Self-management in children and adolescents with chronic illness: An evolutionary analysis of the concept

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Author contributions

Criteria	Author Initials
Made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data;	MC, LM, JS, ZC, CF.
Involved in drafting the manuscript or revising it critically for important intellectual content;	MC, ZC, CF.
Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content;	MC, ZC, CF.
Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.	MC.

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- **Conflict of interest**

  The authors declare no conflict of interest.

- **Data availability statement**

  The data that supports the findings of this study are available in the supplementary material of this article.

Title: Self-management in children and adolescents with chronic illness: An evolutionary analysis of the concept

Abstract

Aim: To increase conceptual clarity regarding the self-management of school-age children and adolescents with chronic illnesses, in a community context.

Design: Concept Analysis:Rodgers' evolutionary approach.

Data Sources: Search conducted in the Cumulative Index to Nursing and Allied Health Literature, Psychology and Behavioral Sciences Collection, Nursing & Allied Health Collection, Academic Search Complete, Cochrane, Web of Science, Medical Literature Analysis and Retrievel System Online, Scopus, Repositório Científico de Acesso Aberto de Portugal, ProQuest Dissertations & Theses, Joanna Briggs Institute Evidence Synthesis. 31 articles were identified, published between 2004 and 2023.

Reporting Method: Followed the Enhancing the Quality and Transparency Of Health Research guidelines - Preferred Reporting Items for Systematic Reviews and Meta-Analyses 2020.

Results: Self-management in children and adolescents with chronic illness, in school age, in a community context, consists of a process of acquiring knowledge and beliefs that promote the self-efficacy of this population in developing skills to face needs inherent to the health condition.

Conclusion: Promoting self-management goes beyond simply educating for skill acquisition. Participants with stronger beliefs in their ability to control their behaviors are more successful in self-management. The activation of resources that position the child as an agent of change is recommended.

Implications for the Profession and/or Patient Care: It contributes to the development of strategies that promote self-management across different healthcare disciplines, focusing on education and change, but also on psychological encouragement to foster confidence in change.

Impact: Competent self-management during childhood promotes autonomy, empowerment, control of the condition, with consequent physical and emotional well-being, quality of life, family stability and social development.

No Patient or Public Contribution: There was no direct contribution from patientsor public in this work (literature review).

KEYWORDS

Adolescent; child; chronic disease; concept analysis; nursing; Rodgers' evolutionary model; self-management.

SUMMARY STATEMENT:

What is already known:

- Self-management refers to the set of skills and behaviors that children/adolescents develop to cope with chronic conditions;
- Self-management behaviors operate within the domains of individual, family, community, and health systems;
- Factors such as developmental stage, disease severity, cognitive and emotional skills of the child, and social support influence the success of self-management.

What this paper adds:

- Identifies how the concept of self-management in pediatric age evolves over time and within different contexts (social, cultural, and technological);
- Highlights new essential attributes defining self-management in pediatrics (understanding action plans, alignment between children/adolescents and formal/informal caregivers—co-creation, management of technology and health devices, mentor support), providing a differentiated perspective from existing literature;
- Enables greater clarity and focus for new interventions.

Implications for practice/policy:

- Integration of intersectoral actions in public policies;
- Development of participatory methodologies to enhance the effectiveness of interventions;
- Exploration of new technologies, such as remote monitoring devices, to promote self-management in children and adolescents.

1. INTRODUCTION

Technological evolution combined with advances in health knowledge has been recognized as a crucial factor in increasing neonatal and pediatric survival rates (Blackwell et al., 2019; Gauci et al., 2021). Epidemiological studies indicate that, in recent decades, the prevalence of children and adolescents living with chronic disease has been on an increasing trend worldwide (Stuckler, 2011; Campbell et al., 2016). The management of these illnesses has evolved, moving away from paternalistic models (Barlow & Ellard, 2004) and emphasizing the active involvement of children, adolescents, and their

families in making decisions about their treatment, daily care, and their health (Barlow & Ellard, 2004; Sparapani et al., 2017; Spray & Hunleth, 2023). This reality introduces a growing need for children and adolescents to develop self-management skills throughout adulthood effectively, playing an active role in the daily management of the disease (Charlier et al., 2016; Gauci et al., 2021; Spray & Hunleth, 2023).

Given the growing global impact of pediatric chronic diseases, understanding and promoting self-management in this population is increasingly recognized as a critical component of international health agendas (World Health Organization (WHO), 2018; United Nations Children's Fund (UNICEF, 2022). It is directly associated with improved health outcomes and reduced healthcare costs in various contexts (Camp-Spivey et al., 2022; Edwards et al., 2021; Lozano & Houtrow, 2018).

This study adopts a structured and evolutionary approach to conceptual analysis in order to delve deeper into the concept of 'self-management' and its implications in the context of the health care to children and adolescents with chronic disease. Through Rogers' evolutionary method, itaims to increase conceptual clarity regarding the self-management of school-age children and adolescents with chronic illnesses, in a community context.

2. BACKGROUND

In the pediatric age, learning self-management skills is a continuous and winding process, which goes far beyond learning fundamental skills for managing daily needs, but involves acquiring knowledge to properly manage the child's or adolescent's long-term health needs (Betz, 2017; Bravo, et al., 2020). The "self" usually involves at least one parent or adult caregiver and the child in pediatric health care (Callery & Coyne, 2019). Self-management behaviors operate in the individual, family, community, and health systems domains, so the focus should be on structures incorporating a triadic perspective (Camp-Spivey et al., 2022; Modi et al., 2012). Children need the support of their parents, teachers, peers, health professionals, and other community members as an essential resource for learning and effectively using self-management strategies (Adams & Crowley, 2021; Callery & Coyne, 2019; Camp-Spivey et al., 2022).

Given the limited applicability of self-management in the pediatric age, the construction of a Pediatric Model of Self-Management emerged, providing a theoretical framework for understanding how self-management behaviors operate within and are influenced by these domains (Modi et al., 2012).

