Home care in rehabilitation and family-centered practice: approaching theories to improve results

Atenção domiciliar no âmbito da reabilitação e prática centrada na família: aproximando teorias para potencializar resultados

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ABSTRACT: This narrative review presents and discusses the assumptions of Family-Centered Practice (FCP) and the influences of this approach in the context of Home Care (HC) in rehabilitation in the Brazilian Unified Health System (SUS). HC and FCP were analyzed from the information obtained, allowing to discuss the potential impact of the assumptions of the FCP in HC of the Brazilian public health system. HC has an important role in networks, producing new ways of caring. However, some problems in the organization of this service generates discontinuity of care and overload of all levels of attention, hampering the bond between professionals/user/family. FCP proposes that home programs be targeted at family members, especially caregivers, so that they develop the skills required for the provision of care, thus enabling comprehensive, contextualized and humanized assistance to the user. The use of FCP in the context of HC in the Brazilian Unified Health System, considering user empowerment and his family, may favor the establishment of emotional and co-responsibility bonds between professionals/user/family, impacting on the quality of the assistance provided and the results expected.

KEYWORDS: Home visit; Unified health system; Caregivers; Rehabilitation.

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RESUMO: Estudo de revisão narrativa que apresenta e discute os pressupostos da Prática Centrada na Família (PCF) e as influências desta abordagem no contexto da Atenção Domiciliar (AD) no âmbito da reabilitação no Sistema Único de Saúde (SUS). Com base nas informações obtidas, a AD e a PCF foram analisadas, permitindo discutir o potencial impacto dos pressupostos da PCF na AD, do sistema publico de saúde brasileiro. A AD tem importante papel na constituição de redes substitutivas, produzindo novos modos de cuidar. Entretanto, alguns problemas na organização deste serviço geram descontinuidade do cuidado, sobrecarga de todos os níveis de atenção e dificultam o vínculo entre profissionais/usuário/família. A PCF propõe que os programas domiciliares sejam direcionados aos familiares, especialmente aos cuidadores, para que estes desenvolvam as competências necessárias para a prestação do cuidado, possibilitando assim assistência integral, contextualizada e humanizada ao usuário. A utilização da PCF no contexto da AD no SUS, tendo em conta o empoderamento do usuário e sua família, pode favorecer o estabelecimento de vínculos afetivos e de co-responsabilidade entre profissionais/usuário/família, impactando na qualidade da assistência prestada e nos resultados esperados.

DESCRITORES: Visita domiciliar; Sistema único de saúde; Cuidadores; Reabilitação.

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INTRODUCTION

Impacted by the global economic crisis and accelerated demographic and epidemiological transformation of the population, health systems have attempted to provide support, improve the functionality and quality of life of patients and families. In Brazil, these changes, combined with the low effectiveness of the public health system to meet the new demands of health, are accompanied by the increase in requests for Home Care (HC). This strategy has been recognized as capable of delivering significant changes in the healthcare model, aiming at a comprehensive, contextualized, and humanized assistance, in addition to rationalize demands and costs.[1,2] For some authors, HC activities are developed in an environment that favors the collection of information, providing an effective adaptation to the reality experienced by reducing social isolation and thus a better quality of life.[3,4]

HC services are considered health care modalities that include actions and rehabilitative care, support, promotion of health, and prevention of diseases, both for chronic and acute health conditions. Its target audience is composed of users unable to go to the nearest health unit, many times with complex cases that require different care professionals and support services.[5,6] In process of expansion in Brazil, HC has three different modalities: home care, which involves activities at home, of ambulatory character, programmed and continued; domiciliary hospitalization for patients in more serious clinical situations, which requires assistance similar to that offered in hospitals, and home visit, which develops actions of guidance, education and possible solutions to the health problems found.[7]

In Brazil, HC is structured from the perspective of health care networks and must be combined with other points of attention and supporting services, in addition to adopting a model of care based on the work of multiprofessional and interdisciplinary teams. It also must be included on lines of care, through practices based on the needs of the individual, to reduce the fragmentation of health care.[5,8] Line of care is understood as an image that represents flows of assistance assured and guaranteed to the users of the Brazilian Unified Health System (SUS), to attend their health needs.

When searching on the current scenario of HC in Brazil, we can observe that the provision of this service and the way relationships involving care are set out in various situations and moments are conditioned to the infrastructure available. Among the limitations that result in important inequity of care provided at home, the difficulty of access of users to rehabilitation professionals of HC teams and the discontinuity in the access to other health services are some of the elements that impact negatively on the results and the continuity of actions. Thus, even if HC has power to stimulate the creation of bonds and co-participation of users and their families, the actions fall short especially regarding the construction of care centered on the needs of individuals.

