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The Consequences of Type 1 Diabetes Onset On Family Life. An Integrative Review

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Abstract

Objectives Type 1 diabetes mellitus (T1DM) is an auto-immune disease that requires an important effort in self-management. The onset of T1DM in a child places a significant burden on parents, requiring careful management of blood glucose levels through insulin injections, diet and exercise. The main aim of our study is to synthesise what is known about the consequences of T1DM onset for families and, in particular, how parents share the emotional, practical and educational burden of care connected with diabetes management.

Methods To accomplish this goal, we conducted an integrative review of 29 studies concerned with the ways in which disease management permeates the daily lives of families. Based on our findings, we offer suggestions for future research. For this study, PubMed, SAGE Journals, Google Scholar, ERIC, Web of Science, Embase and Scopus databases from 2000 to 2017 were searched using keywords related to T1DM management in families, parental roles and learning processes. Our sample included qualitative, quantitative and mixed-method studies which assessed the consequences of T1DM onset for the family and, in particular, the ways through which disease management permeates the daily lives of mothers and fathers of children with T1DM (3–18 years of age).

Results The initial literature search returned 113 papers and 29 studies that met all the inclusion criteria. Through a content analysis, we identified three conceptual categories: (i) 'managing emotions after diagnosis', (ii) 'reconstructing routines around new needs' and (iii) 'educating young patients to enhance autonomy'.

Conclusions The review results strongly support that diabetes is a family illness in which patients and parents are at the centre of emotions, routines and knowledge strictly connected to diabetes. Strong emotions, new routines and educational processes arise after T1DM onset, changing family life definitively.

Type 1 diabetes mellitus (T1DM) is an autoimmune disease characterised by deficient insulin production in the body which tends to develop in childhood. The causes of this chronic disease are not fully understood, but a combination of genetic susceptibility and environmental triggers such as viral infections, toxins and dietary factors has been suggested (You and Henneberg 2016). T1DM is the third most common chronic illness in school-age children, preceded by asthma and epilepsy, and followed by food allergies and hypertension (Miller et al. 2016). In 2017, the International Diabetes Federation (IDF) reported that more than 96,000 children and adolescents under the age of 15 are estimated to be diagnosed with T1DM annually, and the number is estimated to be more than 132,600 when extending the age range to 20 years. In total, 1,106,200 of children and adolescents below the age of 20 are estimated to have T1DM globally (International Diabetes Federation 2017). People with T1DM need proper daily insulin treatment, regular blood glucose monitoring, and healthy diets and lifestyles. In comparison to a typical short-term childhood illness, the day-to-day management of this disease can be extremely challenging, especially as the diabetes regimen requires family support and assistance (Davis et al. 2001; Fritsch and Olshan 2011). Consequently, the family plays a key role, and T1DM can therefore be defined as a 'family disease'

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(Solowiejczyk 2004). The family—not only the patient—is the focus of treatment, and healthcare professionals need to consider the impact of diabetes on the family in order to provide theoretical and practical tools for successful management of the disease (Graber et al. 2010).

A family's lived experience when a child is diagnosed with diabetes has been described as an ongoing learning process (Wennick and Hallström 2006). This learning process starts in the hospital, at the diabetes onset, when doctors and nurses begin educating the family. The homecoming entails several changes, so that the patients and their parents can adapt to the disease and incorporate it into their family routine. This happens through a process whereby the family observes what is familiar (e.g. food, mood and tiredness) through new eyes—partly constructed through their relationship with the hospital personnel—and pays constant attention to experiences, bodily sensations and measurements in order to understand the symptoms of the illness and how to manage them (Mol 2000; 2002). During this learning process, caregivers keep track of patients' values and routines, using logbooks, mobile applications and other objects for care (Piras and Miele 2017), growing increasingly aware of the characteristics of the illness. In this way, over the years, caregivers and patients become highly competent (Piras et al. 2014), eventually becoming 'diagnostic agents' (Oudshoorn 2008) who can act 'like a doctor' (Mol 2000).

A broad, interdisciplinary debate has emerged around the key role of the social context in T1DM management: studies in psychology, sociology, nursing science, medicine, behavioural science and educational science have investigated how social context can ensure that children with chronic illnesses—and in particular, children with T1DM—develop good self-care habits and thus achieve the desired outcomes (e.g. treatment adherence, metabolic control and high quality of life). Consequently, various recent reviews have summarised the results of empirical studies showing how parents and other actors (e.g. family friends, teachers, educators, etc.) participate, directly or indirectly, in diabetes management. Some reviews examined the contextual factors that have positive or negative effects on young patients, often focussing on school-age children (Kelo and Eriksson 2011) or on adolescents (Spencer et al. 2010). These works focus on several dimensions of diabetes care (e.g. independence, relationships with the family and with peers, mundane and clinical daily routines, and learning processes for self-management skills) and, within each dimension, the facilitators of (e.g. professional support, technological support or peer acceptance) and barriers to (e.g. parental anxiety or stigmatisation at school) disease management. Other reviews focus explicitly on the influence of parents and friends on diabetes management (Helgeson and Palladino 2012; Wysocki and Greco 2006) and how social relationships can encourage (e.g. supportive relationships with parents, disclosure to friends and their involvement in diabetes management) or discourage (e.g. conflicts with peers or parents, premature parental withdrawal from diabetes management and excessive emphasis on encouraging children to achieve independence) good diabetes self-care in childhood and adolescence (Barnard et al. 2010). Finally, other reviews investigate the effectiveness of family-based interventions (Armour et al. 2005; McBroom and Enriquez 2009) and healthcare programmes that involve both patients and parents and seek to improve knowledge, skills, routines and relationships in familial contexts.

