readers of all previous research on this specific topic, how it is understood, how studies might differ and what limitations there are. From this platform, new research can be conducted (Gough et al., 2012) or findings may be used to make decisions about developing interventions or making changes to policies (Dickson et al., 2014). The study must be transparent in the reporting and must be able to be replicated to ensure its level of high quality (Grant & Booth, 2009).

A systematic review has specific guidelines or methods to adhere to when conducting a review in order to assure its transparency (Gough et al., 2012). Aspects of transparency to take into consideration are publication bias, thus to include all studies which report both positive and negative findings, also searching for grey literature that might not be in locations like popular databases, the implication of language bias and, lastly, abstract versus full text biases (Dundar & Fleeman, 2014). Furthermore the inclusion and exclusion criteria are of utmost importance (Dundar

& Fleeman, 2014). Cochrane emphasised the update of scientific knowledge by means of providing guidelines by the Cochrane Collaboration or the NHS Centre for Reviews and Dissemination (Grant & Booth, 2009) to ensure this quality of conducting research and the quality of reporting the findings (Booth et al., 2012). These scientific guidelines include strategies that are used to limit bias by conducting a very specific systematic search and critical appraisal thereof. Once that is done, findings from the topic are put together to create something new from separate components, thus a concise synthesis of all relevant studies (Dickson et al., 2014; Gough et al., 2012; Wright, Brand, Dunn, & Spindler. 2007).

Method

Booth et al. (2012) and Wright et al. (2007) identified critical stages in performing a systematic review that differs from a rapid review to ensure utmost transparency. Boland, Cherry and Dickson (2014) redefined and distinguished these stages by describing nine well-defined and transparent steps. These reported stages and steps are described below and is the research design that has been partially followed and will continue to be followed in this review:

Step 1: Scoping Searches - These will be conducted in order to write the protocol. In this first step the researcher will search for and identify literature which will guide her to clearly define a good quality research question and define the inclusion criteria (Wright et al., 2007). Defining the review question determines the ‘map’ or system that can be followed to answer the question (Cherry & Dickson, 2014). In order to define the question, the protocol includes the population, intervention, comparator and outcome formula (PICO) (Cherry & Dickson, 2014). Table 1 sets out the formula that applies to this study (see page 79). The PICO formula will be used to define the research question as follows:

Table 1: PICO Formula Applied to this Study

Review Question	To describe effective interventions to improve the quality of life among parents of children aged 3 to 11 years with type 1 diabetes
Population	Parents of children between the ages of 3 and 11 years diagnosed with type 1 diabetes and managing the child's condition
Intervention	Educational, psycho-social and behavioural interventions
Comparison	Effectiveness of different interventions
Outcome	The quality of life

A feasibility test was conducted on the North-West University Library Catalogue on 18 April 2017 with the help of the assistant librarian. Keywords included: parent or caregiver or family or mother or father AND children or paediatric or young person AND interventions AND type 1 diabetes or Diabetes Mellitus. The initial search (abstracts only) indicated 865 available articles within a year limitation of 2005 to 2017. An additional feasibility test was conducted again on 30 July 2017. More inclusive narrowed-down keywords were used: parent or caregiver or family or mother or father AND children or paediatric or young person AND interventions or strategies or best practice AND type 1 diabetes or Diabetes Mellitus AND family or psycho-social or parent-child AND well-being or wellbeing or well being. The secondary search (abstracts only) indicated 62 available articles within a year limitation of 2005 to 2017.

After the scoping search, the research question will be identified and used as the primary research question that guides the process of conducting the review (Booth et al., 2012; Cherry & Dickson, 2014). The research protocol describes the specific method of how the review will be conducted before retrieving any data (Cherry & Dickson, 2014). The main objective is to minimise bias (Brunton, Stansfield, & Thomas, 2012). The protocol includes the methods for the search, the screening and selecting of data, the quality assessment, the data extraction procedure and the process of analysis, which will be discussed next (Booth et al., 2012; Cherry & Dickson, 2014).

A critical step in performing a systematic review, is stipulating well-defined inclusion and exclusion criteria, as this improves the quality of high-level searches (Booth et al., 2012; Cherry & Dickson, 2014; Wright et al., 2007). Refer to Table 2 for the detail regarding the consideration for initial inclusion and exclusion based on titles and abstracts (see page 70).

Table 2: Initial Inclusion and Exclusion Criteria on Titles and Abstracts

Inclusion Criteria	Exclusion Criteria
• Parents who manage the type 1 diabetes of their young child • Toddler and primary-school age between 3 and 11 years of age • Any relevant type of interventions with parents • Improvement of the quality of life • English language articles • Full-text articles and PhD dissertations • Timespan: from 2005 – current article dates • International and national studies • Qualitative and quantitative studies • Open access and accredited journals	• Type 2 diabetes • Articles not adhering to high ethical standards

Step 2: Literature Search - The search strategy is the description of specific methods by which evidence will be identified to include into the review (Dundar & Fleeman, 2014). A further aim is to search for all relevant published and also unpublished literature, using well-known databases and other sources to assist in addressing the question (Dundar & Fleeman, 2014). Published sources are journals and citing reference lists from retrieved articles. Unpublished sources would be research registers, academic databases and government databases that are available electronically (Dundar & Fleeman, 2014).

Specific resources are guided by the disciplines and approaches taken in the review. In this review approach Health, Education, Humanities, Social Sciences and Multidisciplinary databases

could be relevant (Booth et al., 2012; Dundar & Fleeman, 2014). To narrow it down, databases such as Cochrane Library, Campbell Collaboration Library of Systematic Reviews, EBSCO Host, PsychINFO, SocINDEX, ScienceDirect and Google Scholar will be used to retrieve data. To reduce further bias, additional databases that consist of trials registries and ProQuest dissertations will be considered. The reviewer might also contact experts and organisations that specialise in this field too, and search bibliographies in studies that have been published related to this question topic.

Keywords are typed into the known databases in order to identify literature relevant to the specified inclusion criteria for the study. These keywords of inclusion and exclusion criteria will be combined by the Boolean operators to further narrow down the search and identify references containing all, any and not specific keywords of the same type (Booth et al., 2012; Dundar & Fleeman, 2014). MeSH descriptions on the Cochrane library database that will search for adjectives or something “near” or closely related to the search words will also be used. Further parameters will be searching English literature, specifically from 2015 up to date.

Keywords used for the final search will be: parent or caregiver or family or mother or father AND children or paediatric or young person AND interventions or strategies or best practice AND type 1 diabetes or Diabetes Mellitus or type 1 diabetes AND family or parent-child AND well-being or wellbeing or well being or quality of life AND adherence AND diabetes care plan or diabetes regimen.

Step 3: Screen Titles and Abstracts - Next would then be to screen all titles and abstracts with the inclusion criteria (Dundar & Fleeman, 2014). From the literature searches, only the titles and abstracts of studies will be screened to discard what is not relevant and save what is. It is recommended that a bibliographical software programme such as EndNote is used during the process of the review to save documents, as the purpose is to organise the process but also promote transparency (Dundar & Fleeman, 2014). Two reviewers, the researcher and her study leader, will perform an initial stage screening of titles and abstracts based on the inclusion criteria and exclusion criteria. The reason for two or more reviewers is that it minimises bias by any of the reviewers, in

that any study identified by either one should be included, as well mutual agreement to the settlement of any differences (Dundar & Fleeman, 2014; Wright et al., 2007).

Step 4: Obtaining Papers - After screening the titles and abstracts, a list of potential studies is compiled and the full text papers will be obtained electronically, or by hard copy, from the inter-library loans system, or the authors directly. This will minimise limitations of the review (Brunton et al., 2012; Dundar & Fleeman, 2014).

Step 5: Selecting Full-text Papers and Applying Inclusion Criteria - After the initial screening, full-text articles on relevant articles will be selected for a secondary screening purpose (Dundar & Fleeman, 2014). Inclusion and exclusion criteria will be used to select full-text papers (Brunton & Thomas, 2012). One crucial part of the inclusion and exclusion step is to keep detailed records of all the methods that were used to do the search and find results, as these methods refer to how searches were conducted and results referring to the number of citations were found (Dundar & Fleeman, 2014).

Dundar and Fleeman (2014) suggest that the reasons for certain studies to be excluded in this review should be put in table format and included as an Appendix in the dissertation. In this study the flow of studies, transparency and reliability will be presented by using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Dundar & Fleeman, 2014; Oliver, Dickson & Newman, 2012).

This statement in the form of a 27-item checklist diagram explains exactly why only the finally selected studies were chosen from the process of the initial search, and also keeps track of information during the process of selecting studies (Dundar & Fleeman, 2014). All sub-steps such as the date for each search, version of databases searched, copies of search terms, number of references identified and duplicates removed, number of references screened with title, abstracts and full-texts, as well as number of excluded references and reasons for exclusion will be recorded (Dundar & Fleeman, 2014).

Step 6: Quality Assessment and Critical Appraisal - This step will be done prior to data extraction and aims to assess the methodological quality of each study (Greenhalgh & Brown; 2014). The quality assessment is done to ensure that the review has the best research available at the time (Booth et al., 2012). It also assists in reducing selection bias within the review, to ensure that the study is valid, reliable and generalisable, and contribute in answering this research question (Greenhalgh & Brown, 2014). Both internal validity to be found in the results section and external validity to be found in the discussions section, aid the transparency, trustworthiness and reliability of a review (Booth et al., 2012; Harden & Gough, 2012). Internal validity refers to the extent to which the design and conduct of the review could prevent bias and, if so, the results may be considered reliable and true (Booth et al., 2012). External validity refers to the applicability of a study and entails whether the effect of an intervention being investigated in the review will be expected to produce the same outcome in other locations and with other participants (Booth et al., 2012).

To do an assessment of the studies, specific quality scales and checklists can be implemented (Booth et al., 2012; Greenhalgh & Brown, 2014). The purpose of the assessment will guide the criteria for the scale or checklist (Harden & Gough, 2012). There are assessment tools available that have been designed for the purpose of doing a quality assessment in the specific context of a systematic review (Greenhalgh & Brown, 2014; Harden & Gough, 2012). It is therefore necessary to first identify the designs (e.g. quantitative, qualitative or mixed-method) that are included in this study (Booth et al., 2012; Greenhalgh & Brown, 2014). After they have been identified, the type of quality assessment tool (for example a scale or checklist) can be selected. Greenhalgh and Brown (2014) prefer a checklist, as it provides more detail about the studies.

For this study the National Institute for Health and Care Excellence (NICE, 2012) and the Quality Criteria Checklist (QCC: ADA, 2008) will be used for all quantitative studies, and the Critical Appraisal Skills Programme (CASP, 2006) will be used for all qualitative studies.

For both quantitative and qualitative studies, the assessment tools provided relevant questions pertaining to specific criteria that had to be met in order to qualify as good quality research. The quantitative assessment tool evaluated whether the research question was clearly stated and if the selection of participants were free from bias; whether the study groups were comparable; was the method of withdrawal discussed, was blinding used to prevent bias, was the intervening factors described, were the measurements valid and reliable and outcomes clearly defined; appropriateness of the statistical analysis; do the studies provide information on biases and limitations in the conclusions and what were the author's affiliations and do they identify conflict of interests (QCC: ADA, 2008).

The assessment tools that measured the quality of qualitative articles included questions about the validity of the research results; whether the aim of the study was clear; appropriateness of the methodology and research design; how the recruitment strategy was conducted; evaluation of the data collection process; the relationship between the researcher and participants; if ethical aspects were considered; rigor of data analysis; how evidence and findings were portrayed and how valuable this research seemed to be (CASP, 2006).

Both reviewers will conduct their individual quality assessment using these checklists to identify methodological weaknesses in studies. A mutual agreement on which studies adhere to the quality stipulated in the checklists (Greenhalgh & Brown, 2014; Wright, Brand, Dunn, & Spindler, 2007), will follow. A third reviewer, an experienced researcher and the co-study leader in this study, may be consulted for an additional opinion on studies not agreed upon by these reviewers. These checklists will be included in an additional Appendix as well and aid the transparency of the study (Greenhalgh & Brown, 2014).

Step 7: Data Extraction - In this step, the data from articles selected will be submitted in the process of data extraction in electronic form into a table format (Fleeman & Dundar, 2014). This format promotes a better understanding of the data in a descriptive (study characteristics) and analytical (outcomes) manner, and provides an overview of all relevant data from the selected

articles (Fleeman & Dundar, 2014). The better designed the data extraction tables, the more convenient it will be to conclude the process (Booth et al., 2012; Fleeman & Dundar, 2014). Information that should be considered are study authors, year of publication, titles of the study, the study population such as the age group of the children, the country in which the study has taken place, the research design, a sample description, data collection, the components of interventions for parents, data analysis, whether follow-ups were done with the families, outcomes to better the quality of life while adhering to the type 1 diabetes care plan, as well as examples of mean age, genders, participant characteristics, and specifying study results. A quality rating retrieved from the quality assessment will also be included (Booth et al., 2012; Fleeman & Dundar, 2014).

To ensure transparency, the researcher will extract the data and the study leader will check the accuracy of the extracted data afterwards. Fleeman and Dundar (2014) suggest that encoding of data in the articles will make this an easier, less complicated process. Generally, when reporting extracted data from the table format, it is presented in a summary of descriptive data that can be subdivided in study characteristics and participant characteristics, depending on the variables chosen (Fleeman & Dundar, 2014). The data should then be accompanied by explanatory summaries (Fleeman & Dundar, 2014).

The data in the table format and summaries wherein a descriptive evaluation of each study is presented are then analysed and synthesised in order to address the initial research question on effective interventions to improve the quality of life for parents managing their young child's condition of type 1 diabetes.

Step 8: Analysis and Synthesis of Presenting Results - The modes of synthesis are the process of constructing new knowledge, and organising and aggregating information gathered (Thomas, Harden, & Newman, 2012). Organising means that findings are integrated to form a comprehensible whole, whilst aggregative syntheses will combine homogeneous groups of studies (Thomas et al., 2012), aim to gather evidence and look for generalisations or comparatives which focus on the extent to which different studies either reinforce or agree with one another (Booth et

al., 2012). Synthesis is a process of constructing new knowledge that organises and combines findings from multiple studies (Thomas et al., 2012). The method determines how the results are combined or integrated to give an overarching view, and the type of question asked would indicate the method of synthesis (Blundell, 2014; Booth et al., 2012; Thomas et al., 2012). The aim of this review is to explore a range of possible effective interventions that are specifically designed or developed for the population of parents of young children with type 1 diabetes. This review will attempt to explore the samples used in the intervention studies, the methods of service delivery, the specific content provided within the interventions and take into consideration the duration of interventions and specific time of intervention.

