EDUCATIONAL TECHNOLOGIES FOR FAMILY CAREGIVERS OF CHILDREN AND ADOLESCENTS WITH MOTOR DISABILITIES: AN INTEGRATIVE REVIEW

ABSTRACT

Objective: to identify and describe educational technologies aimed at family caregivers of children and adolescents with motor disabilities presented in the specialized literature. Method: an integrative literature review study was carried out in VHL, LILACS, MEDLINE, Pubmed, and SciELO databases, between 2011 and 2021, in Portuguese, English, and Spanish, using the descriptors caregivers, educational technology, disability, physical disability, handicap, and health education. The articles were analyzed through reflective and careful reading about the main information and elements that make up the study’s theme. Results: twenty-five studies were included, six of which were from 2020; 15 were produced in Brazil; and 13 were found in SciELO. Booklets were the most common educational technology, followed by groups of caregivers; nurses were the most frequent creators of technologies, and the construction/validation processes were described only by a few part of the studies. Conclusion: the identified educational technologies promoted the development of satisfactory knowledge, skills and attitudes of family caregivers of children and adolescents with motor disabilities.

Descriptors: Educational technology; Family caregivers; Motor disability; Children and adolescents; Health education.

RESUMO

Objetivo: identificar e descrever as tecnologias educacionais direcionadas a cuidadores familiares de crianças e adolescentes com deficiência motora apresentadas pela literatura especializada. Método: estudo bibliográfico, do tipo revisão integrativa da literatura, realizado nas bases de dados BVS, LILACS, MEDLINE, PubMed e SciELO, entre 2011 e 2021, em português, inglês e espanhol, utilizando-se os descritores caregivers, educational technology, disability, physical disability, handicap e health education. Os artigos foram analisados pela leitura reflexiva e criteriosa acerca das principais informações e elementos que compõem a temática nos estudos. Resultados: incluíram-se 25 estudos, sendo seis do ano de 2020; 15 produzidos no Brasil; 13 encontrados na SciELO. As cartilhas foram a tecnologia educacional mais encontrada, seguida da formação de grupos de cuidadores; sendo o enfermeiro...
The birth of a baby with a disability promotes unexpected changes in the family dynamics, which go through the impact of the news of the diagnosis and culminate in the process of adaptation to the daily implications associated with the limitations that the child presents, constituting steps that can be helped with the use of Educational Technologies (ET). It is estimated that, in Brazil, the number of persons over two years of age with some motor disability is around 7.8 million.
According to the United Nations (UN), persons with disabilities (PWD) are those who "have long-term impairments, which may be of a physical, mental, intellectual or sensory nature, which, in interaction with various barriers, may compromise the full and effective participation in society on an equal basis with others". The concept of PWD, therefore, encompasses the domains of the International Classification of Functioning, Disability, and Health (ICF), concerning body structure and function (disability), activity (activity limitation), and social participation (participation restriction).

Due to the compromise in these domains, the child/adolescent with motor disability will need assistance daily, which means that they will need a caregiver to help or perform the activities of daily living (ADL). According to the Brazilian Classification of Occupations (CBO), the caregiver's activities involve helping with locomotion, performing postural changes, stimulating leisure and occupational activities, and helping with hygiene and nutrition.

The role of the caregiver can be paid (formal caregiver) or unpaid (informal caregiver). The latter does not have an employment relationship, is usually a family member, does not have the technical training to perform the function, and, in most cases, lives in the same place as the person who is cared for. To exemplify the majority presence of family caregivers of children/adolescents with motor disabilities, a study conducted in the city of João Pessoa (PB), Brazil, found that 68.3% of caregivers of people with disabilities were mothers, and only 9.9% were not part of the family.

Authors of studies on family caregivers of people with disabilities are often concerned with the burden, quality of life, and mental health, as this is a practically uninterrupted occupation with a high emotional burden since some children and adolescents have chronic health impairments. When comparing the average level of anxiety and depression among parents of children with motor disabilities and parents of children without disabilities, it was observed that parents of children with disabilities presented higher anxiety scores associated with lack of social support, parental dissatisfaction, unfavorable family economic situation, and difficult living conditions.

In general terms, research agrees that it is necessary to think about public policies and develop tools that enable caregivers to face the adversities that are part of their daily lives. In this sense, ETs can facilitate access to information, which will contribute to better coping with adversities by caregivers, whether related to the caregiver himself or referring to the people under his care.

