

Primary Health Care in caring for dependent older adults and their caregivers

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Abstract *Primary Health Care is a care model whose attributes contribute to solving most of the health problems of older adults in Brazil's increased longevity. This investigation aims to analyze the care provided to the dependent older adults and their caregivers within Primary Health Care. This is a qualitative study conducted in eight Brazilian municipalities in 2019. A total of 190 subjects participated in the research, whose information was collected through semi-structured interviews and analyzed through the theoretical framework of Dialectic Hermeneutics. Problems with access, home care, the health care network, and interprofessional work were identified. The teams provide practices under the biomedical model's logic focused on the medical professional, although health promotion and disease prevention actions have been identified. There is a need to qualify PHC and expand the scope of practices, incorporating the core of knowledge not traditionally introduced into the teams. Moreover, it is essential to strengthen the State's role and create specific public policies for dependent older adults and their caregivers.*

Key words *Primary Health Care, Elderly, Dependence, Caregivers, Qualitative research*

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Introduction

Brazil exceeded the mark of 30 million older adults, and reached 14% of the total population, ascending people aged 80 and over. Thus, maintaining autonomy and independence has become a challenge for this group, as they are susceptible to disabling diseases and conditions, and require the help of caregivers for long periods¹.

The “long-term care” for older adults is part of non-specialized care practices directed to activities of daily living (ADL) and instrumental activities of daily living (IADL) and can be provided in the community, at home or in institutions. However, the services available are inadequate or insufficient. Relatives or recruited people, often also older adults with health problems^{1,2}, are responsible for implementing this care.

The rights assured to older adults³, including health, are not incorporated into this population’s daily lives. Studies point out the importance of health services promoting preventive actions against chronic conditions, with interdisciplinary care, prioritizing the socio-environmental health care model, considering older adults in their life context, and favoring PHC^{1,4}.

Coupled with the recommendations of these studies, Primary Health Care (PHC) is a care model whose attributes cooperate to solve most of the health problems of the elderly population, reducing unnecessary interventions, increasing access to services, and favoring comprehensive care for the different problems^{5,6}. The Family Health Strategy (ESF) is a Brazilian PHC effectiveness model and builds on health care for older adults and their caregivers, including individual and collective actions to promote health, disease prevention, diagnosis, treatment, rehabilitation, harm reduction, and palliative care⁷.

However, comprehensive care provided to the elderly-caregiver dyad faces hardships that demand political articulation, socio-cultural resignification, restructuring of health services and social equipment, remodeling care practices, and a composite view of home care. In this logical elaboration, the care provided by PHC to older adults and their caregivers requires actions and services that cover the specificities of these users and relatives in search of effective practices guided by existing public policies.

Therefore, we ask how PHC is organized in the care of dependent older adults and their caregivers, and how it is recognized in the face of Brazil’s organizational and care heterogeneity. From this perspective, the study analyzes care provided

to dependent older adults and their caregivers within PHC.

Methods

This is a qualitative study whose theoretical framework is embedded in the dialectic hermeneutics’ perspective⁸, which valued the critical and comprehensive exercise of language, relationships, and social practices of people involved with the older adults’ dependence in Brazil. It is part of multi-center research focusing on the formulation of supporting elements to the construction of public policies on dependence⁹, considering the scenario of growing longevity¹⁰ in a country with deep-seated social inequalities¹¹.

The investigation covered eight Brazilian municipalities, namely, Araranguá (SC), Brasília (DF), Fortaleza (CE), Manaus (AM), Porto Alegre (RS), Recife (PE), Rio de Janeiro (RJ) and Teresina (PI) during 2019, which represent the regions of the country with an aging population in recent years and sociodemographic and cultural heterogeneities¹¹.

A total of 190 subjects participated in the research. Sixty-four were dependent older adults, 27 were formal caregivers, 72 family caregivers, 7 managers, and 20 PHC professionals. First, older adults and caregivers were identified through the Municipal Health Department and the PHC services of each municipality. Afterward, the contact and scheduling of the interviews were performed at the homes of older adults and caregivers. Managers and professionals were interviewed at their workplace.