There are many different approaches to synthesis, such as meta-analysis binary data (expressing one of two possible responses), continuous data (measuring outcomes on a continuous scale), ordinal data (to investigate order), count data (a total of a number of events to individual participants), time-to-event data (involving time frames), result tables (to report any similarities and differences that have been identified across trials) and lastly meta-analysis (Blundell, 2012). It is of good value to plan the initial synthesis strategy by explaining how the literature will be approached (Booth et al., 2012). In this study synthesising might be done by using a meta-analysis approach, as it will help present and conclude the strengths of the individual studies (Wright et al., 2007). A meta-analysis enables the reviewer to combine results from individual studies in a statistical manner in order to give an overall measure of the effects of one intervention to another (Blundell, 2012). Trials might differ, but for a meta-analysis, results must be homogeneous (Blundell, 2012). The benefits of a meta-analysis are that it can detect smaller clinically-significant differences and will be more precise (Blundell, 2012).

Step 9: Writing up and Editing - The final step is to reflect on the possible interpretations and conclusions drawn from the results in the context of your review question (Cherry, 2014). It is each reviewer's responsibility to ensure that the final work is accurate and applicable to the question asked (Cherry, 2014). A logical write-up structure is suggested. Cherry (2014)

recommends the following structure: Firstly discuss the search strategy and its relevance to a representative sample of your question. Then summarise the overall key findings of the results, state how the findings fit to the literature described in the Introduction chapter of the dissertation. Write a comprehensive summary on the strengths and limitations of the included studies and of the review process. Argue whether this review can be generalised to the research question and professional practice. The reviewer's conclusions to her answer on her review question should be discussed next, and lastly implications of the review should be stipulated.

Interpretation of results is done in order to make conclusions based on the best available scientific evidence that has been gathered (Cherry, 2014). With clinical expertise this helps to improve clinical decision making and recommendations for future research studies (Cherry, 2014).

Ethical Considerations

As part of the profession, all psychologists, both practitioners and researchers, need to adhere to the ethical guidelines provided by the Health Professions Council of South Africa (HPCSA) (Health Professions Act 56 of 1974). Here are the most relevant considerations from the reviewer:

1. It is of utmost importance to be familiar with the APA guidelines for referencing literature and to prevent plagiarism (APA Publication Manual, 2010).
2. This dissertation will ensure accuracy and transparency throughout the process. All articles will be independently reviewed by two reviewers (the researcher and the study leader) to minimise bias and to assure the above for conducting research in a respectful manner.
3. Extra effort will be applied in considering only ethical studies by viewing for statements of ethical clearance.
4. Ethical clearance was obtained from the Ethics Committee of the North-West University, Vaal Triangle Campus.

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SECTION II: MANUSCRIPT

Guidelines to Authors

The aim is to submit this article to the *Journal of Diabetes Research*. For this purpose the document will be written up in an APA referencing format as well as follow the criteria that this specific journal requires.

About this Journal

The *Journal of Diabetes Research* is a peer-reviewed, Open Access journal that publishes research articles, review articles, and clinical studies related to type 1 and type 2 diabetes. The journal welcomes submissions focusing on the epidemiology, etiology, pathogenesis, management, and prevention of diabetes, as well as associated complications, such as diabetic retinopathy, neuropathy and nephropathy. *Journal of Diabetes Research* is archived in Portico, which provides permanent archiving for electronic scholarly journals, as well as via the LOCKSS initiative. It operates a fully open-access publishing model which allows open global access to its published content. This model is supported through Article Processing Charges. *Journal of Diabetes Research* is included in many leading abstracting and indexing databases.

Submission

Manuscripts should be submitted by one of the authors of the manuscript through the online Manuscript Tracking System. Only electronic PDF (.pdf) or Word (.doc, .docx, .rtf) files can be submitted through the MTS, and there is no page limit. Submissions by anyone other than one of the authors will not be accepted. The submitting author takes responsibility for the manuscript during submission and peer review.

Terms of Submission

Manuscripts must be submitted on the understanding that they have not been published elsewhere and are only being considered by this journal. The submitting author is responsible for ensuring that the article's publication has been approved by all the other co-authors. It is also the submitting author's responsibility to ensure that the article has all necessary institutional approvals. Only an acknowledgment from the editorial office officially establishes the date of receipt. Further correspondence and proofs will be sent to the author(s) before publication, unless otherwise indicated. It is a condition of submission that the authors permit editing of the manuscript for readability.

Peer Review

All manuscripts are subject to peer review and are expected to meet the standards of academic excellence. If approved by the editor, submissions will be considered by peer reviewers, whose identities will remain anonymous to the authors. Our Research Integrity team will occasionally seek advice outside standard peer review, for example, on submissions with serious ethical, security, biosecurity, or societal implications. We may consult experts and the academic editor before deciding on appropriate actions, including but not limited to: recruiting reviewers with specific expertise, assessment by additional editors, and declining to further consider a submission.

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Article Types

Research Articles, Clinical Studies and Reviews are included in this journal.

Formatting: We recommend that all manuscripts follow the structure below:

Title and Authorship Information

The following information should be included:

- Manuscript title
- Full author names
- Full institutional mailing addresses
- Email addresses

Abstract: The manuscript should contain an abstract. The abstract should be self-contained, citation-free, and should not exceed 300 words.

Introduction: This section should be succinct, with no subheadings.

Materials and Methods: The methods section should provide enough detail for others to be able to replicate the study. If you have more than one method, use subsections with relevant headings, e.g. different models, in vitro and in vivo studies, statistics, materials and reagents, etc.

Hindawi journals have no space restriction on methods. Detailed descriptions of the methods (including protocols or project descriptions) and algorithms may also be uploaded as supplementary information, or a previous publication that gives more details may be cited. If the method from a previous article is used, then this article must be cited and discussed. If wording is reused from a published article, then this must be noted, e.g. This study uses the method of Smith et al. and the methods description partly reproduces their wording [1].

Results and Discussion: This section may be divided into subsections or may be combined.

Main Text (Review only): This section may be divided into subsections or may be combined.

Conclusions: This should clearly explain the main conclusions of the article, highlighting its importance and relevance.

Conflicts of Interest: Authors must declare all relevant interests that could be perceived as conflicting. Authors should explain why each interest may represent a conflict. If no conflicts exist, the authors should state this. Submitting authors are responsible for coauthors declaring their interests.

Funding Statement: If the research did not receive specific funding, but was performed as part of the employment of the authors, please name this employer. If the funder was involved in the manuscript's writing, editing, approval, or decision to publish, please declare this.

Acknowledgments: All acknowledgments (if any) should be included at the very end of the manuscript before the references. Anyone who has made a contribution to the research or manuscript, but who is not a listed author, should be acknowledged (with their permission).

References: Authors may submit their references in any style. If accepted, these will be reformatted in Chicago style by Hindawi. Authors are responsible for ensuring that the information in each reference is complete and accurate. All references should be numbered consecutively in the order of their first citation. Citations of references in the text should be identified using numbers in square brackets e.g., “as discussed by Smith [9]”; “as discussed elsewhere [9, 10]”. All references should be cited within the text and uncited references will be removed.

Preparation of Figures

Upon submission of an article, authors should include all figures and tables in the PDF file of the manuscript. Figures and tables should not be submitted in separate files. If the article is accepted, authors will be asked to provide the source files of the figures. Each figure should be supplied in a separate electronic file. All figures should be cited in the manuscript in a consecutive order. Figures should be supplied in either vector art formats (Illustrator, EPS, WMF, FreeHand, CorelDraw, PowerPoint, Excel, etc.) or bitmap formats (Photoshop, TIFF, GIF, JPEG, etc.). Bitmap images should be of 300 dpi resolution at least unless the resolution is intentionally set to a

lower level for scientific reasons. If a bitmap image has labels, the image and labels should be embedded in separate layers.

Preparation of Tables

Tables should be cited consecutively in the text. Every table must have a descriptive title and if numerical measurements are given, the units should be included in the column heading. Vertical rules should not be used.

Proofs

Corrected proofs must be returned to the publisher within two to three days of receipt. The publisher will do everything possible to ensure prompt publication.

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MANUSCRIPT

**Effective interventions to improve quality of life for parents of young children
living with type 1 diabetes: A systematic review**

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Abstract

Objective – Many studies have shown a link between parental distress, adherence to the diabetes care plan and the impact thereof on the quality of life for all family members. The aim of this study was to systematically review literature pertaining to effective interventions that improve the quality of life for parents of young children (age defined between 3 – 11 years) living with type 1 diabetes.

Method – A comprehensive electronic search from 2000 to 2018 using electronic databases and citation tracking were used. Seven articles were identified for inclusion in this review and data extraction was captured in a table format.

Discussion – The most effective methods of delivery are interventions that are based on group work or telephone-based programmes that strongly emphasise the component of support regardless of content as parents often feel isolated dealing with this life-threatening disease. Psycho-education, cognitive behaviour therapy and coping skills training programmes tailored to child developmental phases were found to be effective interventions in this review. Parents reported diabetes-specific and development-specific information as informative and relevant to their circumstances as they feel incompetent and anxious at times.

Conclusion – This systematic review yielded limited yet valuable findings of interventions that do increase the quality of life for parents of children living with type 1 diabetes. Despite these promising ideas that can contribute to future research, the limitations found in this review, should be considered when planning future research in order to promote healthy outcomes and improve the quality of life for the whole family, especially in South Africa.

(252 words)

Keywords: *Parents, children with type 1 diabetes, effective interventions, quality of life, systematic review*

(Word count in article excluding abstract and references – 11 097)

Introduction

Type 1 diabetes is a chronic disease that entails adherence to a lifelong diabetes care plan and lifestyle changes to abide by in order to control this progressive illness and to prolong or prevent diabetes complications (Gonzalez, Tanenbaum, Commissariat & Persis, 2016; Lohan et al., 2015; Mitchell, Kirk, Robertson & Reilly, 2016). This illness is characterised by a destruction of beta cells in the pancreas that has the fundamental function of manufacturing insulin that regulates the blood sugar levels in the body (Lohan et al., 2016; Mitchell et al., 2016).

Currently, the world population with diabetes is estimated to be 387 million people and predicted to reach 471 million in 2035 (De Domenico & Mendes-Castillo, 2017). Eighty percent of the above estimated number of people live in developing countries. There is a proposed increased health risk for children around the world and an increased risk for children under the age of 5 years to be diagnosed with diabetes (De Domenico & Mendes-Castillo, 2017).

Often, following the sudden initial diagnosis of type 1 diabetes, parents are left feeling overwhelmed and out of control, accompanied by feelings of anger, fear or anxiety, frustration and helplessness (Streisand, Mackey & Herge, 2010; Wiebe, 2016). Parents are confronted with this chronic disease which could affect their child's normal development, in terms of physical complications, developmental disabilities, scholastic problems and psychological problems (De Domenico & Mendes-Castillo, 2017). Type 1 diabetes poses complex behavioural demands that can be challenging for children and their caregivers (Wiebe, Helgeson & Berg, 2017). These challenges can result in physical and psychological strain that can reach clinically-significant levels, even to the extent of meeting the diagnostic criteria for post-traumatic stress disorder for parents (Streisand et al., 2010; Wiebe et al., 2016).

Child rearing can be stressful under normal circumstances (Streisand et al., 2010), but parenting a young child with diabetes adds specific additional stressors in adherence of the diabetes care plan including frequent blood glucose monitoring, managing insulin injections, balancing of insulin

doses, paying attention to nutritional intake and exercise (Coghill & Hodgkins, 2016; Streisand et al., 2010). Parents need to be involved in and take responsibility for the management of diabetes as children are often diagnosed at a young age, before they have the necessary capacity to understand the risks of this illness or skills to manage the complex tasks of diabetes independently (Wiebe et al., 2017).

Vallis et al (2016) argues that understanding chronic illness should not be limited to the individuals with the illness, but should include the impact on the family and that emotional-management interventions can be of value. Families are truly challenged by integrating this threatening, demanding and complex condition into their lives (Gonzalez et al., 2016), which can disrupt family routines, change the family dynamics and future expectations in which the child develops and ultimately effect the quality of life (Vallis, Burns, Hollahan, Ross & Hahn, 2016; Wiebe et al., 2017).

The quality of life, according to the World Health Organization (WHO), is related to an individual's perception of their position in life in relation to their goals, expectations, standards and concerns (WHOQOL, Geneva; 1997). Parents often relate their competence to the management and requirements of the child's diabetes and this impacts their quality of life (Streisand et al., 2010). These authors are of the opinion that it is important to implement interventions designed to decrease stress and improve coping in order to promote parent and child wellbeing and improve the quality of life of parents (Streisand et al., 2010).

The growing occurrence of diabetes and increasing psychological impact on parents, emphasise the important role of psychologists in focussing on reducing emotional distress, equipping parents with tools and improving parent knowledge in order to promote psychological wellbeing in children and parents caring for their child with type 1 diabetes (Gonzalez et al., 2016). Effective interventions for parents can influence and assist in the adaptation of the child to the disease and lessen the negative effects for the child (De Domenico & Mendes-Castillo, 2017). The facilitation

of social support for children and their parents managing their child's diabetes care plan, can furthermore reduce the emotional distress for the family, assist them in managing the illness, offer a sense of cohesion and enhance the quality of life (De Domenico & Mendes-Castillo, 2017). Literature identified the need for interventions for parents focussing on parenting, looking at the effectiveness of interventions in a specific context as well as a focus on more individualised needs including the developmental ages of children (Hilliard et al., 2016; Lohan et al., 2015; Murphy et al., 2006). Literature wanted to emphasise how the field of psychology can translate research into practice and bridge the gap between theoretical approaches, mental health and diabetes care in families (Hilliard et al., 2016).

To contribute to the above identified needs, this study was best approached by the methodology of a systematic review. The benefit of using a systematic review was to be as transparent as possible, to inform the researcher and readers of all previous literature specifically pertaining to interventions for parents of younger children on this specific topic of diabetes care, how studies might differ and what limitations there are (Gough et al., 2012). This platform can be used to develop new research (Gough et al., 2012) or to make decisions about developing interventions for parents or to make changes to policies in the future (Dickson et al., 2014).