This model is based on some principles of social cognitive theory, which extends the concept of human agency to collective agency (Bandura, 2001). People do not operate in isolation but work together to improve the quality of their lives, so they need to receive the necessary resources and empowering guidance to help themselves (Adams & Crowley, 2021; Bal et al., 2016; Lozano & Houtrow, 2018).

Parents are the primary source of health-related information and care (Camp-Spivey et al., 2022; Ochoa-Avilés, et al, 2023). As children grow and develop cognitively, they become more independent (Erikson, 1998; Karpov, 2005). Yet, parents continue to play a crucial role by providing emotional support and encouragement, which are vital for building children's self-worth and confidence significant (Brown et al., 2010; Ochoa-Avilés, et al., 2023). Many children with significant cognitive and physical limitations will continue to have self-management needs that will be provided by their primary caregivers (Modi, 2012; Saxby, et al., 2020). According to the Individual and Family Self-Management Theory, the acquisition of self-management skills can be developed by easing knowledge and beliefs, improving self-regulation skills and promoting social facilitation or self-management of resources (Ryan & Sawin, 2009; Sawin, 2017). In this context, peer groups are also becoming increasingly influential in children's sense of identity in this age group (Erikson, 1998). Children and adolescents with similar illnesses can also support each other through sharing personal experiences (Camp-Spivey et al., 2022; Spray & Hunleth, 2023).

The literature identifies numerous interventions available for health professionals to promote self-management in children with chronic illnesses. These interventions have been developed for children from school age (from 5 to 7 years-old) (Catarino et al., 2021; Bal et al., 2016). During early childhood, children take important steps in developing independence, identity, and coping with life's circumstances. Several key elements in development are essential for the acquisition of self-

management skills. As children grow, they take on more responsibility for their health, thanks to advances in their cognitive, affective, and psychomotor skills (Kelada, et al., 2021; Wray-Lake et al., 2010). This shift aligns with Piaget's theory of cognitive development, where children move from the preoperational stage (ages 2–7) to the concrete operational stage (ages 7–11), developing the logical thinking skills needed for self-management (Piaget & Inhelder, 1997).

Professionals must be trained to work with adolescents and support self-management, encouraging family and peer involvement (Adams & Crowley, 2021; Wong Chung, 2020). Most chronic disease management teams are multidisciplinary, and nurses occupy vital positions (Gauci et al., 2021).

The literature identifies significant gaps in understanding self-management in children and adolescents with chronic illnesses of school age in a community context. It highlights issues such as inconsistent use and application of the concept across different life stages, challenges in synthesizing interdisciplinary knowledge, and varying definitions of self-management (Rodgers', 2000). The analysis aims to address these gaps to improve understanding and practice.
By analyzing the concept of (supported) self-management, we contribute to greater conceptual clarity. The results obtained will facilitate the development and evaluation of interventions that enable the improvement of health outcomes related to the self-management of chronic diseases in children and adolescents.

3. AIM

The aim of this concept analysis is to increase conceptual clarity regarding self-management in school-age children and adolescents with chronic illness, in a community setting.

4. DESIGN AND METHODS

This study adopts a structured and evolutionary approach to conceptual analysis in order to deepen the concept of self-management. Using Rodgers' evolutionary method (Rodgers', 2000), it aims to dissect and contemporise the understanding of this concept, thus shedding light on its meaning and application in the context of healthcare.

4.1. Methodological Framework

This interactive, descriptive, and inductive approach to analysis was chosen for its recognition of the dynamic nature of concepts. Rodgers' (1989, 2000) emphasizes that concepts evolve due to various influences and should not be bound by fixed conditions. This approach helps in understanding a concept by identifying its antecedents, attributes, consequences, and related terms, acknowledging their interrelationships over time (Rodgers, 1989, 2000).
Unlike other models of concept analysis, Rodgers' model allows for the description of the dynamic and contextual nature of the concept in practice. It allows for an in-depth longitudinal analysis that considers changes over time and the influence of various factors, offering a more holistic understanding of the concept under study.

4.2. Review of the Literature

A comprehensive literature search was carried out, using online research platforms and respective electronic health databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL) Complete, Psychology and Behavioral Sciences Collection, Nursing & Allied Health Collection: Comprehensive Edition, and Academic Search Complete, via EBSCO Host; Cochrane Database of Systematic Reviews and Cochrane Central Register of Controlled Trials via Cochrane library, premium version; Web of Science; Medical Literature Analysis and Retrieval System Online (MEDLINE), via PubMed; Scopus; Portuguese Open Access Repository (RCAAP); ProQuest Dissertations & Theses; Joanna Briggs Institute (JBI) Evidence Synthesis. The research was carried out using Medical Subject Heading (MeSH) descriptors, keywords and truncations, identified by the authors, together with Boolean operators (AND E OR): Self-management, Child*, "Chronic illness" OR "Chronic illness", "Chronically ill". Appendix S1 shows the search strategy used in the different databases.
Primary research (experimental, observational, methodological and analytical) and literature reviews were included as

inclusion criteria. All research studies on self-management in children and adolescents that clearly characterized the concept were considered.

Most of the studies referred to strategies/interventions to promote self-management in children and adolescents aged 5 to 19 with a chronic illness, in a community setting. We included studies that addressed self-management in the context of social support systems, community intervention and collaborative practices with the aim of developing autonomy and promoting a better quality of life. We were not necessarily interested in the results of these studies, but rather in how they defined the concept. Research published electronically in Portuguese, English, French or Spanish. Publications with time limitations were not considered.