In this regard, HC organization, mainly in rehabilitation, must be structured by prioritizing shared and interdisciplinary care, with exchange of knowledge and mutual responsibility. Discussions of cases and situations, therapeutic projects, guidance, and joint attendance enhance the act of caring and potentiate the results expected in rehabilitation.[8,11,12] However, it is worth mentioning that the studies do not make clear the role of HC specifically in rehabilitation in relation to work organization (flows, scope, frequency, technologies, and results).[1,2,12-14,17] Professionals discuss whether HC has rehabilitation function when analyzing the articulation of the service with the health care network and the frequency of the activities developed.[14]

Results of a recent study suggest that as professionals adopt in their practices the Patient-Centered Attention (PCA), focusing on the individual's history of life and current needs, they operate in a field larger than their own profession, specialty, and service.[3] In other words, the focus of observation and the horizon of interventions is expanded, with potential changes in the health care model and in the reach of integrality.[3] The study indicated a possible relationship between PCA and the Interprofessional Collaborative Practice (ICP), in which it is possible to trace common objectives between teams and professionals, keeping individual interests and autonomy. This relationship is due to the recognition, in the national and international literature, of three key elements: "extended health care perspective" (user, family, and community), "patient participation in care" (empowerment, self care aid, autonomy), and "professional-patient relationship" (subjectivity and autonomy).[2]

Fundamentals and assumptions of SUS and HC are common to other approaches that also incorporate these three elements.[15] Such elements are considered important to investigate and fulfil the sharing of knowledge between professionals, teams, and users and to constantly reassess the act of taking care with components that include relational skills, building goals, implementation of therapeutic and social support, and evaluation of the results, considering the resources available and the social and family context.[16]

A survey developed by the Center for Study and Research on Disability and Work (NEPIT), Belo Horizonte (Minas Gerais), Brazil, from 2015 to 2016, aimed to investigate HC within the rehabilitation of SUS by using tracer methodology.[17,21] The cases followed-up indicated different routes and itineraries by the public health network, showing how complex work processes, such as HC, come true in practice. The data obtained from observation, document analysis, field diary records and interviews with managers, professionals, users, relatives and others involved in the case allowed to explore different aspects that permeate and challenge HC. Among these, we can highlight the relationships established, which are linked to issues related to the social and economic situation of the families, the history of family conflicts, the overload of the main caregiver and the doubts of the professionals on the ability and responsibility of families to understand and take care, which hinders the execution and may limit the resolution of the demands and problems found in each home.[18]

The research demonstrated the way HC is implemented in practice: a work environment filled with unexpected situations, in which professionals often have fragmented and inaccurate information. It was also found frequent lack of planning and discontinuity of actions, as well as inefficient communication and infrastructure for the implementation of the activities. This situation provides the consolidation of barriers that hinder the performance of professionals and generate unnecessary routes on the health network. However, the study showed that despite the impact these barriers have on the case management, the relations established in the practice of HC were considered potent activators of formal and informal networks of care and support, in addition to the health system. We highlight here the importance to consider the knowledge and active participation of the user, his family, and health professionals to the adequacy of health practices and policies.[18]

Considering the problematization presented, this study aimed to describe the key elements of Family-Centered Practice (FCP) and discuss the possible impacts of its assumptions on HC within SUS context. From a narrative review, it is expected that a careful analysis of these assumptions will favor its incorporation into HC programs in rehabilitation, in the manner as this service has been offered in Brazil.

METHODS

This is a narrative review, i.e., no explicit and systematic criteria were used for search and critical analysis of the literature. The search for studies did not exhaust the sources of information, and sophisticated and exhaustive search strategies were not used. Selection of studies and interpretation of information are made according to criteria defined by the authors.

FCP was analyzed from the international literature available on Pubmed. To do so, the following descriptors in English were used: “family-centred practice or family-centered care or home programmes.” The search was conducted from February 2015 to June 2015 based on the following criteria: studies that treat FCP as main subject and availability of the publication in full and for free.

HC was analyzed based on the legislation that regulates this program within SUS and on the national contributions available at Lilacs and SciELO bases, using the descriptors *visita domiciliar ou assistência domiciliar ou assistência à saúde ou serviços de assistência domiciliar* (home visit or home care or health care or home care services) in the same period of the previous research.

The information provided by the aforementioned sources were analyzed regarding the structure and organization, strengths and weaknesses of HC in Brazil and the assumptions and contributions of the FCP, to allow the discussion of their impacts in HC within SUS, reaching the objectives proposed by this study.