It can be concluded that it is essential to provide interventions to parents or caregivers of children diagnosed with type 1 diabetes. According to De Domenico and Mendes-Castillo (2017) interventions should also guard against offering resources that may end up as a burden or source of conflict to the parent and the family, but to rather focus on resources that add to their quality of life.

Most studies have focused on interventions to support parents of adolescents with type 1 diabetes (Eccleston, Fisher, Law, Bartlett, & Palermo, 2015; Hilliard, Powell, & Anderson, 2016), but very few studies were found for resolution of younger children. This article reviews well-researched interventions to improve the quality of life for parents of younger children with type 1 diabetes. No specific measure was used in this review to measure the outcome of quality of life, but

inclusion criteria stipulated that results from included studies had to comment on improvement of quality of life.

Aim of this study

The aim of this study was to systematically review effective interventions to improve the quality of life of parents of children living with type 1 diabetes. This study will discuss effective outcomes and conclude with limitations and recommendations for future research to inform the development of effective interventions for these parents and subsequently the whole family bearing the consequences of type 1 diabetes challenges within the family. The information in this review can lead to opportunities for tailor-made treatments to address support for parents of children diagnosed with type 1 diabetes.

The research question that this study sought to answer was:

What do effective interventions to improve the quality of life of parents of young children living with diabetes entail?

Method

Data Sources and Search Period

A systematic review has specific guidelines or methods to adhere to when conducting a review in order to assure the study's transparency (Gough et al., 2012). This research approach was chosen to synthesise literature findings on related studies and explore information and answers to the specific research question (Booth, Papaioannou, & Sutton, 2012; Dickson, Cherry, & Boland, 2014). In the process of defining the research question, the protocol included the population, intervention, comparator and outcome applications based on the PICO formula. Table 1 provides more information on the application of the formula.

Table 1: PICO Formula Applied to this Study

Review Question	To describe effective interventions to improve the quality of life among parents of children aged 3 to 11 years with type 1 diabetes
Population	Parents of children between the ages of 3 and 11 years diagnosed with type 1 diabetes and managing the child's condition
Intervention	Educational, psycho-social and behavioural interventions
Comparison	Effectiveness of different interventions
Outcome	The quality of life

Despite the proposal protocol initially stipulated that studies within the duration from 2005 until 2017 will be retrieved, a final review of literature published between the years 2000 and 2018 was conducted in this study. The reason for this is that the reviewers attempted to retrieve more articles given the limited identifying article titles on Search 1. The search was conducted in May of 2018, and therefore including studies from 2018 could identify most recent interventions. The North-West University online library website and search engine provided one single access to various databases that include results from various databases. Studies were primarily selected from the following databases: EbscoHost, SaePublications, Academic Search Premier, ERIC, ScienceDirect, PsycArticles and PsychINFO, SocINDEX and Cochrane Library. Google Scholar was used as an additional search option to ensure a thorough search strategy.

During the proposal phase a feasibility test on the NWU Library Catalogue was done, which indicated a total of 62 studies within the limitation of 2005 to 2017. An initial search strategy (search 1) with the assistant research librarian was conducted and key words used in combination with Boolean operators (AND, OR, NOT) were used to further narrow down the search. The keywords used for this search were: parent or caregiver or family or mother or father AND child or children or paediatric or young person AND well-being or wellbeing or well being or quality of life

AND adherence AND type 1 diabetes or Diabetes Mellitus AND diabetes care plan or diabetes regimen. During the initial search 25 articles were found. The librarian research assistant recommended a further search with more specific terminology. Keywords used in the search (search 2) were: parent or caregiver or family or mother or father AND child or children or paediatric or pediatric 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 for parents NOT adolescent. A further 59 articles were found.

The searches resulted in the identification of 84 studies in total. After 10 duplicates and 7 review articles were removed, a total of 67 articles were included. In an attempt to locate all published literature interventions for parents of children with type 1 diabetes, 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 cited. An additional 15 articles were identified from the review articles. In total 82 potential articles that contained the keywords in the title or abstracts were retrieved for further inclusion and exclusion procedure.

Study Selection

An initial process with well-defined inclusion and exclusion criteria was conducted with only titles and abstracts of retrieved articles. This was done by the main author and independently by an independent reviewer using criteria from Table 2 that provided inclusion and exclusion criteria on titles and abstracts involved:

Table 2: Initial Inclusion and Exclusion Criteria on Titles and Abstracts

Inclusion Criteria	Exclusion Criteria
• Parents who manage the type 1 diabetes of their young child • Toddler and primary-school age between 3 and 11 years of age • Any relevant type of interventions with parents • Improvement of the quality of life • English language articles • Full-text articles and PhD dissertations • Timespan: from 2005 – current article dates • International and national studies • Qualitative and quantitative studies • Open access and accredited journals	• Type 2 diabetes • Articles not adhering to high ethical standards

Of the 82 potential articles, 57 were excluded because of not meeting the above inclusion criteria on abstracts and titles. Reasons for exclusions from title or abstracts were mostly because of: focussing on pregnant women population, type 2 diabetes, the adolescent population and their parents, not referring to an intervention or not focussing on promoting the quality of life for parents. Eight studies were difficult to include or exclude by abstract, as there were no specific clarity on the mean age of the children, and information might only be revealed in the full text and therefore these 8 articles were included for full-text screening. Of the 25 remaining articles, 2 full-text articles were not available or retrievable, but the remaining 23 articles were selected for full-text screening. The researcher and independent reviewer, respectively, reviewed the remaining 23 articles. An overall 15 articles were excluded again, based on the first inclusion and exclusion criteria when reading the full-text article as the content information was clearer than in the abstracts and titles.

A second, more specific selection process of articles was conducted after retrieving the full text articles from the initially-included abstract articles. The remaining eight articles were screened 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 in the studies. Table 3 provides a grid for the Quality Criteria Checklist for Primary quantitative research (see page 80) and Table 4 a grid for the Critical Appraisal Skills Programme for qualitative research (see page 80) by which inclusion and exclusion were condensed by the two reviewers to check whether the articles were of good research quality. A third independent experienced researcher was consulted for an additional opinion on specific themes for the methodology. This researcher was on standby, should the two reviewers not have agreed upon inclusion or exclusion of studies, but this was not required.

Table 3: Quality Critical Checklist: Primary Research (QCC): Quantitative Research**Abbreviations:** Yes (Y), No (N), Can't tell (U), N/A**Reviewers:** Linda Santilli (1) and Elmari Deacon (2)**Date:** 01 – 03 Sept

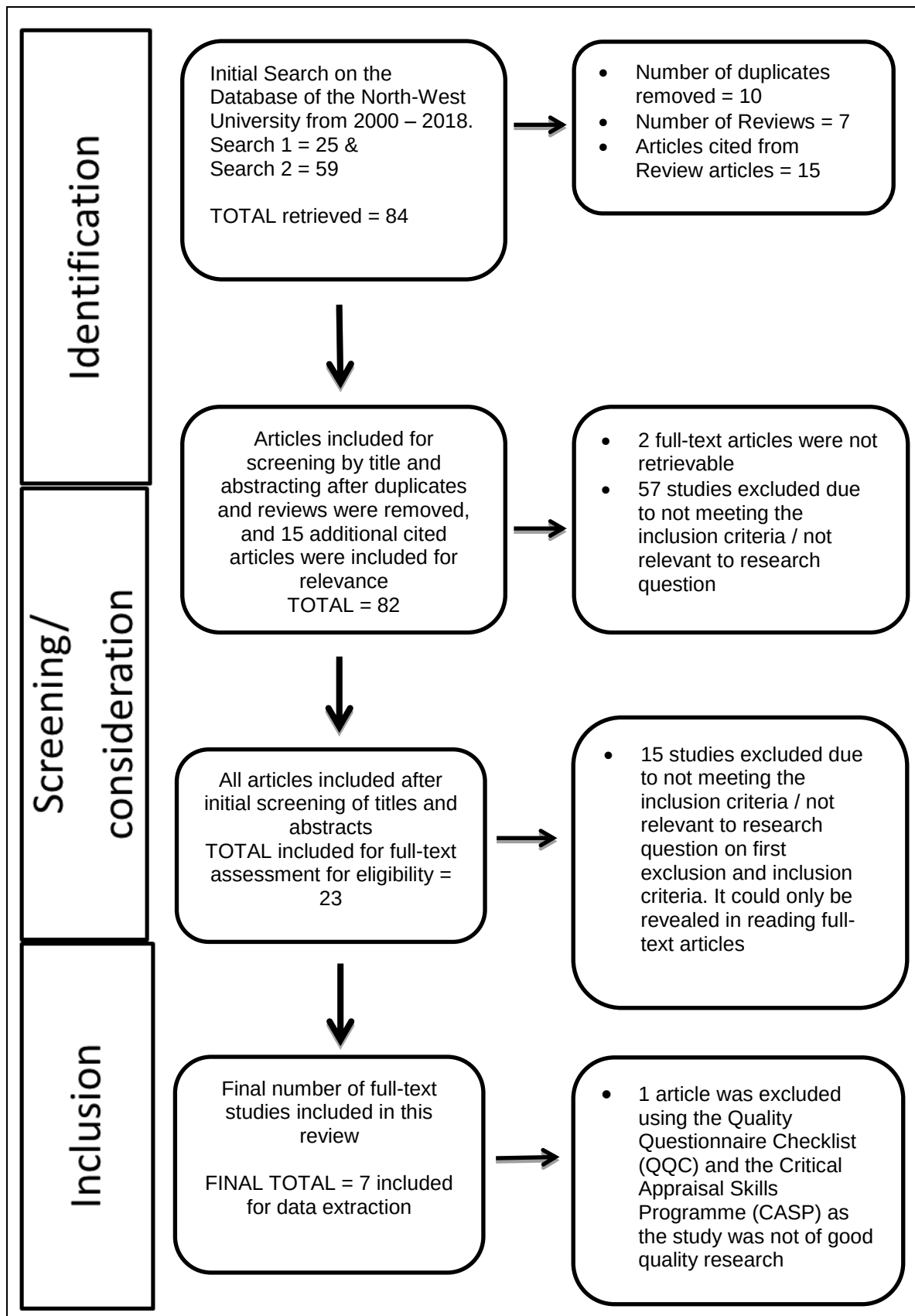
No	Article and Authors	Clearly stated research question		Selection free from bias		Comparing study groups		Withdrawal method described		Blinded to prevent bias		Description of interventions		Reliable/ Valid outcomes		Statistical analysis appropriate		Conclusion supported by results		Funding or sponsors		TOTAL	
		1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2
1	Mackey, E.R., Herbert, L., Monaghan, M., Cogen, F., Wang, J., & Streisand, R. (2016)	Y	Y	Y	Y	Y	Y	N	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
2	Pate, T., Rutar, M., Battelino, T., Drobnic Radobuljac, M., & Bratina, N. (2015)	Y	Y	Y	Y	N/A	N/A	Y	Y	U	U	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y
3	Ambrosino, J. M., Fennie, K., Whittemore, R., Jaser, S., Dowd, M.F., & Grey, M. (2008)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
4	Sassmann, H., De Hair, M., Danne, T., & Lange, K. (2012)	Y	Y	U	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y
5	Sullivan-Bolyai, S., Grey, M., Deatrick, J., Gruppuso, P., Giraitis, P., & Tamborlane, W. (2004)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
6	Grey, M., Jaser, S., Whittemore, R., Jeon, S., & Lindemann, E. (2011)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
7	Monaghan, M., Hilliard, M.E., Cogen, F.R., & Streisand, R. (2011)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Table 4: Critical Appraisal Skills Programme Quality (CASP): Qualitative Research**Abbreviations:** Yes (Y), No (N), Can't tell (U), N/A**Reviewers:** Reviewer 1 and Reviewer 2**Date:** 01 – 03 Sept

No	Article and Authors	Clear aim of research		Appropriate method		Research design appropriate		Recruitment strategy appropriate		Collection of data		Relationship		Ethical considerations		Data Analysis rigorous		Clear statement of findings		How Valuable		TOTAL	
		1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2
8	2005, Davidson, S. & Spowart, K	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	N	N	Y	Y	N	N	N	N

Of the 8 articles, screening the full-text articles by using the critical appraisal and the quality assessment instruments, one article was excluded due to presenting poor quality research. A final number of seven studies remained for data to be extracted in order to answer the research question. Figure 1 provides a presentation of an overview of all reviewed articles from initial to final.

Figure 1: Flow of Information Through the Different Phases of this Systematic Review



Data Extraction

Data from the seven selected articles were extracted and submitted into a data extraction table format in the process of an electronic form. Descriptive (study characteristics) and analytical (outcomes) information were provided in an overview of all relevant data from the selected articles. The main demographic characteristics of included studies were extracted from the articles and presented in Table 5. These characteristics included study authors, year of publication, title of the study, the journal published in, the study population such as the mean age group of the children and/or parents, the country the study has taken place in, the group status and the sample size.