Educational technology (ET) in health can be understood as an instrument that facilitates learning, involving the stages of planning, execution, control, and follow-up for formal and informal educational processes. The health professional interacts in this teaching-learning process with the student (client), so the two build means to develop creative awareness, sensitivity, and creativity in pursuing personal and professional development.

In this regard, health interventions based on the use of ET are promising alternatives to improve the quality of life of family caregivers and, consequently, improve the act of caring. They can also improve the interaction/communication between the team of health professionals and family caregivers, favoring the execution of activities at home.

Therefore, this study is justified by the need to know, from the scientific production, the main ET used with family caregivers of children/adolescents with motor disabilities so that they become more visible and used by professionals (nurses, physiotherapists, etc.) in health education activities, seeking to improve the act of caring and the quality of life of caregivers.

**OBJECTIVES**

To identify and describe educational technologies aimed at family caregivers of children and adolescents with motor disabilities presented in the specialized literature.
METHOD

This is an integrative literature review. This method allowed us to identify and describe studies about ET created for family caregivers of children and adolescents with motor disabilities. The integrative literature review is one of the most comprehensive review approaches, as it allows the inclusion of different study designs, combining data from the theoretical and empirical literature. The integrative literature review admits to incorporating a review of theories and evidence in addition to an analysis of methodological problems of a particular topic.  

The following steps were followed during the development of this review: (a) formulation of the question/problem; (b) study selection; (c) critical evaluation of the studies; (d) data collection; (e) data analysis and presentation; (f) data interpretation; and (g) review improvement and update.  

In the first stage, the central question was formulated using the PVO framework, in which P refers to the problem situation, participants or context; V refers to the variables; and O to the outcome. This framework allows organizing the study elements to better structure research questions. The following question was constructed from the PVO framework: What educational technologies aimed at family caregivers of children and adolescents with motor disabilities exist? The following structure was considered: P (problem situation, participants or context) – family caregivers; V (variable) – educational technologies (ET); and O (outcome) – identification of educational technologies (ET) aimed at family caregivers of children and adolescents with motor disabilities.

Step 2 (study selection) involved defining some descriptors related to the topic. In this step, the authors based themselves on the components of the PVO framework and, subsequently, consulted the Health Sciences Descriptors (DECS). Thus, the following terms were used: Caregivers, Educational Technology, Disability, Physical Disability, Handicap, and Health Education.

With the choice of descriptors, search strategies were constructed to be used in the databases, applying the Boolean operator AND to cross the PVO components and search for terms in titles and abstracts.

The searches were conducted in the Virtual Health Library (VHL): Medical Literature Analysis and Retrieval System Online (MEDLINE), Latin American and Caribbean Health Sciences Literature (LILACS), PubMed, and SciELO, between October and December 2021, through remote access provided by the Federal University of Pará (UFPA). The choice of these databases is justified by their scope of coverage and impact on scientific production in health.

The evaluation of the articles (third stage) was conducted based on the following inclusion criteria: having one of the following terms in the title or abstract: caregivers, educational technology, disability, physical disability, health education, or handicap; complete and available articles; having been published in the last 10 years (2011 to 2021); articles written in English, Portuguese or Spanish; peer-reviewed articles; articles freely accessible; and articles focused on family caregivers of children and adolescents with motor disabilities. Records that did not meet the inclusion criteria mentioned above were excluded. The searches resulted in 25 articles that met the predetermined inclusion criteria.

Data were collected from the articles based on the main characteristics (fourth stage): year; title; authors; journal; study design; objective; methodology; main results; and conclusions. Data were extracted using a script containing detailed information on each study. Thus, for data collection and analysis (fifth stage), the software Excel 2010 was used.

After organizing and analyzing the data, the process of interpreting the information was carried out, and subsequently, the construction and improvement of the integrative review (sixth and seventh stages) proceeded.
The analyzed information was categorized to respond to the purpose of the study and the guiding question. Two categories were created: 1) general characteristics of the reviewed studies (year, country of publication, authors’ names, title, and database), and 2) characteristics of the ETs (types of ET, characteristics of the ET applicator and those who were benefited by the ET, and structuring of the ET: control group, stages of construction and validation).

RESULTS

Initial searches in selected databases allowed locating of 2,073 publications. After applying the selection and eligibility criteria, the database comprised 25 articles for analysis (Figure 1).

The results were organized into two broad categories: general characteristics of the analyzed studies and ET characteristics.

