



Interventions for self-management in adolescents with Type 1 Diabetes: a scoping review protocol

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Abstract

Introduction

Adolescent development involves building autonomy and progressive independence from parental supervision. Challenges that are more complex when they have a diagnosis of type 1 diabetes and have to take responsibility for managing their condition. At this age, it is crucial to implement interventions to promote self-management skills in adolescents with type 1 diabetes.

Objective

The aim of this scoping review is to identify and map interventions that promote self-management skills in adolescents with type 1 diabetes.

Methods

The methodology will follow the Joanna Briggs Institute recommendations for scoping reviews. Studies published in English, Portuguese and Spanish between 2009-2021 will be considered, with no geographical or cultural limitations. The process of data analysis, extraction, and synthesis will be performed by two independent reviewers, based on the inclusion criteria. The results of the study selection will be presented in a Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram for scoping reviews. This protocol is registered at Open Science Framework <https://osf.io/z6wbj>.

Results

Mapping the interventions for adolescents with type 1 diabetes, may constitute a tool for the design of a structured intervention to promote self-management behaviour in adolescents with type 1 diabetes and contribute to the dissemination of available evidence on the topic.

Conclusion

The results from this review are expected to gather relevant information that will serve as a basis for the development of a nursing intervention for adolescents with diabetes.

Keywords

Adolescent; Diabetes Mellitus, Type 1; Program Evaluation; Self-Management.

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Introduction

Worldwide, more than 1.1 million children and adolescents are living with diabetes, and the incidence of Type 1 Diabetes Mellitus (T1D) has been increasing, particularly at ages below 15, with a higher prevalence in Europe than in other regions.¹

Adolescents are in a crucial phase for building their autonomy, becoming progressively independent from their parents and assuming more and more responsibility in decision-making.² During this phase, education and training is essential for promoting T1D self-management.³ Once there is no cure, treating T1D implies fostering healthy growth to minimize the impact of this disease.³ The ultimate goal for adolescents with T1D is to assume increased self-care responsibility for managing diabetes.⁴

T1D is a chronic disease caused by an autoimmune reaction in which the immune system destroys the pancreas beta cells, preventing insulin production.⁵ The treatment of diabetes is demanding and complex requiring continuous control carried out through the management of the following triad: diet, physical exercise, and tuning of insulin doses.⁶ Regarding diet, counting carbohydrates is a complex and challenging task (complex carbohydrates and simple carbohydrates, e.g., glucose, fructose, lactose, sucrose, and maltose). This task becomes even more complex with the management of insulin and diet during physical exercise/sports.^{6,7} Thus, managing T1D entails deep thought on behaviors and decision-making, which is a significant responsibility for adolescents and their families.⁸ Self-management focuses on self-regulation of chronic disease and management of risk factors, and includes goal-setting, self-monitoring, decision-making, self-care planning and participation, self-assessment, and management of physical, emotional, and cognitive responses associated with behavior change.⁹ Promoting self-management is associated with encouraging self-efficacy, knowledge, functionality, and social interactions, improving mental health, providing effective management of symptoms, a better quality of life, and lowering the need for emergency services.^{10,11} An adequate self-management of the disease also drives better health care and resource management¹², preventing or delaying secondary conditions such as micro and macrovascular complications.^{13,14} Self-management of a chronic condition is the individual ability to manage the symptoms and treatment, physical repercussions, psychosocial and emotional dimensions, and changes in the lifestyle, which are inherent to chronic illness.¹⁵ Kate Lorig¹⁶ highlighted three self-management tasks (medical management, role management and emotional management) and several self-management skills (problem-solving, decision-making, resource utilization, the formation of a patient-provider partnership, action planning, and self-tailoring).