By applying the defined inclusion and exclusion criteria, the search generated a total of 1289 results.The references were imported into the EndNote Web X9 citation management software (Clarivate Analytics, Philadelphia, PA, USA) and duplicates were removed, resulting in 709 articles. The title and abstract were analyzed sequentially, which resulted in the exclusion of 447 articles that did not meet the inclusion criteria. 262 articles were obtained for reading the full text. In the reading process, articles were excluded for different reasons: they did not correspond to the concept under study; they did not refer to the community context; they did not apply to the child and adolescent population, or the type of study did not fit the inclusion criteria. 31 articles, published between 2004 and 2023, were considered eligible for analysis (Appendix S2).
Data were extracted and inserted into tables organized with the year of publication, country, authors, title, study objective, study design, population, temporal, interdisciplinary and sociocultural context, concept definitions, attributes, antecedents, consequents, substitute terms, related concepts, self-management assessment instruments and exemplary cases of self-management in the study population. In Appendix S2, some of the characteristics of the studies included in the analysis are synthesized.
The review sample includes studies from various countries, with the USA being the most represented (n=14). The studies span multiple disciplines, including health, technology, and social sciences. Notably, 17 studies were authored or co-authored by nurses.
The review includes 10 literature reviews, 15 primary studies, and 6 text/opinion articles. The literature reviews consist of systematic, scoping, and integrative reviews. The primary studies include qualitative, quantitative, and mixed-methods research. The studies focus on the pediatric population, with some involving caregivers, covering age groups from 5 to 19 years old, and 11 articles focusing exclusively on adolescents aged 10 to 19.
The studies focus on the pediatric population covering ages 5 to 19, including some of their caregivers. Quality assessment using JBI checklists classified 3 studies as medium quality and 28 as high quality, with no low-quality studies (Appendices S2 to S8). Evidence levels were identified, with 35% at level 1, 3% at level 2, 29% at level 4, and 32% at level 5 (Appendix S2). The analysis clarified distinctions between concepts in the Pediatric Self-Management Model (Modi, 2012) and those from other studies. Researchers used Rayyan QCRI software version 0.1.0 (Figure 1) to screen and assess eligibility.
The study's screening process involved two researchers independently reviewing titles and abstracts to eliminate ineligible studies, ensuring consistency and minimizing errors. Discrepancies were resolved through comparison and discussion. In the second stage, full texts of potentially relevant citations were assessed by the same researchers, with a third consulted if needed. Methodological decisions and protocol changes were documented. Additional researchers reviewed the analysis to ensure clarity and context, enhancing the study's validity and relevance.

4.3. Concept Analysis

In accordance with Rodgers' evolutionary approach (2000), the concept analysis was conducted, respecting the following steps: (1) Identification of the concept and associated/substitute terms; (2) Selection of an appropriate domain (a context or a sample) for data collection; (3) Collection of data to identify antecedents, attributes and consequences; (4) Analysis of data relating to the characteristics of the concepts; (5) Identification of an example of a concept; (6) Identification of hypotheses and implications for the future development of the concept.

4.3.1. Identification of the concept and associated/substitute terms

The research focused on the concept of self-management, using search terms identified from literature without adding related or substitute concepts. The authors, familiar with the concept, followed Rodgers' (2000) recommendations. The search included studies in multiple languages and of various types, with no time limits, to understand the concept's evolution over time and across social contexts.

4.3.2. Data collection and analysis using content analysis to determine concept, antecedents, attributes, and consequences

The data extraction process involved a thorough reading of each article to identify critical expressions and phrases related to attributes, antecedents, consequents, and related terms. A second reading followed the authors to identify the underlying ideas precisely. Categories and subcategories were logically identified, with a small proportion of data classified as outsiders. Two researchers ensured reliability and validity using the Joanna Briggs Institute's Critical Appraisal Checklists: for Systematic Reviews and Research Syntheses (Aromataris, et al., 2015) (Appendix S3); for Qualitative Research (Lockwood, et al. 2015) (Appendix S4); for Text and Opinion (McArthur, et al. 2020) (Appendix S5); for Analytical Cross Sectional Studies (Joanna Briggs Institute, 2020) (Appendix S6), for Quasi-Experimental Studies (Joanna Briggs Institute, 2020) (Appendix S7) and for RCTs (Barker, et al ., 2023) (Appendix S8). For assessing the methodological quality of a validation study of a scale, the COSMIN study design checklist for instruments patient-reported outcome results was used (Mokkink, et al., 2019) (Table 1). When applying the checklists, the answers to the questions were "yes", "no", "unclear" or "not applicable". The number of "yes" and "no" answers was counted, and the sum of the two was 100%. The percentage of "yes" answers in each checklist was then calculated. Studies whose checklist had less than 50% of "yes" responses were considered to be of low quality; studies whose checklist had 50 to 70% of "yes" responses were considered to be of medium quality; and studies whose checklist had more than 70% of "yes" responses were considered to be of high quality. The relevance of the studies was also determined by the studies' alignment with the research questions and their contribution to the theoretical understanding of the concept.

4.3.3. Form hypotheses and implications regarding the concept

The concept dating back to 1986, written by Holroyd & Creer, describes self-management as the performance of therapeutic activities in the field of health, in collaboration and supervision of health professionals, and specifically nurses. This interpretation refers to a more limited initial view of self-management as a set of actions or attitudes related to therapy management and medication management.

The conceptual elements extracted from the content analysis of the included studies were connected with the Pediatric Self-Management Model, which provided the theoretical framework supporting the qualitative analysis to understand shared self-management and how its behaviors operate within the domains of the individual, family, community, and health systems (Camp-Spivey et al., 2022; Lozano & Houtrow, 2018; Modi et al., 2012).

5. RESULTS

The concepts identified in the Pediatric Self-Management Model are well established, widely accepted, based on the existing literature and applied in clinical practice. However, areas that are still under development or that require more evidence to support robust clinical practices were identified. These emerging concepts point to new directions and innovations that have the potential to transform pediatric self-management, especially as technology and understanding of mental and emotional health continue to advance.