Although findings indicate that social relationships are a key factor in the management of T1DM and that young patients' ability to become independent in diabetes management are embedded within relationships with parents, peers, health professionals and teachers, these works are mainly focussed on young patients and consider parents a variable that can facilitate or obstruct good self-care. These studies also show a particular interest in the effects of their actions on measurable outputs such as glycaemia, therapeutic compliance, blood glucose monitoring and dietary behaviour. However, they overlook the issue of burden-sharing among family members, and in particular, between parents. Parental burden in T1DM is an important construct that may be amenable to intervention (Butler et al. 2008; Anderson et al. 2002), and these burdens include daily diabetes-related tasks, financial burdens, management of blood glucose fluctuations, and, often, guilt and fear about future medical complications (Butler et al. 2008; Moreland et al. 2004). Studies exploring parents' burden of care are mainly focussed on glycaemic control, reporting how parental fear of hypoglycaemia affects both parental health and quality of life (Barnard et al. 2010; Streisand et al. 2005) or exploring how family involvement is associated with increased adherence and improved glycaemic control (Laffel et al. 2003). What is lacking is further investigation of literature exploring how parents share the burdens of care in daily life and how this could change family routines. Therefore, this review shifts the attention from patients to parents, shedding light on the ways in which diabetes onset dramatically changes family life, bringing a new, heavy burden of care to mothers and fathers. The main aim of our study is to critically synthesise what is known about the consequences of T1DM onset for the family and, in particular, how parents share the burden of care. In order to accomplish this goal, we conducted an integrative review of studies concerned with the ways through which disease management permeates the daily life of families, and based on our results, we offer suggestions for future research.

Methods

We applied an integrative review design (Cooper 1989; Dixon-Woods et al. 2005) to synthesise findings from studies on the impact of T1DM on family life. An integrative review summarises past empirical or theoretical literature to provide a more comprehensive understanding of a phenomenon or healthcare problem (Broome 1993). Strategies described by Whittemore and Knafl (2005) for enhancing rigour in an integrative review were implemented at the various stages of the integrative review to permit the inclusion of studies using different methods. This methodological approach includes five stages that guide the review design: (1) problem and purpose of the review identification; (2) literature search strategy description; (3) data and methodological quality evaluation; (4) data analysis, which includes data reduction, display, comparison and conclusions; and (5) presentation, which synthesises findings in a model that comprehensively portrays the integration process and that describes the implications for practice, policy and research as well as the limitations of the review (Hopia et al. 2016; Whittemore and Knafl 2005).

Search Strategy and Criteria for Inclusion

After identifying the problem area of the contribution, the study began with an exploration of the literature addressing T1DM management within the family. A search of published peer-reviewed studies in scholarly journals was conducted using the following databases: PubMed, SAGE Journals, Google Scholar, ERIC, Web of Science, Embase and Scopus. Only research articles in English were considered. Electronic databases were searched using all combinations of the keywords *family, T1DM, children, care, self-care, self-management, learning process, parents, parental role, fathers, mothers* and *gender*. To account for any relevant references that might have been missed in the original search, manual searches through the selected reference lists of the identified articles and related reviews were conducted. A total of 113 articles were found. Duplicates were removed, after which 86 citations remained for assessment. Additionally, 24 were eliminated because the research involved type 2 diabetes or other chronic illnesses. The initial inclusion and exclusion ratings were made by the first author (SF) based on review of the title and abstract only. For increased reliability, these ratings were then confirmed by a second rater (FM). The studies that were found to be potentially relevant based on the title and abstract were retrieved. This produced 62 full texts to examine for a full article review. The full texts were reviewed by the first author (SF) and confirmed by a second rater (FM) (Fig. 1).

The full texts of the 62 selected articles were then examined again using the inclusion and exclusion criteria.

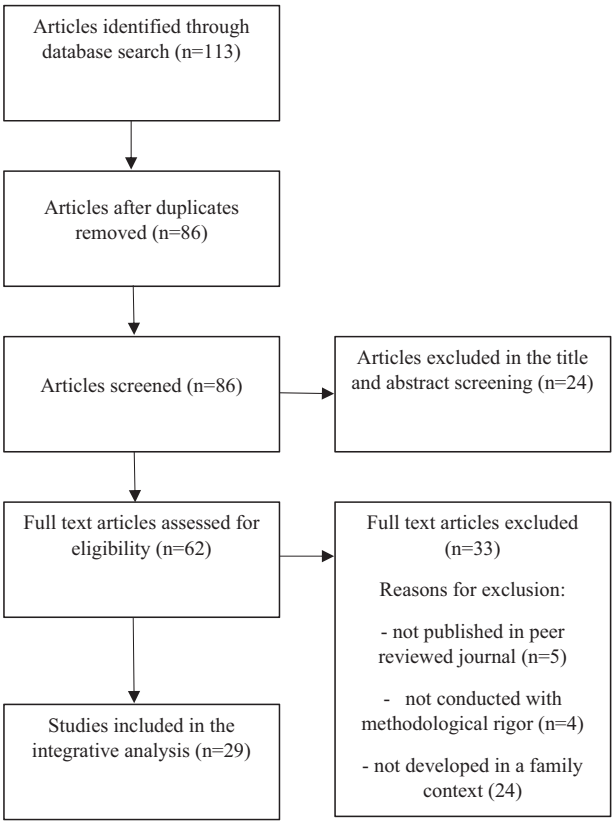

Fig. 1 Flowchart describing the process for identifying relevant literature. The PRISMA Flow Diagram of Study Selection Process. http://prisma-statement.org/PRISMAStatement/FlowDiagram.aspx

The following inclusion criteria were used to determine eligible study characteristics: (a) The full article must have been published in English between 2000 and 2017; (b) the sample population must include youth (ages 3–18) diagnosed with T1DM and their families; (c) the studies could be quantitative, qualitative or mixed-method; and (d) the studies must have been developed in a family context. The identified studies were then coded using the following variables: the authors and year of publication, the total sample size, and the age range of the study participants. The articles that were not published in peer-reviewed journals were excluded to grant quality standards with respect to study's methodological approach, reporting standards, ethical propriety and general credibility. Studies were rejected if they were not developed in a family context (e.g. school or diabetes associations). The methodological rigour was also evaluated, and articles were excluded when the methods of intervention, data collection and analysis were not adequately explicated. After this screening process, a total of 29 articles met the inclusion criteria and were included in this review: 15 are quantitative studies, 14 qualitative studies and 1 is a mixed-method study (see Table 1). All the studies were reviewed by the first author (SF), and the other authors (FM, EMP) agreed with the findings.