We included older adults with physical, mental, or cognitive dependence, of both genders, and who could answer the interview; formal home or family caregivers over 18; health professionals working in PHC; and managers (health secretaries, PHC managers, or in specific elderly-related programs). Older adults linked to Long-Term Care Institutions or living alone were excluded. Physical dependence was the functional, practical, or motor incapacity to perform BADL or IADL, and cognitive and mental dependence was the total or partial loss of orientation in time, memory, attention, calculation, language, and visual capacity¹².

Semi-structured interviews, guided by an instrument built by researchers from different Brazilian universities, with specific questions for each group interviewed (older adults, caregivers, managers, and professionals) guided the collec-

tion of information, which addressed the socio-demographic characteristics, life situations and experiences, functional, cognitive, mental, emotional, and social dependence of older adults; perception of caregivers, professionals, and managers about older adults, including facilities, difficulties, and health care initiatives.

The Thematic Content Analysis technique guided the management of data in three stages: (1) *pre-analysis*, with the completion of the analytical syntheses of each transcribed interview, compilation, and organization in a textual corpus, plus free-floating reading; (2) *exploration of the material*, with the elaboration of analytical categories from the text, mainly related to the aspects that link dependence with the management and care offered in PHC; (3) *management of information and interpretation*, with inferences from the understanding and critical exercise of the participants' statements, valuing the meanings of the subjects' narratives⁸.

Thematic categories related to management and care in actions for the care of the dependent older adults were built in line with the study's objective and the participants' statements: (1) *Teamwork and Care practices*; (2) *Access to PHC and Home Care*. While the research scenario consists of different Brazilian locations, this study did not aim to analyze the loco-regional specificities, but the everyday situations reported by the respondents, especially concerning the micropolitics and the daily work of PHC caring for the dependent older adults.

The Research Ethics Committee of the Oswaldo Cruz Foundation approved the project.

Results and discussion

PHC is a care model that assures access of dependent older adults and their caregivers to comprehensive health practices, under the logic of teamwork with different cores of knowledge and practices, especially in home care^{5,6}. This study favored the analysis of situations that reaffirm the importance of PHC in securing this scope of practices and aspects, signaling weaknesses, showing supporting elements to the qualification and assurance of comprehensive health care for the dependent older adults. Regarding the respondents' characteristics, most older adults were women aged over 80 years, white, with low education, and Catholic. Family and formal caregivers were mostly female between 40 and 59 years of age, from a different ethnic group, since

most formal caregivers were black and relatives were white. Most health professionals and managers were female nurses aged between 30 and 50 years.

Teamwork and practices offered in PHC to dependent older adults

The category analyses how the different centers of health professionals are recognized regarding the production of care, assuming *core* as the identity of an area based on the concentration of professional knowledge and practices; and *field* as the space of imprecise limits where each discipline and profession seek support from others in order to fulfill its objectives¹³.

The statements of the participants focus on (1) care centered on the medical professional, with practices restricted to the health-disease process and medicalization; (2) the importance of Community Health Workers (ACS), with individual and collective health promotion and disease prevention practices; and (3) organizational arrangements that expand the scope of practices, including professionals from different cores of knowledge.

Considering that PHC recommends teamwork, with democratic relationships of knowledge and power, aspects that weaken the exercise of interprofessional care in caring for dependent older adults were observed. The reports indicate that the team professionals do not participate evenly in the care, nor do they offer integrated and collaborative practices:

I go to the clinic, and the doctor comes to make the home visit. Very good, attentive, and dear. I have everything that I need. I go there, and he gets them for me (Family caregiver, 62 years, Araranguá).

The nurse came to give the vaccine and make the dressing. Now she's not coming anymore, but the doctor who follows me up is from the health plan (Older adult, 78 years, Rio de Janeiro).

While many of the needs of older adults could be addressed by interdisciplinary care, the reports reiterate the weak link between actions and social determinants in health, showing the professionals' difficult work to shift from biomedical to comprehensive care. These situations portray the hospital perspective, specialized and circumscribed in the disease, which are historical and hegemonic paradigms in Brazil. Users do not recognize PHC as a device capable of offering practices that understand health from an expanded perspective, which involves social, economic,

political, cultural, and mental aspects, restricting care to the biological body of older adults¹⁴.