5.1. Definition and use of the concept

The literature identifies multiple concepts of self-management, spanning from 1986 to 2023, primarily focused on the pediatric population (Barlow et al., 2002; Barlow & Ellard, 2004; Catarino et al., 2021; Charlier et al., 2016; Gauci et al., 2021; Henry & Schor, 2015) with chronic illnesses. Self-management is described as a multidimensional and complex

phenomenon (Ryan & Sawin, 2009; Modi et al., 2012), involving the ability to manage symptoms, treatment, and lifestyle changes (Catarino et al., 2021; Charlier et al., 2016; Gauci et al., 2021), as well as adopting health-promoting strategies like healthy living and exercise (Adams & Crowley, 2021; Catarino et al., 2021). The concept of self-management is applied in psychoeducational interventions for children and families (Ellard, 2004), including social skills training to manage chronic illness (Barlow & Ellard, 2004). These interventions involve shared responsibilities and decision-making between children, parents, and health teams (Schilling et al., 2002; Mclure et al, 2018; Edwards et al., 2021). Based on the principle of sharing, the concept of "supported self-management" (Lozano & Houtrow, 2018) highlights the need for parental support for young children, emphasizing interdependence, mutual responsibility, and respect for cultural and socioeconomic factors (Spray & Hunleth, 2023).

5.2. Surrogate terms and related concepts

Only one term was identified in the literature considered a substitute term: "taking care", distinct in its semantic root from the concept of "self-care" (Babler & Strickland, 2015). Surrogate terms or related concepts for self-management emerged during content analysis included: "self-care" (Ryan & Sawin, 2009; Sparapani et al., 2017); "self-control" (Bruzzese et al., 2012; Moffatt et al., 2019), "self-monitoring" (Wilde & Garvin, 2007; Knoblock-Hahn et al., 2016 Lertbannaphong et al., 2021); "self-regulation" (Wilde & Garvin, 2007; Adams & Crowley, 2021); "self-efficacy" (Bandura, 1977; Camp-Spivey et al., 2022; Law et al., 2014; Modi et al., 2012)); "adhesion" (Modi et al., 2012; Lorig & Holman, 2003).

5.3. References of the concept

The findings from the content analysis involving the thirty-one articles selected from the literature search are outlined in Tables 2–4, offering insights into the antecedents, attributes, and consequences of the concept self-management. In Table 5 it is possible to identify the distinction between concepts established in the Pediatric Self-Management Model (Modi, 2012) and concepts that emerged in the remaining studies included.

In Figure 2, there is a synthesis representing the conceptual structure of Self-management of children and adolescents with chronic disease.

5.3.1. Antecedents

Representation of Chronic Illness

Chronic diseases are characterized by their long duration, lack of spontaneous resolution, and absence of curative therapy (Gauci et al., 2021). They can impact growth, development, appearance, identity, mental health, daily routines, and relationships and can lead to experiences of stigma (Camp-Spivey et al., 2022; Edwards et al., 2021;Sawyer & Aroni, 2005).

Individual Factors or Characteristics

The factors influence a child's development and health management like age, cognitive, behavioral, and physical development (Gauci et al., 2021; Sparapani et al., 2017), sex and race/ethnicity (Lozano & Houtrow, 2018; Modi et al., 2012; Spray & Hunleth, 2023), minority status (Modi et al., 2012); perception of risk due to non-adherence (Lerch & Thrane, 2019; Sparapani et al., 2017); adherence capacity (Becker, 1974); individual perceptions, adaptive health beliefs, including self-efficacy, internal locus of control and confidence in the usefulness of treatments, as well as motivation and hope (Mickley, et al., 2013; Modi et al., 2012; Lozano & Houtrow, 2018).

Family Factors

The family is a key self-management resource, considering parents' attitudes (Adams & Crowley, 2021; Sparapani et al., 2017). Family factors are considered, parental support; family functioning and dynamics (Sawyer & Aroni, 2005); family structure (Modi et al., 2012); family socioeconomic level (Babler & Strickland, 2015; Mickley, et al., 2013; Modi et al., 2012); family motivation and beliefs regarding their and the child's ability to manage the disease (Mickley, et al., 2013).

Sociocultural Factors

Greater levels of psychosocial support are related to better self-management behaviors (Ahmad & Grimes, 2011; Henry & Schor, 2015), as social support for recommended health behaviors (Adams & Crowley, 2021; Edwards et al., 2021; Modi et al., 2012); care environment and healthcare professional-patient relationship (Mickley, et al., 2013; Modi et al., 2012); support for self-management by health professionals (Adams & Crowley, 2021; Mclure, et al., 2018); support from friends and school (Adams & Crowley, 2021; Edwards et al., 2021; Guo et al., 2012).

Care Network

The importance of the existence of a network of community agencies and support resources is recognized (Lozano & Houtrow, 2018), such as: structural support (Spray & Hunleth, 2023); effective communication between families and the healthcare team (Stokes, et al., 2009; Modi et al., 2012); care partnership (Barlow & Ellard, 2004); preserving the individuality of children and adolescents (Stokes, et al., 2009; Spray & Hunleth, 2023); monitoring follow-up and/or referral to specialists (McClure, et al., 2018).

5.3.2. Attributes

Knowledge and Beliefs

Self-management involves a range of knowledge, beliefs, skills, and behaviors to manage chronic illness effects across physical, social, psychosocial, and emotional dimensions (Adams & Crowley, 2021; Barlow et al., 2002; Gauci et al., 2021). Promoting self-management focuses on patient education, disease self-monitoring, therapeutic management, action plans, emotional management, treatment adherence, and symptom control (Blanson Henkemans, et al., 2017; Catarino et al., 2021; Lozano & Houtrow, 2018). Knowledge and beliefs are crucial for personal change (Barlow & Ellard, 2004), enhancing treatment adherence, and disease control. Interventions using cognitive-behavioral techniques or behavior modification strategies significantly improve self-efficacy beliefs (Burbank, et al., 2015; Buckner, et al., 2018; Gauci, et al., 2021).

Adhesion (as an attribute)

The terms compliance, adherence and agreement are often used to describe self-management behaviors (Gauci et al.,2021). Adherence refers to medication, treatment plans, appropriate use of health devices (Ahmad & Grimes, 2011; Camp-Spivey et al., 2022), as well as social and lifestyle behaviors that affect and are affected for well-being in a more holistic sense (Lertbannaphong et al., 2021; Lozano & Houtrow, 2018; Modi et al., 2012).

