

Fatores que Influenciam a Autogestão nos Adolescentes com Diabetes Tipo 1: Uma Revisão Scoping

Factors Influencing the Development of Self-Management on Adolescents with Diabetes Type 1: A Scoping Review

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Background: There are 303 new known cases of children and adolescents (0-19) with type 1 diabetes in Portugal, only in the year 2014, and more than 79000 new cases worldwide in 2013. The incidence of this chronic condition is rising, and the technological and medical advances in the last years allow for the well-being of individuals who, in other conditions, would not have survived. Health interventions directed to the adolescent with type 1 diabetes aim to motivate and facilitate self-management transition from caregiver to self, having the specificity of the adolescents in mind. The caregiver plays an essential role in this transition. His control and support should not end abruptly at the beginning of the adolescence, but slowly become an orientation that respects the young person's autonomy. Type 1 diabetes has always been a widely studied subject, and the interventions directed specifically to the adolescence period are one of the focus on recent papers.

Methodology: This scoping review was carried out according to the Joanna Briggs Institute Reviewers' Manual (2015). Initial search, including JBI Database of Systematic Reviews and Implementation Reports, CINAHL and MEDLINE, revealed there is not a scoping or a systematic review (published or in progress) about this subject. The objective of this review is to identify and map the knowledge about the self-management development process in adolescents with type 1 diabetes. It takes into account the perspectives of adolescents (aged 10-18) with type 1 diabetes and their parents/caregivers. It also includes the perspectives of health professionals and young adults (aged 18-25) with type 1 diabetes, where the participants are considered experts in their chronic condition.

Results: Six main categories of factors considered as barriers or facilitators in the development process of self-management in adolescents with type 1 diabetes could be found: Adolescent Self; Family; School; Peers; Health Care and type 1 diabetes evolution/Health regimen. Interventions can be adopted by health professionals in order to surpass identified challenges to self-management. Further investigation is needed on the matter, and focus groups are recommended for adolescents, caregivers and young adults regarding this theme.

Palavras-chave: adolescente; jovem adulto; autogestão; autocuidado, diabetes tipo 1.

Background: O número de novos casos de Diabetes tipo 1 (DM1) em crianças e adolescentes em Portugal foi de 303 no ano de 2014, e os números a nível mundial no ano de 2013 ascendem a mais de 79000 novos casos. A incidência desta doen crónica está a aumentar e o desenvolvimento médico e tecnológico dos últimos anos tem contribuído para a sobrevivência e o bem-estar dos indivíduos. As intervenções de saúde dirigidas aos adolescentes com DM1 pretendem motivar e facilitar a transição da gestão da DM1 dos cuidadores para o próprio adolescente, considerando as especificidades próprias desta população jovem. O cuidador tem um papel fundamental nesta transição, já que o seu controlo e suporte não podem ser abruptamente retirados no início da adolescência, mas evoluir suavemente para uma orientação respeitadora da autonomia da emergência da pessoa jovem. A DM1 tem sido um assunto largamente estudado e as intervenções dirigidas para o período da adolescência são um dos focos de estudos recentes.

Methodology: Esta revisão scoping utilizou as orientações do Joanna Briggs Institute Reviewers' Manual (2015). A pesquisa inicial, incluindo o JBI Database of Systematic Reviews and Implementation Reports e as bases de dados da saúde CINAHL e MEDLINE, revelaram não haver registo de revisões scoping ou sistemáticas, publicadas ou em desenvolvimento, sobre este assunto. O objetivo desta revisão é identificar e mapear o conhecimento sobre o processo de desenvolvimento da autogestão da DM1 em adolescentes, considerando as perspetivas quer dos adolescentes (10-18 anos) quer dos seus pais/cuidadores. Inclui ainda as perspetivas dos profissionais de saúde e de jovens adultos (18 - 25 anos) sempre que estes foram considerados perdidos nesta condição crónica.

Results: Encontraram-se seis categorias principais que podem ser facilitadoras ou colocar barreiras ao processo de desenvolvimento da autogestão da DM1 em adolescentes: Self; Família; Escola; Pares; Cuidados de saúde; e Evolução da DM1. Foram identificadas intervenções que podem ser adoptadas pelos profissionais de saúde para ultrapassar os desafios colocados à autogestão. É necessária a realização de mais estudos de investigação nesta área e o método de focus groups é recomendado para a colheita de dados sobre esta temática em adolescentes, prestadores de cuidados e jovens adultos.

Keywords: adolescent; young adult; self-management; self-care; type 1 diabetes.