Most respondents refer to the Health Unit as their “tiny post” and do not recognize the set of professionals on the team. They refer to the doctor as the person responsible for diagnosing and treating diseases. The nursing team is seen as procedural, responsible for applying vaccines, probes, and dressings, and oral health does not appear in the reports.

Overall, teamwork is still fragmented, hierarchical, and asymmetrical, with the subordination of different centers to medical practices. These distortions weaken interprofessional work, whose principle is valuing different knowledge to ensure qualified care to older adults’ needs¹⁵.

Biomedical knowledge influences people’s health practices and subjectivity vis-à-vis their bodies and life¹⁶ and was shown to be cyclical with the recurrence of expressions related to medicines, tests, surgeries, vaccines, and procedures. The nurse’s critical view and the older woman’s report attest to hegemonic knowledge:

We end up creating a medicalization. We medicate and give him medicine repeatedly, but at the same time, do not know what his social context is. We give three hundred medicines and don’t know if he reads! (Nurse, 40 years, Porto Alegre).

When the doctor asks for a test, he asks for a lot: six or seven tests. They come here and collect my blood (Elderly, 83 years, Manaus).

Medication is the practice most often cited as PHC care, although it seeks to act on socioeconomic conditions and contexts and the life history of older adults and their families. However, these practices must be linked to the actions shared by the health team, relevant to the reality and territorial and individual needs¹⁷.

Dependent older adults and their caregivers sometimes crave responses focused on disease, biomedicine, and hard technologies, to the detriment of light technologies that prioritize relational knowledge¹⁸. The appreciation of only structured knowledge and material resources establishes a “biomedical culture” of care, reflecting the understanding of health under the pharmacological market and the discourse of health risks¹⁹.

It is essential to establish a relational, inter-professional, and co-responsible work for team care²⁰. It is still imperative to look closely at the health needs of older adults, involving aspects that transcend biological conditions and medical practices, as the older adult says:

I’m finished now, desperate. I cry alone. I can’t do anything. I only earn a minimum wage (Older adult, 89 years, Araranguá).

Although the hegemonic rationality turns to the biomedical paradigm, strategies for organizing the work process in PHC were evidenced to establish practices to support older adults and their caregivers with light technologies. These care practices end up shaping the toolbox for other avenues in health production, valuing collective, integrative, and complementary activities. The excerpt contains an example of these cautions:

We organize to receive these older adults in groups. The older adults’ group is responsible for physical therapy. The Memory Workshop is with the occupational therapist. We have a partnership with CRAS, where the social worker does a handicraft workshop, the “Empowered” group (Manager, 54 years, Rio de Janeiro).

Groups are essential devices for establishing bonds and socializing for older adults and relatives in PHC. Accompanied inter-professionally, they become resolute, incorporate, and expand practices related to the demands of dependent older adults and their caregivers²¹. In this sense, the ACS is recognized by the respondents for the set of knowledge and practices that come close to the logic of non-disease-centered health production. It is a fundamental core in elderly care, a link between the team and the family context, someone who knows the cultural dynamics of the territory and provides collective health promotion practices:

The health worker is essential because he is in the territory. He knows where older adults are. We register and stratify. He knows who these people are and the family’s reality and where they are. They also form cooperative groups (Manager, 42 years, Fortaleza).

The ACS role in caring for the dependent older adults is of fundamental importance, since the set of disabilities limits this user to seek health care, generating demand for regular home visits. ACS should carry out an active search, identify vulnerabilities, perform home and community activities²², and make home visits a care tool that includes social, economic, relational, and psychological aspects, as their scope of practice occurs where the older adults live²³.

While studies attest to the value of ACS work^{20,22} and the respondents of this research recognize it, the National Primary Care Policy reformulated in 2017 weakens this professional’s performance by reducing the minimum number of ACS per team. Recommending the monitoring of more vulnerable users (without objective parameters) and no longer the population of the territory²⁴ compromises care comprehensiveness,

especially for dependent older adults who may not be understood as “more vulnerable” or even be identified.

