



ISSN: 2230-9926

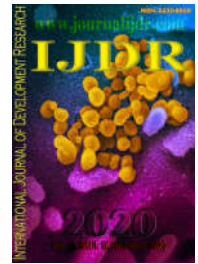
Available online at <http://www.journalijdr.com>

IJDR

International Journal of Development Research

Vol. 10, Issue, 11, pp. 41990-41995, November, 2020

<https://doi.org/10.37118/ijdr.20387.11.2020>



RESEARCH ARTICLE

OPEN ACCESS

BIBLIOMETRIC STUDY ABOUT THE EXPERIENCE OF FAMILY MEMBERS OF CHILDREN/ADOLESCENTS WITH CHRONIC DISEASES UNDER PALLIATIVE CARE

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ARTICLE INFO

Article History:

Received 11th August, 2020

Received in revised form

17th September, 2020

Accepted 06th October, 2020

Published online 24th November, 2020

Key Words:

Bibliometry,
Palliative care,
Family.

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ABSTRACT

The objective of this work was to analyze the scientific production published in online journals about the experience of family members of children/adolescents in palliative care. This is a bibliometric study conducted with 42 articles published between 2007 and 2017, selected from LILACS, MEDLINE, BDNF and SciELO. The years 2014, 2016 and 2017 presented a higher number of publications. Twenty-two dissemination vehicles were identified, of which the Gaucho Nursing Magazine presented the greatest impact factor. Languages in Portuguese and English prevailed and most publications were produced by nursing researchers, predominantly authors with a PhD and collective authorship. It was observed that the publications on the investigated theme present a little expressive quantitative, considering the period researched. Therefore, it aims to expand further studies in view of the importance of the presence of family members in the process of caring for children/adolescents under palliative care.

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Citation: Mayara Cândida Pereira, Maria Liz Cunha de Oliveira, Amanda Martins Dos Santos, Fabiana Claudio Da Silva Costa et al. 2020. "Bibliometric study about the experience of family members of children/adolescents with chronic diseases under palliative care", *International Journal of Development Research*, 10, (11), 41990-41995.

INTRODUCTION

The family of children/adolescents who experience a state of disease in chronic condition plays a fundamental role with regard to their well-being and health, since, preparing their children for the future, teaches to face the limitations established by the disease, besides encouraging the performance of activities that improve their independence throughout adulthood (Ramos, 2017).

Thus, chronicity in childhood compromises both the children's universe and their families, causing suffering and changes in the family context, especially the primary caregiver, who is close to the child's suffering, causing changes in routine and special care (Lyra, 2016). In this context, chronic disease is part of a set of chronic conditions, with long or undefined duration, generally uncertain prognosis and exhibiting periods of remission and symptomatology exacerbation over time, promoting a continuous care process without necessarily resulting in cure (Brasil, 2013).

Worldwide, chronic health problems affect all age and social groups, including the child population. However, despite the difficulty of national indicators on the prevalence of chronic disease in childhood, among those with the highest occurrence in this period of life, cystic fibrosis, liver diseases, congenital heart diseases, cerebral palsy and cancer stand out (Lyra, 2016). The chronicity of the disease in the child makes the family responsible for reducing the effects triggered during this process, as they seek to promote their development and growth in the most satisfactory way possible, sharing losses, limitations and care (Pinto, 2016). Therefore, it is essential that families understand that chronic disease, for the most part, has time-consuming, complex treatment and requires continuous care, thus being important the inclusion of family members in this process. Therefore, it is necessary to know about the pathology, its manifestations and implications. In addition, they need stimulation to develop the ability to care for (Lyra, 2016). From this perspective, it is opportune to implement palliative care in pediatrics.

Over time, the concept of palliative care has changed. The World Health Organization (WHO) defines as "the approach that promotes quality of life of patients and their families in the face of diseases that threaten the continuity of life, by the prevention and relief of suffering. It requires early identification, assessment and impeccable treatment of pain and other problems of a physical, psychosocial and spiritual nature." The early detection of the diagnosis of a chronic-evolutionary disease is already the time to install this follow-up, both of the patient, as well as of the family member and/or caregiver (Sociedade Brasileira de Pediatria, 2018). Unlike the adult population, where the vast majority of patients under palliative care have oncological diagnosis and that its follow-up is usually performed in *Hospices* or at home, in pediatrics, congenital and genetic diseases are the major responsible for the indication of this type of care, followed by chronic and onco-hematological neurological conditions (Sociedade Brasileira de Pediatria, 2018). In this perspective, this care in pediatrics is practiced progressively and adjusted to the needs attributed by the disease and its treatment (evolution, complications, limitations), and should be distinct to that child/adolescent (adjusted for the values and anides of that family/child binomial). Allow *offering better care and increase the perspective of quality of life of children/adolescents with chronic diseases or ongoing diseases that lead to death is an opportunity to exceed the limits of a technical assistance and attached to a medicine attentive only with healing* (Sociedade Brasileira de Pediatria). *Considering that it is essential to understand the experience of family members in this new context in which children/adolescents experience, it is undeniable the need to explore the dissemination of studies on the subject, making it appropriate to conduct a bibliometric study.*

