Home Care within the Unified Health System: challenges and potentialities

A Atenção Domiciliar no âmbito do Sistema Único de Saúde: desafios e potencialidades

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ABSTRACT This study aims to know the scientific production about Home Care in Brazil, discussing the challenges and potentialities of this type of care in the scope of the Unified Health System (SUS). This is an integrative review in electronic health databases, in the period between 2006 and 2017, whose final sample included 23 articles. Three categories have emerged from the analysis: ‘Substitutive potential of Home Care and articulation with the network’; ‘The user and his/her family in Home Care’; ‘Satisfaction of users and the relationship with the team’. The analysis points out as the main potential of Home Care the configuration as a substitute care network, the bond and the horizontal relations between team, users and family. The main challenges are the fragmentation of care and the lack of articulation with the other points of the care network. Home Care is a unique space of health and can be a powerful space for reinventing relationships between users, caregivers and teams, questioning the hegemonic ways of producing care.


RESUMO Este estudo tem por objetivo conhecer a produção científica acerca da Atenção Domiciliar no Brasil, discutindo os desafios e as potencialidades dessa modalidade de assistência no âmbito do Sistema Único de Saúde (SUS). Trata-se de uma revisão integrativa em bases de dados eletrônicas na área da saúde, no período entre 2006 e 2017, cuja amostra final incluiu 23 artigos. Da análise emergiram três categorias: ‘Potencial substitutivo da Atenção Domiciliar e articulação com a rede’; ‘O usuário e sua família na Atenção Domiciliar’; ‘Satisfação dos usuários e a relação com a equipe’. A análise aponta como potencialidades da Atenção Domiciliar a configuração como rede substitutiva de cuidado, o vínculo e as relações horizontais entre equipe, usuários e familiares. Os principais desafios são a fragmentação do cuidado e a falta de articulação com os outros pontos da rede de atenção. A Atenção Domiciliar é um espaço singular da saúde e pode constituir um espaço potente para reinvenção das relações entre usuários, cuidadores e equipes, questionando os modos hegemônicos de se produzir cuidado.

Introduction

Home Care (HC) is defined as a modality of health care that involves actions of health promotion, prevention, treatment, rehabilitation and palliation at home, in an integrated way with Health Care Networks (RAS). This modality has expanded in response to the demographic, epidemiological, social and cultural changes that have been taking place both in Brazil and in the world scenario, in order to meet the need for viability and economic sustainability of health systems, as well as the search for a proposal of care that promotes greater well-being to users and their families, reducing health inequities.

The HC, as a wager on the care of some profiles of users not reached in other spaces, has led managers, workers, researchers, users and families to rethink the health care model and the existing offers, aiming at the production of comprehensiveness. Furthermore, in the perspective of reorganization of the care network, the potential of HC in the articulation of services has been perceived through communication and discussion of therapeutic projects shared with the other points of the network.

Moreover, due to the characteristics inherent to it, HC challenges the traditional logic of care production by overcoming the walls of health institutions and becomes a substitutive modality by enabling the production of new modes of care that transcend the hegemonic model of medicalization. It requires, therefore, that the teams work in the complexity of the territory of the house, in the multiplicity of family dynamics, incorporating their values and knowledge to care.

The regulation of HC in Brazil began with the publication of Resolution RDC nº 11/2006 of the National Health Surveillance Agency (Anvisa)/Ministry of Health (MH), which provided for the operation of the services. However, despite the existence of this resolution, few changes were actually perceived in the daily services at that time.

The year 2011 was profitable for the expansion of HC, with the creation, through Ordinance GM/MS nº 2.029/2011, of the Better at Home Program and the National Policy of HC within the scope of the SUS, which, among other determinations, established the participation of the federal manager in the funding of services. This proposal had an important inducing action for the opening and expansion of services in the Unified Health System (SUS). Currently, the ordinance in force is Ordinance nº 825, dated April 25, 2016, which redefines HC within the scope of the SUS and updates the authorized teams.

