

Family health strategy and older adults with dementia: care provided by health professionals

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Abstract *This is a qualitative, descriptive-analytical study developed in a primary health care facility organized by the ESF. Semi-structured interviews were conducted with five health professionals: two doctors, a nurse, and two community health workers (ACS). The interview's guiding topics were respondent data (name, gender, age, professional category, and seniority in the service); elderly care; care to relatives; perception of the experience of extreme situations in the elderly monitoring; and challenges in the ESF in assisting older adults. Representations related to ESF professionals are directly related to the position held. The ACS are appointed as the facility's thermometer and eyes. Doctors perceive a great demand and see themselves as biomedical knowledge holders and medication prescribers. Nursing is perceived as a professional mediator between ACS and doctors. The walk-in demands of older adults and their families continue to be sustained by the tripod doctor, equipment (tests and procedures), and medication. As family hardships comprise dementia, the perception of care as a burden, and the socioeconomic constraints are intensifying aspects of dementia. The creation of a bond between professionals, relatives, and older adults was perceived as an emotional health care device fundamental for monitoring dementia cases.*

Key words *Older adults with dementia, Care, Health professionals/ESF*

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Introduction

Brazil is in an epidemiological transition process derived from the declining mortality and fertility due to positive socioeconomic changes¹. In this context, an inversion of the population pyramid was observed, with a decreased number of children and an increased number of older adults. Analyzing the population aging process, the last 2010 Census conducted by the Brazilian Institute of Geography and Statistics² showed that older adults already accounted for 10.8% of the population. The higher life expectancy has generated social, economic, political, cultural, and health effects for the Brazilian population.

Concerning health, we emphasize the increase in chronic-degenerative diseases and the involvement of trauma resulting from external causes, such as violence and accidents³. Among chronic-degenerative diseases is dementia, a disease associated with the aging process. Dementia is defined as a progressive alteration of memory and at least one other cognitive function, a decline compared to the level of the previous functioning, impacting behavior and with sufficient intensity to interfere in the personal, social, and professional aspects⁴. In more advanced stages, compromises lead to total dependence.

Dementia significantly affects older adults' families, especially family caregivers, who become responsible for all care routines in families that choose to care for older adults who cannot afford to outsource this care. The disease causes challenging objective and subjective changes in family dynamics, leading to conflicts and breakdowns in the family structure. The dependence situation is aggravated by the social vulnerability of many Brazilian older adults' families. Survival hardships end up transforming the illness of older adults into a daunting experience. Elderly care in dementia is a challenge for health professionals who deal with this disease, considering that family dynamics, symptoms, and the burden of care demarcate the heterogeneity of each dementia case⁵.

According to Bauman⁶, care is related to an "emotional stance" that arises as resistance to the objectification of being by promoting partnership relationships between individuals and not relationships that make them usable objects. Therefore, all actions and thoughts not limited to evaluations or measurements are emotional. The hegemonic health care model is at odds with Bauman's care perspective, as it reproduces the objectification, valuing procedures and tests to the detriment of listening, reception, and bond-

ing. Among others, these postures show the production of emotional distance between health professionals and those requiring care. Pinheiro⁷ states that health care is not restricted only to the performance of care technical skills and tasks. It has to do with positive interactions between users, professionals, and institutions, which include involvement, relationship, acceptance, listening to subjects, and respecting subjects and their life story.

Emotional detachment and objectification of the human being under care can favor situations that are the reverse of care, such as violence. Minayo³ describes three ways in which violence is manifested against older adults: 1) structural, resulting from social and naturalized inequality in the manifestations of poverty, misery, and discrimination; 2) interpersonal, which occurs in everyday interactions and relationships between people; 3) institutional, which happens from an application or omission in the management of public policies by the State and by the care institutions, reproducing asymmetric relationships of power, dominance, contempt, and discrimination.

