



CARE FOR FAMILIES WITH PEOPLE WITH CHRONIC CONDITIONS IN PRIMARY HEALTH CARE: INTEGRATIVE REVIEW

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ABSTRACT

Objective: To identify care for families with people with chronic conditions in Primary Health Care, through an integrative literature review. **Method:** This is an integrative review that included articles published from 2010 to 2020, identified in the databases: International Literature in Health Sciences, Latin American and Caribbean Literature in Health Sciences and Database in Nursing. The keywords "primary health care" AND "family" AND "chronic diseases" and "primary health care" AND "chronic conditions" AND "care" were used. **Results:** Thematic categories emerged: Health Promotion from the perspective of caring for families with people with chronic conditions; Relationship between family of people with chronic conditions and health professionals; and Potentials and challenges for effective care for families with people with chronic conditions. Health promotion emerged as a care tool, with emphasis on home visits. There was a weakness in the approximation of the health teams with the families, the prevalence of the curative ideology and weakened access to health services. **Final considerations:** The findings of this study are important for nursing to promote public policies aimed at the care of families with people with chronic conditions in Primary Health Care.

Keywords: Primary Health Care. Chronic Disease. Family. Care.

INTRODUCTION

The definition of chronic condition refers to chronic diseases, infectious diseases, various disabilities, conditions related to motherhood and the perinatal period, conditions related to the maintenance of health through life cycles, long-term mental disorders, diseases metabolic disorders, non-acute oral diseases and health conditions characterized as illnesses. This is because they have characteristics in common, such as temporality and continuity of care, symptom control and longitudinality of care, interruption and incorporation of life routines^(1,2).

In 2019, 55.4 million people died worldwide and 74% of those deaths were caused by Chronic Noncommunicable Diseases (CNCDs). Brazil, according to the criteria established by the World Bank, is among the countries classified as high

middle income, in which, of the 10 main causes of death in 2019, eight were CNCDs^(3,4).

Thus, CNCDs are a global health problem, causing mortality and disability. Evidence indicates that this scenario affects mainly users who live in regions of risk and vulnerability, which tends to be enhanced by problems of financing, management, provision of professionals and structuring of services. Thereafter, Primary Health Care (PHC) in conjunction with the Family Health Strategy (FHS) provides coverage in relation to the care of individuals and their families^(5,6).

Studies indicate that families of people with CNCDs are also impacted, highlighting the need for care that should be directed, equally, to these families^(7,8). In this sense, the following guiding question was unveiled: what is the scientific evidence on the care of families with people with chronic conditions in Primary Health Care?

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Thus, this article aimed to identify care for families with people with chronic conditions in Primary Health Care, through an integrative literature review.

METHODOLOGY

This is an integrative literature review. This type of study seeks to synthesize and analyze results of independent studies, generating information about the subject addressed. Its elaboration was conducted based on some premises⁽⁹⁾, such as:

(a) Developing a question to be answered. The survey of scientific production was conducted based on the formulation of the following research question: what is the scientific evidence on the care of families with people with chronic conditions in Primary Health Care?

(b) The establishment of inclusion criteria for the studies was based on the epidemiological framework of the evolution of proportional mortality by groups of diseases in the period from 1930 to 2009, in Brazil. In which there was a relative rapid growth in deaths from diseases of the circulatory system, neoplasms and external causes, at the same time as there was a great decrease in deaths from infectious and parasitic diseases, configuring the triple burden of diseases, with chronic conditions⁽¹⁰⁾. The inclusion criteria defined for the selection of scientific productions were studies from the last 10 years, in Portuguese, Spanish and English. As an exclusion criterion, articles that did not answer the research question were disregarded.

(c) Elaboration of a questionnaire for the collection of study data. The questionnaire used was composed of the following items: authors, year, objective, methodology and main results.

(d) Identification of rules of inference in the analysis and interpretation of studies. Inferences led to interpretations, in the sense of seeking evidence in

the selected documents through in-depth reading of the articles, going beyond the apparent reading.

(e) Review of the inclusion criteria. For this stage it was not necessary to review the inclusion criteria.

(f) Reading of the studies in conjunction with the data collection questionnaire. For this stage, the questionnaire built in a previous stage was used, seeking information regarding authors, year, objective, methodology and main results.