However, despite advances in both the legislation that regulates HC in Brazil and the quality of care provided, its construction was not part of the project that originated SUS, assuming a place of complementary modality in health care. Therefore, its supply remains below the needs in the Country, and it is vulnerable to governmental changes and economic priorities.

In this sense, and in view of the impact that HC services have produced on the lives of users who receive the care of the teams in this mode of care, it is necessary to deepen the knowledge about the production of care in the HC, seeking to contemplate its challenges and potentialities.

Investigations have been conducted in order to know and understand how the organization of the teams and care have been occurring in the HC; however, there are few review studies that comprehensively present the evidence produced on HC in Brazil, within the SUS.

In view of this, it was established, for this study, the following guiding question: ‘What questions have been addressed about contemporary scientific production regarding HC in SUS?’ In order to answer this question, the objective of the study is to know the scientific production about HC and to discuss the potentialities and challenges of this type of care within SUS.
Methods

This is an Integrative Review (IR) study related to HC publications within SUS. There was an option for this research method because it is a method that provides a synthesis of the knowledge produced through primary studies developed by means of several research designs, which requires a rigorous data analysis and provides subsidies for the improvement of health care.

For the elaboration of this study, the following steps were followed: (1) identification of the theme and elaboration of the guiding question; (2) search or sampling in the literature; (3) data collection; (4) critical analysis of included studies; (5) presentation of the revision/synthesis of knowledge.

The following databases were searched in the Virtual Health Library (VHL-Bireme): Latin American and Caribbean Literature in Health Sciences (Lilacs), Medical Literature Analysis and Retrieval System Online (MedLine) and Scientific Electronic Library Online (SciELO). The indexes ‘Home Care Services’ OR ‘Home Care’, contained in the Descriptors in Health Sciences (DeCS) were used.

As inclusion criteria, the following were used: researches that addressed the modalities of HC in the SUS provided for in the Brazilian legislation regarding the topic; with full online availability; in Portuguese, English or Spanish; published in the period from 2006 to 2017. Such time period takes as reference the date of publication of Resolution RDC nº 11/2006 of Anvisa/MS, which provides for the technical regulation of the operation of services rendering HC in Brazil.

Considering that the literature brings different concepts and definitions about HC, it is important to indicate the definition adopted for this IR, which is established by Ordinance nº 825, dated April 25, 2016: HC is a modality of health care that involves actions of health promotion, prevention, treatment, rehabilitation and palliation at home in an integrated way with the Health Care Networks (RAS).

Exclusion criteria were: articles that deal with services and/or practices that are not related to the modalities of HC in the SUS provided for in the Brazilian legislation regarding the subject; review articles; theses and dissertations; articles that addressed the HC carried out by the Primary Care (PC) teams.

After the identification of the articles, according to the guiding question and with the inclusion criteria previously defined, the titles and abstracts were read and, in the cases in which the titles and abstracts were not enough to define the initial selection, the reading of the whole of the publication was carried out. After this stage, the articles of review, articles dealing with the HC carried out by the PC teams or by private institutions were excluded; studies reporting HC experiences developed in other countries; studies that deal with practices developed at home by professionals in an isolated way, articles that deal with home visits and dissertations. Duplicated studies were also grouped.

For analysis, the articles included have been exhaustively read; in the aftermath, the data were then extracted for the construction of the first matrix, with the individual specifications of the works, containing: title, databases, journal in which it was published, year of publication, authors and city of origin of the first author, objective, methodological approach, main results, conclusions and observations of the researchers. Subsequently, the grouping was done in thematic categories that configure the central scope of this study. The grouping was carried out according to the theme(s) treated in the original article analyzed, seeking to answer the guiding question of the study. Some articles addressed more than one aspect in the field of HC and, therefore, were used in more than one of the thematic categories, considering the
potentialities and challenges of this type of assistance under the SUS.

The ethical and legal aspects were respected, considering that publications of journals were used whose authors were cited in all the moments in which the articles were mentioned.