RESULTS

Notes on Home Care (HC) within SUS and the role of family/caregiver

HC, although it was not contemplated in the original project of SUS, complements the range of actions and programs provided by the system. As part of the Primary Health Care (PHC), it follows the assumptions of the Family Health Strategy (FHS), i.e., the production of a comprehensive, continuous, longitudinal care, close to the community.[12] Recent studies confirm that, despite the difficulties, HC is structuring itself in these molds and has been offered in the three levels of attention (primary, secondary, and tertiary) by a diversity of teams and services, accessed by the user from the relationships constructed during home care.

Studies suggest that the main points of the guidelines prescribed for PHC and HC – through the ordinance no. 963 of May 26, 2013 –encourage the sharing of knowledge, empowerment of the individual and the family in the decision-making process and the preservation of the autonomy of the user and of his family, caregivers, professionals, and teams.[5] However, some authors argue that, in act, these guidelines and concepts, although essential to the accomplishment of good practices of care and for the resolution of cases, were not implemented in their full potentiality.[19]

Literature has pointed to important structural problems in the organization of HC services, such as the lack of systematization, communication, and professional training, as well as the unpreparedness of caregivers to deal with the complexity of the user's health need.[19,20,21] These three points reflect on discontinuity of care, overload of all levels of attention, in addition to hindering the decision making process and the bond between the professionals/service and the user/family.[28] On the other hand, with the transfer of care to the home, we observed the creation of alternative networks, where many initiatives begin with the family/caregiver, such as mobilization of friends and neighbors, private networking and social security system.[18] In rehabilitation, the limitations of access along with the previous difficulties result in prolonged waiting for a vacancy. The problem worsens for users with mobility restrictions, who face the difficulty of getting transportation to get to the specialized rehabilitation service. This situation makes rehabilitation at home the main alternative for these people.[14]

According to Pereira,[10] the expansion of access due to the implementation of the Center of Support to Family Health (NASF) has been considered inadequate as the resolubility of treatment and rehabilitation, occurring only increased guidance and promotion actions of punctual interventions in some cases. Users considered not eligible for treatment in specialized rehabilitation services and who are under PHC often exceed the capacity to take care of health teams. Thus, rehabilitation professionals must effectively rely on families and/or caregivers to comply with the guidelines and a simplified treatment plan.

The caregiver, according to the ordinance no. 963 of May 26, 2013, which redefines the HC within SUS, is the person with or without family bond with the user, able to assist in her/his needs and activities of everyday life. Caregivers are considered the basis of these programs, responsible for activities ranging from basic health care and assistance in daily living activities (DLA) to the implementation of care oriented by health professionals.[2]

The relationship among caregivers, professionals, and different health care teams has attracted attention as it is often conflicting.[2,23] Issues related to the lack of family support due to complex socio-familiar conditions, the ability of the caregiver to exercise and take some aspects of care and specific procedures guided by health professionals, added to the aging of informal caregivers, especially users' wives from HC services, has been discussed by managers and professionals.[10,18] Some narratives of professionals, caregivers/family members and coordinators, taken from research conducted in Belo Horizonte,[18] illustrate and confirm the problems.

> *"I talk, I answer what they ask me. I try to talk too, but sometimes they don't listen. For example, I research a lot, and I read a lot of things, and ask little. There are a lot of professionals that don't listen...". (Caregiver 3)*

> *"I think the social is much heavier than the motor in her case. There is an important motor issue, but the social aspect is not letting this condition go forward." (Physical therapist 2)*

> *"If the caregiver doesn't do her/his part, professionals can use the best techniques in the world, they can invest, but it's gonna be very little. The family has to take its part! When the family does not take it, that begins to generate all the stress...". (Physical therapist 2)*

> *"I had to drop everything for him. It changes a lot, our lives, I mean... It changes a lot! You have to take care of this now, just me. I've always worked, I had my money, now I can't...". (Caregiver 5)*

To remedy these difficulties, some countries are investing in the qualification of the workforce involved in home care, providing financial support to the family caregiver for the work performed and the lost life opportunities, and are accrediting programs, to ensure the constant and sufficient supply of caregivers.[19]

The partnership between health team professionals and caregiver is essential to ensure support, considering that many of these people take this position suddenly and thus unprepared to exercise it. It is important that professionals involved in HC not only guide and supervise the caregiver in the execution of patient care, but also offer constant support and monitoring, since those are complex activities for the family member who has never performed such care.[22]

In summary, the caregiver is the bond between the health team and the user, and is the person with whom the professionals share responsibilities. In many cases, the caregiver is seen and treated as a simple executor of procedures, therefore, having the obligation to respond to what was prescribed unilaterally by the HC professional. This situation produces tension, and any questioning by the caregiver is seen as resistance, leading the professionals to impose rules and norms to maintain the continuity of the activities, which can negatively affect not only the relations established in households, but mainly in the quality of care provided by both the caregiver and the professionals.