To manage T1D is essential to have well-planned and organized strategies and well-defined objectives.⁹ Management of diabetes involves knowledge about the pathophysiologic of diabetes and acute and chronic complications of the disease: hypo and hyperglycaemia, insulin administration, measurement of blood glucose, and health maintenance (diet, and physical exercise).¹⁷

Self-management support is the process of educating and supporting people with a chronic condition, helping them and their families understand their central role in managing their disease.¹⁸ It includes a commitment to patient-centered care. Implementing programs with specific strategies could be helpful. Structured programs for T1D should integrate topics within education, the definition of goals and objectives, social inclusion, and self-efficiency associated with glycaemic control measures.¹⁰ These programs comprise psychoeducational principles, training of daily routines, continuous support in promoting self-management, parental engagement and participation, and the use of new cognitive-behavioral techniques and new technologies as motivators for adolescents is recommended.¹¹

It is up to the health teams within a multidisciplinary network, particularly nurses, to facilitate and encourage the self-management of diabetes in adolescents, therefore contributing to a healthier and more capable population in managing their disease.¹¹ The team's intervention focuses on the individual, their family, the group, and the community; their intervention can occur in many contexts: work-based during regular appointments, home-based, community-based, school-based, or informal scenarios such as summer camps.¹⁹

A preliminary search of MEDLINE (PubMed), CINAHL (EBSCO), the Cochrane Database of Systematic Reviews and JBI Evidence Synthesis, PROSPERO, and Open Science Framework (OSF) was conducted, and no current or underway systematic reviews or scoping reviews (published or in progress) on the topic were identified.

More precisely, this scoping review seeks to answer the following questions:

- What are the characteristics of the interventions that promote self-management in adolescents with Type 1 Diabetes?
- Who are the professionals responsible for implementing the interventions?
- What are the indicators of change in self-management skills after the intervention?

This scoping review aims to map interventions that promote self-management skills in adolescents with type 1 diabetes.

Methods

This scoping review follows the Joanna Briggs Institute (JBI) guidelines for scoping reviews.^{20,21} This review protocol was registered in the Open Science Framework (OSF) (<https://osf.io/z6wbi/> accessed on 11 November 2022).

Eligibility criteria

Participants

This scoping review will consider studies focused on interventions to adolescents aged 10 to 19 years old with T1D and/or their parents/family, that have participated in an intervention focused on self-management of diabetes, developed, or implemented by any health professionals.

Concept

The concept considered in this review will include studies that analyse programs and interventions to promote self-management in adolescents with T1D: medical management, role management, and emotional management. Programs or interventions that do not show results will be excluded.

Context

This scoping review will consider all interventions implemented and evaluated to promote self-management in adolescents carried out in any context. The context may include interventions via virtual or attendance in a health care setting (hospital or ambulatory), diabetic camps, or at a person's home.

Types of Sources

This scoping review aims to identify and map any interventions developed to promote self-management in adolescents with T1D. For this purpose, the authors will consider experimental and quasi-experimental study designs, including randomized controlled trials, non-randomized controlled trials, before and after studies. Qualitative studies focusing on qualitative data will be included, but are not limited to, designs such as phenomenology, grounded theory, ethnography, qualitative

description, action research. In addition, systematic reviews that meet the inclusion criteria will also be considered.

Search strategy

The search strategy will aim to locate both published and unpublished studies. This review will use a three-step search strategy. An initial limited search of MEDLINE (via Pubmed) and CINAHL (via EBSCO) to identify articles on the topic. We used the text words contained in the titles and abstracts of relevant papers and the index terms "AND" or "OR" to describe the articles were used to develop a complete search strategy. The search strategy, including all identified keywords and index terms, will be adapted for each database and information source (Table 1). Afterwards, we will screen the reference list of all included articles for additional studies. Studies published in English, Portuguese and Spanish between 2009-2021 will be considered.

The databases to be searched will include CINAHL Plus with Full Text, PubMed, Cochrane Central Register of Controlled Trials, LILACS, Scopus, Library, Information Science & Technology Abstracts, PsycINFO, JBI Connect, and the Cochrane Database of Systematic Reviews. Will also include sources of unpublished studies and grey literature from the RCAAP – Repositório Científico de Acesso Aberto de Portugal.