Results

From the inclusion and exclusion criteria, 23 articles were selected, 14 of them available in Lilacs, 7 in Medline and 12 in SciELO. All 23 articles were maintained after full reading of the texts and they constituted the final sample of this review, as represented in figure 1.

Figure 1. Flow diagram for selection of articles

Regarding the year of publication, it was observed that 2013 was the year with the highest number of publications (4), and, in the years 2014 and 2015, no publications that met the inclusion criteria were identified. The distribution of the articles by year of publication is shown in graph 1.
The selected articles were organized in a synoptic chart for the systematized presentation of the knowledge produced on the topic, containing the following topics: number, database or portal, title, authorship, journal, year of publication, objectives, origin of the first author and methodological approach (chart 1). As for the approach of the studies, it can be verified that 14 were of qualitative approach (60.9%), 7 of quantitative approach (30.4%) and 2 of mixed approach (8.7%). As for the state of origin of the first author of each article, there was a concentration in the South and Southeast Regions, with 13 (56.5%) and 8 (34.8%) articles, respectively, especially in the Rio Grande do Sul states. South (12 articles – 52.2%) and Minas Gerais (5 articles – 21.7%).
| VII | SciELO | Home care in the structuring of the healthcare network: following the paths of comprehensiveness | Brito MJM, Andrade AM, Caçador BS, Freitas LFC, Penna CMM. | Anna Nery School (print version) | 2013 | MG | Qualitative |
| VIII | Medline and SciELO | Factors associated with home care: support for care management within the SUS | Pires MRGM, Duarte EC, Goittems LBD, Figueiredo NVF, Spagnol CA. | Journal of School of Nursing | 2013 | DF | Quantitative |
| IX | Lilacs | Characterizing a home and palliative care program in the Municipality of Pelotas, State of Rio Grande do Sul, Brazil: a contribution to full attention to cancer patients at the National Unified Health System | Fripp JC, Facchini LA, Silva SM. | Epidemiology and Health Services | 2012 | RS | Quantitative |
| X | SciELO | Home care and hospital assistance: similarities and differences from the perspective of the family caregiver | Oliveira SG, Quintana AM, Budó MLD, Kruse MHL, Beuter M. | Text & Context Nursing Journal | 2012 | RS | Qualitative |
| XII | Lilacs and Medline | The construction of care by the health team and the caretaker within a home-care program for bedridden patients in Porto Alegre (RS, Brazil) | Freitas IBA, Meneghel SN. | Science & Collective Health | 2011 | RS | Qualitative |
| XIII | SciELO | Organization dynamics of family caregivers of the terminal patient in home care | Oliveira SG, Garcia RP, Quintana AM, Budó MLD, Wunsch S, Silveira CL. | Science Care and Health | 2011 | RS | Qualitative |
| XIV | Lilacs and SciELO | Home care: profile of patients attended by a home care program | Martelli DRB, Silva MS, Carneiro JA, Bonan PRF, Rodrigues LHC, Junior HM. | Collective Health Journal | 2011 | MG | Quantitative |
| XV | SciELO | Right of the Citizen and Evaluation of Health Services: Theoretical-Practical Approaches | Kerber NPC, Kirchhof ALC, Cezar-Vaz MR, Silveira RS. | Latin American Journal of Nursing | 2010 | RS | Qualitative |
| XVI | Lilacs and SciELO | Home care as change of the technical-assistance model | Silva KL, Sena RR, Seixas CT, Feuerwerk-LCM, Merhy EE. | Journal of Public Health | 2010 | MG | Qualitative |
| XVII | Lilacs and SciELO | The nurse’s work in the home care service: family caregivers’ view | Silva DC, Santos JLG, Guerra ST, Barrios SG, Prochnow AG. | Science Care and Health | 2010 | RS | Qualitative |
| XVIII | Lilacs | Pilot-experience in home care: bedridden aged patients of a Basic Health Unit, Porto Alegre, Brazil. | Marques GQ, Freitas IBA. | Journal of School of Nursing | 2009 | RS | Qualitative |
Discussion

After the critical reading and data systematization, the articles were grouped into three thematic discussion categories: ‘HC substitutive potential and articulation with the network’, ‘The user and his/her family in HC’ and ‘User satisfaction and relationship with the team’, discussed below.