In view of the above, considering the relevance of palliative care implemented to children/adolescents who experience a chronic disease, as well as the follow-up of these patients and their families in this process, the question is: "What are the bibliometric indicators about the scientific production on the subject, available in online journals?". To this end, this investigation aims to analyze bibliometric indicators of publications about the experience of family members of children/adolescents under palliative care, published in online journals.

METHODS

This is a bibliometric study that consists of a method of quantitative approach through mathematical and statistical patterns and methods, with the purpose of examining the production of articles in a given field of knowledge, grouping and synthesizing research results on a delimited theme or a leading question and identifying the networks of researchers and their motivations, in a systematic way that collaborates for the construction and improvement of knowledge of the investigated theme (Chueke, 2015). Thus, it can be verified and understood that bibliometry is welcome in the context of investigations, mappings, explorations and analyses of various academic themes (Ribeiro, 2019). To carry out this study, three operational steps described in (Vanz, 2010). 1st Stage - Bibliographic survey of scientific productions: At this stage, the scientific productions were surveyed on the proposed theme. This occurred from August to October 2018, followed by the screening of publications for sample selection. Thus, a search was carried out in the Virtual Health Library (VHL), and in the following databases such as Latin American and Caribbean Literature (LILACS), Nursing Database (BDENF), Scientific Electronic Library Online (SciELO), National Library of Medicine (MEDLINE).

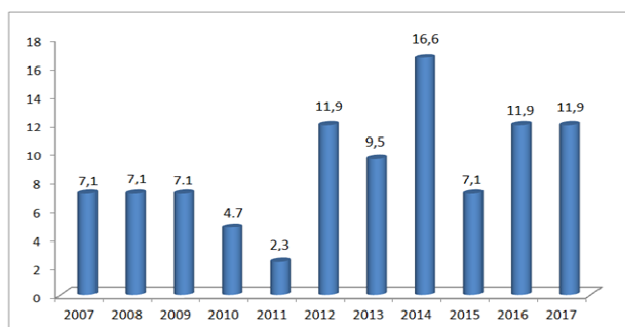
It should be emphasized that, in the search for articles in the mentioned data sources, health terminology was used from the Descriptors in Health Sciences (DeCS), such as "*cuidados paliativos*", "*criança*", "*família*", "*doença crônica*", "chronic disease", "child", "family", "palliative care", were identified and combined with the Boolean operator AND, as well as representing keywords related to the theme addressed. Thus, to select the sample, the following inclusion criteria were adopted: publication in the scientific article modality; full-text available free of charge in *acquis online*; written in the Portuguese, English and/or Spanish; to address children, families, chronic disease and/or palliative care as the central focus of the study; with mothers or family members and had been published from 2007 to 2017. However, as exclusion criteria, duplicate articles and publications were eliminated in the modalities of experience report, review study, as well as monographs, dissertations and theses.

Step 2 - Data collection and organization: To enable the analysis of the articles, a script elaborated by the authors was used, composed of the following items: data related to publication (name and qualis journal, country, year of publication, language in which it was published, number of keywords); to authors (number of authors per article, vocational training and titration) and the methodology (geographic location, type of research, methodological approach, participants, data collection technique used). In relation to the authors, it is important to highlight that there was no distinction between author and co-author, since all researchers who collaborated with the publications were considered. Moreover, it was considered the highest titration they had in the course of the publication of the articles. Step 3 - Treatment and presentation of the results: Considering this last stage, the program was used Microsoft Excel Office 2010 organization of the material obtained. Thus, it was possible to perform the analysis by calculating the frequencies and percentages of the data. Finally, they were presented through graphic representations and analyzed in the light of the pertinent literature.