Table 1 – Search Strategy conducted in March 2021

CINAHL complete Cochrane Central Register of Controlled Trials; Nursing & Allied Health Collection; Library, Information Science & Technology Abstracts (via EBSCO)	Results Retrieved
S6 TI (adolescen* OR teen* OR youth* OR young*) AND TI (diabetes OR "diabetes mellitus, type 1" OR T1DM OR "diabetes mellitus type 1" OR "DM1" OR "type 1 diabetes") AND TI (manage* OR "self management" OR "self care" OR "self-efficacy" OR "health and life quality" OR "quality of life" OR "glycaemic control" OR "glycemic control" OR Glycosylated hemoglobin* OR hemoglobin A*) AND AB (intervention* OR program* OR strateg* OR project* OR action* OR function* OR care* OR preparation OR education OR instruction* OR train*). Filters: Boleano, English, Portuguese and Spanish, from 2009-2021	485
S5 TI (adolescen* OR teen* OR youth* OR young*) AND TI (diabetes OR "diabetes mellitus, type 1" OR T1DM OR "diabetes mellitus type 1" OR "DM1" OR "type 1 diabetes") AND TI (manage* OR "self management" OR "self care" OR "self-efficacy" OR "health and life quality" OR "quality of life" OR "glycaemic control" OR "glycemic control" OR Glycosylated hemoglobin* OR hemoglobin A*) AND AB (intervention* OR program* OR strateg* OR project* OR action* OR function* OR care* OR preparation OR education OR instruction* OR train*). Filters: Boleano, from 2009-2021	974
S4 TI (adolescen* OR teen* OR youth* OR young*) AND TI (diabetes OR "diabetes mellitus, type 1" OR T1DM OR "diabetes mellitus type 1" OR "DM1" OR "type 1 diabetes") AND TI (manage* OR "self management" OR "self care" OR "self-efficacy" OR "health and life quality" OR "quality of life" OR "glycaemic control" OR "glycemic control" OR Glycosylated hemoglobin* OR hemoglobin A*) AND AB (intervention* OR program* OR strateg* OR project* OR action* OR function* OR care* OR preparation OR education OR instruction* OR train*)	1,280
S3 TI (adolescen* OR teen* OR youth* OR young*) AND TI (diabetes OR "diabetes mellitus, type 1" OR T1DM OR "diabetes mellitus type 1" OR "DM1" OR "type 1 diabetes") AND TI (manage* OR "self management" OR "self care" OR "self-efficacy" OR "health and life quality" OR "quality of life" OR "glycaemic control" OR "glycemic control" OR Glycosylated hemoglobin* OR hemoglobin A*)	2,245
S2 TI (adolescen* OR teen* OR youth* OR young*) AND TI (diabetes OR "diabetes mellitus, type 1" OR T1DM OR "diabetes mellitus type 1" OR "DM1" OR "type 1 diabetes")	15,567
S1 TI adolescen* OR teen* OR youth* OR young*	640,993
Pubmed	
adolescent [MeSH Terms] AND diabetes mellitus, type 1 [MeSH Terms] AND ("self-management" [MeSH Terms] OR self-care [MeSH Terms] OR quality of life [MeSH Terms] OR "glycated hemoglobin a" [MeSH Terms]) AND (Program Evaluation [MeSH Terms] OR "health promotion" [MeSH Terms]). Filters: English, from 2009-2021	59
Medline complete (via EBSCO)	
adolescent [MeSH Terms] AND diabetes mellitus, type 1 [MeSH Terms] AND ("self-management" [MeSH Terms] OR self-care [MeSH Terms] OR quality of life [MeSH Terms] OR "glycated hemoglobin a" [MeSH Terms]) AND (Program Evaluation [MeSH Terms] OR "health promotion" [MeSH Terms]). Filters: English, from 2009-2021	27