Table 1 Description of included studies (n = 29) concerned with the ways in which T1DM management permeates the daily life of the family

ID number	Author and year	Design and purpose	Sample	Data collection method	Method of analysis
Quantitative studies					
1	Anderson et al. (2002)	The study investigates the relationship between diabetes-related parental behaviours (conflict around and involvement in treatment tasks), adherence to blood glucose monitoring (BGM) and glycaemic control in youth with short-duration type 1 diabetes mellitus.	104 youth with T1DM, aged 8–17 years.	The Diabetes Family Conflict Scale and the Diabetes Family Responsibility Questionnaire.	Multivariate analyses, controlling for age, sex, disease duration and BGM adherence.
2	Chisholm et al. (2011)	The study investigates the relationship between maternal communication style and adherence to the dietary regimen in patients with type 1 diabetes mellitus.	40 children with T1DM, aged 2–8 years, and their mothers.	T1DM dietary adherence interview, child Behaviour Checklist—Parent Report, relationship subscales (cohesion, expressiveness and conflict) from the Family Environment Scale	Analyses of variance and chi-square analyses, Pearson product-moment correlations and t-tests.
3	Gruhn et al. (2016)	The study examines the impact of collaborative and intrusive parenting on depression and glycaemic control in children with type 1 diabetes mellitus.	81 youth with T1DM, aged 10–16 years, and their mothers.	Stress Questionnaire.	Bivariate correlations and linear regression.
4	Landolt et al. (2005)	The study explores the prevalence, course, and predictors of posttraumatic stress disorder in mothers and fathers of children with newly diagnosed type 1 diabetes mellitus.	49 mothers and 48 fathers of 52 children aged 6.5–15 years with newly diagnosed T1DM.	Posttraumatic Diagnostic Scale.	Multivariate analyses.4-point (0–3) Likert severity scale.
5	Marker et al. (2017)	The study examines how parental and youth responsibility for type 1 diabetes mellitus care relates to adherence and glycaemic outcomes, namely glycaemic variability and risk of glycaemic excursions.	135 parents of youth with T1DM, aged 10–16 years.	Diabetes Family Responsibility Questionnaire.	Bivariate correlations and path analysis.
6	Nieuwesteeg et al. (2016)	The study compares levels of paediatric parenting stress in the fathers and mothers of young children with type 1 diabetes mellitus and studies the variations in this stress over time.	112 parents (56 mothers and 56 fathers) of young children (0–7 years) with T1DM.	Questionnaire: Paediatric Inventory for Parents.	Independent and paired sample t-tests and Cohen's d effect sizes.
7	Palmer et al. (2004)	The study examines how autonomy and pubertal status explain age-related decreases in maternal involvement in type 1 diabetes mellitus management across adolescence, how they relate to metabolic control and the reasons that guide declines in maternal involvement.	127 children aged 10–15 years with T1DM and their mothers.	the Diabetes Responsibility and Conflict Scale	Responsibility items from the Diabetes Responsibility and Conflict Scale.

Table 1 (continued)

ID number	Author and year	Design and purpose	Sample	Data collection method	Method of analysis
8	Pattison et al. (2006)	The study measures the relationships among perceived child competence, parental self-efficacy and children's glycaemic control.	78 parents of children aged 6–12 years with T1DM diagnosed for at least one year.	Questionnaire on parenting style and illness perceptions and perceived child competence and self-efficacy.	Analysis of variance and multiple linear regression.
9	Powers et al. (2002)	The study explores parent reports of mealtime behaviour and parenting stress in preschoolers with type 1 diabetes mellitus.	40 children aged 1–6 years with T1DM from a paediatric hospital and another 40 children matched for age, sex, and socioeconomic status used as control subjects.	Behavioural Paediatrics Feeding Assessment Scale and the Parenting Stress Index.	Multivariate analysis of variance.
10	Streisand et al. (2005)	The study explores stress faced by parents of children with type 1 diabetes mellitus.	134 parents of children with T1DM.	Adapted Self-Efficacy for Diabetes Scale, The Diabetes Family Responsibility Questionnaire, The Hypoglycemia Fear Survey.	Bivariate analyses
11	Streisand et al. (2008)	The study examines demographic and clinical characteristics that are associated with parental anxiety and depression, such as paediatric parenting stress and self-efficacy related to diabetes care, of parents of children newly diagnosed with type 1 diabetes mellitus.	134 parents of children with T1DM.	42-item self-report Paediatric Inventory for Parents.	Bivariate analyses
12	Wiebe et al. (2005)	The study examines how children's appraisals of maternal involvement in coping with type 1 diabetes mellitus are associated with adherence, metabolic control and quality of life across adolescence.	127 children, aged 10–15 years, with T1DM.	Berg's structured interview for assessing dyadic coping, Diabetes Responsibility and Conflict Scale, Self-Care Inventory and Diabetes Quality of Life for Youth scale.	Regression analysis
13	Worral-Davies et al. (2002)	The study measures expressed emotion (EE) in parents of young children with type 1 diabetes mellitus and examines the relationship between EE and glycaemic control in children with type 1 diabetes mellitus.	47 children with T1DM and their parents.	Adapted version of the Camberwell Family Interview.	Multiple regression models
14	Wu et al. (2013)	The study examines the relationships between parental involvement and adolescent depressive symptoms in predicting blood glucose monitoring and glycaemic control.	150 young people with T1DM (mean age 15.3 years) and their parents.	Diabetes Family Responsibility Questionnaire, Children's Depression Inventory self-report and parent report.	Descriptive statistics (means, standard deviations, frequencies) and bivariate correlations.
Mixed-method studies					
15	Robinson et al. (2011)	The study develops a measure of diabetes-specific parenting goals for parents of children with type 1 diabetes	Primary caretakers of 87 children with T1DM aged 10 to 16 years.	Formative semi-structured interviews, the Diabetes Independence Survey and the Diabetes Behaviour Rating Scale.	Paired sample t-tests and Spearman correlation.