Positive family dynamics are related to better adherence and better results (Sawyer & Aroni, 2005). Studies recommend that approaches to this population include activating resources, helping them learn to live with the condition and developing the necessary tasks and skills (Moffatt et al., 2019).

Skills

The attendance at appointments, accessing and administering prescribed medications, participating in diagnostic and therapeutic procedures such as supportive therapies, monitoring, managing technology and health devices (Lozano & Houtrow, 2018), recognizing and mitigating symptoms, self-reaction (Shegog, et al., 2006), problem-solving, physical activity and diet management are Self-management skills are acquired by children, but also by their caregivers (Adams & Crowley, 2021; ; Blanson Henkemans, et al., 2017; Edwards et al., 2021).

Gradually, the child/adolescent must also acquire the ability to seek support from parents, professionals, colleagues and share tasks (Klassen, et al., 2015; Spray & Hunleth, 2023). Adolescents need to establish their place before their parents and fight for their independence (Lerch & Thrane, 2019).

Social support

Several studies have shown that children can be tasked with managing their own condition (Lozano & Houtrow, 2018; Modi et al., 2012; Spray & Hunleth, 2023). Children or adults can be instructed, but no one is fully independent or dependent, both are entangled in the interdependencies of family and caring communities (Lozano & Houtrow, 2018; Spray & Hunleth, 2023). Guidance provided by formal and informal caregivers increases participants' self-efficacy and confidence (Camp-Spivey et al., 2022; Henry & Schor, 2015; Mickley, et al., 2013).

Health professionals also play the role of partners for the child/adolescent (Adams & Crowley, 2021; Barlow & Ellard, 2004; Spray & Hunleth, 2023), such as mentoring groups, co-workers, friends (Edwards et al., 2021; Lozano & Houtrow, 2018), public entities/organizations (Edwards et al., 2021; Lozano & Houtrow, 2018; Spray & Hunleth, 2023).

Communication about the disease

Self-management requires communication, planning and organization (Spray & Hunleth, 2023). Achieving a relationship that provides organization between children and other family members is essential for developing strategies, maintaining control over their lives, becoming more self-sufficient and achieving treatment success (Klassen, et al., 2015; Lerch & Thrane, 2019; Spray & Hunleth, 2023).

It is essential for health professionals to facilitate interaction and guide families in identifying and negotiating roles in supporting children (Blanson Henkemans, et al., 2017; Spray & Hunleth, 2023). Children must learn to recognize when to notify adults (Spray & Hunleth, 2023), as well as acquire the ability to question and answer questions (Adams & Crowley, 2021; Klassen, et al., 2015). Other elements of society may be involved in this communication, such as colleagues and teachers (Lerch & Thrane, 2019; McClure, et al, 2018).

Emotional Management

In situations of chronic illness, there are many common problems experienced by children, in relation to emotional well-being, which sometimes lead to situations of isolation (Barlow & Ellard, 2004) and difficulty in maintaining self-esteem (Knoblock-Hahn et al., 2016). The child needs to acquire coping strategies, emotional adjustment and self-regulation skills, make decisions about disclosing the chronic illness, adopting effective communication (Adams & Crowley, 2021; Babler & Strickland, 2015; Guo et al., 2012).

5.3.3. Consequences

Quality of life

Results from different studies, mainly studies on educational self-management interventionsappropriate to the developmental stage, lead to improvements in self-management skills and behaviors for chronic conditions in children and young people (Ahmad & Grimes, 2011; Gauci et al., 2021; Saxby, et al., 2020) and reduced symptoms, better monitoring and control of the disease are identified. There are, therefore, strong arguments for promoting competent and effective self-management skills as early as possible in the disease trajectory, with the aim of achieving a higher quality of life for affected individuals, reducing morbidity and mortality (Camp-Spivey et al., 2022; Moffatt et al., 2019).

Adhesion (as consequent)

Better adherence is a marker of better self-management, resulting in better chronic disease control (Ahmad & Grimes, 2011; Catarino et al., 2021; Gauci et al., 2021). Self-management improves health outcomes in children and adolescents with chronic illnesses, as it improves adherence to the treatment plan and develops the individual's ability to face challenges (Mickley, et al., 2013).

Condition Control

Mastering health condition leads to a feeling of self-control and satisfaction (Catarino et al., 2021). Interventions that promote self-management for children enable them to recognize and act, becoming effective in controlling signs and symptoms (Camp-Spivey et al., 2022; Horner, 2020). Functional improvements and a reduction in the number of admissions to health departments were found, mainly at the level of urgent care (Barlow & Ellard, 2004; Camp-Spivey et al., 2022). There were also reductions in symptoms and days lost at work and school (Camp-Spivey et al., 2022; Henry & Schor, 2015). Studies have shown that activated patients have better health outcomes, fewer complications, and lower healthcare costs (Camp-Spivey et al., 2022; Henry & Schor, 2015; Modi et al., 2012).

Empowerment

The ability to self-manage leads to empowerment, considered a process through which individuals acquire control over their own lives and become proactive in matters of social policy and social change (Barlow & Ellard, 2004). Evidence-based protocols that promote self-efficacy represent a contribution to the healthy development of children, not only in terms of treatment management, but also by increasing confidence in participating in everyday activities (Camp-Spivey et al.,2022; Mickley , et al., 2013). Self-management interventions can influence an increase in knowledge, regardless of the underlying disease or its severity (Moffatt et al., 2019) by promoting a sense of competence, responsibility, self-esteem, self-confidence (Knoblock-Hahn et al., 2016; Malheiro et al., 2019). With the acquisition of self-management skills, improvements in locus of control, as well as family functioning, are also identified (Barlow & Ellard, 2004).