BACKGROUND

There are 303 new known cases of children and adolescents (0-19) with type 1 diabetes mellitus (DM1) in Portugal only in the year 2014, and more than 79000 new cases worldwide in 2013 (Sociedade Portuguesa de Diabetologia, 2015). The incidence of this chronic condition is rising (Sociedade Portuguesa de Diabetologia, 2015), and the technological and medical advances in the last years allow for the well-being of individuals who, in other conditions, would not have survived. Diabetes is the fourth most prevailing chronic condition in adolescence (Barros, 2003).

DM1, also known as "insulin-dependent diabetes", is usually diagnosed during childhood or youth. In this type of diabetes, pancreas β -cells are destroyed and no longer produce insulin. The etiology of this chronic condition is yet unknown, however, it is believed to be an auto-immune process (Associação Protectora dos Diabéticos de Portugal, 2004). Only approximately 3% of people diagnosed with diabetes have DM1 (Record &

Ballard, 2013).

As a chronic condition, it cannot be cured, relying on treatment adherence and suited management to ensure survival and strengthen quality of life (Barros, 2003). An inappropriate management of DM1 can, in short term, lead to serious and even life-threatening situations. The hypoglycemia is one of the most common examples of such situations, and diabetic ketoacidosis is also potentially fatal, requesting immediate hospital care (Record & Ballard, 2013). These negative consequences may imply the need of hospitalization and/or invasive treatment, which most of the times translates into distress, suffering/pain and anguish of the adolescent and family.

Long term consequences of poor metabolic control can lead to other health conditions, such as nephropathy (which can lead to chronic renal failure), arterial hypertension, neuropathy (with serious consequences like diabetic foot on adulthood), retinopathy, among others (Couto & Camarneiro, 2002).

These may imply the need of frequent hospitalizations, dialysis, dealing with pain, missed school days, among many other factors that influence negatively the quality of life of these individuals, interfering with their education and social development (Kollar, 2013). The consequences of a poor metabolic control in adolescence have also consequences in future adult life (Docherty, Barfield, Thaxton, & Brandon, 2013).

The family is also affected, and although the pursue of the family's optimal adjustment to the child/adolescent's chronic disorder is one of the objectives of health interventions, it is a difficult equilibrium to achieve (Docherty et al., 2013).

More so, the money spent on treatments associated with long term consequences of an inappropriate diabetes management is an important slice of the Portuguese National Health Service budget (Sociedade Portuguesa de Diabetologia, 2015). Alas, we can say that a good management of DM1 is not only favorable for the individual, but also for the Health Service, predicting future lower costs, since it can prevent secondary conditions, decrease emergency services recurrence and days of hospitalization, among others (Lorig et al., 2001).

Adolescence is a life stage, a period of transition between childhood and adulthood. Although the boundaries of adolescence differ from individual to individual, its beginning can be identified by the onset of puberty, and the end with the completion of body growth. It can be hard to find an agreement between authors about a specific age interval, however, adolescence can be defined as from 10 to 18 years of age, including all its sub-phases: early adolescence, middle adolescence and late adolescence (Kollar, 2013; World Health Organization, 2014).

Psychosocial theory identifies the crisis of group Identity versus alienation as characteristic from this period. The adolescent looks for a framework of values and behaviors inside his group of peers, the approval from the peers, the autonomy from the family, and the search of a sense of personal identity (Erikson, 1976).

According to Piaget, it's also during adolescence that the individual acquires an abstract thinking ability, which means he can understand the consequences of his actions, without having to live them (Kollar, 2013). Simultaneously, it is said that the adolescent lives the present as his only moment of existence, not valuing or projecting his own self into the future (Cordeiro, 2009). Adolescents can solve complex problems, but their

thoughts can also be immature (Papalia, Olds, & Feldman, 2001).

There is some consensus when it comes to assume that adolescence tends to be the most difficult period when it comes to living with a chronic condition, since adolescents are identified as a vulnerable group, where “being different” usually isn’t something positive. It is a life period known for its’ progressive autonomy from parental/adult care, a process that can be hard and disrupted, considering restrictions and mandatory medical care imposed by DM1 (Barros, 2003). In addition, puberty implies a decreased sensitivity to insulin (Hockenberry, Baker, & Mondozi, 2013), making it harder to achieve an adequate metabolic control.

Since a chronic poor metabolic control in adolescence predicts poor metabolic control in adulthood (Ellis et al., 2005), we can assume an intervention in developing self-management in adolescence as a short, medium and long term investment.