Table 1 (continued)

ID number	Author and year	Design and purpose	Sample	Data collection method	Method of analysis
		mellitus and examines whether parenting goals predict a change in parental involvement in disease management.			
Qualitative studies					
16	Bowes et al. (2009)	The study explores parents' longer-term experiences of having children with type 1 diabetes mellitus.	17 parents of children with T1DM.	In-depth interviews.	Theoretical framework of grief, loss, adaptation and change
17	Lowes and Gregory (2004)	The study explores parents' experiences of having children diagnosed with type 1 diabetes mellitus, management at home and their first year following diagnosis.	40 parents of 20 children with T1DM.	In-depth interviews.	Content analysis
18	Lowes et al. (2005)	The study provides a new theoretical understanding of parental grief responses and the process of adapting to a diagnosis of childhood type 1 diabetes mellitus.	38 parents of 20 children with T1DM.	Audiotaped in-depth interviews.	Framework of the Theory of Psychosocial Transition.
19	Marshall et al. (2009)	The study explores the experiences of children and their parents living with type 1 diabetes mellitus from diagnosis onwards.	10 children with T1DM and their parents.	Conversational interviews	Thematic analysis
20	Rifshana et al. (2017)	The study explores experiences of parents as they look after their children with type 1 diabetes mellitus, whose bodies present unique challenges to both maintaining health and meeting expectations for conventional childhoods.	17 parents of children with T1DM.	Semi-structured interviews	Interpretative phenomenolog-ical analysis
21	Schilling et al. (2006)	The study describes the division of labour between youth with type 1 diabetes mellitus and their parents, self-management conflict and three patterns of self-management in youth across four developmental stages: preadolescence, early adolescence, mid-adolescence and late adolescence.	22 youth (8–19 years) with T1DM and one of their parents.	Semi-structured interviews	Qualitative content analysis of interviews
22	Smaldone, Ritholz (2011)	The study explores perceptions of psychosocial adaptations in parenting young children with type 1 diabetes mellitus from diagnosis through childhood.	14 parents of 11 children with T1DM.	Semi-structured interviews	Content analysis

Table 1 (continued)

ID number	Author and year	Design and purpose	Sample	Data collection method	Method of analysis
23	Sparud-Lundin et al. (2013)	The study describes parents' process of changes and challenges in their patterns of daily activities after the onset of type 1 diabetes mellitus in their children.	21 mothers and 15 fathers of 23 children with T1DM	Qualitative interviews	Comparative analysis method
24	Sullivan-Bolyai et al. (2002)	The study examines the day-to-day experiences of mothers raising children 4 years of age and younger with type 1 diabetes mellitus.	Mothers of children with (n = 25) and without T1DM (n = 25).	Descriptive design and observation	Qualitative content analysis
25	Sullivan-Bolyai et al. (2003)	The study describes the day-to-day experiences of mothers raising young children under 4 years of age with type 1 diabetes mellitus.	28 mothers of children with T1DM.	Descriptive, naturalistic interviews	Descriptive, naturalistic enquiry
26	Sullivan-Bolyai et al. (2006)	The study describes fathers' experiences parenting and managing the care of their young children with type 1 diabetes mellitus.	14 fathers of 15 children with T1DM.	Open-ended, in-depth interviews	NVivo software
27	Wennick, Hallström (2006)	The study elucidates the whole family's lived experience when a child in the family is diagnosed with type 1 diabetes mellitus.	Family members in 12 families with children with T1DM.	A longitudinal, descriptive, inductive study including qualitative interviews.	Hermeneutic phenomenolog-ical reflection
28	Wennick and Hallström (2007)	The study elucidates families' lived experience of type 1 diabetes mellitus one year after a child was diagnosed with diabetes.	11 family members with children with T1DM aged between 9 and 14 years.	Hermeneutic phenomenology and qualitative conversational interviews.	Selective reading approach
29	Wennick et al. (2009)	The study illuminates the everyday experiences of family members three years after a child was diagnosed as having type 1 diabetes mellitus.	35 family members in 11 families with children with T1DM.	Qualitative interviews	Content analysis

Quality Appraisal of Included Studies

The quality appraisal was undertaken using the Critical Appraisal Skills Programme (CASP) systematic review checklist (CASP 2017) based on items relating to study design, selection bias, data collection, data analysis and the reporting of outcomes. Each article was awarded a quality rating of high, moderate or low depending on the percentage of answers which were coded as having met the criteria. The principal reviewer (SF) assessed the quality of all the articles, and the other two members of the research team (FM and EMP) checked for accuracy within their subsets. Any disagreements were resolved through discussion or through consultation. The quality appraisal was undertaken to aid the interpretation of findings and to assist in determining the strength of the conclusions drawn; no study was excluded based on the results of the quality assessment.

Data Collection and Analysis

Following the logic of an integrative review, we obtained a heterogeneous group of contributions, including studies following quantitative and qualitative research traditions.

A content analysis (Schreier 2012) of the articles which met the criteria for inclusion was performed. During this process, the articles were examined separately by the three authors, who identified thematic segments related to the sharing of the emotional, practical and educational burdens of care connected to T1DM management. A spreadsheet was used to record reasons for further inclusion and the main empirical findings of the articles. A subsequent comparison of the thematic segments led to the identification of interpretative categories through which the final analysis was conducted. The three conceptual categories include 'managing emotions after diagnosis' (13), 'reconstructing routines around new needs' (12) and 'educating young patients to enhance autonomy' (9). Four papers provided findings in more than one area and were therefore listed in more than one category. After a careful analysis of the selected articles, we organised each category into subcategories to facilitate the synthesis of findings within each area (see Table 2).

Results

Overview of Studies and Study Characteristics

To aid the reporting, all studies were allocated a reference number, and this number is what was used in what follows. The review included 14 quantitative studies, 14 qualitative studies and 1 mixed-method study. As for their geographical spread and setting, the studies were conducted primarily in the USA (N = 15) with the remainder undertaken in the UK (N = 8), Sweden (N = 4), Switzerland (N = 1) and New Zealand (N = 1). The sample size of the parents involved varied from 10 to 134. Just over half of the studies (N = 21) included a combination of both mothers and fathers, whereas seven included mothers only (2, 3, 5, 7, 12, 24, 26) and one included fathers only (25). The sample size of the children involved varied from 150 to 10. The children's ages ranged from 18 months to 18 years. As for the diabetes onset, most of the studies included children diagnosed with T1DM for at least two months, and five studies (4, 10, 10, 17, 18) included children with newly diagnosed diabetes.

Managing Emotions after Diagnosis

Several studies addressed the emotions of parents at the moment of the disease onset and during the first admission to the hospital, even speaking of 'trauma' (Landolt et al. 2005). The authors reported diabetes diagnosis as a turning point in the lives of patients with diabetes and their families. Some of these studies focussed on how diabetes onset leads to a feeling of chaos and of being shaken for the family as a whole and for family members individually.

Coping with the Diagnosis

During hospitalisation, the family members receive their first training, and tasks are allocated within the care network. In a study exploring parents' experience of home management and the first year following diagnosis (Lowes and Gregory 2004), the authors describe how parents often enter the hospital department convinced that diabetes only means that their children will require dietary restrictions and how they initially found the information provided by clinicians to be 'a lot to take in' and preferred to receive it on a 'need-to-know' basis, in 'small chunks'. Moreover, parents' perceptions of the efficiency of the hospital staff or the speed of diagnosis differed in each family: the onset can be likened to experiences such as 'roller coasting', 'railroading' or 'steam-rollering' (Lowes and Gregory 2004).