Concerning public health, the Brazilian Family Health Strategy (ESF) as a primary care model aims to promote comprehensive care for individuals and the community and meet all health and suffering demands in its territory⁸. This study hypothesizes that the ESF model is a fundamental public health device to intervene and take care of the demented older adults and their family caregivers' issues, as it views the "individual in a relationship", as opposed to the "biological individual" as mentioned by Merhy⁹.

The ESF considers the territory and socio-affective relationships, and as a gateway to the health system, it receives the demand from older adults due to the aging process of the Brazilian population. This study aims to understand ESF health professionals' perception of how the demented older adults and family caregivers are perceived, received, and assisted by this service, given the complex care of this population.

Methodological design

Qualitative research was chosen because it allows an understanding of the subjects' perceptions and beliefs, unveiling the history, senses, meanings, and ideologies of this way of seeing the world. Minayo¹⁰ states that this type of research causes the saying to reveal structural conditions, value systems, norms, and symbols. The respondent

acts as a spokesperson for specific groups' representations in a particular historical, socioeconomic, and cultural condition. Qualitative research provides an in-depth understanding when considering singular and relational human aspects escaping from epidemiological and statistical evaluation and quantification, but which is as relevant as these methods in understanding life, in studies and research.

The qualitative, descriptive, analytical study was developed in a PHC unit organized by the ESF, located in the northern part of Rio de Janeiro. The unit serves around 14,000 users and has eight family health teams composed of 83 health professionals, such as nurses, doctors, and community health workers, and other oral health professionals, health surveillance, pharmacy, and the clinic's manager.

Semi-structured interviews allowing a more balanced relationship between interviewer and respondent were conducted to consider this study's objective, favoring the exposure of feelings, perceptions, and expectations, unveiling this individual's subjectivity, and allowing the analysis from the respondent's perspective. The interviews had the following guiding topics for the questions asked: data on the respondent (name, gender, age, professional category, and service seniority); ESF care for older adults with dementia; care to family caregivers; perception about experiencing borderline situations in monitoring demented older adults; and difficulties in the ESF for assisting demented older adults.

This study is nested in the results of a master's dissertation. The research was submitted to the Ethics Committee of the Municipal Health Secretariat of Rio de Janeiro and approved, and to the National School of Public Health, and was approved. It complied with the norms of Resolution N°466/12 of the CNS. The respondents signed an Informed Consent Form.

The names used in this study are fictitious to preserve anonymity. Seven months were left out to conduct the field research and data analysis after acceptance by the Ethics Committee. Thus, five health professionals were interviewed: two doctors, one nurse, and two community health workers (ACS) who were part of teams within the researched health facility. The professionals selected to participate in the research met the following criteria: with higher education, secondary or elementary school level, working directly with the user, and at least six months experience in the facility. Trainees and professionals with no direct contact with health service users were excluded.

The interviews were recorded and transcribed for discourse analysis (DA).

The DA addresses the content collected in the interviews as a process of meaning, transcending the idea that the respondent's statement would transmit information. The discourse is understood as an object that fuses language, the subject, and history. The DA begins with *denaturalizing the word-thing relationship*¹¹, understanding that the meaning of the word does not arise with it and that there is no one way of saying about something, thus transforming language into a discursive object. Then, the *conceptual axes* throughout the statement of respondents become visible. Given these conceptual axes, the *signifying nuclei* were unveiled based on each statement's uniqueness, gesture, and the unspoken¹².

Results and discussion

The health professionals interviewed

João – 32 years, from Bahia, graduated in Medicine in 2015, with previous experience in secondary and tertiary health care. He has been a resident of the Family and Community Medicine program since 2016.

Laura – 32 years, from Rio de Janeiro, graduated in Medicine in 2010, with previous experience in primary, secondary, and tertiary health care. She has been a resident of the facility's Family and Community Medicine program since 2016.

Daniela – 25 years, from Rio de Janeiro, graduated in Nursing in 2013, with previous experience in PHC coordination. She is a nurse contracted under the Consolidated Labour Laws (CLT) scheme since 2015.