1. General characteristics of the analyzed studies

In Figure 2, the general characteristics are observed: year, country of publication, authors’ names, title, and database.

Twenty-five articles published between 2011 and 2021 were analyzed, distributed by year as follows: 2011 - one study (4%); 2012 - two studies (8%); 2013 - two studies (8%); 2014 - one study (4%); 2016 - one study (4%); 2017 - two studies (8%); 2018 - three studies (12%); 2019 - four studies (16%); 2020 - six studies (24%); and 2021 - three studies (12%).

Concerning the countries of origin of the selected studies, 15 publications (60%) came from Brazil; three publications (12%) from the United States of America; two (8%) from the UK; and one of each (4%) from Portugal, Spain, South Africa, Chile, and Sweden, demonstrating the attention to this theme in the Brazilian research scenario.

Concerning the database variable, 13 articles (52%) were found in SciELO; eight (32%) in PubMed;

Figure 1. Study selection flowchart. Belém (PA), Brazil, 2021.
three (12%) in the Virtual Health Library (VHL), and one (4%) in LILACS.
Table 1: Distribution of scientific publications included in the integrative review, according to year and country of publication, authors’ names, title, and database.

<table>
<thead>
<tr>
<th>Items</th>
<th>Years and countries</th>
<th>Authors</th>
<th>Titles</th>
<th>Databases</th>
</tr>
</thead>
<tbody>
<tr>
<td>9.</td>
<td>2016-Spains</td>
<td>Brücher, Martin, Randles, et al.</td>
<td>Influido de um programa de orientação fisioterapêutica no saber de cuidadores de crianças com paralisia cerebral.</td>
<td>VHL</td>
</tr>
<tr>
<td>18.</td>
<td>2019-Brasil</td>
<td>Oliveira, Barbosa, et al.</td>
<td>Educational technology for caregivers of children and teenagers dependent on special care in the home.</td>
<td>VHL</td>
</tr>
<tr>
<td>23.</td>
<td>2019-Chile</td>
<td>Bení, Santos, et al.</td>
<td>Effectiveness of the motivational interviewing with caregivers for the oral health of special patients.</td>
<td>Pubmed</td>
</tr>
</tbody>
</table>

Figure 2. Distribution of scientific publications included in the integrative review, according to year and country of publication, authors’ names, title, and database. Belém (PA), Brazil, 2021.
2. ET characteristics

The analysis of the ETs made it possible to categorize the data found into types of ET, profession of the ET applicator/creator, characteristics of the caregivers benefited by the ET, and composition of the ET (control group, stages of construction, and validation).

<table>
<thead>
<tr>
<th>ET types</th>
<th>Frequency</th>
<th>Percentage</th>
<th>Applicator/creator</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Booklet/manual/</td>
<td>8</td>
<td>32</td>
<td>Nurse</td>
<td>8</td>
<td>32</td>
</tr>
<tr>
<td>Illustrated guide</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver group</td>
<td>7</td>
<td>28</td>
<td>Physiotherapist</td>
<td>7</td>
<td>28</td>
</tr>
<tr>
<td>Lecture</td>
<td>5</td>
<td>20</td>
<td>Dentist</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>Practical training</td>
<td>4</td>
<td>16</td>
<td>Speech therapist</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Digital tool</td>
<td>1</td>
<td>4</td>
<td>No registry</td>
<td>7</td>
<td>28</td>
</tr>
</tbody>
</table>

Figure 3. Distribution of ET type and profession of the applicator/creator. Belém (PA), Brazil, 2022.

Five different types of ET were identified: 1) booklet/manual/illustrated guide, found in eight studies (32%); 2) groups of caregivers, present in seven studies (28%); 3) lecture, identified in five studies (20%); 4) practical training, approached by four studies (16%); and 5) digital tool, found in one study (4%), as shown in Figure 3.

Concerning the applicator/creator of the ET, the presence of nurses was found in eight studies (32%); the physiotherapist in seven studies (28%); the dentist in two studies (8%); the speech therapist in one study (4%); and no information on the professional who created the technology was found in seven studies (28%), as shown in Figure 3.

The target audience of the analyzed studies were family caregivers of children/adolescents with motor disabilities. It is noted that the gender of these caregivers was identified in sixteen studies (64%), and in seven (43.7%), the sample was composed only of female caregivers. No reference to the gender of caregivers was found in nine studies (36%), as shown in Figure 4.