The diagnosis of diabetes may result in psychological trauma (Landolt et al. 2005), with an acute phase (e.g. diagnosis and initial treatment) followed by subsequent chronic stressors (e.g. invasive treatment, threat of hypoglycaemia, hyperglycaemia and medical late effects). To this end, Streisand et al. (2008) conducted a study of 100 parents of children with a recent onset of T1DM, and they found that depressive symptoms were present in high numbers following the initial diabetes diagnosis, with 61% of parents reporting clinically significant levels of depression. Parents' shock, hurt and disbelief are due mainly to the suddenness and perpetuity of the diagnosis, and they often

Table 2 Emerging categories and sub-categories

Categories	Sub-categories	Contributions
Managing emotions after diagnosis	Coping with the diagnosis Accepting the loss of 'normality' Sharing the stress of responsibility among parents	Bowes et al. (2009) Landolt et al. (2005) Lowes et al. (2004, 2005) Marshall et al. (2009) Nieuwesteeg et al. (2016) Smaldone, Ritholz (2011) Streisand et al. (2005) Streisand et al. (2008) Wennick and Hallström (2006) Wennick et al. (2009) Sullivan-Bolyai et al. (2003) Sullivan-Bolyai (2006) Wennick et al. (2009)
Reconstructing routines around new needs	Managing glycaemia at home Balancing diabetes and childhood needs Re-thinking parental tasks and roles	Gruhn et al. (2016) Lowes et al. (2005) Marker et al. (2017) Marshall et al. (2009) Rifshana et al. (2017) Robinson et al. (2011) Smaldone, Ritholz (2011) Sparud-Lundin et al. (2013) Sullivan-Bolyai et al. (2002) Wennick and Hallström (2006) Wennick and Hallström (2007) Wu et al. (2013)
Educating young patients to enhance autonomy	Parental support in the acquisition of self-care competencies Parents sharing educational roles	Anderson et al. (2002) Chisholm et al. (2011) Palmer et al. (2004) Pattison et al. (2006) Powers et al. (2002) Schilling et al. (2006) Wiebe et al. (2005) Wennick and Hallström (2007) Worrall-Davies et al. (2002)

find accepting the diagnosis difficult because they cannot be given a definite reason why their children have developed diabetes. Parents' first impulse is to find a cause or someone to blame. Subsequently, however, they start to blame themselves, questioning what they could have done differently to prevent the diabetes (Lowes and Gregory 2004). Parents worry about disease-related complications and death caused by the illness, possibilities that weigh heavily on their shoulders and fill them with sorrow and despair, even though they rarely verbalise their thoughts to anyone else. They feel as if life will never be all right again and that they will not get over their children's diabetes diagnosis while simultaneously pondering why they did not detect the illness sooner (Wennick and Hallström 2006). Streisand et al. (2005), in a study of 134 parents of children with T1DM, found that in one-third of cases, paediatric parenting stress is associated with parents' beliefs in their ability to execute aspects of the diabetes regimen, their amount of responsibility for diabetes management and their fears related to hypoglycaemia. Other times, parents may be traumatised as a consequence of being responsible for administering a treatment that involves a considerable amount of stress for their child (Landolt et al. 2005).

Emotions Associated with the Disease Onset

Stress and difficulties can persist even after the time of diagnosis: studies report that parents often feel a continued

sense of loss, including loss of spontaneity, loss of freedom and loss of their children's health, for up to one year after diagnosis (Bowes et al. 2009; Lowes et al. 2005; Marshall et al. 2009). Parents experience a sense of failure in protecting their children from developing this illness, have concerns about being able to protect their children in the future and experience decreased confidence as parents (Marshall et al. 2009). The memory of the diagnosis, the out-of-control blood sugar, the complex care responsibilities and the diet management can often lead to feelings of sadness and stress in parents and children. Bowes et al. (2009) remarked that when parents describe their experiences, they all begin with how they felt at the moment of diagnosis, with most describing feelings similar to those associated with grief.

Several studies report parents' constant anxiety that their children might experience hypoglycaemia and faint (Streisand et al. 2005; Wennick and Hallström 2006; Wennick et al. 2009), although most of the children have never experienced such severe hypoglycaemia. Their concern and anxiety grow at night, as glycaemia may rise without their noticing it. Thus, they feel that they have to monitor blood glucose at night as well (Wennick and Hallström 2006; Wennick et al. 2009). Specifically, lower self-efficacy, greater responsibility for diabetes management and greater fear of hypoglycaemia are associated with more frequent and difficult paediatric parenting stress (Streisand et al. 2005). Other times, as reported by Lowes and Gregory (2004), parents find it difficult to accept the diagnosis because it could be considered the end of a normal day-to-day family lifestyle. Most parents put diabetes to the 'back of their minds' and continue to attach their children's symptoms to other, more common infections or conditions (Lowes and Gregory 2004).

Finally, in a qualitative research study with 14 mothers and fathers of children with T1DM, Smaldone and Ritholz (2011) reported that parents often saw sleepovers as anxiety-provoking events because they were unsure about their children's safety in another person's home. They also experienced parental concerns about the future well-being of their children in relation to the social and psychological impact of the disease. In particular, parents were concerned about whether their children would be able to effectively engage in such activities in safe conditions, and yet they recognised the need to encourage such experiences to promote their children's growth. This study found that parents were often anxious about their children growing up and becoming independent, and that these fears arose when the young patients faced typical youth activities.

Impact of Stress and Responsibility Among Parents

Several studies showed that diabetes affects mothers more deeply than fathers. Mothers typically take on the primary caregiver role and are more likely to accompany their children to clinics (Bowes et al. 2009; Smaldone and Ritholz 2011). Immediately after diagnosis, mothers also displayed stronger stress reactions (Nieuwesteeg et al. 2016) and reported greater levels of depressive symptoms (Streisand et al. 2008) than fathers.

These differences continue throughout the other phases of the illness. Streisand et al. (2005) found that mothers develop a more acute sense of responsibility for their children's health and more fears about diabetes-related complications, reporting higher level of paediatric parenting stress than fathers. Taking care of children with T1DM can be a shocking and stressful experience for mothers; some reported feelings of abandonment, loneliness and isolation, or an initial feeling of incompetence and insecurity with regard to their ability to provide the necessary care (Sullivan-Bolyai et al. 2003).