RESULTS

This section presents the results found, meeting the indicators chosen for the research from the selected scientific publications. The sample section of this study covered publications between 2007 and 2017, and consisted of 72 scientific articles related to the theme investigated. Of these, 42 articles met the inclusion criteria established in the methodology.

Data on journals: The universe of this research consisted of 42 scientific articles published between 2007 and 2017. However, 2014 was the period of greatest production on the theme, totaling seven (16.6%) followed by 2012, 2016 and 2017, with five (11.9%) articles, respectively. A decrease was observed in the following years, as shown in graph 1.



Source: Survey data, 2018.

Graph 1. Distribution of studies in relation to the year of publication between 2007 and 2017. João Pessoa, PB, Brazil

Regarding the journals, 22 journals were identified who disclosed studies related to the child/adolescent, among which the majority is national and two international, according to the distribution in Table 1.

Table 1. Distribution of scientific productions for the journal, in the period from 2007 to 2017 (n= 42).

Journals	N	%	Country of publication
Gaúcho Nursing Magazine	5	22.7	Brazil
Anna Nery School Nursing Magazine	4	18.1	Brazil
Science, Care and Health	4	18.1	Brazil
Brazilian Journal of Nursing	4	18.1	Brazil
Text & Nursing Context	3	13.6	Brazil
Journal of Nursing UFPE Online	3	13.6	Brazil
São Paulo Nursing Act	2	9.0	Brazil
UERJ Nursing Journal	2	9.0	Brazil
Electronic Journal of Nursing	1	4.5	Brazil
Interface	1	4.5	Brazil
Psychology of USP	1	4.5	Brazil
Acta Scientiarum Health Sciences	1	4.5	Brazil
Journal of Pediatrics	1	4.5	Brazil
Cuidarte Magazine	1	4.5	Brazil
Central West Minas Gerais Nursing Journal	1	4.5	Brazil
Cogitare	1	4.5	Brazil
Santa Maria Nursing Journal	1	4.5	Brazil
Online Brazilian Journal of Nursing	1	4.5	Brazil
Latin American Journal of Nursing	1	4.5	Brazil
Bionorte Magazine	1	4.5	Brazil
Uruguay Journal of Nursing	1	4.5	Uruguay
Journal of Pediatrics and Child Health	1	4.5	Australia

Source: Survey data, 2018.

Considering the journals in which the dissemination of studies was prevalent, the Gaúcho Nursing Journal of the Federal University of Rio Grande do Sul, which led with five 22.7%,

followed by the journals, Anna Nery School Journal of Nursing, Science, Care and Health and The Brazilian Journal of Nursing, with four (18.1%) Each. The journals Text & Context Nursing and Journal of Nursing UFPE Online presented three (13.6%), respectively, followed by Acta Paulista of Nursing and UERJ Nursing Journal, with two (9.0%). The other journals represent one (4.5%) publication in each. With respect to Qualis/CAPES - Coordination of Improvement of Higher Education Personnel, of the journals, the distribution of the strata occurred as follows: A1 - 4.5%; A2 - 18.1%; B1 - 22.7%; B2 - 22.7%; B3 - 4.5% and B5 - 4.5%. It is noteworthy that 22.7% of the journals are not classified in the Qualis of CAPES. About the languages in which the studies were published, it was found that 45.2% were edited only in Portuguese, 42.8% were published in Portuguese and English, 7.1% in Spanish, while 2.3% were published in the three languages Portuguese, English and Spanish.

Data on authors: Investigating the authorship of the selected articles, a total of 167 authors were verified. Due to the repetition of the same author in more than one article, duplicates were excluded resulting in a total of 144 authors; of which 134 (93%) present undergraduate professional training in nursing. The other authors are from other areas of knowledge, such as: Medicine (4.1%), Psychology (1.3%) followed by Pedagogy and Occupational Therapy, with 0.69% each. Regarding titration, it was observed that 38 (26.3%) were doctors; 37 (25.6%) masters; 46 (31.9%) have no titration; 16 (11.1%) experts; and only three (2.08%) were post-doctors. Regarding the number of authors in each article, the predominance of studies with four authors was found, i.e., 28.5%, followed by articles with six authors 21.4%. The articles with five authors represent about 16.6%, and articles with two and three authors total 14.2% each.