(g) Data analysis in a systematic way carried out through the thematic analysis that comprises three stages: pre-analysis, exploration of the material and treatment of the results obtained and interpretation⁽¹¹⁾.

(h) Discussion and interpretation of data and (i) report of the review clearly. The discussion was made according to the pertinent literature and the synthesis of the results was made through the consolidation of the evidence and presented as contributions of the present work.

The research also met the recommendations Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (identification, selection, eligibility, and inclusion), which contains a checklist for the elaboration of review studies, considering the specificities of the integrative review; the review was made by peers⁽¹²⁾.

The online search was carried out through the Virtual Health Library (VHL), in the period between November and December 2020, in the following databases: International Literature in Health Sciences (MEDLINE), Latin American and Caribbean Literature in Life Sciences Health (LILACS), Nursing Database (BDENF). For the selection of articles, the standardized terminology of the Health Sciences Descriptors (DECS) was used, in English and Portuguese, namely: “primary health care” AND “family” AND “chronic diseases”. Figures 1 and 2 address the stages used in the selection of the study samples:

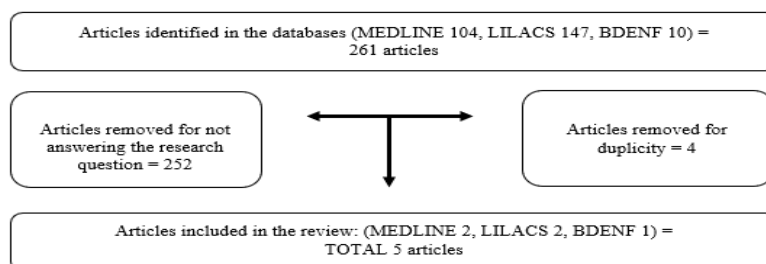


Figure 1. Stages for selecting the studies included in the literature review with the descriptors “primary health care” AND “family” AND “chronic diseases”. Sobral, Ceará, Brazil, 2020.

Source: The authors.

Thus, 10 articles were included in the review. The analysis of the findings was carried out from the detailed reading of the productions with a view to the research objective.

Data collected from the studies were displayed in a box, containing: authors, year, objective, methodology and main results for further analysis in a descriptive manner, with the provision in thematic

categories: Health promotion from the perspective of caring for families with people with chronic conditions; Relationship between family with people with chronic conditions and health professionals; and Potentials and challenges for effective care for families with people with chronic conditions

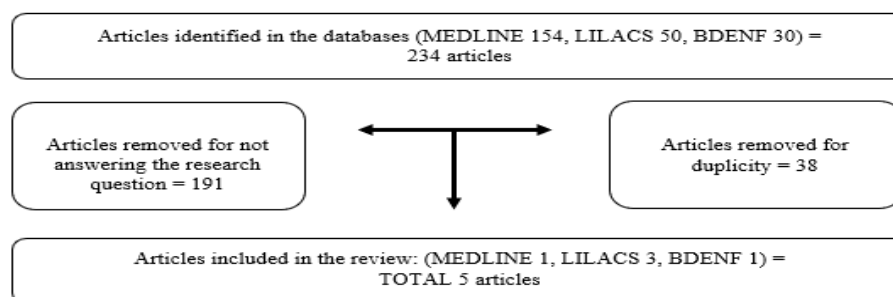


Figure 2. Stages for selecting studies included in the literature review with the descriptors “primary health care” AND “chronic conditions” AND “care”. Sobral, Ceará, Brazil, 2020.

Source: The authors.

RESULTS

The review consisted of ten articles, whose information related to identification is described in Box 1. An article published in 2010, an article published in 2012, an article published in 2013, an article published in 2015, an article published in 2016, three articles in 2017, an article published in 2019 and an article published in 2020 were found. There was predominance of national publications in relation to international publications related to the subject in focus. It is

noted the impetus for national research related to Chronic Conditions in PHC with a view to understanding the proposal for health care networks and the discussion of a new Model of Attention to Chronic Conditions, after studies and publications on the theme from the year 2012⁽¹⁰⁾. Regarding the methodological approach, there was a predominance of qualitative research, of the descriptive type. The publication areas were mostly Nursing, Medicine and also Interdisciplinary⁽¹³⁻²²⁾.

Box 1. Distribution of scientific findings in relation to care for families with people with chronic conditions, regarding authors, year, objective, methodology and main results. Sobral, Ceará, Brazil, 2020.