While the above-mentioned studies indicate that mothers take primary responsibility for the completion of daily diabetes management tasks, there is also evidence that fathers compensate for the mothers' increased burden by taking on more responsibility for other household and family management tasks (Sullivan-Bolyai et al. 2006). In an exploratory study, Mitchell et al. (2009) focussed on the overlooked paternal parenting stress, considering a sample of 43 fathers of children 2–6 years old with T1DM. The authors showed that fathers' paediatric parenting stress is positively associated with state anxiety and mother-reported difficult child behaviour, suggesting that mothers can easily transmit stress to fathers and that paternal stress has important implications for child health and behavioural outcomes as well as maternal mental health and family routines.

Reconstructing Routines Around New Needs

The onset of T1DM obliges patients and their family members to entirely recast their lives, as they face new challenges. During hospitalisation, parents are gradually invited to take on greater responsibility for their children's management regimen. Coming home from the hospital, the family often feels that the theoretical knowledge they acquired at the hospital is not sufficient and that everyday life has to be reconstructed around the child's illness.

Managing Glycaemia at Home

At home, new dimensions of the illness become noticeable, and family members often feel unprepared and insecure. Wennick and Hallström 2006, through a qualitative study of 12 families with children with T1DM, explored in depth the efforts parents made after diabetes onset to maintain good blood glucose levels. They considered the difficulties that

mothers and fathers experienced in adapting the regimen routines to their ordinary ways of living. The parents felt an increased need to stay in control, often expressing feelings of being a total failure if the levels were high or low. The interviewed parents felt as if their family lives consisted solely of blood glucose monitoring, injections and eating; then, after an hour, the procedure started all over again. They felt as if they could not do anything spontaneously because of their regimented existence. Other studies explore how parents and their children found that the diagnosis brought with it a constant need to make plans, reporting that the renewed parents' role is to manage the complex interactions of diet, physical activity and medication in their children. The most striking aspect of this process is the notion of the 'constant-ness' of diabetes (Rifshana et al. 2017). According to this author, family life has to be carefully planned, the family members have to live their lives by the clock, and parents feel that their parental role morphs into a controlling and supervising role. Families have to carefully organise previously spontaneous activities such as shopping, cooking and family outings in order to include the needs of children with diabetes. Moreover, another study by Wennick and Hallström (2007) found that activities that appear harmless (e.g. bringing a child to play at a friend's home) were seen as highly risky for the parents of children with T1DM. Consequently, they try daily to find alternatives (e.g. inviting other children to their homes) to reduce their anxiety.

Balancing Diabetes and Childhood Needs

According to the literature (Robinson et al. 2011), parental goals for children with T1DM should include goals that are specific to issues around diabetes management. Over the first year after diagnosis, parents gradually rebuild new models of their worlds to reach these goals, establishing routines that minimise the impact of diagnosis. Parents and children return to work or school, and many parents encourage their children to restart daily activities with friends (Lowes et al. 2005). A lifestyle adapted to incorporate the needs of a child with diabetes becomes normal. Nevertheless, these studies report that within this new normality, parents have to cope with the tension between diabetes priorities and other dimensions of daily life, and diabetes-specific parenting goals (e.g. maintaining blood glucose levels within a target range) may conflict with broader child development goals (e.g. playing sports as other children do).

Other studies reported that parents do not want their children's lives to be different from those of other children. They need to balance the seriousness of diabetes with the need to lead a 'normal' life; consequently, they make deliberate efforts to ensure their children's lives are as 'normal' as possible (Lowes et al. 2005). Parents feel the need to ensure that their sons or daughters have many typical life experiences. Especially during childhood, it is important that parents and children work together on the activities of diabetes management without limiting participation in mundane activities and important events (Marshall et al. 2009; Sullivan-Bolyai et al. 2006). After a destabilising period immediately following diabetes onset, mothers and fathers become concerned that their children regard external activities as more meaningful than their diabetes care. Moreover, parents are anxious about their children growing up and becoming independent, but they generally learn to trust and support their children as they make decisions and choices (Marshall et al. 2009; Sullivan-Bolyai et al. 2006).

Re-Thinking Parental Roles

Several studies have analysed the ways in which parents share diabetes care responsibilities. In a study about gender relations among parents of children recently diagnosed with T1DM (Sparud-Lundin et al. 2013), the authors interviewed the mothers and fathers of 23 children with T1DM from eight to ten months after onset, exploring parents' daily patterns of activities and the reconstruction of a common family project. In particular, authors focussed on how gender relations can restrain or create functional strategies for managing the changes and challenges of illness, depicting the dimensions of how gender relations are constructed during this process in the categories of 'reinforced mothering' and 'adjusted fathering'. On one hand, mothers reinforce their involvement in the care of their children, confirming that they are primarily responsible for the development of their children and feel a constant concern for their children's health; on the other hand, fathers become more active in the sphere of care, including taking on new tasks in their daily lives and trying to reconcile traditional masculine roles with diabetes needs (Sparud-Lundin et al. 2013). Other studies focussed on the role mothers play in diabetes management. A study about mothers' experiences raising young children with T1DM (Sullivan-Bolyai et al. 2002) refers to mothers' activity as 'constant vigilance' because mothers expressed concerns about future complications and felt that their present day-to-day management actions could greatly reduce long-term complications. After the onset of diabetes, earlier habits established during the children's infancy reoccurred in mothers, such as the need to nourish and watch over the children, initially around the clock. Mothers also felt that, despite the children's age or their ability to care for their diabetes themselves, it was necessary to check on them to reassure themselves that their children were well (Marshall et al. 2009). Finally, some studies focussed on the effects of sharing responsibilities between fathers and mothers, with

conflicting results. One study (Marker et al. 2017) found that shared responsibility was associated with lower glycaemic variability and risk of glycaemic excursions, while primary parent responsibility was associated with greater variability and increased risk of glycaemic excursions outside of the target blood glucose range. In contrast, other studies found collaborative parenting or a sustained high level of parental involvement in T1DM care throughout adolescence to be directly associated with better glycaemic control (Gruhn et al. 2016) or indirectly related to analysis of glycated haemoglobin through adherence (Wu et al. 2013).