Table 5: Demographic Characteristics of Included Studies

	Authors	Title of article	Year	Journal	Country	Group status	Sample size	Mean age
1	Ambrosino, J. M., Fennie, K., Whittemore, R., Jaser, S., Dowd, M.F. & Grey, M.	Short-term effects of coping skills training in school-age children with type 1 diabetes	2008	Pediatric Diabetes	United States of America	Predominantly white 86 % Black/Hispanic 14%	87 Parents Predominantly mothers	Child: 9.91 Parents: 40.01 (Children 8-12 years)
2	Grey, M., Jaser, S, Whittemore, R., Jeon, S. & Lindemann, E.	Coping skills training for parents of children with type 1 diabetes: 12-month outcomes	2011	Nursing Research	United States of America	Unspecified	Intervention group 75 Control group 106	Child intervention group 8.1 Control group 7.9 (Children 1 – 12 years) Parent age unspecified
3	Mackey, E.R., Herbert, L., Monaghan, M., Cogen, F., Wang, J. & Streisand, R.	The feasibility of a pilot intervention for parents of young children newly diagnosed with type 1 diabetes	2016	Clinical Practice in Pediatric Psychology	United States of America	Caucasian 70%	30 Mothers	Children 1 – 6 years Parent 33.64
4	Monaghan, M., Hilliard, M.E., Cogen, F.R. & Streisand, R.	Supporting parents of very young children with type 1 diabetes: results from a pilot study	2011	Patient Education and Counseling	United States of America	Caucasian 75% Other unspecified	24 Parents: Mothers 88%	Child 4.10 Parent 34.80 (Children 2 – 5 years)
5	Pate, T., Rutar, M., Battelino, T., Drobic Radobuljac, M. & Bratina, N.	Support group for parents coping with children with type 1 diabetes	2015	“Zdrav Var” Zdravstveno varstvo/Slovenian Journal of Public Health	Slovenia	Unspecified	34 Parents	Parent 42.4 Child 8.9

6	Sassmann, H., De Hair, M., Danne, T. & Lange, K.	Reducing stress and supporting positive relations in families of young children with type 1 diabetes: a randomized controlled study for evaluating the effects of the DELFIN parenting program.	2012	BMC Pediatrics	Germany	Unspecified, but German speaking	Intervention 37 Control 28 65 parents (mothers 33) (fathers 32)	Mothers 39.11 – 40.4 Fathers 42.41 – 43.3 (Children 2 –10)
7	Sullivan-Bolyai, S., Grey, M., Deatrick, J., Gruppuso, P., Giraitis, P. & Tamborlane, W.	Helping other mothers effectively work at raising young children with type 1 diabetes	2004	The Diabetes Educator	United States of America	White 38 (90%) African American 1 Hispanic (5%)	41 Mothers	Mothers 35 (Children 1 – 10 years)

The main theme and outcome categories that were extracted from the articles into Table 6 were the study measures, the research design, the main objective of the study, the main findings or outcomes to better the quality of life while adhering to the type 1 diabetes care plan, as well as the author's conclusions. Table 6 provides a summary of these main findings. Transparency was insured as the independent reviewer checked the accuracy of the extracted data after it had been extracted by the researcher and compacted into table format. The reporting of extracted data from the table format, a summary of descriptive data that was sub-divided in study characteristics and participant characteristics were presented. The data was then accompanied by explanatory summaries.

This study strived to adhere to the ethical guidelines provided by the Health Professions Council of South Africa (HPCSA) (Health Professions Act 56 of 1974). Most relevant considerations from the reviewers were: to use APA guidelines for referencing literature and to prevent plagiarism (APA Publication Manual, 2010); that articles were reviewed independently by two reviewers to ensure accuracy and transparency as well as minimise bias, and to consider only ethical studies.

Table 6: Main findings of study

	Authors	Measures	Study design	Main objectives of study	Main findings	Author conclusion
1.	Ambrosino, J. M., Fennie, K., Whittemore, R., Jaser, S., Dowd, M.F. & Grey, M. (2008)	For children: - Baseline questionnaire Disease-related variables medical chart - Issues in Coping with IDDM – child scale - Self-efficacy for Diabetes Scale - Diabetes. Quality of Life Scale for Youth (DQOL) - Diabetes Family Behaviour Scale (DFBS) For parents: - Demographic information - Issues in Coping with IDDM – Parent scale - Center for Epidemiological Depression Scale (CES-D) - Diabetes Responsibility and Conflict Scale - Family Adaptability and Cohesion Scale (FACES)	Randomized prospective two-group experimental design. Follow-up at 1, 3, 6 and 12 months post-intervention Only baseline, 1 and 3 months' data are reported in this study	To evaluate the short-term efficacy and feasibility of a psychosocial coping skills training (CST) intervention for the child and parent compared with an educational group education. The intervention is for young children and parents to increase sense of competence and mastery, retraining non-constructive coping styles with more positive styles and patterns of behaviour. Small groups with children were conducted. Parents met simultaneously but separately.	Both CST and GE (group education) contributed to modest positive changes in many areas of psychosocial adaptation. CST parents showed greater improvement in parent-reported family functioning and child-reported satisfaction with quality of life compared to the control group. The children in the CST group indicated greater improvement in life satisfaction than in the control group and may be linked to insulin pump therapy too.	Both groups contributed to modest positive changes in many areas of psychosocial adaptation, while the CST group showed more specific changes. Ongoing longer-term follow-up of this cohort will help determine whether being introduced earlier to CST will enhance outcomes and help prevent the deterioration in glycaemic control and increased family conflict.
2.	Grey, M., Jaser, S., Whittemore, R., Jeon, S., & Lindemann, E. (2011)	- Disease-related variables from children's medical folders - Bayer Diagnostics DCA2000 for assessing metabolic control via HbA1c - Demographic information reported by parents (relationship to child, age, socio-demographic, gender, etc.) - Demographic information by parents - Issues in Coping with IDDM-Parent scale - Center for Epidemiological Depression Scale (CES-D) - Diabetes Responsibility and Conflict	Two separate randomized clinical trials of Coping skills training intervention. One group for parents and child of 8 - 12 years, and one group for parents and child younger than 8 years. Data reported on	To determine the effects of a Coping skills training (CST) intervention program conducted with younger children and their parents compared to an attention-control group on the outcomes of parental coping, family functioning, quality of life, and child metabolic control. Secondary aim to explore mediators (parental coping) en moderators (age, gender,	CST did not have the expected effect 12 months post intervention in this relatively well-controlled sample. The hypothesis that parents of the CST intervention would demonstrate better coping, increased family functioning, and higher quality of life, was not supported. There were not significant treatment effects on any outcome variable, but changes over time indicated improvement in parenting coping and quality of life. However, both groups reported improved coping, less responsibility for treatment	The author is of the opinion that although there were no expected outcomes, there were significant time effects demonstrated over time. The supportive group-based educational and behavioural interventions may be associated with improved parental and diabetes outcomes. Further interventions are needed to determine if it is appropriate to

		Scale (DRC) Parents Diabetes Quality of Life Questionnaire (PDQOL)	baseline, 1, 3, 6 and 12 months post intervention	etc.) outcome over a period of 12 months.	management and improved quality of life on parent and family outcomes in this trial.	provide group-based diabetes care programmes for families coping with diabetes.
3.	Mackey, E.R., Herbert, L., Monaghan, M., Cogen, F., Wang, J., & Streisand, R. (2016)	- Demographic and medical questionnaire - Center for Epidemiological Studies Depression (CES-D) - Pediatric Inventory for Parents (PIP) - Pediatric Quality of Life Inventory - Multidimensional Scale of Perceived Social Support - Project acceptability interview with parents - PP (Peer parent) post-session questionnaire - PP project acceptability with research team member - Measuring Glycemic control	Pilot randomized controlled trial (RCT) Data reported on baseline, 1, 6 and 12 months. Also open-ended questions asked on follow-up	Examining the feasibility and acceptability of a phone-based pilot intervention among parents of young children immediately following a diagnosis of type 1 diabetes as well as a secondary focus on the preliminary efficacy of the parent-focused intervention to improve glycaemic control and parental and child wellbeing Similar to the study below (Monaghan et al., 2011), but this intervention was created to provide diabetes-related parenting support by telephone. including developmentally-tailored education, cognitive behavioural strategies and parenting strategies.	The pilot intervention to support parents by using parents as peers and a phone-based approach to intervention is feasible. It was well received among parents. However, findings indicated that there were not significant effects of the intervention of parenting stress, depression, social support, quality of life or HbA1c. Either anything would be helpful or the intervention was not potent enough to assure changes in the above mentioned moderators. Families still indicated a need for additional support, as findings indicated that there were no significant effects of the intervention on parenting stress, depression, social support, quality of life, or HbA1c in this newly diagnosed sample.	The newly-diagnosed period represent a unique period in which parents seek additional support, is needed. This intervention can buffer the negative effects of maternal depressive symptoms on child glycaemic control. This study was feasible and acceptable, despite no evidence of preliminary efficacy. A larger trial is warranted in order to evaluate broader efficacy and examining other outcomes (e.g. health care, cost effectiveness).
4.	Monaghan, M., Hilliard, M.E., Cogen, F.R., & Streisand, R. (2011)	- Background Information Questionnaire - Center for Epidemiological Studies-Depression (CES-D) - Multidimensional Scale of Perceived Social Support (MSPSS) - Pediatric Inventory for Parents (PIP) - State-Trait Anxiety Inventory (STAI) - Treatment Satisfaction Questionnaire	Pilot study randomized control trial (RCT) Pre- and post-intervention 3 weeks after the intervention Second intervention phase initiated for waiting-list participants	To assess and identify trends in intervention effects and to assess the efficacy and feasibility of telephone-based supportive programme intervention for parents of young children with type 1 diabetes (T1D) Although similar to the above study (Mackey et al., 2016). This intervention focussed on the general social-cognitive theory	The Social Cognitive Theory (SCT) appears to be useful for decreasing diabetes-related parenting stress and increasing social support in the intervention group. The findings indicated high satisfaction with the intervention's content and telephone-delivery format. These effects were not present in the wait-control group comparison and there were no significant group differences at follow-up. This intervention is promising to enhance parents' emotional functioning and	The implementation of a telephone-based structured intervention is promising and parents may benefit from such an intervention. The rate of newly diagnosed cases for children between 0 – 4 years of age has increased and these parents are at risk for anxiety, depression and parenting stress. The author concluded that further studies were underway with larger, multi-site samples with longer-term

			Also open-ended questions asked on follow-up	(SCT) and cognitive based strategies	quality of life. SCT also provides a framework for this diabetes-focussed parenting intervention that is useful to decrease diabetes-related parenting stress and increase social support	post-intervention follow-ups and examination of the child's health outcomes.
5.	Pate, T., Rutar, M., Battelino, T., Drobnic Radobuljac, M., & Bratina, N. (2015)	- Demographic questionnaire - Self-evaluation questionnaire designed by the authors - Questions on a five-point Likert scale related to parents' well-being - Open-ended questions regarding topics most interesting for participants	Mixed-method study - quantitative and qualitative research	To assess parental satisfaction with participation in the group and their perceptions of the impact of the intervention A parent support group programme is based on the relational family theory. The primary aim is to create a space for the awareness, understanding and development for more flexible and adaptive coping strategies for regulating parental emotions and empower them to the sensitivity of their children's needs.	Quantitative data indicated that parents were overall satisfied with almost all measured items such as wellbeing in the group, feeling secure, experiencing new things, being able to talk and feeling being heard, during the 4-year period. Parents from the second and third season indicated that the support group has better fulfilled their expectations than the parents from the first season (the program of the group developed through the seasons so that the needs of the parents could be better met). Qualitative data was underpinned by four themes: support when confronting the diagnosis, transformation of the family dynamics, me as a parent, exchange of experience and good practice and facing the world outside the family. The group member's perceived change aided them to recude anxiety and stress in the family	This parent support group showed to be a promising supportive, therapeutic and psycho-educational space in which parents felt safe, could express their concerns, give support and to strengthen their role in the rearing of their child with type 1 diabetes. Quantitative analysis of the changes in the experiences of the parents could be included. Following the process and dynamics in the group can also be a focus.
6.	Sassmann, H., De Hair, M., Danne, T., & Lange, K. (2012)	- Socio-demographic data - The Parenting Scale - Questions to Education Behaviour - Depression-Anxiety-Stress Scale DASS - Parents' version of the Strengths and Difficulties Questionnaire (SDQ) - Structured questionnaire to assess satisfaction with the DELFIN program - Biomedical data	Randomized controlled group design with control group being wait-listed Data on baseline, 3 months and 12 months post-intervention	Evaluate the feasibility and effectiveness of the structured behavioural parenting training program (DELFIN) for parents of children with type 1 diabetes. Developed to integrate general parenting strategies and diabetes	Participants from the DELFIN program reported reduction in adverse parenting behaviour and partial improvement of psychological wellbeing. Unexpectedly reduction in psychological distress, adverse parenting behaviour and behavioural difficulties of the child were also seen in the control group. The reduction of negative parenting behaviour was stable after 12 months,	This study has brought first evidence for the efficacy and feasibility of such a DELFIN program. According to the authors, a multicentre study with a larger sample is necessary to confirm the current findings in this study that efficacy and feasibility of the program is evident.

				specific conflict situations in order to reduce parental stress, anxiety and depression as well as children's behavioural difficulties by improving parenting skills.	indicating that parents implemented new strategies in their day to day behaviour on the longer term as well. No changes were detected for positive parenting behaviour. Despite the positive outcomes, the differences between both study arms failed to reach statistical significance. Results point to improved parenting skills and slightly reduced parenting stress. The Depression-Anxiety-Stress Scale (DAS) indicative of Parents psychological distress, decreased significantly in the DELFIN group. Over time, there were no significant group effects and the control group had a significant reduction of anxiety, stress and of the total DASS-score as well	
7.	Sullivan-Bolyai, S., Grey, M., Deatrick, J., Gruppuso, P., Giraitis, P., & Tamborlane, W. (2004)	• Demographic data • Banion Diabetes Management Concern Questionnaire • Parental Confidence Questionnaire • Impact on Family Scale • Home Care Resources Instrument • Child related cost outcome measures include HbA1c levels and number of consultation calls to medical staff.	A mixed-method Prospective randomized controlled clinical trial design for the experimental group and the control group received intervention after 6 months trial	Examining the feasibility of a post-diagnosis parental mentoring intervention (HOMEWARD) for mothers of young children newly diagnosed with type 1 diabetes receiving support from mothers who have successfully raised young children with type 1 diabetes. Home visits and phone call support to mothers in the experimental group were given during a 6 months trial by experienced mothers (mentors).	It was evident that parent mentors provided important, practical day-to-day management information, reassurance, affirmation and emotional support during times of crises for mothers in the experimental group as they reported fewer concerns, more confidence, identified more resources and perceived the illness having less of a negative impact on the family compared to the control group mothers. Over a 6 months period parent-mentored mothers had a significantly greater reduction in diabetes related concerns and perceptions of the illness. Mothers identified more resources. Quality of life was not measured with quantifiable measures, but the article reported that subtle suggestions and emotional cost-saving effects did contribute to the reduction of parental	A post-diagnosis parent mentoring intervention for mothers of children with diabetes appears to be feasible and potentially effective. It improved parental wellbeing and lessens parental concerns. The author is of the opinion that continuing research in this area is suggested and that intervention effectiveness should be explored over a longer time and with a larger sample size.

					anxiety and the quality of life effects (Sullivan-Bolyai et al., 2004).	
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Results

The data in the table format and summaries wherein a descriptive evaluation of each study was presented, was analysed and synthesised. Afterwards extraction and analyses results were discussed to address the initial research question on effective interventions to improve the quality of life for parents managing the demands accompanying their young child's condition of type 1 diabetes.