Authors/year	Objective	Methodology	Main results
Carreira, Rodrigues ⁽¹³⁾ 2010	To identify difficulties experienced by families of elderly people in a chronic condition and who seek assistance in the Basic Health Unit (BHU)	Qualitative study Methodological framework the Grounded Theory and the theoretical framework Symbolic Interactionism. Eight families of elderly people with chronic disease participated in the research.	Families report problems with the non-continuity of the programs carried out by the BHU when the political management changes, as well as the frequent alteration of the members of the health team, which may lead to the discontinuation of treatment and the disruption of bonds between the population and health professionals.
Prata, Cunha, Pereira; Nichiata ⁽¹⁴⁾ 2012	To report experiences in pharmaceutical care performed by a Basic Health Unit (BHU) in the city of São Paulo	Experience report. The Unit's pharmacist developed, in conjunction with the manager and professionals who participate in the service's technical meetings, the assistance strategy for monitoring the use of medications at home for users with more difficulties in adhering to treatment.	Dialogue with the patient and family about the importance of monitoring the use of the prescription and the proper disposal of medications, including approach concerns about the environment.
Tracy, Bell, Nickell, Charles, Upshur ⁽¹⁵⁾ 2013	To design and evaluate a new interprofessional care model for elderly residents in the community with complex health needs. A secondary objective was to explore the potential of this new model as an opportunity for interprofessional training.	Cross-sectional study The IMPACT clinic is an innovative model of interprofessional primary care for elderly patients with complex health needs. The comprehensive team consists of family doctors, community nurse, pharmacist, physical therapist, occupational therapist, nutritionist and community social worker. The model is designed to accommodate trainees in each discipline. Patient consultations last from 1h 30min to 2 hours, during which a wide range of medical, functional and psychosocial issues are investigated by the entire interprofessional team.	The IMPACT model is consistent with policy initiatives underway in the reform of primary care and improves community care for the elderly. Continuous refinement and evaluation of the interprofessional practice model, in addition to the extended interprofessional visit for patients and family members, which allowed sufficient time and space for them to raise and discuss multiple problems with a team of professionals.

To be continued...

Duarte, Silva, Tavares, Nishimoto, Walty, Sena ⁽¹⁶⁾ 2015	To analyze the nursing work in caring for children with chronic conditions in primary health care	Qualitative approach study developed through interviews with 23 nursing professionals from 16 Basic Health Units in the city of Belo Horizonte. Data were analyzed from a critical perspective, seeking to identify common themes in the empirical material.	
Costa, Cazola, Tamaki ⁽¹⁷⁾ 2016	To evaluate the application of the Assessment of Chronic Illness Care (ACIC) and its results with professionals from teams of the Family Health Strategy, in Campo Grande (MS)	Descriptive study with a quantitative and qualitative approach. The sample consisted of 30 professionals in 5 teams and data collection was carried out in May and June 2014, through the ACIC instrument.	Results pointed to educational practices, such as guidance to family members on care with the use of medications and diets, in addition to guidance on characteristics of children's growth and development.
Almeida, Cruz, Fernandes, Lima, Lago ⁽¹⁸⁾ 2017	To analyze the training of nurses on educational actions developed in Primary Care with people living with <i>Diabetes mellitus</i> .	Qualitative research carried out with 28 nurses of Primary Care, in Teresina, state of Piauí, Brazil. Data were collected from April to June 2015 through interviews and analyzed using the collective subject discourse technique.	Carrying out Health Education activities with relatives of people with Diabetes, as well as the search to better understand family characteristics in domestic environments.
Salci, Meirelles, Silva ⁽¹⁹⁾ 2017	To evaluate the health care developed by the members of Primary Health Care for people with diabetes mellitus from the perspective of the Care Model for Chronic Conditions.	Qualitative and methodological study of evaluative research. For data collection, 38 interviews were carried out with health professionals and managers; observation of activities performed by health teams; and analysis of 25 medical records of people who received this service.	At the meso level, there was disarticulation among professionals in the Family Health Strategy, between them and users, family and community.
Wong-Cornall, Parsons, Sheridan, Kenealy ⁽²⁰⁾ 2017	To analyze the contribution of family caregivers to the continuity of care in alignment with the Haggert model.	Case study. Analyzed data from interviews of 13 family caregivers in a case study of primary health care in New Zealand - a Maori Provider Organization - to determine the alignment of family care with the three levels of continuity of care (relational continuity, informational continuity and continuity managerial).	Alignment of family care tasks, responsibilities and relationships with the three levels of continuity of care. Family caregivers 1) they established a partnership with providers to extend chronic care to the home; 2) they transferred and contributed information from one provider/service to another; 3) they supported the management of consistent and flexible care.
Ramvalho, Silva, Machado, Vaz, Souza, Collet ⁽²¹⁾ 2019	To evidence the discourse of community health agents about the contribution of their care actions to the management of the chronic disease of children/adolescents in primary care.	Qualitative study, carried out in a municipality of Paraíba, from November 2015 to May 2016, with 10 Community Health Agents that work in the Family Health Strategy. Data were collected by semi-structured interview and interpreted based on discourse analysis.	In primary care, care actions do not meet to the specific needs of the health of children/adolescents with chronic disease, requiring the monitoring of these by specialized attention network. The care is disjointed between team members and is centered on the acute conditions or updating medical prescriptions. Despite these weaknesses, the work process of community health agents allows qualified listening, trust and security in the relationship with the family, enabling the formation of bonds.
Favaro, Marcon, Nass, Reis, Ichisato, Bega, Paiano, Lino ⁽²²⁾ 2020	To apprehend how nurses of the Family Health Strategy are perceive in relation to knowledge and preparation to assist children with special health needs and their families and how they assess their access healthservices.	Descriptive, exploratory study of approach qualitative carried out in primary health care. Data were collected through a semi-structured interview with 14 nurses from the teams of the Family Health Strategy. Interviews were transcribed in full and then submitted to content analysis, thematic modality.	Unpreparedness for assistance and its implications and access to health services in the care network for children with special health needs that shows nurses, for the most part, do not feel empowered to offer quality assistance; assess access of these children and their families to health services as difficult due to multiplicity of conditions presented by them.