Data related to methodology: Regarding the keywords, it was possible to identify about 166 terms. We highlight a child with 24 terms (14.4%), a family with 22 (13.2%) and chronic disease with 16 (9.6%). The other terms that were mentioned in more than one article were Pediatric Nursing with 9 terms (5.4%), neoplasms with 7 (4.2%), nursing with 6 (3.6%), cancer with five (3.0%), oncology and palliative care totaling four terms (2.4%), respectively. When analyzing the bibliometric indicators related to the methodology of the articles, it was possible to verify that the 42 publications were original articles (100%), which adopted the following approaches: qualitative 38 (90.4%), quantitative were three (7.1%) and mixed approach, one (2.3%), i.e., quantitative-qualitative. Regarding the place where the studies took place, it is observed that the prevalence occurred at the hospital level, 11 studies occurred in the pediatric clinic of public hospitals (26.1%), followed by pediatric oncology units with 5 studies (11.9%), pediatric outpatient clinic and home with four (9.5%) respectively. The other places where the data were collected stand out: support home and palliative care unit with three studies (7.1%); support groups, pediatric chemotherapy center and Family Health Strategy with two (4.7%), respectively, and reference center for treatment of children's cancer, associations, Pediatric Intensive Care Unit, cancer hospital and Pediatric Oncology Institute, total 2.3% each. Regarding the origin of the original articles, it was observed that 95.2% were of national origin, while 2.3% presented international origin developed in Australia. Of the national productions, it was found that the Northeast region, with 16 (45.2%), was the one

that most developed studies on the theme, while the Southeast region presented 13 (30.9%) studies, south region with seven (16.6%) and the Midwest region contributed one (2.3%) Study. The study participants were around the family context, in which most publications were conducted with 20 mothers (47.6%), followed by family members such as fathers, grandparents, siblings of children with chronic disease with 16 (38%), as well as other companions and caregivers, five (11.9%). Regarding the techniques and instruments for data collection, the interview technique was prevalent in all productions, using forms, observation, field diary, questionnaire and digital media, such as the use of a recorder.

DISCUSSION

Analyzing the incidence of publications in the 2007-2017 section, there is a predominance of scientific studies on the experience of family members of children/adolescents in chronic condition, in 2014, and in 2016 and 2017. This ancestry in recent years is due to the need to expand the knowledge about the experience of family members of children and adolescents with chronic disease by researchers, especially in the nursing area in order to understand the family support of these patients in the face of the situation experienced. In this perspective, it is necessary to carry out further investigations and maintain a regularity in the dissemination of this information, through printed journals and/or Online that ensure an uninterrupted flow of information. In this context, considering the journal that published the most on the subject, the *Gaúcho Nursing Journal* stands out, with five (22.7%) Publications. It is a journal founded in 1976 by the School of Nursing of the Federal University of Rio Grande do Sul, with the objective of providing nurses in the south of the country with a vehicle for dissemination of their work, being the fourth oldest publication in the country (*Revista Gaúcha de Enfermagem*, 2018). As for the Qualis of CAPES, it was noticed that about 4.5% of the articles were published in journals with Qualis A.

Qualis/CAPES is a national indicator of journal quality from the analysis of the condition of the dissemination vehicles, that is, scientific journals and events. The journals, once recorded are classified in strata of highest quality, called A1, passing through A2, B1, B2, B3, B4, B5 to the lower called C (Gomes, 2018). In this sense, only 25% of journals are eligible to be included in a higher level of classification, which are A1 and A2 (Fundação Capes, 2018). Therefore, it is observed that most of the productions analyzed in this study are relevant both for scientific society and for the quality of publications on chronic conditions in childhood and palliative care. About the authors' titration, the data show that most publications have the collaboration of masters and doctors in the development of studies, as well as graduate students of master's and doctorate levels.

This data evidences the dissemination of graduate programs in Brazil. According to the Brazilian Society for the Progress of Science (SBPC), at its annual meeting in 2018, it showed that the National Graduate System (SNPG) is constantly evolving¹². In the years 1998 to 2017, the number of graduates increased by about 307%, demonstrating that education is the sector that most employs master and doctors (Mestres e doutores, 2016). When analyzing the distribution of authors per article, it was found that collective authorship is based.