The number of caregivers participating in the selected studies was categorized into four numerical intervals: one to ten caregivers - eight studies (32%); eleven to fifty caregivers - thirteen studies (52%); over fifty-one - three studies; and no registration of the number of participants in one study, as shown in Figure 4.

<table>
<thead>
<tr>
<th>Gender of the caregiver</th>
<th>Frequency</th>
<th>Percentage</th>
<th>Number of caregivers</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>16</td>
<td>64</td>
<td>1-10</td>
<td>8</td>
<td>32</td>
</tr>
<tr>
<td>No</td>
<td>9</td>
<td>36</td>
<td>11-50</td>
<td>13</td>
<td>52</td>
</tr>
<tr>
<td></td>
<td>Over 51</td>
<td>3</td>
<td>12</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>No registry</td>
<td>1</td>
<td>4</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Gender of the caregiver</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female only</td>
<td>7</td>
<td>43.8</td>
</tr>
<tr>
<td>Female and male</td>
<td>9</td>
<td>56.2</td>
</tr>
</tbody>
</table>

Figure 4. Distribution of caregiver gender identification and number of caregivers in the studies. Belém (PA), Brazil, 2022.

By analyzing the articles, it was inferred that the structuring processes of the ET, such as the use of a control group, construction, or validation of the ET, were present as follows: a control group was evidenced in six studies (24%); in nine studies (36%), an ET was built, and of these, seven (28%)
described the process used in the construction; and the validation process was presented by four articles (16%), as shown in Figure 5.

<table>
<thead>
<tr>
<th>Control group</th>
<th>Frequency</th>
<th>Percentage</th>
<th>ET Construction</th>
<th>Frequency</th>
<th>Percentage</th>
<th>Validation</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>6</td>
<td>24</td>
<td>Yes</td>
<td>9</td>
<td>36</td>
<td>Yes</td>
<td>4</td>
<td>16</td>
</tr>
<tr>
<td>No</td>
<td>19</td>
<td>76</td>
<td>No</td>
<td>16</td>
<td>64</td>
<td>No</td>
<td>21</td>
<td>84</td>
</tr>
</tbody>
</table>

**Construction stages**

<table>
<thead>
<tr>
<th>Yes</th>
<th>7</th>
<th>77.8</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>2</td>
<td>22.2</td>
</tr>
</tbody>
</table>

Figure 5. ET structure: control group, construction, and validation of the ET. Belém (PA), Brazil, 2022.

**DISCUSSION**

This review aimed to identify and analyze educational technologies aimed at family caregivers of children and adolescents with motor disabilities. The searches allowed the construction of a database with 25 articles published in the last 10 years.

The ET consists of tools capable of promoting greater engagement in care, a better understanding of the pathology of the child/adolescent, and support for the self-care of informal caregivers, which can lead to changes in behavior and new outcomes. The impact of ET is associated with the principles and practices of communication involved in the processes of elaboration and application.

Booklets are educational materials created to facilitate access to information for people from different socio-cultural contexts and levels of education. In general terms, different theoretical models mark the creation of booklets. Some of these materials can be organized based on traditional biomedical practice, while others can be based on a constructivist model of knowledge, which encourages the user's active participation, so that knowledge is shared horizontally, dialogically, and in a participative manner. In this perspective, the elaboration of booklets needs to be based on the adaptation of scientific knowledge on messages that are easy to understand so that the target audience can widely use them.

The construction and validation of a booklet for family caregivers of children with cerebral palsy in Rio Grande do Sul comprised a step in which the target public was consulted, so that the content addressed was related to the identified health education needs. The booklet included psychological aspects of mothers and family members who experience the process of caring for children with cerebral palsy through information about the pathology, support network, mental health of caregivers, and specialized services in the city.

The nurse's presence in the use of ET is understood because, as established by art. 11, item II, of the Law nº 7498/86, which regulates the exercise of this profession, health education is defined as a nursing activity carried out by the nurse as a health team member, aiming at improving the population's health. The prevalence of this professional in the studies analyzed in this review occurred partly due to the presence of patients and caregivers in the various areas of health services, including guidance and planning of actions that promote health education.