The samples investigated (captured in Table 5) included interventions done with parents caring for their young child with type 1 diabetes, specifically focussing on the quality of life as an outcome (Ambrosino et al., 2008; Grey, Jaser, Whittemore, Jeon, & Lindemann, 2011; Mackey et al., 2016; Monaghan, Hilliard, Cogen, & Streisand, 2011; Pate et al., 2015; Sassmann, De Hair, Danne, & Lange, 2012; Sullivan-Bolyai et al., 2004). The aim of this review was to focus on a population of parents of young children with type 1 diabetes, because reported effective interventions for this age group appear to be limited (Hilliard et al., 2016; Hunter, 2016; Streisand & Monaghan, 2014).

Despite the exclusion and inclusion criteria in the methodology stipulating that children diagnosed with type 1 diabetes should be between 3 and 11 years, children's ages in this review ranged between 1 and 12 years, but had a mean age between 4.10 and 9.91. This is a sufficient reflection on the aim of this review. The sample sizes ranged from 30 to 87 parents, the mean age of parents ranged between 33.64 and 43.3, participants were mostly mothers, and the group status predominantly reflected a higher proportion of White/Caucasian middle-class participants compared to other ethnic groups. Participants were mostly recruited from paediatric diabetes clinics (Sullivan et al., 2004) or hospitals (Mackey et al., 2016; Monaghan et al., 2011) and they often worked in collaborations with a university-based medical centre (Ambrosino et al., 2008; Grey et al., 2011) or department of endocrinology (Pate et al., 2015).

Five studies were conducted in the United States of America (Ambrosino et al., 2008; Grey et al., 2011; Mackey et al., 2016; Monaghan et al., 2011; Sullivan-Bolyai et al., 2004). Of the

remaining two studies, one was from Slovenia (Pate et al., 2015) and one from Germany (Sassmann, 2012). Studies were published between 2004 and 2016.

According to data in Table 6, six studies used a randomised control group design for the purpose of implementing a trial for an intervention and compare it to a control group (Ambrosino et al., 2008; Grey et al., 2011; Mackey et al., 2016; Monaghan et al., 2011; Pate et al., 2015; Sassmann et al., 2012). Participants in these six studies reported on the baseline and post-intervention follow-ups using quantifiable measures with questionnaires and scales. One of the six studies (Sassmann et al., 2012) and the seventh study (Sullivan-Bolyai et al., 2004) used a mixed-method approach, as they made use of questionnaires and scales, as well as semi-structured qualitative interviews.

Discussion

What does effective interventions to improve the quality of life of parents of young children living with type 1 diabetes entail?

The aim of this review was to explore a range of possible effective interventions that are specifically designed or developed for the population of parents of young children with type 1 diabetes. Results from this review identified two main methods of intervention delivery, namely Group interventions (Ambrosino et al., 2008; Grey et al., 2011; Mackey et al., 2016; Monaghan et al., 2011; Pate et al., 2015; Sassmann et al., 2012) and Telephone-based interventions (Mackey et al., 2016; Monaghan et al., 2011; Sullivan-Boyai, 2004). The content within these two methods of intervention delivery includes various programmes of which one was based on Peer Parent support/Mentoring interventions (Mackey et al., 2016; Sullivan-Boyai, 2004) and the other were programmes focussed on Behavioural interventions. The latter comprised of cognitive-based strategies (Mackey et al., 2016; Monaghan et al., 2011; Sassmann et al., 2012) and coping skills training (Ambrosino et al., 2008; Grey et al., Monaghan et al., 2011; Sassmann et al., 2012).

Facilitators who implemented the different interventions and facilitated programmes, varied from experienced clinical psychologists (Grey et al., 2011; Sassmann et al., 2012) to therapists who used group and psychotherapeutic intervention techniques (Pate et al., 2015) to 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.

Some studies intervened after a longer period after the child has been diagnosed with type 1 diabetes (Ambrosino et al., 2008, Grey et al., 2011), and other studies believed that parents of newly-diagnosed children (in the first 6 months of diagnosis) should receive interventions immediately after diagnosis (Mackey et al., 2016; Monaghan et al., 2011; Sullivan et al., 2004), as this period presents a unique opportunity to provide additional support to buffer negative effects (Mackey et al., 2016). During this phase parents may need more regular contact with a professional and may appreciate additional support from their clinical team during this period (Mackey et al., 2016), as these parents are at risk of anxiety, depression and parenting stress (Monaghan et al., 2011). The above methods of intervention delivery are discussed in more detail.

Group-based interventions

This review revealed that group-based interventions are one of the most useful methods of delivery (Ambrosino et al., 2008; Grey et al., 2011; Mackey et al., 2016; Monaghan et al., 2011; Pate et al., 2015; Sassmann et al., 2012). In these articles the group consisted of an experimental group implementing a specific programme, and a control group that provides basic psycho-education to compare the efficacy of the interventions in each study. In two articles (Ambrosino et al., 2008; Grey et al., 2011) both interventions focussed on parents of children between the ages of 8 – 12 years, and Grey et al., (2011) included a group for parents of children younger than 8 years. The interventions consisted of 6 sessions and aimed to increase a sense of competence and mastery in parents and children. They implemented small groups consisting of 2 – 5 children and their parents at the same time, but in different venues, with parents and children having joint discussions at the end of the session. These combined sessions included role plays and discussions of salient issues were conducted to promote connections and family concerns. Outcomes measured in this study (Grey et al., 2011) included metabolic control, parental coping, family functioning and parent

quality of life that was measured 3 months after the intervention (Ambrosino et al., 2008) and also 12 months after the intervention (Grey et al., 2011).

The findings in these articles indicated that both the experimental groups and control groups contributed to modest positive changes in some areas of psychosocial adaptation (Ambrosino et al., 2008; Grey et al., 2011). The experimental group indicated more promising statistical trends for more adaptive family functioning and greater child-reported life satisfaction compared to the control groups (Ambrosino et al., 2008). In the similar intervention of Grey et al. (2011) the outcomes were measured 12 months after the intervention and had no significant effects indicated on blood sugar levels (HbA1c), but results indicated that supportive group-based psycho-educational, behavioural and coping skills content within the programme may be associated with trends of increased parental coping, less responsibility for treatment management and improved quality of life (Grey et al., 2011).

Another group intervention identified by this review is called the DELFIN parenting programme by Sassman et al. (2012). This intervention integrated general parenting strategies and diabetes-specific conflict situations in order to reduce parental stress, anxiety and depression as well as children's behavioural difficulties by improving parenting skills. It is a structured group intervention for parents trained in small groups of 7 families who met weekly for about 2 hours over a period of 5 weeks and received one individual phone call the week after (Sassmann et al., 2012). The results point to improved parenting skills and slightly reduced parenting stress. This programme predominantly reduced negative parenting behaviour. The results of the Depression-Anxiety-Stress Scale (DASS) measuring parents' psychological distress, decreased significantly in the DELFIN group. Over time, there were no statistical significant group effects, and the control group also had a reduction of anxiety and stress in the total DASS-score (Sassmann et al., 2012), which was similar to the two studies above.

The intervention from Pate et al. (2015) was designed to provide psychosocial support and was grounded on relational family theory. Four different groups, called "seasons", were held over a

4-year period, where the first three were open groups and the last was a closed-group experience. The primary aim was to create a space for awareness, understanding and development for more flexible and adaptive coping strategies for regulating parental emotions and empowering the parents to be sensitive to their children's needs (Pate et al., 2015). This parent support group showed to be a promising supportive, therapeutic and psycho-educational space in which parents experienced the support group as a safe space, especially in the last closed group (Pate et al., 2015). Parents reported on greater wellbeing in the group due to being able to express their concerns, give support and strengthen their role in the rearing of their child with type 1 diabetes (Pate et al., 2015). They reported experiencing new things, being able to connect, to talk and to feel heard during the 4-year period and, most of all, the emotional support felt important and beneficial (Pate et al., 2015). This perceived change in group members, aiding them to reduce anxiety and stress in the family (Pate et al., 2015).

The review also identified that, despite one predominantly individually-based intervention in the article of Mackey et al. (2016), their programme included one group phone call with other participants to provide further social support for parenting a young child.

Telephone-based Interventions

The second powerful method of delivery revealed from this review is based on telephone interventions for parents caring for children with type 1 diabetes. Information from two similar articles explained that their telephone-based interventions were based on 5 phone call sessions that addressed psychosocial factors (Mackey et al., 2016; Monaghan et al., 2011). The one intervention (Monaghan et al., 2011) developed a telephone-based supportive programme to provide diabetes-related parenting support, and in the second article (Mackey et al., 2016), written 5 years later, researchers had a secondary focus that aimed to view the preliminary efficacy of the parent-focused intervention to improve glycaemic control and parental and child wellbeing.

From this review it became apparent that participants yielded high satisfaction with intervention content in telephone delivery format and felt it was informative and relevant to their experiences (Mackey et al., 2016; Monaghan et al., 2011). From baseline to follow-up, the intervention group focussing primarily on the support to parents demonstrated valuable results, indicating a decreased difficulty with parenting stress and increased perceived social support (Monaghan et al., 2011). The review further yielded that, in comparison to the two interventions, the phone calls that were all scheduled at the convenience of the parent, related to higher feasibility of the study, as they reduced barriers such as travelling, work schedule, etcetera (Mackey et al., 2016).

A third study that was identified using a telephone-based method of delivery, was described as a parent-mentor intervention (HOMEWARD) for mothers of young children newly diagnosed with type 1 diabetes and receiving support via telephone from mentors who are also mothers and who have successfully raised young children with type 1 diabetes (Sullivan-Bolyai et al., 2004). In this article the programme comprised of characteristics that include knowledge of managing the illness and child developmental aspects, help to identify community resources and successfully manage their own child's diabetes (Sullivan-Bolyai et al., 2004).

Given the two main methods of intervention delivery discussed above, the programme content in each article was extracted and synthesised to identify various content themes. Two articles were based on Peer Parent support/Mentoring interventions (Mackey et al., 2016; Sullivan-Bolyai, 2004) and the other group-focussed articles referred to programmes with Behavioural interventions, which focussed on cognitive-based strategies (Mackey et al., 2016; Monaghan et al., 2011; Sassmann et al., 2012) and coping-skills training (Ambrosino et al., 2008; Grey et al., Monaghan et al., 2011; Sassmann et al., 2012). This will be discussed below.

Peer support and Mentoring interventions

It was clear from the review that mentoring or support from peer parents were greatly welcomed (Mackey et al., 2016; Sullivan-Bolyai et al., 2004). The one specific intervention that focussed on supporting parents via more structured psycho-educational telephone sessions, also incorporated support calls from “Peer Parents” (Mackey et al., 2016). Trained Peer Parents were assigned to each participant and were instructed to call the participant four times, with each call following after a psycho-educational session. Four Peer Parent mothers with children who were now slightly older, were chosen (Mackey et al., 2016). The Peer Parents’ phone calls were based on specific content including eating, general adjustment, school and daily management, sleep, childcare, child behaviour, resources, special events, and peers and parent support (Mackey et al., 2016).

This pilot intervention was feasible and well received among parents. Participants expressed a need for more contact with the Peer Parents on follow-up (Mackey et al., 2015). However, findings in this article (Mackey et al., 2016) indicated that there were no statistically significant effects of the intervention of parenting stress, depression, social support, the quality of life or HbA1c compared to the control group, but that both groups reported improved quality of life in open ended questions asked on follow-up. Authors of this study came to the conclusion that this might mean any form of support might be helpful or that the intervention was not potent enough to assure changes in the above-mentioned moderators in this group of parents with newly-diagnosed children. Families still indicated a need for additional support, and this might be due to the overwhelming implications after diagnosis (Mackey et al., 2016).

Similar to the study above, a parent-mentor intervention (HOMEWARD) for mothers of young children newly diagnosed with type 1 diabetes received support from mentors who are also mothers and who have successfully raised young children with type 1 diabetes (Sullivan-Bolyai et al., 2004). These mentors were selected carefully on a basis of being nurturing and good listeners, but also advocating for diabetes management. Mentors provided important, practical day-to-day

management information, reassurance, affirmation and emotional support during times of crises for mothers in the experimental group via phone calls, but also limited home visits to the experimental group (Sullivan-Bolyai et al., 2004).

This study's feasibility was tested over a 6-months' trial, and parents in the experimental post-intervention group reported improved parental wellbeing and lessened parental concerns, worries, distress and strains (Sullivan-Bolyai et al., 2004). Participants reported more confidence, identified more resources and perceived the illness having less of a negative impact on the family compared to the control group mothers (Sullivan-Bolyai et al., 2004). Quality of life was not measured with quantifiable measures, but the article reported that subtle suggestions and emotional cost-saving effects did contribute to the reduction of parental anxiety and increased the effect on the quality of life (Sullivan-Bolyai et al., 2004).

Behavioural interventions

Cognitive-based strategies (CBT)

In the study of Ambrosino et al., (2008) participants were, amongst other coping skills training themes, facilitated to recognise associations between thoughts, feelings and actions and guided self-dialogue in order to improve competence and mastery which focussed on cognitive behavioural therapy (Ambrosino et al., 2008).

The intervention of Monaghan et al., (2011) and Mackey et al., (2016) focussed on the general social-cognitive theory (SCT) and cognitive-based strategies. They incorporated cognitive behavioural strategies to support parents in their daily management of the diabetes and parenting strategies relating to the young child. In the intervention of Mackey et al., (2016) they described the following themes, divided into sessions:

(1) discussing age-appropriate levels of development and related expectations, and incorporating these into future sessions. They also discussed positive thinking and breathing exercises for stress reduction;

- (2) focussing on glycaemic goals and strategy of problem solving;
- (3) focussing on behavioural strategies targeting eating, sleeping and behaviour;
- (4) a group phone call with other participants to provide further social support for parenting a young child, and
- (5) in this session they conducted a review of all calls and discussions of importance for parental self-care and wellbeing.

Findings in this study, which aimed to improve glycaemic control and parental and child wellbeing, indicated that there were no significant effects of the intervention on parenting stress, depression, social support, the quality of life or HbA1c (Mackey et al., 2016). Researchers in this intervention (Mackey et al., 2016) felt that any type of group would be beneficial, that the intervention was not potent enough to ensure changes in the above-mentioned moderators, and concluded that management of glycaemic control may be harder to impact.