This study revealed that dependent older adults face challenges that transcend diseases, including functional disabilities, violence, neglect, poverty, inadequate nutrition, emotional and family problems, and the lack of social support networks. Furthermore, the work of caregivers is permeated by concerns, uncertainties, and insecurity. This situation imposes the need to incorporate professionals who are not traditionally provided for in PHC teams, reducing the referrals of older adults to other points of the Health Care Network, since it can cause delay and travel of users with no mobility conditions, which extrapolates knowledge and practices from medical-nursing traditionally incorporated into PHC, and is consistent with knowledge from other knowledge cores:

I would like a psychologist to visit our home. This professional is great. There are times when older adults are sick of our conversations. Only the daughter-in-law and the grandchildren. A physiotherapist would also be excellent (Family caregiver, 38 years, Manaus).

Some units have NASF and social workers, and they help a lot. They have the older adults' group, and the boss is from physiotherapy. The Memory Workshop is with the occupational therapist (Manager, 54 years, Rio de Janeiro).

For the comprehensive and resolving meeting of these needs, the care produced by “specialists”, whose core of knowledge and practice is not incorporated into the PHC teams, is mandatory. While many of these situations can be addressed from the concept of a field underpinning professional practices, older adults' conditions require specific care, such as psychologists in cases of mental distress, physical therapists and occupational therapists in rehabilitation events, and nutritionists conduct food security.

Among the issues that contribute to the low resolution of PHC is insufficient and inadequate clinical accountability, resulting from hegemonic rationality, which reduces the object of work to procedures, diseases, or body parts, to the detriment of person-centered care. This inversion requires professionals from different areas, as their scope of practice is limited and focal¹³. When necessary, these older adults are referred to specialists, in different services, and without any bond, besides waiting lists. A bureaucratic rationality can exacerbate care fragmentation by devaluing the team-user bond²³. Patients are of-

ten referred to distant places, hindering not only access but integration between health services:

The doctor referred me to the cardiologist and orthopedist. I still did not manage to schedule a visit to either of them. I only depend on the cardiologist to see whether I am hypertensive (Family caregiver, 62 years, Manaus).

The caregiver's report, which also refers to illness, shows how the health care models are clinically fragmented, both within the service and externally, unequally valuing different knowledge. One of the mentioned arrangements to overcome these challenges is the institutionalization of multidisciplinary support through the Extended Family Health Center (NASF) to ensure specialized support for PHC teams and professionals. It is a work methodology complementary to that provided in hierarchical systems, which use referral and counter-referral mechanisms, protocols, and central regulations²⁵.

While studies show the importance of the NASF, in 2019, Decree 2.979 extinguished it as a State funded policy²⁶. However, professionals were not included in the Family Health teams, which will possibly hamper access to specialists and contribute to aggravate care for dependent older adults. It is the reduced role of the State and limits the assurance of rights to more vulnerable people.

Finally, the findings show that the intricate living conditions of dependent older adults require considering new arrangements in health teams, incorporating other professional groups, whose practices extrapolate the disease and the biomedical model. It is imperative to ensure comprehensive care for older adults, besides interprofessional teamwork, strengthening ACS performance, and combating work insecurity in PHC.

Access and home care in PHC: comprehensiveness and social protection for dependent older adults

This section presents the findings of the access of dependent older adults to PHC and the strategies for the production of care through home care, reiterating that one of the essential PHC attributes is the first contact, which is a gateway to the health care system⁹. In this sense, respondents report difficulties:

People arrive at the unit at midnight, or one, two in the morning. Before, my nephew used to pay when I went. There are always people who stand in line, and you give them twenty reais. My nephew

takes me there at 7:30 am. I stay until they open. They said they were coming to see me at home. I am still waiting (Female older adult, 89 years, Porto Alegre).