Source: The authors

Based on the evidence found, the contributions of the aforementioned studies are presented in the form of thematic categories.

Health promotion from the perspective of caring for families with people with chronic conditions

It was observed in the studies^(13,14,17,18) included in this review the importance of carrying out health education activities with family members of people with *Diabetes mellitus*; also the realization of educational practices, such as guidance to family members on care with patients, use of medications and diets, as well as guidance on characteristics of the growth and development of children with chronic conditions. Thus, health education activities with family members are an important care strategy for this population.

The realization of home visits was also evidenced in the promotion of health education practices with families and notes for the actions developed by the community health agents, identifying in their work process the construction of bonds with the family, which facilitates the experience and the family members coping with chronic illness^(13,14,17,18).

Relationship between family of people with chronic conditions and health professionals

In the relationship of the family of people with chronic conditions and health professionals, studies in this review^(13,19) pointed out, in the assistance to people with *Diabetes mellitus* in PHC, deficit in the integration of health professionals with the family, as well as the social context. What raises the discussion that the lack of integration of health professionals with the family, as well as its social context, points to the lack of convergence of the practice with the principles of the FHS, of comprehensiveness and of the Care Model for Chronic Conditions, where the family should be involved in the care plan.

The Model for Attention to Chronic Conditions incorporates the macro, meso and micro scopes. The macro scope corresponds to the macropolitics that regulate the health care system; the meso scope deals with health and community organizations; and the micro scope contemplates the relationships between the health teams and the users and their families⁽¹⁰⁾.

In contrast, other studies in this review^(20,21) also showed that the relationship of family

caregiver and health professionals was essential to allow the continuity of the relationship between professionals and patients and more specifically the bond established between the community health agent and the family to carry out care actions for children and adolescents with chronic illness in PHC, which are facilitated through the relationship of trust that exists between these subjects. In addition to taking care of the health conditions of their patients, health professionals took care of other family members, revealing a family-centered understanding of chronic care management.

Potentialities and challenges for effective care for families with people with chronic conditions

The evidence from the studies in this review⁽¹⁵⁾ showed the potential to care for families with people with chronic conditions, like the study carried out in Canada, which presents the clinic of the Innovative Model of Primary Interprofessional Care (IMPACT), which contributed to the refinement and continuous assessment of the interprofessional practice model, in addition to the extended interprofessional visit for patients and family members, which allowed sufficient time and space for them to raise and discuss multiple problems with a team of professionals.