Study/Source of Evidence selection

Following the search, all identified records will be removed as duplicates using the Mendeley. Two independent reviewers will be screening titles and abstracts for assessment against the inclusion criteria for the review. Potentially relevant studies will be retrieved in total. Two independent reviewers will assess the full-text citations against the inclusion criteria. The scoping review will report, in the full text, the reasons for the exclusion of sources of evidence in full text that do not meet the inclusion criteria. Any disagreements between the reviewers will be discussed with a third reviewer. The search results and the study inclusion process will be reported in full in the final scoping review and presented in a Preferred Reporting Items for Systematic Reviews and Meta-analyses extension for scoping review (PRISMA-ScR) flow diagram.²⁰

Data Extraction

Quantitative and qualitative data will be extracted from articles included in the review by two independent reviewers using a data extraction tool developed by the reviewers as indicated by the methodology for scoping reviews proposed by JBI.²² The data extracted will include specific details about the participants, concept, context, study methods, and critical findings relevant to the review questions. A draft extraction form is provided (Table 2). The draft data extraction tool will be modified and revised as necessary while extracting data from each included evidence source. We will detail all modifications in the scoping review. Will resolve any disagreements between the reviewers through discussion or with an additional reviewer/s. If appropriate, we will contact the authors of papers to request missing or additional data, where required.

Table 2 - Data Extraction Instrument

Main Field	Extraction Categories	Category Description
Study ID	Reference number; Authors; Year; Title; Journal; Issue no; Vol no.	
	Type of reference	1. Primary research 2. Systematic review
Inclusion/ Exclusion criteria	P – Adolescents with T1D C - Programs and/or interventions to promote self-management in adolescents with T1D. Excludes programs do not should results.	1. Yes 2. No
	C - Interventions via virtual or attendance in health care setting (hospital or ambulatory), diabetic camps or at person's home.	
Characteristics population	Who are the participants involved in the intervention?	1. Adolescents 2. Adolescents and parents/ family
	Who are the healthcare professionals in the healthcare practice/intervention?	1. Physicians 2. Nurses 3. Psychologists 4. Physiotherapists 5. Nutritionists 6. Multidisciplinary 7. Other, please specify
Characteristics interventions	How is the intervention designed?	1. Educational 2. Psychosocial 3. Supportive 4. Communicational 5. Other, please specify
	General characteristics of interventions	1. Contents 2. In group 3. Individually 4. Duration of the sessions
Characteristics context	What is the setting of intervention delivery?	6. Health care setting (Hospital or ambulatory) 7. Person's home 8. Virtual 9. Other, please specify
	What are the indicators of change in self-management skills after the intervention?	1. Self-management (Acute and chronic complications of the disease:

hypo and hyperglycemia, insulin administration, measurement of blood glucose, health maintenance: diet, and physical exercise)

2. Self-efficacy
3. Knowledge
4. Quality of life
5. Self-care
6. Glycated Hemoglobin

Results

Data analysis and presentation

The results will be summarized and presented in a tabular form. A draft results table has been developed to address each question (table 3). A narrative summary accompanies

the tabular results and describes how these are related to the review's objective and questions. We will present what is known, the literature gaps in the field, and the potential implications for health care and research.

Table 3 - Tabular Summary for Results Presentation

Review questions	Study 1	Study 2	Study 3	...
a) What are the characteristics of the interventions that promote self-management in adolescents with T1D?				
b) Who are the professionals responsible for implementing the interventions?				
c) What are the indicators of change in self-management skills after the intervention?				

Discussion

Mapping of the available interventions implemented for adolescents with T1D may constitute a tool to design of a structured intervention to promote self-management behaviour in adolescents with T1D and contribute to the dissemination of available evidence on the topic. This scoping review will only consider English, Portuguese, and Spanish studies, which can be registered as potential study limitation. In order to minimize the effects of this limitation, if we find an article relevant to the topic, in another language, we undertake to use tools so that can be integrated in this review.

Conclusions

The literature points to the development of interventions in different contexts for adolescents with T1D focused on self-management and empowerment to promote autonomy to promote better quality of life and reduce complications. The scoping review, which will result from this protocol is expected to gather relevant information that will serve as a basis for the development of a nursing intervention for adolescents with T1D.

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