Maurício – 58 years, from Rio de Janeiro. He has been living in the facility's neighborhood since he was born and has been an ACS since its inauguration in 2012. He says he was one of the pioneers. This was his first health work experience.

Letícia – 41 years, from Rio de Janeiro. She has been living in the neighborhood since she was born and is an ACS. She worked for 10 years in public hospital administration in the region before joining the facility in 2012. She says she was one of the facility's first thirty workers.

The discourse of health professionals

A signifying mosaic was created in the DA process, consisting of the conceptual axes identified in health professionals' discourse and the sig-

nifying nuclei unveiled in the statements on each conceptual axis.

Figure 1 is a Signifying Mosaic: analysis of the discourse of health professionals.

Conceptual Axis - ESF Health Professionals

Signifying nuclei: Performance of community health workers, doctors, and nurses

The ESF multiprofessional team must comprise at least a general practitioner, a family health specialist or family and community doctor, a general nurse or family health specialist nurse, a nursing assistant or technician, and an ACS⁸.

According to ACS *Leticia*, the ACS performance is fundamental to realizing the ESF model. *It is the perspective of the doctor, the nurse in the territory, say ACS Leticia and Maurício, as they are present more frequently in homes and circulating in the territory and are part of the community's history. The nurse and the doctors interviewed praised the ACS work during the interview, describing them as a critical piece, a thermometer.*

The ACS work aspect for nurses and doctors is related to territorialization. According to doctor *Laura*, *they determine whether the territory has a lot of pregnant women or older adults. They produce numbers and statistics that are vital to define the*

work strategy. In other words, they know the community in which they work and favor the linkage of that community with the health facility. Territorialization has been advocated in several SUS initiatives. However, a determined geometric extension, space formatting is reduced several times. We should also consider that this extension has a demographic, epidemiological, administrative, technological, political, social, and cultural profile and is in constant construction¹³.

The ACS are recognized in the discourse of doctors and nurses as fundamental workers in identifying the family issues of the demented older adults. The worker signals to doctor *Laura*: *doctor or nurse, something is wrong with Mrs. M. (patient attended by the health facility). Shall we go there and visit her?*

This work is vested with significant responsibility for the ACS, as they are required to have a clinical perspective to notice the initial, intermediate, and late difficulties of dementia and perceive and manage the changes in the family context of the demented older adults. ACS *Leticia and Maurício* report that they do not have training for this type of evaluation and clinical observation.

Doctor *Laura* emphasizes in her statement: *success is not the same if there is not a thing of the health worker with a lot of dedication [...] if the*

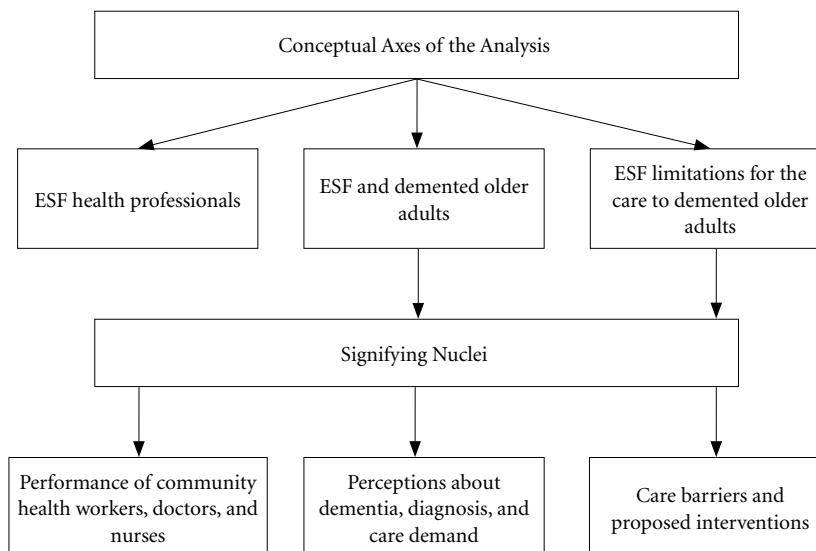


Figure 1. Signifying Mosaic.

worker is not dedicated, he misses out many situations. This statement conveys the idea of ACS accountability in the ESF, and the team's errors are associated with the ACS work, a situation that can generate tension and overload for these professionals.