According to Barlow, Wright, Sheasby, Turner and Hainsworth, optimal self-management of a chronic condition implies the own use of cognitive, behavioral and emotional strategies, allowing a quality of life that suits the individual (Malheiro, 2015). So, “self-management” implies that the own individual will be responsible for his daily care and management of his condition (Lorig & Holman, 2003). Six skills have been identified by these authors for an efficient self-management: Formation of a patient-provider partnership; resource utilization; problem solving; decision making; action planning; and self-tailoring (Lorig & Holman, 2003).

Health interventions directed to the adolescent with DM1 aim to motivate and facilitate self-management transition from caregiver to self, having the specificity of the adolescence in mind. The caregiver plays an essential role in this transition. His control and support should not end abruptly in the early adolescence, but slowly become an orientation that respects the young person’s autonomy (Barros, 2003).

The DM1 has always been a widely studied subject, and the interventions directed specifically to the adolescence period are one of the focus on recent papers. However, an initial search including JBI Database of Systematic Reviews and Implementation Reports, CINAHL, and MEDLINE revealed there is not a scoping review or a systematic review (published or in progress) about this subject.

The practical implication of this mapping will be to identify the self-management process influencing factors. Without this identification, it is not possible to develop and implement an effective educational self-management program specific to adolescents with DM1.

This scoping review followed the JBI methodology guidelines, which suggests identification of the research objective/questions, the inclusion criteria, search strategy and some specificities of extraction and presentation of the results (Joanna Briggs Institute, 2015).

OBJECTIVES/QUESTIONS

The objective of this review is to identify and map the literature about the self-management development process in adolescents with DM1. The review will

focus specifically on the following questions:

What factors positively influence the self-management development process of adolescents with DM1?

What factors negatively influence the self-management development process of adolescents with DM1?

INCLUSION CRITERIA

Participants

This scoping review considered all studies that focus on adolescents (aged 10-18) with DM1 and their parents/caregivers. Studies where the adolescents were part of a larger sample of patients with DM1, but it was possible to accurately identify data that is from adolescents separately, were also included.

Studies with young adults (aged 18-25) with DM1, where the participants, considered experts in their condition, reported factors that influenced the development of self-management skills, were included.

Studies with health professionals and parents/caregivers of adolescents with DM1 on self-management development process were included.

Concept

This scoping review considered all research studies that addressed the self-management process of adolescents with DM1, namely:

Practices or interventions used to promote self-management on adolescents with DM1;

Young adult and adolescents' experiences about the self-management competences development;

Healthcare providers' experiences with adolescents with DM1 during the self-management competences development.

Context

This scoping review considered studies where influencing factors (such as barriers or facilitating factors) of the self-management process of DM1 in adolescence were reported.

Types of studies

This scoping review case studies

METHODS

Search strategy

This review used a three-step strategy, as recommended by the Joanna Briggs Institute for all types of reviews (Joanna Briggs Institute, 2015). The search was limited to the last 5 years, from 2011 to 2016, and accepted documents published in English, Portuguese, Spanish and French. The searched databases for published documents were CINAHL, MEDLINE, JBI, COCHRANE Database of systematic reviews; ERIC and MEDLATINA.

The first step used MEDLINE complete and CINAHL complete through the Ebsco Platform, with preliminary keywords drawn from the natural language terms about the subject, namely, self-management process; self-care process; autonomy; independence; treatment adherence; diabetes type 1; adolescent; young adults; teenager; barriers; facilitating factors; influencing factors; adherence. Relevant studies were identified and text words in the title and the abstract were highlighted as well as the identification of the index terms used by databases to describe the articles.

The second step used the following boolean search expression adapted for each of the databases :

((Adolescen* OR Teen* OR Young adult) AND (Diabetes type 1 OR Diabetes Mellitus type 1)) AND (Self-management OR Self-care OR Autonomy OR Treatment adherence OR adherence) AND (Barriers OR Facilitating factors OR Influencing factors OR Difficulties OR Risk Factors OR Motivators OR Obstacles OR Challenges)

For the final step, references from retrieved articles were searched for additional studies. The overall steps are depicted in PRISMA flow diagram presented in Figure 1.