Another aspect presented by articles in this review⁽¹⁷⁾ was supported self-care, demonstrated by the greater knowledge on the part of health professionals in relation to chronic conditions, in welcoming the concerns of people and their families, and to effective interventions, which lead to changes behavior of people and families.

As challenges for the realization of care for families with people with chronic conditions, a study in this review⁽²¹⁾ evidenced the weakened access by families to the Basic Health Unit, because they discredit the resolution of the service or because they have a health plan. This disbelief in the service on the part of family members is based on both the difficulty of access and resolution, as well as the delay, leading them to seek other services in the health care network or even to invest in private health plans to maintain the continuous monitoring of their children.

DISCUSSION

Primary Health Care is recognized as fundamental for universal access to health services. In Brazil, one of the mechanisms for strengthening Primary Health Care is the Family Health Strategy, which is based on the health care of families with people with chronic conditions in the perspective of including individual and collective actions for health promotion, prevention of diseases, diagnosis, treatment, rehabilitation and harm reduction^(23,24).

Results of the present study point to health education in the care of families with people with chronic conditions as a necessary aspect, and the specific social and cultural circumstances of each subject must be contextualized and valued, in his knowledge, experiences and values.

Although health education has a broader character, it is considered one of the main devices for making health promotion feasible, assisting in the development of individual responsibility and in the prevention of diseases in the person and in the family. Thus, promoting health works as a tool to drive changes not only in the health sector but also in society, performing care in human relations and health practices and that, together with the premises of PHC, allows the rescue of essential values for the construction of new social relations based on respect, ethics, solidarity and care, with health education as a strengthening device for the effectiveness of health promotion⁽²⁵⁾.

It is also observed the use of the home visit strategy as a practice for carrying out care and promoting the health of people with chronic conditions and their families, but specifically carried out by community health agents, as they deliver material for dressing, make monitoring of possible changes in blood pressure and care with the use of medications, in order to verify the correct use, thus providing communication between the community health agents and other health professionals involved in the care⁽²⁶⁾.

In this sense, it is considered that health professionals with access to the narratives of family members and the knowledge of the meaning of the experiences are essential and decisive for the construction of effective therapeutic interventions that enable the family's

well-being⁽²⁷⁾. What raises a key element evidenced in this study for the care of families of people with chronic conditions, which was the interprofessional practice, with the expanded perspective of health care with regard to professional performance and health concepts that lead to recognition the need for a varied cast of professionals, in order to contemplate the multiple dimensions, present in the health needs of users and families. Thus, the complexity of health needs and the organization of services points to the growing trend of replacing the isolated and independent performance of professionals by teamwork and interprofessional collaboration⁽²⁸⁾.

Self-care was also evidenced as a potential for effective care for families and people with chronic conditions. Supported self-care actions aim to empower people with chronic conditions and their families, helping them to understand their central role in managing the disease, making informed decisions about care and engaging in healthy behaviors⁽²⁹⁾. A study⁽³⁰⁾ with children with chronic conditions revealed that in the experience of the child's chronic condition, their families were accumulating essential knowledge for carrying out daily care. However, the construction of this knowledge must be subsidized by the performance of health professionals, through dialogue, exchange of knowledge and provision of information.

In this sense, in the relationship between family and health professionals in situations where the patient is limited, nurses must also provide care with support and guidance for the patient's family, who will need their help⁽³¹⁾.

Another important finding of this review was the way in which families with people with chronic conditions have faced difficulties in relation to access to public health services. A study⁽³²⁾ on the institutional capacity of health services before, during and after the implementation of the Model for Attention to Chronic Conditions (MACC) corroborates by presenting a relevant participation in the provision of private services in the care of these conditions, which even with high coverage of public health services, coverage of an important

private plan (34.9%) is higher than that of Brazil (24.1%).

Thus, as a challenge to the care directed to families with people with chronic conditions, there is a predominance of care with a focus on the management of the disease, curative, and not exactly on the need of the family, with the use only of strategies to increase the degree of co-responsibility of care. Research shows that services offered in Primary Health Care are geared towards the disease and the medicalization of the problems presented by users and families, with the health needs being summarized in the daily practice of the services to the demands of the pathophysiological processes that involve the illness^(33, 34).