Older adults and caregivers pointed out the several challenges to access PHC health services, ranging from geographical barriers to the organization of the health team's work process. These issues are more complex in the case of dependent older adults, as they often have reduced mobility, depending on others to move around, or their access needs to reorganize the work process, with a preference for home visits²⁷.

Home care is one of the PHC priorities²⁸, especially for those who cannot travel to health services. Home care (HC) for older adults involves actions by the team at home, favoring the development and adaptation of their functions to restore independence and autonomy²⁹.

HC is one of the healthcare points that must be carried out by professionals of the teams and contribute to the access of dependent older adults to health actions. The management of home care can be understood in three dimensions: the professional, characterized by the moment of the meeting between workers and users; the organizational, which concerns the institutionalized practices, such as the organization of the work process and registration of information; and the systemic, considering health services, their different roles, and technological incorporation to ensure comprehensive care. The interdependence of the three dimensions is fundamental for home care services for the dependent older adults^{20,30}.

A study carried out in Porto Alegre shows that less than half of the older adults referred to habitually accessing the PHC service, pointing out that half of the services corresponded to that recommended for the first contact attribute. As PHC units are the gateway to the health system, the level of ease or difficulty found to access them determines the path of this individual in the health care network in the search for care³¹. Here is a strategy to facilitate access for the elderly:

In the Post where I work, there is a specific telephone reservation of vacancies for older adults. It is a strategy that the manager negotiated to avoid having to go to the Post and stand in line or waiting at the desk's window. Then he calls there, and the appointment is made (Nurse, 40 years, Porto Alegre).

Care requires different arrangements in the organization of work to meet the needs of dependent older adults. While institutional actions at the municipal management level are essential,

the teams must evaluate the best strategy to meet the demands of the assigned population. Reservation of vacancies, home care, reception, advanced access, and patients' list are mechanisms that can overcome barriers to access.

Not only the older adults and their caregivers reported difficulties in access and home care, but also health professionals and managers, with an emphasis on insufficient transportation for home visits, higher than recommended assigned population, and the high demand for clinical care. In the organizational scope and referring to comprehensiveness, the organization of the visit agenda and the availability of transportation are perennial obstacles:

If the dependent older adult is restricted to the home and needs a home visit, we have one day for four family health teams, which limits access because it ends up having teams that only visit every fortnight, due to the availability of the car, and families are unable to pay to bring in the older adult (Manager, 46 years, Fortaleza).

The conditions for a qualified work process and planning before home visits are strategies for a resolving HC. However, the solution to overcome the hurdles to access home care is also conditioned to different management levels. While one is subject to the organization of team professionals, the other depends on municipal management's conduct. Thus, the dimension of systemic and socio-environmental care is required to reinforce PHC agreements with dependent older adults and their families. Regarding these difficulties and facilities observed by health professionals in the care of older adults, a debate comes to the fore: programmatic actions and closed agendas vs. walk-in demand:

Nothing is easy for older adults; there is a strict scheduling system. We have to check if there is a vacancy on the day of demand. Older adults have more comorbidities. He/she or a relative has to come in and try to schedule an appointment. It depends on the availability of the agenda (Doctor, 44 years, Fortaleza).

Sometimes, when they can't find a spot on the agenda, you can service the walk-in demand with the reception, which most of the time is just a prescription renewal (Nurse, 41 years, Fortaleza).

The agenda's issues encompassed the statements, most of the time to justify older adults' difficult access to visits. In turn, the walk-in demand raised disagreements, as some identify it as potential, while others that education and health promotion activities are losing ground with the expansion of this type of demand.

The Ministry of Health advises the teams to organize the access of older adults through reception, understanding that individuals can define what health and needs are; that most of the demands can be resolved in PHC; that walk-in demand can be used to establish a bond; and that, even if monitored longitudinally in programmatic actions, older adults may present conditions different than those they are being monitored for, requiring care at unscheduled times. Many of the dependent older adults heard in this research are included in this last group, as can be seen in the excerpts discussed here²⁷.