In accordance to the findings in Monaghan et al. (2011), these interventions appear to be useful for decreasing diabetes-related parenting stress and increasing social support in the intervention group as high satisfaction with the content that was reported, but these effects were not present in the wait-control group comparison and there were no statistical significant group differences at follow-up.

Coping skills training (CST)

Most articles incorporated interventions focussing on Coping Skills Training for parents (Ambrosino et al., 2008; Grey et al., 2011; Monaghan et al., 2011; Pate et al., 2011; Sassman et al., 2012). In articles of Ambrosino et al., (2008) and Grey et al., (2011), the interventions aimed to increase a sense of competence and mastery in parents and children. These interventions comprised of 6 sessions, and specific emphasis was on retraining non-constructive coping styles with more positive styles and patterns of behaviour. It entailed learning to deal better with day-to-day problems that arise, rather than the management of type 1 diabetes. Coping skills specifically

addressed communication, social problem-solving, stress management and conflict resolutions (Ambrosino et al., 2008).

Few statistically significant improvements were identified across the psychosocial outcome variables of the coping skills training group and the educational group. Yet there was a trend of greater improvement over time in parents' perception of family adaptability in the coping skills training group after 3 months into the intervention (Ambrosino et al., 2008). Improvements in parental coping were associated with decreased parental responsibilities for diabetes management in the short term, and both the experimental and control groups reported significant decrease in parental responsibility after the first 3 months, indicating children were taking more care of their part of the treatment management (Ambrosino et al., 2008). In the sample of Grey et al. (2011) there was no intervention effect on child metabolic control in this sample, as it was already sufficient at baseline, and intervention may have had more significant outcomes if the sample had poorer metabolic control at baseline. The authors are of the opinion that, although there were no expected outcomes on HbA1c, both groups reported improved coping, less responsibility for treatment management, and improved quality of life on parent and family outcomes over time.

Psychotherapeutic techniques were used in the intervention of Pate et al. (2015) and included problem-solving skills, feedback, modelling, the validation of feelings with further questioning in collaboration with all other participants in search of alternative solutions (Pate et al., 2015). The authors reported that the programme of the group developed throughout the "seasons", so that the needs of the parents could be better met (Pate et al., 2015).

Combined CBT and CST programmes

Some studies incorporated themes that included increased support and efficacy for diabetes management tasks, promoting mastery learning through skills training and encouraging use of cognitive behavioural coping strategies (Mackey et al., 2016; Monaghan et al., 2011; Sassmann et al., 2012).

The DELFIN parenting programme is based on principles of behavioural therapy and also includes effective coping strategies of other general training programmes (Sassmann et al., 2012). The content of the DELFIN programme focusses on (1) the processing of dysfunctional cognitions, goal setting and theoretical discussion, (2) communication skills, (3) parenting skills to solve typical family conflicts and sessions (4) and (5) focused on practical skills training with regards to the particular challenges within families living with a child with type 1 diabetes. Weekly homework included transition of new strategies into family routine (Sassmann et al., 2012). This review already reported on the failure of these interventions to reach statistical significance, but participants from the DELFIN programme reported a reduction in adverse parenting behaviour, a slight reduction in parenting stress and a partial improvement in psychological wellbeing (Sassmann et al., 2012), but unexpectedly, so did the control group. A reason can be that reductions in psychological distress and parenting behaviour might improve step by step without external intervention (Sassmann et al., 2012).

Lastly, this review yielded evidence of interventions that were tailored to the developmental level of the child and included them in some programmes. Although similar to the study of Monaghan et al. (2011), the intervention programme developed by Mackey et al. (2016) was enhanced, as it made additional provision for integrating developmentally-tailored education, cognitive behavioural strategies to support parents in their daily management of the diabetes, and parenting strategies relating to the young child. In this intervention the authors incorporated age appropriate levels of development and related expectations into all the sessions. With regards to comparisons between the studies of Ambrosino et al. (2008) and Grey et al. (2011), the content was tailored to the developmental level of the child for each group in the intervention of Grey et al. (2011), by using different examples. In the article of Sullivan-Bolyai et al. (2004), the programme comprised of characteristics including knowledge of managing the illness and child developmental aspects.

Another significant finding in this review pertained to the limitations identified by the different studies included. The researchers of all seven studies included in this review, acknowledged that they did not have a representative sample size and that their studies could not be generalized to the larger population (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 et al., 2004). Researchers also felt that their studies were too homogenous in terms of recruiting from a specific institution (Ambrosino et al., 2008; Sassman et al., 2012) and in terms of either focussing too much on mothers and not both parents or more fathers (Monaghan et al., 2011; Pate et al., 2015) or including other caregivers (Monaghan et al., 2011). A study also included parents who already indicated a relatively good quality of life at baseline (Grey et al., 2011). This review also identified the limitations in terms of a need for more diverse ethnic and socioeconomic demographic distribution in participants (Ambrosino et al., 2008; Grey et al., 2011; Monaghan et al., 2011; Sassman et al., 2012).

Sassman et al. (2012), Sullivan-Bolyai et al., (2004) and Pate et al. (2015) all indicated that a limitation to their studies was to broaden their content of interventions to more tailored developmental stages of children and meet specific needs of parents in order for them to gain relevant skills relating to challenges within specific age groups. The implication of time constrains for participants in this study was also identified and was partially related to parents having difficulty committing to complete the intervention (Ambrosino et al., 2008; Mackey et al., 2016; Sassman et al., 2012).

Some researchers were of the opinion that they might have received greater outcomes if they were to do longer term post intervention follow-ups and evaluations (Mackey et al., 2016; Monaghan et al., 2011; Sullivan-Bolyai et al., 2004).

Ambrosino et al. (2008) and Grey et al., (2011) had many children in their studies that had an insulin pump therapy intervention and they admitted that this method may be positively related

to improved quality of life compared to people who does not have this advanced treatment prescription.

Conclusion

It was evident from this review that there were limited studies available reflecting interventions that improve the quality of life for parents living with young children with type 1 diabetes. Literature emphasises that when parents feel competent managing the child's diabetes, this improves coping and decreases stress in order to promote wellbeing or a better quality of life for the parent and the whole family (Brown et al., 2010; Streisand, et al., 2010). Methods of delivery highlighted are interventions that are based on groupwork or telephone-based programmes aimed at providing support. Some studies provided content based on general psycho-education (Ambrosino et al., 2008; Grey et al., 2011; Sassmann et al., 2012) and some incorporated cognitive behavioural therapy and coping skills training programmes (Ambrosino et al., 2008; Grey et al., 2011; Monaghan et al., 2011) based on child developmental phases (Mackey et al., Grey et al., 2011; Sullivan-Bolyai et al., 2004). Literature supported the findings in this review, namely that cognitive behaviour therapy and coping skills training programmes are important (Hampson et al., 2000; Hunter, 2016). Literature also strongly recommended tailored interventions, as findings reported a parental need for guidance about their child's specific developmental phase (Chiang et al., 2014; Hilliard et al., 2016; Streisand & Monaghan, 2014; Patton et al., 2006). This review identified tailored programmes that fit the individual or the group's needs and were reported to be beneficial.

It became apparent in this review that, regardless of content, the quality of life improved in experimental and control groups. Participants 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; Sassman et al., 2012). Groups for children may also

facilitate social support from peers (Grey et al., 2011). The above finding is very relevant, as parents living with children with type 1 diabetes often deal with social isolation and feelings with regard to experiencing the loss of a healthy child that their peers who do not have these challenges, do not understand (Streisand & Monaghan, 2014).

Limitations

When interpreting the results and the discussion, it is important for the reader to take into consideration that there are limitations within this review. On a basic practical level, only articles that were available in English language, were included which might have excluded some relevant articles. It may be that, in other literature, the concept “quality of life” is described differently and in a broader context, and therefore relevant literature could be missed in this review when using these specific search keywords. It may also be that literature pertaining to the research question could have been missed with the inclusion and exclusion criteria in this review for children within the age range (3 – 10 years), as this may have been too specific and articles reflected on a wider age range and scope were missed.

In this review no specific measure was used to evaluate the outcomes of quality of life, thus different ways of improving this quality of life was acceptable. The criteria only required an improvement of quality of life for parents, but future research may consider more specific outcome measures. However, in this review the reflection of the current search for literature still implied that a limited number of studies are available that specifically focus on **the quality of life** for parents of **young** children living with type 1 diabetes. Some studies are outdated and have been published more than ten years ago. The criteria for years included in the electronic search of the systematic review had to be adjusted in an attempt to obtain more published literature, but had limited success. The researcher might have had to consider doing a rapid review due to the lack of available literature studies and additional time limitations hampering the search to confidently report that an exhaustive search was conducted. More time could have been spent on finding the articles that

were unavailable or citing relevant articles to adhere to the requirements of a comprehensive systematic review. In a rapid review the completeness of a search is determined by the time constraints and analysis involves overall quality and direction of the effect of the literature (Grant & Booth, 2009).

However, by following the steps of a systematic review, great emphasise are put on what is known and what remains unknown (Grant & Booth, 2009). Research also acknowledges the uncertainty around findings, limitations and future recommendations (Grant & Booth, 2009). This lack of relevant literature in this review poses many of these questions. One question that has been asked, was how seriously this avenue of parental wellbeing has been investigated and intervened in the past decade, and yet, statistics of younger children diagnosed with type 1 diabetes, increase yearly. This limited number of available studies emphasises the need for interventions to improve the quality of life for parents living with young children with type 1 diabetes and was a further motivation to pursue this review.

The reviewers of the articles acknowledge that all articles in this review conducted interventions on relatively small samples, and thus caution should be taken when findings are generalised to other populations. All the studies in this review were conducted with parents in developed countries, with the majority being middle-class White/Caucasian mothers and therefore conclusions may not be widely accepted in all clinical practices. This reflects on the lack of literature investigating ethnic minority groups and poses a further question on the content of basic service delivery and treatment for the population in developing countries.

It was, for example, evident from articles in this review (Ambrosino et al., 2008; Grey et al., 2011) and additional literature, that parents and children who have a diabetes care plan that includes insulin pump treatment, had higher levels of child self-management and increased levels of quality of life (Lieberman, Buckingham & Phillip, 2012; Streisand, Swift, Wickmark, Chen, & Holms,

2005). The hypothesis is that insulin pump treatment is expensive and unaccessible in developing countries (Singha et al., 2017).

Furthermore, the reviewers had measures in place to ensure the rigor of the study, but this is unlikely to guarantee a transparent and rigor-free process, so different researchers will not be able to completely replicate the current study.

Implications and Recommendations

Intervention studies with larger samples from developing countries are necessary to represent the population and to confirm findings. These interventions need to focus on supporting parents. Some of the studies in the articles in this review should be useful for follow-up and, more importantly, follow-ups should focus on more longitudinal studies with post-intervention outcomes.

In this review it was found that parents often experienced constraints despite the already overwhelming time-consuming challenges of caring for a child with type 1 diabetes. Interventions should aim to develop programmes in such a manner that they meet the needs of parents who are busy or who have to spend lengthy periods of time travelling to participate in interventions. The use of technology (such as telephone based or internet based) to support parents' needs in the light of the above implication, should be explored.

Another implication identified is the fit between peer parents or mentors to participants or to fit participants to a parent group in general, as inclusion criteria for children's age range need to be taken into account. Sullivan-Bolyai et al. (2004) identified in their study that participants often do not have a child similar in age to that of the mentor. Studies should explore the different combinations of age groups and compatibility of knowledge from a developmental phase from facilitators, group members, peer parents or mentors to support the idea of interventions that are tailored to childrens' developmental phase/age.

Group-based interventions seem to be more cost and clinically effective than interventions for individuals (Grey et al., 2011). Future research can explore the development of interventions

that take a combination of methods of delivery and different content information in a programme into account. Mackey et al., (2016) support the suggestion by the World Health Organization (2008) to rethink delivery of mental health services by training lay community members to deliver a relevant service to reduce healthcare users' costs.

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SECTION III: CONCLUSION AND REFLECTION

Conclusion

This systematic review aimed to investigate effective interventions for parents of young children living with type 1 diabetes, specifically in search of interventions that improve parents' quality of life. The objective was to identify and describe current research on effective intervention programmes that are available and to look specifically at what these interventions entail.

It was confirmed in this review that limited studies reflecting on interventions that improve the quality of life for parents living with young children with type 1 diabetes, were available. It appears that receiving support is the most important and welcomed aspect identified in this review despite support not being the main aim of some of these studies. Two main methods of delivery highlighted in this review are interventions that are based on group work and those that were designed on telephone-based programmes. Secondary to support, content including psycho-education, cognitive behavioural therapy and coping skills training based on developmental phases of children, were viewed as informative and helpful.

Groups consisted of experimental groups implementing a specific programme, and control groups that provided basic psycho-education to compare the efficacy of the interventions. The finding pertaining to quality of life was evident in the experimental and control groups and a conclusion drawn is that many basic psycho-educational control groups also experienced an increase in quality of life due to the support received. A limitation in this review was that the researcher did not specify specific outcomes and measures for quality of life as such limited studies were available. The researcher further admits to time being a limitation in this review and doing a rapid review should have been considered.

All the studies in this review were conducted with parents in developed countries with the majority being middleclass White/Caucasian mothers, lacking in literature-investigating ethnic

minority groups and treatment for the population in developing countries. This investigation holds promising ideas that can contribute to future development of interventions. In order to promote healthy outcomes and better quality of life for the whole family living with children diagnosed with type 1 diabetes in developing countries, the limitations in this review should be taken into account when planning future research, especially when conducting research in South Africa.

Future Recommendations

Interventions need to focus primarily on supporting parents. Continuous incorporation of educational content relating to diabetes-specific information will add to the richness of effective supportive interventions. Research pertaining to cognitive behavioural strategies and coping skills training content are still most effective and could continue to integrate specific developmental phases, depending on the age of the child of the participating parents. Studies should endeavour to research larger samples from more diverse developing countries and include ethnic minority groups. More longitudinal studies with post-intervention outcomes are also suggested, given diabetes being a lifelong chronic condition. Researchers that develop interventions should be wary of implications such as parents' daily time constraints and focus on what is helpful rather than what could be viewed as an additional burden to parents' already heavy load. Therefore methods identified in this review, such as telephone-based interventions, can be explored further, and creative technology-based group platforms could be a pillar of future support. For more individualised cost-effective support, the suggestion of including and training by community members can be considered. It is important that future research should conduct more scientific rigour and that greater thought should be put into whether the chosen methodology fits to the current accessible research and available time in which the review is conducted.