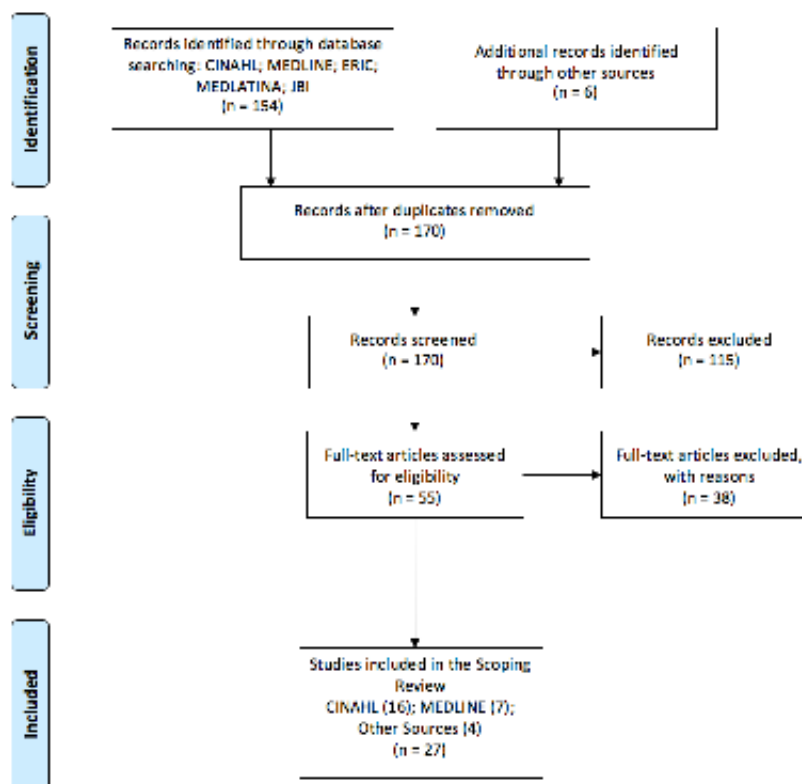


Figure 1 - PRISMA Flow Diagram for identification, screening, eligibility and inclusion of studies

Fonte: Moher, Tetzlaff, and Altman (2009).

Data extraction

Data from included studies were extracted by two reviewers using a template developed for the purpose, including details about the interventions, populations, study methods and outcomes of significance to the review question and specific objectives.

RESULTS

Most of studies included in this scoping review were conducted in the USA 2,5,6,8,10,11,12,13,14,16,17,18,19,20,21,24,26,27 , UK 4,9,22,23, Taiwan 3, Norway 15 and Sweden 25 in table 1.

ID	Author	Year	Country	Study Design	Participants
1	Neylon; O.; et. el. 1	2013	Austrália	Systematic Review	
2	Mulvaney, S. A.; et.al. 2	2011	USA	Randomized controlled pilot trial	41 (13-17 years)
	Chen, C.; et.al. 3	2017	Taiwan	Cross-sectional	265 (10-19 years)
	Spencer, J; et. al..4	2013	UK	Interpretive phenomenological	20 (13-16 years)
	Lu Y.; et.al. 5	2015	USA	Quantitative	54 (13-18 years)
	Palladino, D.K. and Helgeson, V.S.6	2013	USA	Mixed , qualitative with interviews and quantitative with a questionnaire (likert)	48 adolescent (13-16 years) / parent dyads and 21 pediatric endocrinologists
	Eilander, A. ; et.al. 7	2016	Netherland	Quantitative	598 (8-15 years)
	Datye K.A.; et. al..8				
		2016	USA	Literature review article	
	Cox, L.and Hunt, J.9				
		2015	UK	Literature review article	
	Céspedes-Knadle, M.and Muñoz,.E.10				
	Muñoz,.E.10	2011	USA	Qualitative approach, descriptive	Adolescents (one group of girls)
	Naranjo, D.; et.al. 11	2014	USA	Literature review article	
	Tse, J.; et.al. 12	2012	USA	Cross-sectional	151(13 -18years)
	Holmes, C.S.; et.al.13	2015	USA	Randomized Control Trial	226 (11-14years)
	Cox, D. et al.14	2014	USA	Development and validation of a Problem Recognition in Illness Self-management	425(13-18years) adolescents DM1/parents
	Frøisland, H; Årsand E. 15	2015	Norway	Qualitative	12 (13-19 years)
	Kornides, L. et al.16	2003	USA	Cross-sectional	282 (8-18 years)
	Mulvaney, A. et al.17				
		2011	USA	Development and validation barriers to diabetes adherence measure for adolescents	123 (12-17years)
	Babler, E. and Strickland, J.18	2015	USA	Grounded Theory	15 (11-15 years)
	Seiffge-Krenke, I.; et al.19	2013	USA	Quantitative, descriptive and correlational	109(12 -16years)
	Mlynarczyk, M.20				
		2013	USA	Cross-sectional quantitative.	102 (12-18years)
	Rechenberg, K.; et al.21	2016	USA	Quatitative cross-sectional	320 (10-18years)
	Edwards D; et al.22	2014	UK	Mixed-Method Systematic Review	
	Freeborn, D.; et. al..23	2012	UK	Qualitative descriptive	16 (6-18 years)