This scientific collaboration shows how the interaction that occurs in a social context between two or more researchers facilitates the sharing of new scientific knowledge, as well as the performance of tasks in search of the dissemination of information (Sampaio, 2015). Regarding the modalities of study, the original works were predominant, since they present new ideas and opinions about current issues, in order to obtain a new and expansive knowledge, expanding the view on the same theme (Marconi, 2010). Regarding the scenario of the studies of the publications, the data show that the prevalence occurred in the hospital environment, with mothers and relatives of children/adolescents in their hospitalization periods. Thus, because it is a place where the length of stay is longer, contact with participants allows facilitating data collection. In addition, other scenarios were observed, such as support home, households, Pediatric Intensive Care Unit and palliative care units, contributing to the dissemination of the theme in various scenarios, involving children/adolescents with chronic diseases and palliative care.

It is worth noting that palliative care can be performed in different contexts, such as in general health institutions in which the patient is undergoing treatment, whether it is a characteristic unit within the health institution, intended exclusively for this purpose or in social institutions of reception as support homes or even at home (Andrade, 2017). Regarding the approach, the number of qualitative articles was significant. The use of this approach provides the deepening of the investigation of issues related to the phenomenon under study and its relationships. It is an investigative activity that positions world observation, that is, it consists of a set of interpretive and material practices that make the world visible. It encompasses an interpretive and naturalistic approach to the world in which researchers study things in their natural contexts, providing direct and prolonged contact of the researcher with the environment and the situation being investigated (Silva, 2019). In qualitative approach, data collection can happen in several ways. In the studies surveyed, the interview was more prominent, since it is one of the main techniques of data collection, being quite adequate to obtain information about what people, since they enable a variety of impressions and perceptions that the various groups have in relation to the study variables, allowing answers as greater scope and favoring efficiency in obtaining the data, classification and quantification (Silva, 2015).

The questionnaire was also used in the analyzed studies. This technique follows a pattern of obtaining answers by a formula in which the interviewee himself fills out. Because it is an economic technique, it allows to reach a larger number of people and standardizes the questions allowing a more uniform interpretation of the answers, but presents disadvantages, since it does not ensure sincerity in the answers obtained, because the questions can interpret the questions in their own way, leading to low return in the analysis of the data (Oliveira, 2011). In terms of keywords, the most used as descriptors were child, family and chronic disease reinforcing the search for the study. These terms are indexed in the Health Science Descriptors of the Virtual Health Library (DeCS/VHL), as well as in the Medical Subject Headings Pub Med. In this context, Descriptors in Health Sciences (DeCS), it is a structured and trilingual vocabulary (Portuguese, Spanish and English), created to serve as a unique language in the indexation of articles from scientific journals, books, congress annals, technical reports, and other types of materials, as well

as to be used in the research and recovery of subjects of scientific literature. Structured vocabularies serve as maps that lead users to information of interest. Its use becomes increasingly relevant as the volume of information available increases (Cavalcante, 2017). In addition, other terms such as oncology, oncology nursing and palliative care were observed in a smaller amount. They are descriptors that are included in chronic conditions in children/adolescents, which should have more emphasis on publications. In this perspective, the changes that occur in the family context and in the life of the child/adolescent when faced with chronic disease, encompass factors beyond the organic or physical alterations of the sick child/adolescent, permeate this angle and promote emotional and social changes throughout the family, requiring constant care and adaptations.

Thus, the ruptures of the structures of everyday life lead to uncertainty about the future, the adaptation of a personal and family routine, fears of losing affective partners due to the distancing of the body and soul, for dedicating themselves to the child/adolescent. For this, it is important to listen to the experience of these family members, since it provides an internal elaboration of care to support the chronic condition of the child/adolescent and health professionals, they must understand the world in which these families live and thus draw lines of care, helping in coping and comfort (Afonso, 2015).

Conclusion

This bibliometric review allowed the analysis of 42 references on the theme addressed. Thus, the study demonstrated that publications on palliative care in children/adolescents have been developed in recent years, predominantly in the national and hospital scenarios. The bibliometric indicators showed the prevalence of original articles of qualitative approach, using the interview as a data collection instrument. The participation of collective authorship was evident. This collaboration, in addition to enabling learning, stimulates creativity and ideas, generating new perspectives and knowledge.

Although the study presented a quantitative little expressive in the established period, many professionals, especially nursing professionals, show interest in developing and disseminating research that brings the theme of chronic condition and the relationship with relatives of children/adolescents. In view of the above, it is aimed at expanding further studies of this nature, given the importance of the presence of family members in the process of caring for a child/adolescent with chronic disease under palliative care, since all actions aimed at relieving the suffering of both the disease and resulting from treatment, enable a more respected, educated, humanized vision and action, comfort, individuality and dignity to the child/adolescent and family.

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