Self-reflection of the Study Process

When I entered into this study, I was not yet sure which aspect of diabetes I wanted to explore. With a lot of reading, I managed to capture a glimpse of how it felt to walk around in

parents' shoes – specifically those who live and care for their young child diagnosed with type 1 diabetes. After extensive reading and a discussion with my supervisor, my interest was triggered and I had an urge to find literature that might bring me and the reader closer to a remedy for parent support, and subsequently increased the quality of life for these parents. A longstanding view of mine was that, without parental wellbeing, children might not experience wellbeing either, as children are dependent on significant others to provide them with a safe and protected space to develop (Cassidy, Jones & Shaver, 2013). Parents need to manage this life-threatening disease of their child, but at the same time a safe and protected space needs to be created so that parents can have a better quality of life, given their circumstances.

During my second year working as an intern, I surprisingly had encounters with people relating to either diabetes or to the development of a support group for a different condition. Even though the latter was not related to diabetes, I could explore different methods of support delivery that I have come to know and implement in such a group. I realised that taking this avenue had various benefits. Primarily it directed me in my search to advocate for these parents of children living with type 1 diabetes in their search for support. Secondary, this review process provided gains in terms of equipping me to be more compassionate towards people with this condition that I encounter. I was mindful of my father throughout this research journey as he has been living with type 2 diabetes for many years.

My wish is that holistic diabetes care will be emphasised, that much more research and pilot interventions for parents with children diagnosed with type 1 diabetes will be conducted, producing promising outcomes, and that South Africa will develop programmes that are tailored to the needs of our unique population.

Authors' Contributions

All authors contributed to the article.

Conflict of Interest

The Authors declare that there is no conflict of interest associated with this publication and there has been no financial support for this work that could have influenced its outcome.

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LIST OF TABLES

Table 1: PICO Formula Applied to this Study

Review Question	To describe effective interventions to improve the quality of life among parents of children aged 3 to 11 years with type 1 diabetes
Population	Parents of children between the ages of 3 and 11 years diagnosed with type 1 diabetes and managing the child's condition
Intervention	Educational, psycho-social and behavioural interventions
Comparison	Effectiveness of different interventions
Outcome	The quality of life

Table 2: Initial Inclusion and Exclusion Criteria on Titles and Abstracts

Inclusion Criteria	Exclusion Criteria
• Parents who manage the type 1 diabetes of their young child • Toddler and primary-school age between 3 and 11 years of age • Any relevant type of interventions with parents • Improvement of the quality of life • English language articles • Full-text articles and PhD dissertations • Timespan: from 2005 – current article dates • International and national studies • Qualitative and quantitative studies • Open access and accredited journals	• Type 2 diabetes • Articles not adhering to high ethical standards

Table 3: Quality Critical Checklist: Primary Research (QCC): Quantitative Research**Abbreviations:** Yes (Y), No (N), Can't tell (U), N/A**Reviewers:** Linda Santilli (1) and Elmari Deacon (2)**Date:** 01 – 03 Sept

No	Article and Authors	Clearly stated research question		Selection free from bias		Comparing study groups		Withdrawal method described		Blinded to prevent bias		Description of interventions		Reliable/ Valid outcomes		Statistical analysis appropriate		Conclusion supported by results		Funding or sponsors		TOTAL	
		1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2
1	Mackey, E.R., Herbert, L., Monaghan, M., Cogen, F., Wang, J., & Streisand, R. (2016)	Y	Y	Y	Y	Y	Y	N	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
2	Pate, T., Rutar, M., Battelino, T., Drobnic Radobuljac, M., & Bratina, N. (2015)	Y	Y	Y	Y	N/A	N/A	Y	Y	U	U	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y
3	Ambrosino, J. M., Fennie, K., Whittemore, R., Jaser, S., Dowd, M.F., & Grey, M. (2008)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
4	Sassmann, H., De Hair, M., Danne, T., & Lange, K. (2012)	Y	Y	U	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y
5	Sullivan-Bolyai, S., Grey, M., Deatrick, J., Gruppuso, P., Giraitis, P., & Tamborlane, W. (2004)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
6	Grey, M., Jaser, S., Whittemore, R., Jeon, S., & Lindemann, E. (2011)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
7	Monaghan, M., Hilliard, M.E., Cogen, F.R., & Streisand, R. (2011)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Table 4: Critical Appraisal Skills Programme Quality (CASP): Qualitative Research**Abbreviations:** Yes (Y), No (N), Can't tell (U), N/A**Reviewers:** Reviewer 1 and Reviewer 2**Date:** 01 – 03 Sept

No	Article and Authors	Clear aim of research		Appropriate method		Research design appropriate		Recruitment strategy appropriate		Collection of data		Relationship		Ethical considerations		Data Analysis rigorous		Clear statement of findings		How Valuable		TOTAL	
		1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2
8	2005, Davidson, S. & Spowart, K	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	N	N	Y	Y	N	N	N	N

Table 5: Demographic Characteristics of Included Studies

	Authors	Title of article	Year	Journal	Country	Group status	Sample size	Mean age
1	Ambrosino, J. M., Fennie, K., Whittemore, R., Jaser, S., Dowd, M.F. & Grey, M.	Short-term effects of coping skills training in school-age children with type 1 diabetes	2008	Pediatric Diabetes	United States of America	Predominantly white 86 % Black/Hispanic 14%	87 Parents Predominantly mothers	Child: 9.91 Parents: 40.01 (Children 8-12 years)
2	Grey, M., Jaser, S., Whittemore, R., Jeon, S. & Lindemann, E.	Coping skills training for parents of children with type 1 diabetes: 12-month outcomes	2011	Nursing Research	United States of America	Unspecified	Intervention group 75 Control group 106	Child intervention group 8.1 Control group 7.9 (Children 1 – 12 years) Parent age unspecified
3	Mackey, E.R., Herbert, L., Monaghan, M., Cogen, F., Wang, J. & Streisand, R.	The feasibility of a pilot intervention for parents of young children newly diagnosed with type 1 diabetes	2016	Clinical Practice in Pediatric Psychology	United States of America	Caucasian 70%	30 Mothers	Children 1 – 6 years Parent 33.64
4	Monaghan, M., Hilliard, M.E., Cogen, F.R. & Streisand, R.	Supporting parents of very young children with type 1 diabetes: results from a pilot study	2011	Patient Education and Counseling	United States of America	Caucasian 75% Other unspecified	24 Parents: Mothers 88%	Child 4.10 Parent 34.80 (Children 2 – 5 years)
5	Pate, T., Rutar, M., Battelino, T., Drobnic Radobuljac, M. & Bratina, N.	Support group for parents coping with children with type 1 diabetes	2015	“Zdrav Var” Zdravstveno varstvo/Slovenian Journal of Public Health	Slovenia	Unspecified	34 Parents	Parent 42.4 Child 8.9

6	Sassmann, H., De Hair, M., Danne, T. & Lange, K.	Reducing stress and supporting positive relations in families of young children with type 1 diabetes: a randomized controlled study for evaluating the effects of the DELFIN parenting program.	2012	BMC Pediatrics	Germany	Unspecified, but German speaking	Intervention 37 Control 28 65 parents (mothers 33) (fathers 32)	Mothers 39.11 – 40.4 Fathers 42.41 – 43.3 (Children 2 –10)
7	Sullivan-Bolyai, S., Grey, M., Deatrick, J., Gruppuso, P., Giraitis, P. & Tamborlane, W.	Helping other mothers effectively work at raising young children with type 1 diabetes	2004	The Diabetes Educator	United States of America	White 38 (90%) African American 1 Hispanic (5%)	41 Mothers	Mothers 35 (Children 1 – 10 years)

Table 6: Main findings of study

	Authors	Measures	Study design	Main objectives of study	Main findings	Author conclusion
1.	Ambrosino, J. M., Fennie, K., Whittemore, R., Jaser, S., Dowd, M.F. & Grey, M. (2008)	For children: - Baseline questionnaire Disease-related variables medical chart - Issues in Coping with IDDM – child scale - Self-efficacy for Diabetes Scale - Diabetes. Quality of Life Scale for Youth (DQOL) - Diabetes Family Behaviour Scale (DFBS) For parents: - Demographic information - Issues in Coping with IDDM – Parent scale - Center for Epidemiological Depression Scale (CES-D) - Diabetes Responsibility and Conflict Scale - Family Adaptability and Cohesion Scale (FACES)	Randomized prospective two-group experimental design. Follow-up at 1, 3, 6 and 12 months post-intervention Only baseline, 1 and 3 months' data are reported in this study	To evaluate the short-term efficacy and feasibility of a psychosocial coping skills training (CST) intervention for the child and parent compared with an educational group education. The intervention is for young children and parents to increase sense of competence and mastery, retraining non-constructive coping styles with more positive styles and patterns of behaviour. Small groups with children were conducted. Parents met simultaneously but separately.	Both CST and GE (group education) contributed to modest positive changes in many areas of psychosocial adaptation. CST parents showed greater improvement in parent-reported family functioning and child-reported satisfaction with quality of life compared to the control group. The children in the CST group indicated greater improvement in life satisfaction than in the control group and may be linked to insulin pump therapy too.	Both groups contributed to modest positive changes in many areas of psychosocial adaptation, while the CST group showed more specific changes. Ongoing longer-term follow-up of this cohort will help determine whether being introduced earlier to CST will enhance outcomes and help prevent the deterioration in glycaemic control and increased family conflict.
2.	Grey, M., Jaser, S., Whittemore, R., Jeon, S., & Lindemann, E. (2011)	- Disease-related variables from children's medical folders - Bayer Diagnostics DCA2000 for assessing metabolic control via HbA1c - Demographic information reported by parents (relationship to child, age, socio-demographic, gender, etc.) - Demographic information by parents - Issues in Coping with IDDM-Parent scale - Center for Epidemiological Depression Scale (CES-D) - Diabetes Responsibility and Conflict Scale (DRC) - Parents Diabetes Quality of Life	Two separate randomized clinical trials of Coping skills training intervention. One group for parents and child of 8 - 12 years, and one group for parents and child younger than 8 years. Data reported on baseline, 1, 3, 6 and 12 months post	To determine the effects of a Coping skills training (CST) intervention program conducted with younger children and their parents compared to an attention-control group on the outcomes of parental coping, family functioning, quality of life, and child metabolic control. Secondary aim to explore mediators (parental coping) en moderators (age, gender, etc.) outcome over a period of 12 months.	CST did not have the expected effect 12 months post intervention in this relatively well-controlled sample. The hypothesis that parents of the CST intervention would demonstrate better coping, increased family functioning, and higher quality of life, was not supported. There were not significant treatment effects on any outcome variable, but changes over time indicated improvement in parenting coping and quality of life. However, both groups reported improved coping, less responsibility for treatment management and improved quality of life on parent and family outcomes in this trial.	The author is of the opinion that although there were no expected outcomes, there were significant time effects demonstrated over time. The supportive group-based educational and behavioural interventions may be associated with improved parental and diabetes outcomes. Further interventions are needed to determine if it is appropriate to provide group-based diabetes care programmes for families coping