	Berlin KS; et. al. 24	2014	USA	Quantitative descriptive and correlational	142(10-18 years)
	Hanas, R.;et. al..25	2011	Sweden	Literature Review article	
	Mulvaney, S. A. et al.26	2011	USA	Quantitative, development and initial validation of an instrument	123 (12-17years)
	Mulvaney, A.; et.al.27	2012	USA	Quantitative, experimental RCT	28 (13-17years)

The 27 articles found were read and analyzed, opinions and experiences of adolescents, young adults, caregivers and healthcare professionals were considered on the matter of the factors that influence the development of self-management in adolescents with DM1, including health practices, interventions and contexts.

From the articles collected, a pattern seems to appear, revealing several factors that influence this process. They can be divided into 6 main categories: Adolescent Self; Family; School; Peers; Health Care and DM1 evolution / Health regimen.

Adolescent Self

Every individual is a complex being, influenced by many factors, intrinsic and extrinsic. Several articles found in this Scoping Review point to personal characteristics as being predictors of a good or poor self-management of DM1. In fact, adolescents point their own personal qualities as their best resource for solving diabetes related problems (Mulvaney, Rothman, et al., 2011).

There are findings that relate the adolescent's not fully developed discipline, knowledge of DM1 and cognitive skills with a poor self-care behavior, when there is a higher emotional detachment from parents (Chen et al., 2016).

Several other individual factors pose as barriers or facilitators in the development of self-management competences, such as Psychological and Spiritual Factors (Chen et al., 2016; Lu et al., 2015; Mulvaney, Rothman, et al., 2011; Spencer, Cooper, & Milton, 2014); Self-Concept (Husted et al., 2014; Palladino & Helgeson, 2013) and Self-efficacy (Husted et al., 2014; Kristensen, Thastum, Mose, & Birkebaek, 2012), the idea being that if the adolescent believes that he is capable of a specific behavior, its fulfillment is more likely (Eilander, De Wit, Rotteveel, & Snoek, 2016). It was also found that some associated conditions may challenge even more the acquisition of self-management skills, Depression/depressive symptoms being the most mentioned (Chen et al., 2016; L. Cox & Hunt, 2015; Datye, Moore, Russell, & Jaser, 2016). Depression is proposed to reduce social motivation and consequentially, the individual's ability to engage in optimal diabetes care (Céspedes-Knadle & Muñoz, 2011). However, a study describes that depressive symptoms are negatively correlated with life satisfaction but positively correlated with HbA1c levels (Chen et al., 2016) and contribute to a poorer self-management (Naranjo, Mulvaney, McGrath, Garnero, & Hood, 2014).

Disordered Eating Behaviors are also described as a challenge when it comes to a healthy management of DM1, posing as a predictive factor for lower diabetes adherence, less frequent blood glucose monitoring and higher HbA1c (Tse, Nansel, Haynie, Mehta, & Laffel, 2012). Insulin omission is also reported by Hanlan et al. (2013) as a way of

manifestation of eating disorders (one of the consequences of these omissions is weight loss). They also found that individuals with DM1 are more likely to suffer from Disordered Eating Behaviors than their peers, evidencing the need of screening directed for such disorders.

Knowledge and Understanding of the Disease plays an essential role on self-management, as it is referred in several articles retrieved. Being recommended reeducation of youth after diagnosis in a routinely manner, it seems that this domain is sometimes neglected (Holmes, Chen, Mackey, Grey, & Streisand, 2014). This is also a factor identified in the development of a survey tool to identify diabetes self-management barriers (Cox et al., 2014).

As such, interventions that focus the development of knowledge and understanding of the disease, such as Education Sessions, in some stances, seem to have a positive impact on glycemic control and on treatment adherence (Holmes et al., 2014). However, Christie et al. (2014) found no effect on HbA1c on their intervention, that consisted on a two 1-day workshops that taught intervention delivery, but found only approximately half of the recruited families attended at least one module, and that young people with higher HbA1c levels were less likely to attend (Spencer et al., 2014). Education Sessions are not the only intervention capable of increasing understanding and knowledge of the disease. A Mobile-Phone-Based intervention that focused on promoting self-management competences, found that the adolescents reported a better understanding of the relation between administered insulin, carbohydrates and blood glucose levels after its use, improving self-management behaviors and consequently, metabolic control (Froisland & Arsand, 2015).