Educating Young Persons to Enhance Autonomy

A final group of studies explores how the acquisition of new routines involves a redistribution of tasks among family members. In particular, these works focus on the role of parents in direct diabetes management and the gradual sharing of responsibilities with the young patient. Although the healthcare literature has a substantial body of research outlining the self-care capabilities of children, little is known about how youngsters and their parents share responsibility for illness management.

Parental Support in the Acquisition of Self-care Competencies

After diabetes onset, parents begin to educate their sons and daughters on self-management practices, sharing competencies with them daily. Powers et al. (2002) conducted a study with 40 children with T1DM to evaluate the most effective educational styles related to mealtime behaviours. This study indicates that the physiological parameters are better in young patients whose parents establish rules during the meals and praise their children's positive choices. In contrast, some parent behaviours that seem potentially successful in the short term (e.g. cooking something else if their children refuse the served meal) can negatively impact the parents' authority and their overall ability to ensure consistent dietary adherence. Other studies argue that parents can influence young patients through their example. For instance, children and adolescents whose parents are less involved in diabetes management are less adherent, make more mistakes in their self-care and have poorer metabolic control than youths whose parents are more involved and engaged in diabetes tasks at home in a developmentally appropriate manner (Anderson et al. 2002).

Other works explore the moment at which children grow up, and the expectation is that they will become autonomous. During this important transition period, parents play a dual role: they both are fully involved in diabetes management and are encouraging their children to become more independent. A qualitative study on 22 youth with T1DM (Schilling et al. 2006) reveals that as children began to take on more responsibility for their diabetes care in early adolescence, their parents reported the practice of 'pinch hitting' (i.e. completing a self-management task instead of the patient when he or she needs a break from the responsibility). This study contributes to a broader understanding of the nature of how children and parents share the activities of diabetes self-management and how this sharing changes as children grow older. Parents tend to be less involved in diabetes care during adolescence, which can interfere with the effective family management of the illness, and both adherence and glycaemic control tend to deteriorate across the teen years. This process can often be tortuous and full of ambiguity. Parents tend to employ age as the primary indicator of their children's readiness for increased responsibility rather than such constructs as the child's maturity or autonomy in other domains (Palmer et al. 2004). Additionally, some parents may perceive their children to be competent enough to manage their diabetes and give them more responsibility for monitoring and treatment when they are not yet fully prepared for these tasks (Pattison et al. 2006).

Parents Sharing Educational Roles

Parents play an important role in the education of children with T1DM. Few studies have tried to shed light on the different ways in which parents try to support their children, focusing almost exclusively on mothers. Chisholm et al. (2011) conducted a qualitative research study on maternal communication and its effects on adherence to a dietary regimen in 40 children with T1DM. This study underlines how mothers, by promoting children's participation and intellectual engagement in problem-solving activities, can dramatically contribute to improving their dietary adherence and diabetic control. In contrast, mothers' use of authoritative educational styles which constrain children's participation in diabetes management lead to poor diabetic control. Weibe et al. (2005) claim that adolescents who rated their mothers as involved and supportive in diabetes care tended to enjoy more favourable adherence, metabolic control and quality of life. Among older adolescents in particular, better adherence occurred when the mothers were perceived as collaborative rather than controlling. It is likely that the nature of parental support must evolve as children mature in order to yield an optimal impact on diabetes outcomes and adaptation.

In spite of the growing literature on the role of fathers in T1DM management (see the literature review proposed by Dashif et al. 2008), few studies have shifted the attention from mothers to fathers in the self-management education

of youngsters. For example, in a longitudinal study about the effect of expressed parental emotion on glycaemic control in children with T1DM (Worrall-Davies et al. 2002), the authors found that fathers are absent and play a relatively minor role in the management of diabetes, and children perceive this lack of involvement negatively. In this work, the presence of paternal hostility in discussions about the child was the only significant variable related to metabolic control in a longitudinal assessment.

Discussion

What are the consequences of T1DM onset for family life, and how do parents address and share the burden of care? The present study, through a review on existing literature in different scientific domains, seeks to provide a comprehensive answer. We identified three overarching themes.

T1DM brings with it a significant emotional burden of care. T1DM onset causes an emotional trauma which can manifest itself in different forms: disbelief about the diagnosis, anxiety about the future, blame for failing to prevent the disease and a sense of loss. These emotions affect families during hospitalisation, when the traumatic moment of diagnosis is accompanied by the request to become familiar with a large amount of information (Lowes and Gregory 2004). The onset may lead to depression (Streisand et al. 2008; Wennick and Hallström 2006; Lowes and Gregory 2004) and stress due to the new responsibility (Bowes et al. 2009; Landolt et al. 2005; Nieuwesteeg et al. 2016; Smaldone and Ritholz 2011; Streisand et al. 2005, 2008). As for depression, some of these studies attribute it to the perpetuity of the diagnosis (Streisand et al. 2008; Wennick and Hallström 2006), others attribute it to parental guilt (Lowes and Gregory 2004), and others report a greater amount of depression for mothers (Bowes et al. 2009; Nieuwesteeg et al. 2016; Smaldone and Ritholz 2011; Streisand et al. 2008). As for the amount of responsibility, some parents are worried for themselves (Streisand et al. 2005), and others are worried for their child (Landolt et al. 2005). These emotions also affect families as they return home and reorganise their daily life around the disease: studies report a sense of loss (Bowes et al. 2009; Lowes et al. 2005; Marshall et al. 2009), a sense of incompetence (Streisand et al. 2005; Sullivan-Bolyai et al. 2003; Wennick and Hallström 2006, 2009) and anxiety for future (Smaldone and Ritholz 2011). As for the sense of incompetence, most of the studies report a fear of hypoglycaemia (Streisand et al. 2005; Wennick and Hallström 2006, 2009), and some studies explore the distribution of roles among parents, finding a sense of anxiety among both mothers and fathers (Streisand et al. 2005), although this finding is stronger among mothers (Sullivan-Bolyai et al. 2006).