Autonomy

The acquisition of self-management skills promotes the child's sense of autonomy, competence and relatedness (Blanson Henkemans, et al., 2017). It also helps improve a young person´s transition from pediatric to adult care (Saxby, et al., 2020).
Achievements, such as the identification of triggers that unbalance stability; understanding treatment and alternative therapies, as well as the importance of having an effective and close relationship with the caregiver (doctor/nurse), help in making appropriate decisions (Catarino et al., 2021; Stokes, et al., 2009). These decisions also result from the child's own values (Catarino et al., 2021; Stokes, et al., 2009).
Other consequences have also been identified, including knowledge/literacy (Catarino et al., 2021), greater independence in problem solving, ability to communicate about the disease, responsibility (Camp-Spivey et al., 2022; Lerch & Thrane, 2019; Malheiro et al., 2019) and a gradual acquisition of self-assessment skills (Shegog, et al., 2006).

Physical and emotional well-being

Children/adolescents report improvements in their emotional state (Ahmad & Grimes, 2011; Gauci et al., 2021) and better levels of satisfaction, with the mastery of self-management skills (Barlow & Ellard, 2004; Blanson Henkemans, et al., 2017; Catarino et al., 2021). Better self-management is related to better development, a greater sense of competence, productivity and well-being (Camp-Spivey et al., 2022; Catarino et al., 2021; Henry & Schor, 2015). Some studies, report a reduction in days with acute symptoms and episodes, which is indicative of a reduction in associated suffering (Barlow & Ellard, 2004; Horner, 2020).
One of the most difficult self-management tasks is dealing with stigma (Adams & Crowley, 2021; Stokes, et al., 2009). One of the factors influencing good self-esteem, despite the child having a stigmatizing illness, may be good social support (emotional, instrumental or informational) (Adams & Crowley, 2021).

Family Stability

Adopting comprehensive self-management support models in pediatric care has the potential to improve health outcomes and reduce utilization, costs, and caregiver burden (Barlow & Ellard, 2004; Henry & Schor, 2015). Evidence was found of actions promoting self-management based on cognitive-behavioral techniques in variables such as family functioning, psychosocial well-being, reduced isolation, social competence (Barlow & Ellard, 2004).

Social Development

Mastering self-management allows adolescents/young people to engage in social interactions (Mickley, et al., 2013). Allows learning to live, work and actively participate in society, with knowledge of how to manage their condition and how to prevent complications in the short and long term (Malheiro et al., 2019). It enables gaining control over their own life and become proactive in matters of policy and social change (Barlow & Ellard, 2004).

6. DISCUSSION

The increasing prevalence and duration of chronic illnesses has led to a gradual demand for self-management needs for children and families and a greater need for supports for both (Henry & Schor, 2015). Illness representations provide a framework for action, influencing coping strategies and action plans. Leventhal, et al. (2008) categorized disease representations into five main dimensions: identity, timeline, consequences, cause and control/cure.

In the literature, strong arguments are identified to promote competent and effective self-management skills as early as possible. Children and adolescents report improvements in knowledge, adherence to treatment regimens, self-efficacy, improvement in disease-related symptomatology, emotional stability, and quality of life over time (Adams & Crowley, 2021).

Individual, family and sociocultural factors are predictors of self-management, in a process of support, interdependencies and mutual responsibility. Children, adolescents, family and other informal caregivers are involved in decisions about their care and can play a participatory role in the daily management of their illness (Barlow & Ellard, 2004; Saxby, et al., 2020).

The model by Modi, et al., (2012) helps to explain how modifiable and non-modifiable influences interfere with everyday self-management behaviors. He describes that self-management strategies are influenced by four domains (individual, family, community, and health systems), and for each of these, he identifies factors that can be modified through interventions and those that are not subject to change.

Communication is an essential vector in the process, which can occur through different physical or virtual means, with family, school and health professionals being crucial elements in this contact (McClure, et al, 2018). Among different studies in this area, we find that by McClure, et al., (2018), which recognizes the importance of using a symptom recording form (provided to each teacher) to communicate with parents, in order to guarantee the continued compliance with an action plan for managing the disease at school and at home.

The use of technological resources or face-to-face contact enables social facilitation between health units, health professionals, family and friends, and influences the responses of individuals and families and the level of adaptation (Adams & Crowley, 2021; Guo et al., 2012). Digital technologies have been found to support and empower patients and promote the development of effective self-management skills, thereby promoting adherence to treatment regimens. Studies found indicate several examples in which technologies are accessible, viable and usable and have a positive impact on adherence, such as mobile applications, websites, blogs, wearables, in order to promote self-management skills capable of acting early, during the course of the disease (Edwards et al., 2021; Lerch & Thrane, 2019; Mattison, et al., 2022).

Technologies bring children, and especially adolescents, closer to their caregivers, so that, in symbiosis, good adherence to treatment and effective self-management of the disease can be achieved, thus promoting a better quality of life for both (Liu et al., 2016). These responses were created so that children and parents have access to information and application features 24 hours a day in order to better manage their disease (Edwards et al. 2021). The use of smartphones has grown in recent decades, and with it we have also seen an increase in the popularity of health applications. With regard to the use of these technologies to facilitate self-management, mobile applications are expected to play an increasingly prominent role (Kumar et al., 2013). Major advantages stand out, such as promoting adherence to therapy, access to information, the possibility of recording crises, sharing information between the child/family and healthcare professionals, among others (Edwards et al. 2021; Liu et al., 2016). The integration of care plans into electronic health records can facilitate the sharing of plans between different caregivers and healthcare teams. These plans must contemplate the evolution of self-management skills over time and be based on the child's developmental trajectory (Edwards et al., 2021; Lerch & Thrane, 2019).

The capacity for self-management demands knowledge about the disease and compliance with a care plan, for physical and emotional control (Sawyer & Aroni, 2005), which becomes demanding for an adult, and especially for children due to their

stage of development. and maturity (Sparapani et al., 2017). Effective chronic disease self-management programs delivered in hospital, clinic, or school settings have reduced hospitalizations and emergency room visits (Horner, 2020; Magzamen, et al., 2008).

According to Spray & Hunleth (2023), caregivers must involve the child in self-management programs and promote child inclusion, which must go beyond considering the child as a recipient of education. These researchers identify children as actors, that is, considered agents in the management of their health, in which all their capabilities must be valued.