Over the years, there has been an increase in the production of ET by these professionals, whether light, light-heavy and heavy, covering care and management ET, leading the nurse to the role of educator. As perceived, a study developed in Portugal, which aimed to identify interventions by nurses in the home context as a way to train the person and informal caregivers in the disease management process, found that this professional acts in the training of the person and the caregiver to carry out daily living activities, identifying architectural barriers and proposing their elimination, maintaining a safe environment and monitoring the condition of disabled people.
The interval with an n between 11 and 50 caregivers is acceptable since for clinical-epidemiological or experimental investigative studies, which aim to describe phenomena or compare the behavior of variables in subgroups of a population, it is not necessary to study the population universe, as this is not accessible or feasible, but mainly because this is not necessary when a representative sample is available to make inferences to the target population. Additionally, given the data saturation, it is considered unnecessary to collect new interviews/information.

Studies with more than 50 participants indicate that the articles have arguments in favor of generalization but are careful with constructing future propositions. Corroborating this assumption, a study conducted in the state of Pernambuco with 94 mothers/caregivers evaluated the oral health care of children/adolescents with cerebral palsy and found that there are problems related to daily oral health care that can be faced with comprehensive, inclusive and equitable socioeconomic and public health policies.

An eminently female sample corroborates that caring is seen socially as natural for women, who often experience work abandonment and overload regarding caring for people with disabilities and household activities. Given the above, one study that aimed to understand how the woman-mother of a child/adolescent with cerebral palsy takes care of herself, concluded that caregivers need strategies capable of facilitating these women to take care of themselves, helping them in the process of adapting to the new situation and taking care of their children/adolescents.

The absence of a control group in the analyzed studies reveals that the studies are not randomized, that is, in which each individual has an equal or known probability of belonging to any of the groups, eliminating trends related to attributes that may affect the outcome variable. This was done in one study that proposed an intervention to reduce the emotional problems of 25 mothers of children with cerebral palsy. The intervention enabled the mothers to deal with their children’s behavioral problems, as there was a significant decrease in mothers’ emotional problems and the intervention was proven clinically effective.

The process of creating an ET with the involvement of the target audience provokes ever greater adherence and confidence in the multiplication of content. When these products are creative, they generate appreciation for developing innovative methodologies, which help improve communication, health, and community outcomes. This step was well defined in a study that described the construction of an educational product in video format with stimulation activities for caregivers of children with disabilities, whose result was a video with 1 minute and 53 seconds, emphasizing interaction actions between children and caregivers.

Additionally, the validation stage consists of the analysis and judgment of specialists, also called "analysis by judges and target audience", which is considered one of the most used methods for validating the pertinence, reliability, and consistency of a material. This method was used in a study that aimed to validate the content of a booklet called "Guidelines for maintaining the quality of life-spina bifida", whose authors analyzed the adherence to the proposed activities. The booklet proved to be a great resource to increase adherence to physiotherapeutic treatment of children and adolescents with spina bifida. However, the authors found a moderate/low adherence by participants.

The use of ET by caregivers of children/adolescents with motor disabilities proves to be very important in the development of health education, as it aims to go beyond the traditional methods towards the axis of the production of autonomy and knowledge, in which they become protagonists in educational practices. One of the limitations of this study is the short description of the construction processes of the analyzed technologies, making it impossible to understand their suitability for promoting the health of adolescents, as well as the lack of quasi-experimental studies that use these technologies, demonstrating their effectiveness.
Despite the contributions, this study has limitations, such as the small search interval. Possibly, by extending the search period, other ETs could be identified, covering a larger scope of forms and types of technology. Another limiting factor was the scarcity of studies describing the construction and validation processes of the analyzed technologies, making it impossible to understand their suitability for health promotion and prevention of harm to caregivers.

**CONCLUSION**

ETs for health promotion present a wide spectrum of possibilities, with printed materials and groups of caregivers being the main types, permeating health services and daily use. The recommendations and use of these technologies effectively ensure the development of adequate knowledge, skills, and attitudes.

The study contributes to synthesizing technologies constructed and adopted by family caregivers of children/adolescents with motor disabilities, enabling health professionals to learn about the most adopted technologies and the themes they address. Thus, the adoption of technologies for health promotion is enhanced, listing the possibilities, and pointing out gaps in the production of these tools.

**AUTHORS’ CONTRIBUTIONS**

Conception, study planning, data analysis and interpretation, writing and critical review: Tatiane Oliveira Nascimento, Yuri Leandro do Carmo de Souza, and Simone Souza da Costa Silva.

Study planning and critical review: Rodolfo Gomes do Nascimento and Katiane da Costa Cunha.

**CONFLICTS OF INTEREST**

The authors declare that there is no conflict of interest.

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