T1DM leads families to reorganise daily routines. Before the diagnosis, families have social networks, ways of living and educational goals that are then suddenly put into crisis. After the diabetes onset, new care practices arise, and patients and their parents have to manage diets and physical activities. Consequently, a constant tension emerges between illness management and the activities of school, work and mundane daily life. Several studies explore how routines changed immediately after the diagnosis (Marker et al. 2017; Rifshana et al. 2017; Robinson et al. 2011; Sparud-Lundin et al. 2013; Sullivan-Bolyai et al. 2002; Gruhn et al. 2016; Wu et al. 2013). These studies focussed on how families reorganise previously spontaneous activities (Wennick and Hallström 2006) and on how parents organise specific plans and goals around diabetes management (Rifshana et al. 2017; Robinson et al. 2011). One study explored the changes that occurred long after the initial diagnosis (Lowes et al. 2005): parents described that their new lifestyle becomes normal because they feel the need to ensure that their children have typical life experiences. There is also a consistent group of studies exploring how parents share diabetes care responsibilities: most of these analysed how both mothers' and fathers' roles change to accommodate functional strategies for managing the challenges of illness and glycaemic control (Gruhn et al. 2016; Marker et al. 2017; Sparud-Lundin et al. 2013; Wu et al. 2013). Two studies (Marshall et al. 2009; Sullivan-Bolyai et al. 2002) explored and reported the predominant role of mothers in diabetes management.

T1DM activates educational processes. With diabetes onset, families begin to acquire self-management skills, gradually becoming autonomous from healthcare professionals. In doing so, mothers, fathers and children share roles and care practices vital to good management of diabetes. During this time, parents educate their children to become autonomous, trying to share increasingly more skills and responsibilities with them. Studies in this category explore two moments of children's lives: first youth and then adolescence. As for the children, the focus was on the most effective educational style: Powers et al. (2002) found that establishing rules was most effective, Anderson et al. (2002) found that setting a good example was most effective and Chisholm et al. (2011) found that promoting participation is more effective than an using an authoritative style. As for adolescents, the focus was on the process of becoming autonomous, through which responsibilities begin as activities shared between parents and their early-adolescent child (Schilling et al. 2006) and through which parents take on a more controversial role during later adolescence (Palmer et al. 2004; Pattison et al. 2006). Additionally, in this category, some studies explore how parents share their educational responsibilities, demonstrating a predominant role for mothers (Chisholm et al. 2011; Wiebe

et al. 2005) and an absence of fathers (Worrall-Davies et al. 2002), a factor that was perceived negatively by children.

The considered studies aim to understand in depth the short- and long-term effects of T1DM on families. Looking at the review results, we can confirm that diabetes is a family illness (Solowiejczyk 2004) in which patients and parents are at the centre of emotions, routines and knowledge strictly connected to diabetes, and this complexity is difficult to understand from the outside.

To conclude, it seems useful to indicate the knowledge gaps in the current research which we identified during our literature analysis and, consequently, our suggestions for future research. Scholars have rarely focussed on the ways in which diabetes influences gender relations that exist prior to diabetes onset (Sparud-Lundin et al. 2013). The analysed studies generally showed that after the diagnosis, parents play different roles in childcare: mothers are depicted as more anxious and as fully involved in daily diabetes management tasks and in the children's self-care education; in contrast, fathers seem to play a secondary role and intervene to support partners in some care tasks. These differences usually are not problematised; these studies seem to consider them almost natural, although over the past several years, a broad, interdisciplinary debate has developed around this topic. In particular, gender studies have shown how the ascription of certain roles and practices to fatherhood and motherhood is connected to complex historical and social processes (Brandth and Kvande 1998; Hearn 2004; Murgia and Poggio 2009). In the future, it will be necessary to shed light on the processes that construct these inequalities after diabetes onset. In doing so, it could be useful, for example, to focus on the ways in which healthcare professionals, patient associations, employers and colleagues converge to assign different expectations to mothers and fathers of children with T1DM. In this way, it will be possible to go beyond the mere statement of gender inequalities, making it clear how they are built and, in some cases, how they can be challenged.

Although some works claim that the successful management of diabetes entails the participation of an extended set of actors (Butler and Lawlor 2004), the considered studies are focussed mainly on the roles that mothers and fathers play. In recent years, several theoretical and empirical contributions have focussed on the work of patients and their wide networks—including close and extended family, friends and neighbours—showing how these actors play crucial roles in healthcare systems (Hodgetts et al. 2011; Langstrup 2013; Unruh and Pratt 2008). These networks facilitate the work of healthcare professionals, replacing them if necessary through informal practices of care and guaranteeing the achievement of the goals of a healthcare system. In response to this debate, it is necessary to focus on the consequences of diabetes onset on patients and their broad networks, concentrating on the ways in which the emotional, practical and educational burdens of care are managed. For example, it could be interesting to analyse the role of other close family members (e.g. siblings) and extended family members (e.g. grandparents and uncles) in diabetes management and whether they acquire new care competencies after diabetes onset. Moreover, the role of other adults who interact daily with patients (e.g. teachers) could also be investigated, with attention given to the ways in which they cooperate (or do not) with parents.

Strengths and Limitations

This integrative review provides a multifaceted view of the impact of T1DM on family life, discussing 29 empirical studies selected for their relevance. The results from this integrative review define the current knowledge about this topic. Until now, reviews of T1DM management have focussed on young patients; this work synthesises the main results of the studies on the consequences of T1DM onset for families, identifying the dominant topics and indicating research directions for the future. The synthesis of the considered studies supports the hypothesis that T1DM is a family disease that affects not only the patients, but also their relatives, and particularly their parents. Strong emotions, new routines and educational processes arise after T1DM onset, changing family life definitively. However, there are some key limitations relevant to the present systematic review. First, unpublished and non-English language studies were excluded. Second, the study search was limited to published literature only and therefore cannot report on any grey literature that may provide further information. We did not conduct manual searches of work known to the authors or search the reference lists of relevant studies and manuscripts. Third, the three types of studies describing the ways in which parents share T1DM burdens of care (i.e. 'T1DM brings with it significant emotional burden of care', 'T1DM leads family to reorganises daily routines' and 'T1DM activates educational processes') are the result of the authors' reflections, and other categories may have therefore been excluded. In conclusion, while the scientific debate on this topic is growing, it currently lacks important aspects. The present review can be a good reference point for scholars and practitioners interested in producing innovative projects and research about the familial management of T1DM.

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reasons individual responsibility is to be assigned, SF wrote paragraph "Methods" and "Managing emotions after diagnosis"; FM wrote the Introduction, paragraphs "Reconstructing routines around new needs" and "Strengths and limitations", and EMP wrote the paragraphs "Educating young persons to enhance autonomy" and "Discussion".

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

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