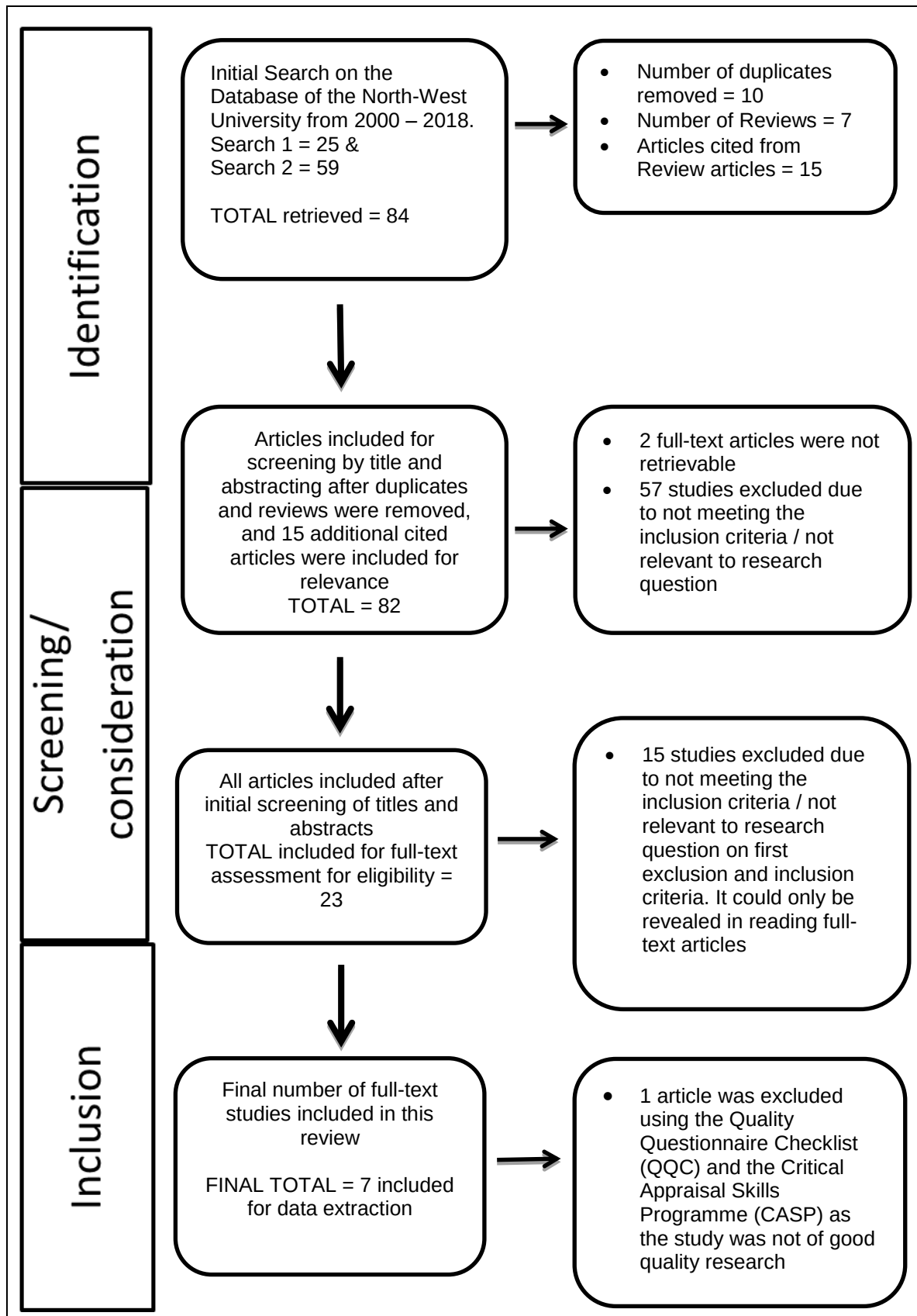
		Questionnaire (PDQOL)	intervention			with diabetes.
3.	Mackey, E.R., Herbert, L., Monaghan, M., Cogen, F., Wang, J., & Streisand, R. (2016)	- Demographic and medical questionnaire - Center for Epidemiological Studies Depression (CES-D) - Pediatric Inventory for Parents (PIP) - Pediatric Quality of Life Inventory - Multidimensional Scale of Perceived Social Support - Project acceptability interview with parents - PP (Peer parent) post-session questionnaire - PP project acceptability with research team member - Measuring Glycemic control	Pilot randomized controlled trial (RCT) Data reported on baseline, 1, 6 and 12 months. Also open-ended questions asked on follow-up	Examining the feasibility and acceptability of a phone-based pilot intervention among parents of young children immediately following a diagnosis of type 1 diabetes as well as a secondary focus on the preliminary efficacy of the parent-focused intervention to improve glycaemic control and parental and child wellbeing Similar to the study below (Monaghan et al., 2011), but this intervention was created to provide diabetes-related parenting support by telephone. including developmentally-tailored education, cognitive behavioural strategies and parenting strategies.	The pilot intervention to support parents by using parents as peers and a phone-based approach to intervention is feasible. It was well received among parents. However, findings indicated that there were not significant effects of the intervention of parenting stress, depression, social support, quality of life or HbA1c. Either anything would be helpful or the intervention was not potent enough to assure changes in the above mentioned moderators. Families still indicated a need for additional support, as findings indicated that there were no significant effects of the intervention on parenting stress, depression, social support, quality of life, or HbA1c in this newly diagnosed sample.	The newly-diagnosed period represent a unique period in which parents seek additional support, is needed. This intervention can buffer the negative effects of maternal depressive symptoms on child glycaemic control. This study was feasible and acceptable, despite no evidence of preliminary efficacy. A larger trial is warranted in order to evaluate broader efficacy and examining other outcomes (e.g. health care, cost effectiveness).
4.	Monaghan, M., Hilliard, M.E., Cogen, F.R., & Streisand, R. (2011)	- Background Information Questionnaire - Center for Epidemiological Studies-Depression (CES-D) - Multidimensional Scale of Perceived Social Support (MSPSS) - Pediatric Inventory for Parents (PIP) - State-Trait Anxiety Inventory (STAI) - Treatment Satisfaction Questionnaire	Pilot study randomized control trial (RCT) Pre- and post-intervention 3 weeks after the intervention Second intervention phase initiated for waiting-list participants Also open-ended questions asked on follow-up	To assess and identify trends in intervention effects and to assess the efficacy and feasibility of telephone-based supportive programme intervention for parents of young children with type 1 diabetes (T1D) Although similar to the above study (Mackey et al., 2016). This intervention focussed on the general social-cognitive theory (SCT) and cognitive based strategies	The Social Cognitive Theory (SCT) appears to be useful for decreasing diabetes-related parenting stress and increasing social support in the intervention group. The findings indicated high satisfaction with the intervention's content and telephone-delivery format. These effects were not present in the wait-control group comparison and there were no significant group differences at follow-up. This intervention is promising to enhance parents' emotional functioning and quality of life. SCT also provides a framework for this diabetes-focussed parenting intervention that is useful to	The implementation of a telephone-based structured intervention is promising and parents may benefit from such an intervention. The rate of newly diagnosed cases for children between 0 – 4 years of age has increased and these parents are at risk for anxiety, depression and parenting stress. The author concluded that further studies were underway with larger, multi-site samples with longer-term post-intervention follow-ups and examination of the child's health outcomes.

					decrease diabetes-related parenting stress and increase social support	
5.	Pate, T., Rutar, M., Battelino, T., Drobic Radobuljac, M., & Bratina, N. (2015)	- Demographic questionnaire - Self-evaluation questionnaire designed by the authors - Questions on a five-point Likert scale related to parents' well-being - Open-ended questions regarding topics most interesting for participants	Mixed-method study - quantitative and qualitative research	To assess parental satisfaction with participation in the group and their perceptions of the impact of the intervention A parent support group programme is based on the relational family theory. The primary aim is to create a space for the awareness, understanding and development for more flexible and adaptive coping strategies for regulating parental emotions and empower them to the sensitivity of their children's needs.	Quantitative data indicated that parents were overall satisfied with almost all measured items such as wellbeing in the group, feeling secure, experiencing new things, being able to talk and feeling being heard, during the 4-year period. Parents from the second and third season indicated that the support group has better fulfilled their expectations than the parents from the first season (the program of the group developed through the seasons so that the needs of the parents could be better met). Qualitative data was underpinned by four themes: support when confronting the diagnosis, transformation of the family dynamics, me as a parent, exchange of experience and good practice and facing the world outside the family. The group member's perceived change aided them to recude anxiety and stress in the family	This parent support group showed to be a promising supportive, therapeutic and psycho-educational space in which parents felt safe, could express their concerns, give support and to strengthen their role in the rearing of their child with type 1 diabetes. Quantitative analysis of the changes in the experiences of the parents could be included. Following the process and dynamics in the group can also be a focus.
6.	Sassmann, H., De Hair, M., Danne, T., & Lange, K. (2012)	- Socio-demographic data - The Parenting Scale - Questions to Education Behaviour - Depression-Anxiety-Stress Scale DASS - Parents' version of the Strengths and Difficulties Questionnaire (SDQ) - Structured questionnaire to assess satisfaction with the DELFIN program - Biomedical data	Randomized controlled group design with control group being wait-listed Data on baseline, 3 months and 12 months post-intervention	Evaluate the feasibility and effectiveness of the structured behavioural parenting training program (DELFIN) for parents of children with type 1 diabetes. Developed to integrate general parenting strategies and diabetes specific conflict situations in order to reduce parental stress, anxiety and depression as well as children's behavioural	Participants from the DELFIN program reported reduction in adverse parenting behaviour and partial improvement of psychological wellbeing. Unexpectedly reduction in psychological distress, adverse parenting behaviour and behavioural difficulties of the child were also seen in the control group. The reduction of negative parenting behaviour was stable after 12 months, indicating that parents implemented new strategies in their day to day behaviour on the longer term as well. No changes were detected for positive parenting behaviour. Despite the positive outcomes, the	This study has brought first evidence for the efficacy and feasibility of such a DELFIN program. According to the authors, a multicentre study with a larger sample is necessary to confirm the current findings in this study that efficacy and feasibility of the program is evident.

				difficulties by improving parenting skills.	differences between both study arms failed to reach statistical significance. Results point to improved parenting skills and slightly reduced parenting stress. The Depression-Anxiety-Stress Scale (DAS) indicative of Parents psychological distress, decreased significantly in the DELFIN group. Over time, there were no significant group effects and the control group had a significant reduction of anxiety, stress and of the total DASS-score as well	
7.	Sullivan-Bolyai, S., Grey, M., Deatrick, J., Gruppuso, P., Giraitis, P., & Tamborlane, W. (2004)	• Demographic data • Banion Diabetes Management Concern Questionnaire • Parental Confidence Questionnaire • Impact on Family Scale • Home Care Resources Instrument • Child related cost outcome measures include HbA1c levels and number of consultation calls to medical staff.	A mixed-method Prospective randomized controlled clinical trial design for the experimental group and the control group received intervention after 6 months trial	Examining the feasibility of a post-diagnosis parental mentoring intervention (HOMEWARD) for mothers of young children newly diagnosed with type 1 diabetes receiving support from mothers who have successfully raised young children with type 1 diabetes. Home visits and phone call support to mothers in the experimental group were given during a 6 months trial by experienced mothers (mentors).	It was evident that parent mentors provided important, practical day-to-day management information, reassurance, affirmation and emotional support during times of crises for mothers in the experimental group as they reported fewer concerns, more confidence, identified more resources and perceived the illness having less of a negative impact on the family compared to the control group mothers. Over a 6 months period parent-mentored mothers had a significantly greater reduction in diabetes related concerns and perceptions of the illness. Mothers identified more resources. Quality of life was not measured with quantifiable measures, but the article reported that subtle suggestions and emotional cost-saving effects did contribute to the reduction of parental anxiety and the quality of life effects (Sullivan-Bolyai et al., 2004).	A post-diagnosis parent mentoring intervention for mothers of children with diabetes appears to be feasible and potentially effective. It improved parental wellbeing and lessens parental concerns. The author is of the opinion that continuing research in this area is suggested and that intervention effectiveness should be explored over a longer time and with a larger sample size.

LIST OF FIGURES

Figure 1: Flow of Information Through the Different Phases of this Systematic Review



APPENDIX A: TURN-IT-IN

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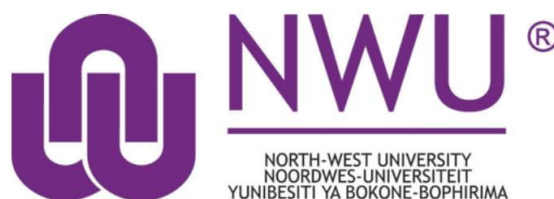
ORIGINALITY REPORT

21 %	15 %	15 %	9 %
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

PRIMARY SOURCES

1	www.ncbi.nlm.nih.gov Internet Source	4 %
2	bmcpediatr.biomedcentral.com Internet Source	2 %
3	Eleanor Race Mackey, Linda Herbert, Maureen Monaghan, Fran Cogen, Jichuan Wang, Randi Streisand. "The feasibility of a pilot intervention for parents of young children newly diagnosed with type 1 diabetes.", Clinical Practice in Pediatric Psychology, 2016 Publication	1 %
4	www.gdm1.org Internet Source	1 %
5	Submitted to Grand Canyon University Student Paper	1 %
6	www1.paho.org Internet Source	1 %
7	Jodie M Ambrosino. "Short-term effects of coping skills training in school-age children with	1 %

APPENDIX B: ETHICS CLEARANCE CERTIFICATE



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Research Ethics Regulatory Committee

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ETHICAL APPROVAL LETTER OF STUDY

Based on approval by the **North-West University Human Social Sciences Research Ethics Committee (NWU-HSS-REC)** on **22/10/2018**, the North-West University Research Ethics Regulatory Committee (NWU-RERC) hereby approves your project as indicated below. This implies that the NWU-RERC grants its permission that, provided the special conditions specified below are met and pending any other authorisation that may be necessary, the project may be initiated, using the ethics number below.

Study title: Effective interventions to improve quality of life for the parents of young children living with type 1 diabetes: A systematic review

Study Leader/Supervisor (Principal Investigator)/Researcher: Deacon, E & Santilli, L

Student: -

Ethics number:

N	W	U	-	HS	-	2	0	1	8	-	0	0	9	2
Institution				Year				Project Number						

Application Type:

Commencement date: 2018-10-17

Expiry date: 2019-10-17

Risk:

low

Special conditions of the approval (if applicable):

- Translation of the informed consent document to the languages applicable to the study participants should be submitted to the NWU-HSS-REC (if applicable).
- Any research at governmental or private institutions, permission must still be obtained from relevant authorities and provided to the NWU-HSS-REC. Ethics approval is required BEFORE approval can be obtained from these authorities.

General conditions:

While this ethics approval is subject to all declarations, undertakings and agreements incorporated and signed in the application form, the following general terms and conditions will apply:

- The study leader (principle investigator) must report in the prescribed format to the NWU-HSS-REC:
 - annually (or as otherwise requested) on the monitoring of the study, and upon completion of the study; and
 - without any delay in case of any adverse event or incident (or any matter that interrupts sound ethical principles) during the course of the study.
- Annually a number of studies may be randomly selected for an external audit.
- The approval applies strictly to the proposal as stipulated in the application form. Would any changes to the proposal be deemed necessary during the course of the study, the study leader must apply for approval of these amendments at the HHREC, prior to implementation. Would there be deviation from the study proposal without the necessary approval of such amendments, the ethics approval is immediately and automatically forfeited.
- The date of approval indicates the first date that the study may be started.
- In the interest of ethical responsibility, the NWU-RERC and NWU-HSS-REC reserves the right to:
 - request access to any information or data at any time during the course or after completion of the study;
 - to ask further questions, seek additional information, require further modification or monitor the conduct of your research or the informed consent process;
 - withdraw or postpone approval if:
 - any unethical principles or practices of the study are revealed or suspected;
 - it becomes apparent that any relevant information was withheld from the NWU-HSS-REC or that information has been false or misrepresented;
 - the required amendments, annual (or otherwise stipulated) report and reporting of adverse events or incidents was not done in a timely manner and accurately; and/ or
 - new institutional rules, national legislation or international conventions deem it necessary.
- NWU-HSS-REC can be contacted for further information via Daleen.Claasens@nwu.ac.za or 016 910 3441.

The NWU-HSS-REC would like to remain at your service as scientist and researcher, and wishes you well with your study. Please do not hesitate to contact the NWU-RERC or NWU-HSS-REC for any further enquiries or requests for assistance.

Yours sincerely

Prof Chrizanne van Eeden

Chair NWU Human Social Sciences Research Ethics Committee

APPENDIX C: OPTENTIA APPROVAL FORM



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Ms Linda Santilli

[29077060]

24 May 2018

“Effective interventions to improve quality of life for parents of young children living with type 1 diabetes: A systematic review”

Dear Ms Santilli,

This letter serves to confirm that your research proposal has been accepted and approved by the **Optentia Research Committee**.

Kindly note the changes communicate to your supervisor as per the suggestions of the reviewers:

Panel:

Prof. Ian Rothmann	Dr Tamlynn Jefferis
Dr Karen van der Merwe	Dr Laura Weiss

The ethics application is referred to the Humanities and Health Research Ethics Committee (HHREC).

Best Regards,

Prof. S. (Ian) Rothmann

Director: Optentia Research Focus Area