Substitutive potential of Home Care and articulation with the network

The analysis of the articles indicates that HC, in its different conformations, has been on the center of changes in the networks in the perspective of the substitutability of the organization of the care, that is, as a device for the production of care that is not being produced in hospitals, clinics and other spaces health care.

Articles XVI, V, VII and VIII indicate that HC, in its many modalities, has contributed to techno-assistential reordering with a focus on substitutive networks of care, although the rationalization of expenditures by means of abbreviation or substitution of hospitalization hospital is one of the main motivators of implantation in most of the Brazilian experiences.

Article XVI, which presents a study carried out in four HC outpatient services of the Municipal Health Department and a service of a philanthropic hospital in the city of Belo Horizonte (MG), indicated that the HC forms a care network with the potential to contribute to continuity and comprehensiveness of care.

However, although several articles point to HC’s contribution to the restructuring of the care model – because of the tension that it establishes between the different knowledge, realities and life dynamics, for example –, being able to generate significant changes in the health approach, the Article VIII raises
the low power of pressure of the users in the relationship with the professionals as an obstacle to their realization.

Regarding the classification and distinction between the modalities of HC (HC1, the responsibility of the PC teams and the Family Health Care Centers (Nasf), HC2 and HC3, which are the responsibility of the specific HC services) expressed in the National Policy of HC in the SUS, the authors of article VIII evaluate that are the social, family and clinical context variables that determine the type of HC offer that users need. The authors state that the classification in the modalities HC1, HC2 and HC3 contributes to the management of care in health care networks, besides helping in the integral approach and in the decision making by the team.

Article XX, when analyzing seven experiences of home care in five Brazilian municipalities, finds that HC can adopt different conformations and be inserted in several points of the health care network, be it PC, UPA or hospitals. When HC becomes a substitute modality in the organization of care, it allows the production of more caring practices. The Ordinance nº 963/2013, which redefines HC within the scope of the SUS, inserts in its text the substitutive or complementary potential for hospital admission or outpatient care of HC services and warns of the importance of considering other spaces and ways of organizing the care technologies, such as palliative care.

The articulation of HC with the health care network has also been a great challenge, as identified by the authors of article V, which evidences the lack of understanding about the role of HC, hindering this systemic view. With this, there should be improvements in communication and in the training of the individuals involved in the network. Article VII, which reported on the experience of integrating two HC programs with different local network equipment, noted the difficulties in overcoming the fragmentation of health care practices and that these fragilities need to be addressed by improving communication between services with a view to comprehensiveness of care.

Article XVI maintains that discontinuation of care occurs, most often, after HC discharge, due to the inability of family health teams to absorb this demand due to the flow and the work rhythm they already have.

In general, the articles analyzed highlight the potential of HC to produce a different logic of care in networks, promoting its reorganization focused on the unique needs of users and their families, which is corroborated by other studies. This conception is evidenced by the fact that several services have been organized according to the profile of their users, modeling their offer – modalities, place of insertion in the network, etc. – which does not always meet the criteria set out in the policies. Nevertheless, it is observed that the insertion of users into HC services does not guarantee the substitutive character of the care, which has already been perceived by other authors and there may be a simple transfer of the locus of care to the home, without the its logic of production is questioned.

**The user and his/her family in Home Care**

The profile of the users assisted by HC services and the family’s participation in care were themes that have also appeared in the articles analyzed.

In the program analyzed by Article XIV, the public is mostly composed of elderly, low-income women with short periods of hospitalization; as well as in Article XXIII, in which the majority was composed of elderly women, widows, with 1 to 4 years of schooling, income between 2 and 4 minimum wages and who lived with a multigenerational family.