Children and young people who believe that their illness or symptoms can be controlled or managed by themselves are more likely to engage in self-management behaviors (Law et al., 2014). Bandura's research also confirmed that when people have a sense of control, they can control their behavior and that self-efficacy should be considered synonymous with behavioral control (McClure, et al, 2018). This information is also consistent with social cognitive theory, as it describes that the more confident people are in their ability to self-manage, the less they experience the negative consequences of the disease (Law et al., 2014). From this perspective, incorporating cognitive-behavioral strategies into interventions that promote self-management makes it possible to achieve self-efficacy and acquire the respective disease self-management skills (Barlow & Ellard, 2004).

The degree of correspondence or incompatibility between adolescent and parental illness representations can influence self-management (Law et al., 2014).

In the adolescence stage of the life cycle, children really need to establish their place before their parents, making it essential to promote self-management and family stability. Lerch and Thrane, (2019) found that teens' challenges with the parental relationship included struggling for independence and building trust between teen and caregiver. Adolescents must achieve involvement in decisions and establish their place before their parents, towards autonomy.

Some of the manifestations of self-management skills that reveal adolescent readiness in the transition to adulthood, identified in the study by Klassen, et al. (2015) and Spray and Hunleth, (2023), corroborate the defining characteristics of readiness for improved health self-management defined by Herdman, et al., 2021 in NANDA (2021-2023): “expressing the desire to increase acceptance of the condition”, “improving daily living choices to meet health goals”, “increasing commitment to follow-up care”, “improved decision making”, “inclusion of treatment regimen in daily life”, “improved management of risk”, “sign management”, “symptom management”, “recognizing signs of disease”, “increasing recognition of disease symptoms” and “satisfaction with quality of life” (p. 203).

Controlling the condition through achieving self-management develops a feeling of empowerment and autonomy in children and adolescents. This stage promotes physical and emotional well-being, considered synonymous with quality of life (Gauci, et al., 2021; Guo et al., 2012). The stability of the health condition generates balance in the adolescent's development, which provides the acquisition of social skills (Barlow & Ellard, 2004) and the possibility of being a more active element in society (Malheiro et al., 2019).

Modern healthcare systems are often reactive rather than proactive (Edwards, et al., 2021). Health policies can generate improvements in care for children with chronic conditions by including, in co-production with families, innovative tools to promote effective management of the condition throughout life (Chief Medical Officer, 2012; Edwards, et al., 2021).

These findings, which result from the studies included in the analysis, summarize the knowledge on the concept of self-management, in an interdisciplinary context, and highlight its use and specific application in pediatric age. The analysis advances the field in comparison with previous research, as it adopts an evolutionary perspective, which allows proposing a current concept of self-management for children and adolescents with chronic illness, of school age, in a community context.

6.1. Cases of self-management in adolescents with chronic illness

Two cases are evident in the literature, which were considered representative of the process of acquiring self-management skills, at different moments in the process. These allow for a more concrete sense of the concept, clarifying the direction of

the research (Rodger, 2000). Both reproduce the adolescence phase, the most identified in the literature on self-management in pediatric age. One of the cases is available in the study by Spray & Hunlet (2023) and corresponds to the beginning of adolescence, sometimes defined as pre-adolescence (New Oxford American Dictionary, 2005). This concerns Beca, who was diagnosed with asthma when she was 10. It demonstrates how asthma management was not transmitted unidirectionally from adult caregiver to child, but that children with asthma actively constructed it.

Beca did not use technical terms to identify her therapy, she referred to it as the purple inhaler and her yellow and blue medications. She knew how to use them,however, Beca's acquisition of self-management skills did not begin with inhaling medication. During school periods, her inhaler was kept by the school health nurse. The strategy that the nurse and Beca used for the child to begin self-management in the initial phase of diagnosis involved a set of activities aimed at controlling acute symptoms. If breathing difficulties started, she would stop, drink water, try to remain calm and get help. Its role in preventing asthma involved always having water available with her and avoiding continuous running, preventing excessive exertion from triggering an asthma episode. Her actions aimed at treating asthma were essentially social. She emphasized the importance of telling people so they could get help in a crisis situation. Chose some adults and other colleagues, also with asthma, because she considered them to have more skills. She knew three children in her class with asthma and had already observed one of them helping another classmate, guiding her breathing and taking her to a teacher.

The second example was identified in the study by Sawyer & Aroni (2005) and refers to Mark, aged 16, effectively representing the adolescence phase (WHO, 1986). Despite being considered a stage of greater physical and cognitive capacity, during it there is often difficulty in adherence when the diagnosis appears at this age or a decline when it has already appeared previously, and a need for parental support again more active, due to the feeling of doubt in the search for identity, which is associated with this phase (Bruzzese, et al., 2012; Gauci, et al., 2021).

In the case mentioned, Mark had recently been diagnosed with epilepsy and his mother was worried because he was becoming increasingly moody and had lost interest in school and football. Mark was informed that he would not be able to participate in the school camp due to poor seizure control. From the mother's perspective, the main problem was "Mark's refusal to take care of himself." She was always reminding him to take his medication and believed he was mature enough to do it on his own. The health professional who accompanies Mark at the neurology consultation suggested talking to Mark alone and identified that, since Mark had a seizure at school, he has been mercilessly stigmatized. He said that due to his absence from school during the period of crises, he was kicked off the football team and spent less time with his friends, feeling sad. Despite knowing that adherence to therapy will reduce the likelihood of seizures, he reported that he is unable to organize himself.

The healthcare professional suggested that Mark try to identify some daily routines that would help him remember to take his medication. He also suggested that his mother remind him to take his medication if, when he fell asleep, there was no record that it had been taken. With Mark's permission, encouraged the mother to talk to the student coordinator about concerns about bullying and sports activities. Mark agreed to more frequent check-ins before camp to decide if he felt comfortable participating. In the following consultations, he confirmed that adherence had improved, with the establishment of regular medication routines (linked to tooth brushing). His mother gradually became more confident allowed Mark to participate in the school camp. With some encouragement, Mark agreed to participate in the camp, which turned out to be uneventful and socially enjoyable. Over the following months, his social confidence gradually improved and, the following year, he returned to his usual sporting activities.