A crucial matter when it comes to self-management is the individuals' motivation. Motivation can be increased or diminished according to environmental factors. For instance, young people described felling motivated after education sessions, but also stated that they lost that motivation not after long (Spencer et al., 2014).

Gaining attention recently, has been Motivational interviewing/Self-determination programs, where is sought to empower the individual to make positive health life choices, motivating for self-management behaviors. Although this is an intervention being explored nowadays, data results are not consistent, not showing dependable results on improved metabolic control (Datye et al., 2016; Husted et al., 2014).

Mobile and Web-based interventions have been gaining some attention in recent years, associated with technological advances in general. A pilot trial of a web-based diabetes messaging system for adolescents was tested, intending to motivate and remind adolescents about self-management of DM1, with positive effects in maintaining HbA1c (Mulvaney, Anders, Smith, Pittel, & Johnson, 2012). However, long-term efficacy of text-messaging interventions is still yet to prove (Datye et al., 2016). Another selected article takes advantage of new technologies to adopt an internet self-management problem solving program, a low cost implementation program, that proved that barriers to self-management can be addressed through technology (Mulvaney, Rothman, et al., 2011).

The adopted interventions to improve self-management and adherence directed to adolescents are many and varied, as described previously, but it was found that multicomponent interventions had a larger effect (Datye et al., 2016; Naranjo et al., 2014). Exemplifying one of such multicomponent interventions, the development and implementation of a group intervention called Teen Power was found. It aimed to an

increased diabetes knowledge, personal motivation and social support, designed to: “improve medical adherence in teens with DM1 by promoting psychosocial adjustment, eliminating psychological barriers associated with poor diabetes management, and reducing diabetes specific stress in caregivers” (Céspedes-Knadle & Muñoz, 2011).

Family

Most of the articles mentioned the importance of the family in the development of DM1 self-management in the adolescence period.

Parental support is an important factor to take into consideration in this process (Babler & Strickland, 2015; Christie et al., 2014; E. D. Cox et al., 2014; L. Cox & Hunt, 2015; Datye et al., 2016; Holmes et al., 2014; Husted, Thorsteinsson, Esbensen, Hommel, & Zoffmann, 2011; Kornides et al., 2014; Kristensen et al., 2012; Mulvaney, Rothman, et al., 2011; Mulvaney, Hood, et al., 2011; Seiffge-Krenke, Laursen, Dickson, & Hartl, 2013; Spencer et al., 2014). The selected articles that approach this theme, point to the parents as caregivers, essential to a healthy transition of management of DM1. In fact, adolescents point their parents as one of their best resources for solving diabetes related problems (Mulvaney, Rothman, et al., 2011).

Family conflict is a predictor for poor-self-management and poor glycemic control (Naranjo et al., 2014). However, several conditions are predictors of a good self-management development. They include: parents being prepared to transfer responsibility; adolescent having developed skills to assume self-care; older age from the adolescent and when the adolescents are emotionally ready to do so (Babler & Strickland, 2015). According to Mlynarczyk (2013), supportive parents aim to limit the adolescents’ exposure to risks and to encourage protective factors, and states that the perception of this parenting style is related to better adherence/self-management, even if it does not reflect on metabolic control.

It is important to bear in mind that parent supervision and support should not be overprotective or highly restrictive, or their role could be perceived as intrusive instead of collaborative and cause the adolescent with DM1 to struggle to assume management (Babler & Strickland, 2015; Datye et al., 2016; Husted et al., 2011; Seiffge-Krenke et al., 2013).

It also transpires that the lack or absence of parental supervision during adolescence period is likely to lead to a poor self-management. One article even shares an adolescent’s testimony where he states that he could cope with his DM1 for a period of time by himself, but not full time (Spencer et al., 2014). The insufficient parental assistance can lead to the adolescent experiencing burnout, feeling DM1 as a burden they could not control or deal with, making its management difficult and frustrating (Babler & Strickland, 2015).

Family meal habits have also been described to influence DM1 management. It was found that adolescents belonging to families with Regular Family Meal Habits not only had a better quality diet, but it also was a predictor for better adherence and management (Kornides et al., 2014). Parents establishment of this practice has been described as an adaptation strategy to support their child, integrating healthy eating habits into a family routine (Spencer et al., 2014).

Even though it is only mentioned in one article, we find it important to refer Siblings, sometimes viewed by the adolescent with DM1 as an extra support, mainly when parents

are not available to do so, working as a “safety net”, providing a sense of security when parents are absent (Spencer et al., 2014).