In the same direction, article IV, which presents the results of a cross-sectional study carried out with elderly people from 23 Brazilian states, pointed out that older women, with lower levels of education and purchasing
power, with a diagnosis of chronic morbidity, a history of falls, previous hospitalization and medical consultation in the last three months, were those who used the most home care. The priority association of HC with a certain sociodemographic profile – female sex, low socioeconomic power, chronic diseases and functional dependence – is corroborated by other studies and is in line with the tendencies of population aging in Brazil.

Concerning the family participation in care for users, Article XVIII points out that the family, as caregiver, assumes care activities related to hygiene, clothing, food, medicines, dressings and bed mobilization. Articles X and XIII, which have as participants family caregivers of terminal patients linked to a home hospitalization program, demonstrate that the family’s involvement in daily care to the users, although capable of providing feelings of freedom, comfort, safety, life and preserving social contact with people in their social circle, also causes negative feelings such as physical and emotional fatigue, loss of freedom and lack of social support.

In addition to the tiredness that the care of a relative can generate, another difficulty is related to the moment of discharge, given the difficulty of articulating the different points of the network, including the continuity of care after HC. Article XXII identified that mothers of infants enrolled in a neonatal home stay program felt unsafe before discharge because they would have less support to build full care for their children in disarticulated health care networks.

Such findings reinforce the need to establish interinstitutional articulation spaces where flows agreement is a priority, especially with HC. The authors of Article XXI corroborate this understanding, stating that home care with the support of the care network is fundamental, requiring a dynamic articulation at different levels of care and services.

Article IX addresses the perspective of death in the home as a factor that frequently causes feelings of insecurity and distress in families, especially in situations of material insufficiency, which often requires the transfer of the user and death outside the family nucleus and the home.

In the face of daily demands on patient care, strategies should be pursued to reduce the suffering of families, both at discharge and during home care. Articles I and XI show that communication – verbal and nonverbal – between professionals, users and caregivers, seeking to solve doubts, appease fears and reduce anxiety, can be an important tool in this sense to be developed by the teams. However, the availability of a minimum material structure to ensure care at home, or even to prevent them, as well as facilitating access to other health network services in cases that cannot be resolved at home, are fundamental elements to guarantee the tranquility of families and the integral care in HC. These, however, depend mainly on institutional articulations and adequate investment of resources in the HC.

Users’ satisfaction and the relationship with the team

The analysis has revealed that, all in all, users are satisfied with the work done by HC teams. This positive perception of HC has appeared in both article XIX, which deals with research conducted with users and caregivers of the HC program of a hospital in Southern Brazil, and in article XV, which discusses the results of the evaluation process of a public health service Brazilian HC. However, these same studies have identified that such evaluation may be linked to feelings of gratitude for the public character and, therefore, gratuitous of the evaluated services and for the perception of health as a right, masking possible criticisms and dissatisfactions related to the services.

Regarding the relationship with the team, Article XXII reports that the health team of a neonatal home hospitalization program in a Brazilian capital has become a mediator of mothers in caring for their children. The light technologies used by the team contributed to
the building of bonds between the mothers and the health team, facilitating information, education and communication between these actors. In this same perspective, Article III emphasizes that the construction of ties with the team and the stimulation of new habits of life helped the development of autonomy, quality of life and improvement of the health of users.

Likewise, Article VI concludes that creativity and invention in the face of the unique needs and demands of users are, in general, part of the work process of the teams in the HC and that their conformation facilitates the incorporation of the family as the focus of the caution. Article XV also points to HC as a privileged locus for the development of shared assessment processes between workers and users and that its non-achievement culminates in the exclusion of the user from the production of improvements in services.

The analysis also suggests that nursing have occupied a fundamental place in work in HC. Article XVII reports that the caregivers consider the nurse a reference professional in the management of the care, helping the family to organize in front of the difficulties of the care in the home. Article II indicates that, since the twentieth century, nursing was one of the first health professions to enter the home to perform care, in the figure of visiting nurses.