6.2. Self-management Assessment Tools

The TRANSITION-Q has been identified as a significant instrument for measuring self-management skills in adolescents with chronic health conditions (Klassen, et al., 2015). It is a valid, clinically meaningful and psychometrically sound 14-item scale that can be administered to adolescents aged from 12 to 18 with a wide range of chronic health conditions. It can be used by health professionals, to help adolescents develop the necessary skills to take care of their health, in search of autonomy, in the transition to adult life. Authors, such as Lozano & Houtrow (2018), suggest that self-management tasks and behaviors can also be mapped onto the International Classification of Functioning, Disability and Health (ICF)

constructs 'activities and participation', making the ICF a useful framework to examine the factors that influence self-management of the disease in children and young people. By being mindful of the dynamic nature of child and youth development, health professionals and caregivers can tailor self-management support to the developmental trajectory.

6.3. Definition of the proposed concept

Self-management in children and adolescents with chronic illness, in school age, in a community context, consists of a process of acquiring knowledge and beliefs that promote the self-efficacy of this population in developing skills to face the physical, social and emotional needs inherent to the health condition. In this population, this process develops through co-creation between children/adolescents and formal and informal caregivers, with emphasis on parents, health professionals and teachers. The intensity of support from these links varies, according to the stage of cognitive, motor, language, social and emotional development, following the evolution of the health condition. Self-management is, in turn, influenced by these and other factors that may be modifiable or non-modifiable in the aforementioned individual, family, community and health systems domains.

6.4. Strengths and limitations of this concept analysis

This study presents a revealing conceptual robustness, which, in addition to analyzing and proposing the concept in the pediatric population (ages 5 to 19), provides an evolutionary perspective on it by following Beth Rodgers' method. Describing what self-management represents in this population could contribute to promoting the creation of community agencies with a network vision to support self-management for children and adolescents. Healthcare professionals, educators and policy makers could build support mechanisms, in a network, based on these results, from a perspective of teaching, monitoring, as well as psychological encouragement to foster confidence in change, regarding self-management of chronic disease.

Despite these possible contributions, Beth Rodgers' model does not fully demonstrate the challenges of transferring theoretical knowledge into practical healthcare interventions. To address this gap, it is useful to combine conceptual rigor with practical approaches, such as encouraging the use of clinical reasoning models. It may also involve evidence-based guidelines, together with training of healthcare professionals and interdisciplinary collaboration.

Although strengths arising are identified, it is essential to recognize some limitations when interpreting and applying the results of the concept analysis:

- Focus on the Adolescent Population: It is observed that most of the studies identified refer to the adolescent population, often directing the concept to this age group, possibly because it is the developmental phase in which the capacity for self-management becomes more active. These results may limit generalizability to other age groups, so extrapolating the results to other ages requires caution;

- Language and Source Restriction: Including only studies published in Portuguese, Spanish, French or English may restrict the overall interpretation of the concept. Relevant information in other languages or cultural contexts may have been excluded, affecting applicability in different regions;

- Publication Bias: The fact that the inclusion criteria considered only studies published in peer-reviewed journals may introduce publication bias. Unpublished studies or reports in other formats (such as theses) may offer additional insights;

- Cultural and Geographic Context: The geographic distribution of studies may influence the applicability of results in different cultural contexts and health systems. Considering regional variations is important to avoid inappropriate generalizations.

The practical application of concepts such as self-management faces specific challenges. The transition from theoretical knowledge to effective interventions requires contextual considerations, adaptation and concrete strategies. The development of studies that represent objective assessments and experiences of children and adolescents should be considered.Continued research in this regard will allow for greater accuracy in nursing diagnoses and interventions in the

context of clinical practice.

7. CONCLUSION

The chronic health condition represents a characteristic and transversal nature in children or adolescents: its long duration, the absence of curative therapy, and the changes in routines or limitations in participation in various daily activities, in addition to the health, social, and educational needs required to maintain its management.

It is extremely important to acquire awareness of the capabilities and importance of individual actions in the effectiveness of treating chronic conditions. The focus of much of the literature is on helping patients "self-manage" without being conceptually clear about what this means. The literature often refers to self-management of chronic disease, from the point of view of therapeutic management, monitoring, rather than broader issues such as the importance of self-efficacy in promoting adherence to treatment. Self-efficacy beliefs can go through several different stages, ranging from nonadherent behavior to long-term motivated adherence. The results identified in the literature showed that participants with greater beliefs in their abilities to control their behaviors are more likely to adopt self-management strategies with more successful results. In pediatric age, self-management can be compromised when self-management responsibilities exceed the young person's intellectual capacity or level of maturity, and these factors must be considered. The promotion of self-management must adapt to the child's level of development, their type of illness and their family and social context. Approaches that include activating resources that position the child as an agent of change are recommended.

Competent adherence to self-management during childhood will enable repercussions in adult life, through the acquisition of autonomy, empowerment, control of the condition, with consequent physical and emotional well-being, quality of life, family stability and social development. These results will strengthen the cost-benefit ratio of health services and overall social sustainability.

It has been identified that self-management is much more than educating to acquire skills, so self-management programs should be developed that incorporate a holistic approach that includes not only education on disease management, but also psychological stimulation to strengthen adolescents' confidence, self-efficacy and resilience for transformation, i.e. to actively take control of their health. Policies should prioritize interventions adapted to the developmental stage and socio-familial context of children and adolescents. Co-developing strategies with children, families and health professionals can ensure that interventions are practical and impactful.

Future research should focus on evaluating the effectiveness of integrated self-management models that combine the health, education and family sectors. Longitudinal studies are also essential to understand how early self-management practices impact long-term health outcomes and social participation.

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