In the next section, we discuss the assumptions of FCP to identify how this approach can assist in the basement of the interventions of HC, especially in the organization and planning of care.

Family-Centered Practice (FCP): assumptions and contributions

The notion of a person-centered approach originated in the work of psychologist Carl Rogers, who gave a voice to his patients. In this model, the assumption that the professional has the knowledge of the patient's needs is shifted to the recognition of the ability and the right of the customer to drive and direct his own treatment and the understanding of the role of the therapist as a facilitator of the therapeutic process.[23] This approach influenced several international health systems, initially in child care and later extended to other populations, guided by the relevance of the family nucleus as the main supporting institution of the individual to be cared for.

Among the various definitions of the family-centered approach, we can cite three that, in a complementary way, broaden the conception that sustains this model of health care by moving the unit of intervention from the individual to the family relations under the pillar of interaction among health professionals, services, patients, and family.[23,24] It is a philosophy and a service method that recognizes the family's expertise about the patient's needs, promoting a partnership between family members and service providers, supporting the family to make decisions about the priority services for its family member/patient.[24] Patient and family-centered care can then be understood as an innovation in the planning, supply, delivery, and evaluation of health care, which is mutually constructed for the benefit of patients, families, and providers.[25]

According to Bamm et al.,[23] the assumptions that guide this approach can be summarized as follows: centrality and constancy of the family in the patient's life; particularity and diversity of patients and families; focus on reinforcing skills more than pointing out weaknesses and deficiencies; stimulus to a more collaborative relationship between family and health services, and promoting a network of emotional and financial support that meets family needs.[23]

The family-centered approach can be used at different levels of health care. Some authors have demonstrated that this approach may potentiate home programs, recognizing the families' expertise, as well as the importance of implementing health care actions in the context of daily living and goals of care for families. It is worth mentioning that home care programs require a conceptual base for its effective implementation, to guide the identification of problems and objectives, the development of the program, the selection of the intervention, and evaluation. The family-centered approach has been used as theoretical support for the implementation of rehabilitation interventions at home.[24] In this sense, Australian researchers presented a model to guide the implementation of home-based programs for children with cerebral palsy that can assist professionals to structure and define their interventions at home.

The home care program model by Novak and Cusick[24] is divided into five phases of action. The first phase aims to increase the bond and the family involvement with the home care program, by constructing collaborative relationships between the professional and the family. Thus, in the second phase, the goals of the treatment program are defined and shared. For this, professionals must have interpersonal skills, create strategies and carry out a comprehensive assessment to help the family to identify problems, main needs, and aspects that influence the goals prioritized by the family.[24]

In the third phase, we proposed that the activities of the program be incorporated into daily activities. This strategy seeks to ensure that interventions be carried out daily, increasing the functionality and participation of the child, in addition, reduces the overload and wear of the caregiver.[24] Aiming at the effective implementation of the program, Novak and Cusick[24] propose in the fourth phase that professionals maintain frequent contact with families, providing support, opening space for the discussion of the interests and concerns of the family. It is important to give feedback and positive reinforcement to construct and strengthen the confidence of the family.[24] In the last phase, we idealize that standardized instruments or formal individualized measures be used to evaluate the results, thus enabling a better planning of future actions.[24]

From the perspective of Novak and Cusick,[24] home program and visit program must be differentiated. The programs are designed to be implemented in the daily lives of families and are directed and evaluated by themselves, who also develop the necessary skills for care. The central task is not to treat the patient, but to improve the skills of the caregiver to reach the strategies guided by the reference professional's approach. However, improving the skills of the caregiver is a complex notion and need to go beyond a theoretical definition. It means providing families with knowledge, skills, and resources to identify problems in the routine, arising from the conditions of a family member's illness, to know how and to whom to address these problems, how to get support from specialists and resources, how to determine if progress is happening and if it is within the interests of family members, and if the objectives reflect the values and priorities of families.[24]

In summary, in this proposal, home programs should be sensitive to the direction and goals agreed upon with the family, the daily routine of the home, the resources available, as well as the attributes and characteristics of the patient, and the potential and ability of family members to improve the skills of the caregiver. Therefore, the program needs to be well designed, properly implemented, and well evaluated. In other words, the success of this proposal is anchored in an adequate planning, based on consensual and agreed decisions between health professionals, patients and family, especially the main caregiver.