In another study, it has been arisen that nursing workers have been pointed out as essential in performing home care, bringing benefits to users and their families when their practices are performed with understanding and responsibility. Nurses play a fundamental role in HC, both by coordinating the care plan at home and by the bond he/she establishes with users, family members and caregivers.

Accordingly, it is undeniable, when analyzing the relationship with the team and the users’ satisfaction with the care taken in HC, that this has been confirmed as a modality of care that, in several experiences, has potentiated the production of bonds; in an understanding of bond as something built in symmetrical relations based on the recognition of our non-knowledge and the need for active action in the quest to share the production of care with the user in a lively and singular way.

However, Article XII has shown that biopower still supports, in large part, the teams’ performance, through normative and disciplinary attitudes and discourses regarding those they consider inferior in the production of care – users and caregivers; however, it was also observed the desire to change these workers in the direction of less asymmetric relations.

In this sense, Article VI argues that curricula should cover elements that allow the development of skills and ethics that cover the complexity and specificity of work in the HC. Therefore, the development of a practice linked to the demands of society requires that the focus be on the training of professionals, who will be pillars for informal and family caregivers.

In addition to changes in training, in order to sustain the HC towards a different techni-assistential model, transformations are necessary in the health work process, especially in the relationships between professionals and service users. It is essential to incorporate light technologies in this process, because only this way the biomedical paradigm can be overcome. Thus, it is evident that HC can be a powerful space for reinventing relationships between users, caregivers and teams, questioning the hegemonic ways of producing care.

This review was carried out in three important databases – Lilacs, MedLine and the SciELO website, in which a very expressive percentage of the developed out in Brazil were found, although it did not exhaust the totality of databases that could possibly have publications on the study, which can be considered a limitation of this study. Thus, there is no pretension to exhaust the subject or to extend possibilities regarding the research on HC in the Country within the SUS. It is considered that this IR contributes to present
a systematization and an analysis of knowledge produced on the subject and that can subsidize reflections related to the potentialities and the challenges of this modality of assistance, which is essential to qualify health care in SUS.

Final considerations

The research has evidenced the complementary power of HC in the production of care and in the work process in health, considering the complexity and the singularity of users, teams and contexts in its modeling. However, this is not an a priori guarantee, since, without questioning the current logic of care production, HC can simply reproduce in the space of the household hegemonic practices of other health spaces.

Another relevant aspect identified is the difficulty of articulating HC with the other RAS services, evidencing that there is a path to be covered for the comprehensiveness of care, especially in relation to HC. The authors propose the creation of spaces and devices that facilitate communication between the various points of the network and that allow the other services to understand the role and the work process of the HC teams.

Equally important, the reality of family caregivers in HC experiencing feelings permeated by affection, trust, security, but also by emotional and physical exhaustion, insecurity and lack of support is striking. In this sense, the uniqueness of the care production in HC requires a look at the multiplicity of the lives of users and caregivers, which does not fit into the ‘organization of the network and its pre-established flows’, which impels thinking strategies capable of giving visibility and readability to the needs of users and their families.

This is not an easy task. It demands from all the actors involved with the HC – managers, workers, social movements, researchers, etc. – that they adopt a deterritorializing look that questions the established forms of health care production; requires thinking of solutions and strategies that take the demands and needs of users and their families as central, be it in the elaboration of policies, in the management of networks or in the daily work at home. It is an exercise that calls for problematizing and reinventing care, with openness to the multiple possibilities of health and life production in the singular and complex space of households.

Collaborators

Procópio LCR (0000-0003-0404-1849)* participated in the drafting stages of the research project, collection and analysis of the data and preparation of the manuscript. Seixas CT (0000-0002-8182-7776)* and Santos MLM (0000-0001-6074-0041)* participated in the research project, data analysis and manuscript preparation stages. Avelar RS (0000-0001-6320-5095)* and Silva KL (0000-0003-3924-2122)* contributed to the drafting of the manuscript.

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