Access to home care is essential to establish a relationship between staff and family and extrapolate the concept of disease prevention and incorporate health promotion proposals. Mazza and Lefèvre³² assert two types of home care: technical, offered by health professionals, and lay, resulting from intuition and support in ADLs for older adults. Thus, in some cases, the existence of a “dispute” of care plans can be considered, in which the caregiver assumes one part of the care and the health team provides the other³³. One of the main aspects of older adults’ life is the relationship they establish with their caregivers, in which they also appeared in the reports on access to PHC:

There is no SUS policy for caregivers. We hardly think about the caregiver. Many are unable to leave home because they are dedicated to these people. People change their lives totally to take care of that older adult. So, to come to the unit, we would have to see what could be done, because sometimes she is the only one who can take care of that person (Manager, 38 years, Fortaleza).

The caregiver’s health and access to the service is also a factor to be considered by PHC. The family caregiver is usually a user of the same health team as the older adult, although this caregiver does not seem to be approached as a user of the unit during the home visit, with his demands, but as an informant of the health conditions of the dependent older adult.

Technical or lay home care also occurs as social protection, monitoring risk factors, and developing actions to prevent diseases or conditions. In some cases, the caregiver himself is also an older adult. Thus, monitoring these older adults and family caregivers by the teams could work as some sort of protection and prevention, considering that work can weaken physical and mental health. Besides social aspects, caring for older adults affects the emotional and affective

aspects of the caregiver’s life, since it implies reshaping his/her life, with restrictions in several fields, such as leisure and personal life³⁴.

Pereira and Soares³⁵ concluded that the literature on this topic is scarce nationally and internationally, and it is essential to discuss the quality of life of these caregivers and the policies and programs aimed at this audience. Access to PHC was one of the factors identified in the study that directly influences the family caregiver’s quality of life, concerning work overload, the difficulty of moving around, the fear of leaving older adults alone, and the repeated pilgrimage to the unit to schedule appointments. However, the lack of policies for families and caregivers of older adults and, consequently, their access to the health services, is restricted to the specific flows of the units³⁶.

The possibility of PHC being close to families and the community would provide the solution to most people’s health problems and the impact on reducing cost-effectiveness. When properly organized, home care can increase the autonomy of older adults and their caregivers, reduce hospitalizations and resulting complications, such as mortality and financial and psychological costs. Thus, home care is a cost-effective approach and can also ensure comprehensiveness³⁰.

Home care is a care humanization practice that determines the formation and condition of live work, a sophisticated and complex health-care technology. However, the cases of dependent older adults and the relationships established in the home routine between caregivers and staff reveal the need for protective and supportive social networks at the macro and micropolitical level. These conceptions reaffirm the role of home care for the care of dependent older adults and family caregivers from two dimensions: 1) comprehensive care and 2) social protection in care. Thus, it is essential to reaffirm the need for a permanent analysis of health care for caregivers and dependent older adults, and access to the home care offered³⁰.

Discussions about access and home care for dependent older adults and their caregivers in PHC raises diverse and complex issues, as care for this group challenges many of the structures already established in the routine of the health service network. Thus, this paper does not intend to end such a discussion, but to encourage it, bringing to light the issues that are still barely addressed in the literature, despite the growing number of older adults in Brazil and around the world.

Final considerations

This study shows PHC's weaknesses in caring for the dependent older adults and their caregivers in most of the cities investigated. However, it is an essential care model for comprehensive health care, with the potential to meet most of this population's needs. Problems with access, home care, the health care network, and interprofessional work in PHC were observed in the study. Moreover, the teams provide practices under the biomedical model's logic and centered on the

medical professional. However, actions for health promotion and disease prevention have been identified, mainly at the home level and carried out by community health workers.

There is a need to qualify PHC and expand the scope of practices, incorporating knowledge cores that are not traditionally introduced in the teams. Furthermore, it is essential to strengthen the role of the State and create specific public policies for dependent older adults and their caregivers.

Collaborations

RF Ceccon, CCSA Matos, CAS Garcia Júnior worked on the design, analysis, interpretation of data, and initial and final drafting; LJES Vieira participated in data interpretation, critical review, and final drafting; MDHA Pascoal and K Soares collaborated in the analysis, compilation and initial interpretation of the data.

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