FINAL CONSIDERATIONS

The care of families with people with chronic conditions in Primary Health Care has the potential to promote health, and the fundamental role of home visits as an extended health care for families is also highlighted.

As a challenge to care for families with people with chronic conditions in Primary Health Care, the discussion about studies that reflect on the fragility of approximation between health teams and families was evident. It is necessary to reflect on the importance of interprofessional health work as a way out of resolving issues that involve chronic health situations and especially in caring for families.

In addition, the study also points out as challenges the prevalence of curative ideas, weakened access to primary health care services, aimed at families of people with chronic conditions.

The importance of the findings of this review for the area of Nursing is highlighted, in order to promote public policies aimed at the care of families with people with chronic conditions in Primary Health Care.

As a limitation of the study, it is pointed out that the selected articles had a greater emphasis on the national literature, which held a greater number of articles, restricting the variety of evidence.

CUIDADO A FAMÍLIAS COM PESSOAS EM CONDIÇÕES CRÔNICAS NA ATENÇÃO PRIMÁRIA À SAÚDE: REVISÃO INTEGRATIVA

RESUMO

Objetivo: Identificar o cuidado a famílias com pessoas em condições crônicas na Atenção Primária à Saúde, por meio de uma revisão integrativa da literatura. **Método:** Trata-se de revisão integrativa que incluiu artigos publicados no período de 2010 a 2020, identificados nas bases de dados: Literatura Internacional em Ciências da Saúde, Literatura Latino Americana e do Caribe em Ciências da Saúde e Banco de Dados em Enfermagem. Foram utilizados descritores “atenção primária à saúde” AND “família” AND “doenças crônicas” e “atenção primária à saúde” AND “condições crônicas” AND “cuidado”. **Resultados:** Emergiram categorias temáticas: Promoção da Saúde na perspectiva do cuidado às famílias com pessoas em condições crônicas; Relação entre família de pessoas em condições crônicas e profissionais de saúde; e Potencialidades e desafios para a efetivação do cuidado às famílias com pessoas em condições crônicas. A promoção da saúde surgiu como ferramenta do cuidado, destacando-se a visita domiciliar. Evidenciaram-se fragilidade de aproximação das equipes de saúde com as famílias, prevalência do ideário curativista e acesso fragilizado aos serviços de saúde. **Considerações finais:** Os achados deste estudo são importantes para Enfermagem para fomento de políticas públicas voltadas ao cuidado das famílias com pessoas em condições crônicas na Atenção Primária à Saúde.

Palavras-chave: Atenção Primária à Saúde. Doença Crônica. Família. Cuidado.

CUIDADO A FAMILIAS CON PERSONAS EN CONDICIONES CRÓNICAS EN LA ATENCIÓN PRIMARIA A LA SALUD: REVISIÓN INTEGRADORA

RESUMEN

Objetivo: identificar el cuidado a familias con personas en condiciones crónicas en la Atención Primaria de Salud, por medio de una revisión integradora de la literatura. **Método:** se trata de una revisión integradora que incluyó artículos publicados en el período de 2010 a 2020, identificados en las bases de datos: Literatura Internacional en Ciencias de la Salud, Literatura Latino Americana y del Caribe en Ciencias de la Salud y Banco de Datos en Enfermería. Fueron utilizados descriptores “atención primaria a la salud” AND “familia” AND “enfermedades crónicas” y “atención primaria a la salud” AND “condiciones crónicas” AND “cuidado”. **Resultados:** surgieron categorías temáticas: Promoción de la Salud en la perspectiva del cuidado a las familias con personas en condiciones crónicas; Relación entre familia de personas en condiciones crónicas y profesionales de salud; y Potencialidades y desafíos para la realización del cuidado a las familias con personas en condiciones crónicas. La promoción de la salud surgió como herramienta del cuidado, destacándose la visita domiciliar. Se evidenciaron fragilidad de aproximación de los equipos de salud con las familias, prevalencia del ideario curativista y acceso debilitado a los servicios de salud. **Consideraciones finales:** los hallazgos de este estudio son importantes para la Enfermería para el fomento de políticas públicas dirigidas al cuidado de las familias con personas en condiciones crónicas en la Atención Primaria de Salud.

Palabras clave: Atención Primaria de Salud. Enfermedad Crónica. Familia. Cuidado.

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Submitted: 23/06/2020

Accepted: 03/03/2021