It was also found a strong relation between parents’ high income and education status, with a better self-management and problem-solving skills. Lower socioeconomic status is associated with higher HbA1c (Chen et al., 2016; Neylon, O’Connell, Skinner, & Cameron, 2013). Adolescents from moderate-income families were as challenged with DM1 as those from low-income families (Rechenberg, Whittemore, Grey, & Jaser, 2016).

Taking into account the parents’ essential role in this management transition from caregivers to self, it is of no surprise that interventions were found focusing not only the adolescents with DM1, but also their home environment and family. A Randomized Control Trial was conducted with adolescent/parent dyads, where four joint appointments were scheduled throughout a year, conducted in a clinical context. There was a Coping versus an Education comparison group, and it was found that both programs had a positive impact on preventing deterioration in diabetes management, but the Education group was found to perform better than the Coping group on study outcomes, particularly in terms of improving HbA1c (Holmes et al., 2014). On another study, Christie (2014) and her colleagues found that their structured educational and motivation program did not decrease HbA1c at 12 or 24 months. A Randomized Controlled Intervention study, where both adolescents and parents participated in the Guided Self-Determination-Young method along their routine clinic appointments, also didn’t show differences in HbA1c, but it significantly increased motivation for self-management (Husted et al., 2014).

School

Since a big part of the adolescents’ time is spent on school, this is also a context pointed as an influencer on the development of self-management (Edwards, Noyes, Lowes, Haf Spencer, & Gregory, 2014; Spencer et al., 2014; Wang, Brown, & Horner, 2013). The adolescent generally requires less and less assistance to fulfil the needed procedures and choices for self-management (Edwards et al., 2014). An important responsibility befalls the school in establishing an environment that promotes the self-management of these adolescents, simultaneously assuming a caregiver role.

There are documented strategies adopted by the school that allow the adolescent to manage this chronic condition with better results (e.g. free passes for cutting the cafeteria queue if they needed to eat urgently, being able to leave the classroom on request to check glycaemia, or disseminate information amongst the teachers about the identity of the student with DM1 (Spencer et al., 2014)). It can be argued that different criteria in relation to other classmates can bring the adolescent with DM1 the sense of “feeling different” (Freeborn, Dyches, Roper, & Mandelco, 2013), and some option to avoid these advantages in order to “feel normal” (Wang et al., 2013).

However, some negative and harmful approaches and decisions from school personnel regarding DM1 are referred by adolescents, influencing their management at school (Edwards et al., 2014; Wang et al., 2013). Not taking into consideration some special needs can be frustrating for the adolescent, and even dangerous in some cases (such as hypoglycaemia). Students also report that in some schools, they are not allowed to check blood glucose in the classroom, or that there is a lack of a private location to do so, which can affect their choices in terms of self-management (Edwards et al., 2014).

An intervention in particular is documented that is directed to school personnel that deals with adolescents with DM1, with the objective of enabling them to supervise and help adolescents with DM1 (Edwards et al., 2014).

Peers

Peers play an essential role on the adolescent's development, this being the period when their opinion is generally most valued by the individual. Their support or non-support can play an important role on the development of self-management of the adolescent with DM1 (L. Cox & Hunt, 2015; Spencer et al., 2014). However, it is also found that peers have a more important role as emotional supporters of these adolescents than on self-management or metabolic control (Datye et al., 2016).

It was also found that conflict with peers has a stronger effect on diabetes outcomes than their support (Palladino & Helgeson, 2013). As such, social context will pose as a barrier in an easier way than as a facilitating factor for self-management.

Several adolescents "feel different" from their peers and friends (even if a distinction is made regarding friends and peers, being the latest more prone to be seen as having a negative perception by the adolescent (Berlin, Hains, Kamody, Kichler, & Davies, 2015)), a subject already brought up in this review when talking about adopted strategies by the school to facilitate DM1 management. This sentiment is also reported by some individuals when they need to measure their blood glucose, administer insulin or when they have a symptomatic hypoglycemia (Spencer et al., 2014). The feeling of being stigmatized or the fear of it happening is described by some of the adolescents with DM1 (Mulvaney, Hood, et al., 2011; Wang et al., 2013). This could act as a barrier to self-management in presence of peers (such as in school) (Edwards et al., 2014; Freeborn et al., 2013; Wang et al., 2013), which leads us to another point: disclosure of DM1.

Non-disclosure can lead to potentially dangerous situations, such as severe hypoglycemia, where loss of consciousness implies the need of help from others that know what is happening and what to do (Spencer et al., 2014; Wang et al., 2013). Even so, some adolescents choose not to disclose their DM1, in hopes that peers don't treat them differently (Lu et al., 2015). Some adolescents adopt a strategy to avoid such a situation, by telling one or two close friends about their chronic condition and educating them on how to act in emergency situations related to DM1, such as a severe hypoglycemia (Edwards et al., 2014).