DISCUSSION

Rethinking Home Care (HC) from the Family-Centered Practice (FCP)

Home care rescues the basic principles of SUS, its actions must be based on a comprehensive approach to the individual, which contributes to the humanization of care. For a comprehensive approach of the user and his family, the space and the individuality of the subjects must be respected and valued, encouraging the active participation of all in the health-disease process. However, home health care involves complexity and constant transformation, which often creates barriers that must be faced all the time.[22] The little explored exchange of knowledge and experiences among professionals, and of these with the families, suspicions about the skills and commitment of the caregiver and even social issues, and family conflicts are some of the factors that hinder the interaction between professional and family, which affects the comprehensive assistance to the patient and his family in HC.[18]

The Novak and Cusick[24] model of home-based caregiving with family-centered approach reinforces the importance of establishing cooperative and collaborative relationships between professional, user, and family, with a special focus on the caregiver. Health professionals must value the experiences and skills of caregivers in the decision-making process, stimulating the bond and involvement of the caregiver in the provision of care. The active participation of the user, family, and caregiver is an important trait for the implementation of HC, which may contribute to increase the competencies for the care.[24] The assistance provided at home cannot be imposed by the team involved in the care, since the context of family relationships is always more dynamic than the actions developed by the professionals.[22] Therefore, valuing the caregiver's experiences in the decision-making process may, especially regarding the exchange of experiences and knowledge, increase complicity and co-responsibility.

Although attributions must be agreed between team, user, and caregiver, democratizing knowledge and responsibilities, there is a lack of dialogue and shared planning. FCP recommends that all individuals involved in the process of care be responsible for setting goals and selecting therapeutic activities to be carried out. To do so, the professional must provide information on the importance of certain approaches and, in addition, to help the family in the decision-making process. The identification of objectives, considering the family's perspective, may contribute to the understanding of home care by family members, increasing the trust among the individuals involved, regarding the competencies and commitment of the family/caregiver in the care delivery.[24]

Not always the whole family is involved and committed along with the health team in carrying out the activities to be developed, and the act of caring becomes an overload for whom assumes it.[22] Thus, Novak and Cusick[24] suggest the selection of therapeutic activities to be made combined with the social context and according to the family's goals and the patient's abilities. These interventions must be incorporated into the family's daily routine, to not become just another task to be performed by the caregiver, contributing to the accomplishment of activities and reduction of the overload of the main caregiver.

For the implementation of the home care program, according to Novak and Cusick,[24] regular therapeutic support and systematic assessment of results are important. Regular contact with the family is essential to ensure that the program is practicable.[24] In addition, if this aspect is considered and applied, it would contribute to adequate attention to the family's needs, increase the caregiver's confidence in carrying out the targeted guidelines, favor professional-caregiver-patient bonds, and reduce delay when returning visits. The evaluation process of the results is essential to monitoring the progress and evaluating the program, considering the family goals. In practice, this systematization, through standardized assessments, would enable the sharing of knowledge, exchange of experiences, and contribute to increase the caregiver's skills, based on the results found.[24]

The change in the focus of health care offered at home, including rehabilitation, is an important component of changing the care model, considering not only the individual but all aspects of his history, family context, and social-environmental conditions. Thus, FCP in HC within SUS enables comprehensive care to individuals, and has the potential to encourage the establishment of bonds between professionals and caregivers, increase family involvement in care and improve the quality of care provided to users.

CONCLUSION

From the discussions presented about HC services, we highlight its potential to provide changes in the health care model, stimulating the creation of bonds and the empowerment of families. However, there are several barriers that compromise the provision of home care, such as: difficulty of users' access to professionals and other points of the network, mainly for rehabilitation.

FCP arises to redirect health practices to the family's needs. Given this scenario, caregivers are essential to the success of HC, especially in the context of rehabilitation, being responsible not only for primary care, but also for the execution of the guidelines provided by professionals. Therefore, the assumptions of FCP, in addition to the patient improvement, seek to develop the caregiver's skills to improve the provision of care to users.

It is essential for the implementation of PCF, structured home programs based on decisions agreed between health professionals, patients, and family members, with goals based on the daily routine and resources available, as well as on patient characteristics and caregiver's skills. In this model of care management, the risks of HC to become just one more way of transferring health care responsibility to the family universe would be reduced.

We expect the results of this study to favor the use of the elements of FCP in the real context of home rehabilitation within SUS, aiming at a comprehensive care and improvement in the quality of care.

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