Contact with peers with the same diagnostic of DM1 as proved to be beneficial to the adolescent, improving their adherence and knowledge (Céspedes-Knadle & Muñoz, 2011). A study even found that it's participants would be exited as they shared similar experiences and shared strategies to deal with challenges they faced (Freeborn et al., 2013). As such, peers as mentors is an intervention to be taken into account, as a way to facilitate learning and sharing essential DM1 management skills and experiences that the mentor has already developed (Freeborn et al., 2013; Lu et al., 2015).

Health Care

The health care can be perceived by the individual with DM1 as a safe place where they can expose their doubts, fears, difficulties and needs related to their chronic

condition. It can also be perceived as a connection point of their life with diabetes, which can become a symbol of unwelcome attention. The representation assumed in the adolescent's mind is determined by many factors. The healthcare team's approach on the subject can be essential on this matter. In fact, one of the influences on self-management of the adolescent with DM1 is the relation with the Healthcare Team. Testimonies from adolescents point their positive perception of diabetes clinic, referring friendly treatment and interest in their lives aside from diabetes (promoting a feeling of normalization), enabling health care professionals to develop a relationship of trust (Spencer et al., 2014).

Communication between the adolescent/family and the healthcare team should be fluid and perceptive, in order to allow information sharing. Communication problems can pose as a barrier in getting information, making it an aspect to take into consideration when in clinical context. Listen to patients, spending enough time with patients and explaining concepts appropriately are some aspects to pay attention to (Datye et al., 2016).

Cost of care is also mentioned, stating it as a barrier, either relating to distance needed to travel to have access to health care, insurance or finances (Datye et al., 2016; Naranjo et al., 2014). This was not clearly found in other studies, whether if for need of further investigation on the subject or because other countries developed costs support in such situations, this scoping review could not assess.

An interesting approach to diabetes clinic attendance is documented as "Care Ambassadors", consisting of non-medical personnel that monitored and helped to schedule appointments and track hospitalizations and emergency room visits, resulting in a significant improved attendance to clinic visits (Datye et al., 2016). This intervention also reduced hypoglycemia and emergency room visits, but no effect was proved on HbA1c.

DM1 Evolution / Health regimen

Important factors influencing self-management development process through adolescence in individuals with DM1 has to do with the evolution of their chronic condition and the adopted health regimen. It can be discussed that longer duration of diabetes can relate to higher levels of burnout related to treatment, translated into a bigger probability of difficulties with self-management (Naranjo et al., 2014), but Chen et al. (2016) found no significant correlation with duration of diabetes and self-care behaviors.

Regimen pain/bother and burden is widely reported as a barrier to adherence to treatment. Adolescents' reports could be found referring to pain and bother of glucose blood checking and administration of insulin, as the procedures interfered with their school or extra-curricular activities (Freeborn et al., 2013; Spencer et al., 2014). Believing diabetes is a burden is not uncommon during adolescence. It can lead to an improper management of this chronic condition, with behaviors of not checking blood glucose levels or lying about them, acting lazy, omitting insulin doses or needing a break (Babler & Strickland, 2015). Burnout is referred as an important barrier to treatment adherence (Mulvaney, Hood, et al., 2011).

The health regimen is often demanding in terms of time management and planning, being identified by adolescents as one of the main issues when it comes to adopt self-management behaviors (Mulvaney, Rothman, et al., 2011).

Insulin administration is several times described as painful, being one of the reasons

described for insulin omission. There are several ways to administer subcutaneous insulin, and a study from 2011 compares discreet devices such as insulin pens with conventional syringe-based regimens, both in terms of pain, ease and accuracy, and states that the first is significantly easier, more accurate and less conspicuous, making the latter method of administration obsolete and in disuse (Hanas, de Beaufort, Hoey, & Anderson, 2011; Mulvaney, Hood, et al., 2011). Research also shows that the use of continuous subcutaneous insulin therapy (also known as insulin pump) tends to improve glycemic control and self-management (Naranjo et al., 2014).

Implications for Research

This scoping review intends to be a contribution to the research conducted on the field of empowerment of the adolescent with DM1, and as such, will benefit from further investigation.

We also understand the importance of experiences and opinions of health professionals and parents/caregivers in relation to self-management development process of adolescents with DM1, and suggest that a Focus Group should be conveyed with such a sample as well.

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