Maurício's statement reflects the ACS place's perception and reveals an overloaded work routine: we should take care of 600 people so that we don't get sick. I already had 1,057, a little over 900; my base is this: a little over 800 and a little over 900, 980 ... I never had an ombudsman case against me to date, and I even receive gifts: this is inevitable.

Despite the perceived overload by the number of assisted people, which can hinder his work and make him sick, *Maurício* is proud of the bond established with the community and being recognized by the users – these feelings appear as a defense strategy to address the overload experience.

Health care requires time availability to build and maintain care for families, and resisting the health model that focuses on and overuses procedures and tests instead of listening and receiving. In the statement of doctors and nurses, the representation of the ACS work reflects a paradigm shift among ESF health professionals when they see the individual *in a relationship*⁹ in the community, his family, and the health facility's professionals.

In the discursive training of doctors and ACS, nursing work was understood as the one going to home visits the most and following the ACSs more closely. *The nurse gives me a lot of basic information*, says doctor *João*. Nurse Daniela's perception of her performance is different from that observed by doctors and ACS: *The doctor focuses on his biomedical part. In nursing care, we try to focus on a particular therapeutic project [...] to attend holistically according to the user's needs.* In this discourse, nursing work reflects intermediation linking the doctor's biomedical knowledge and ACS in the community. The meaning attaching to the nursing work as the holder of an expanded clinical view mischaracterizes all ESF health professionals' shared responsibility in the face of the Singular Therapeutic Project. Care management must be jointly produced and managed among all family health professionals.

Doctors *Laura* and *João* are residents. They stay for two years in the same territory and health facility and build bonds with staff, users, and the community. When the residency ends, they are disconnected from the community, breaking the bond, compromising work continuity, and the therapist-patient relationship. This is different from contracted professionals, such as ACS and

nurses, who establish themselves in the community for a longer time and have a more significant opportunity to build bonds.

Doctor *João* considered: *the family doctor does not treat older adults only.* In this case, *João* refers to the wide range of care demand from pregnant women, children, and even older adults. The number of patients under the responsibility of the health team to which he belongs had around 5,000 patients. Dr. *João's* statement points to multiple demands, which implies difficulty addressing specific situations such as dementia, which can contribute to the underdiagnosis of dementia, as doctors are responsible for the diagnosis of service users. The issue of underdiagnosis studied by several authors¹⁴⁻¹⁹ involves low quality in the registration and screening of dementia. Difficulties in differential diagnoses, service practice features, and doctors' attitude in screening cases, can also affect underdiagnosis.

Doctor *João* reports: *the doctor can recognize and make the diagnosis, but some diagnoses are required from neurology*, showing the need for a referral and counter-referral care network. Doctor *Laura* summarizes the family doctor's care to the demented older adults: *avoid the consequence of the consequence, that is, addressing secondary and tertiary prevention, with the comorbidities resulting from the symptoms and the aging process.* *Laura* points out the need for more direct and specific intervention and family education to avoid confrontations and accidents. She emphasizes in her statement: *ESF care for all, not just for older adults.*

From the perspective of ACS *Leticia*: *the doctor sees that the patient requires a medication; he transcribes the medication prescribed by the other doctor (specialist)*, a perception of the medical practice associated with the prescription and transcription of medications. The short time that the resident is established in the territory and the high demand from users can impact the limitations and quality of care.

Another issue reported by the professionals was the lack of a Family Health Support Center (NASF) in the facility studied. The issue of support for health professionals was also addressed in research^{20,21}, showing that it would be a facilitating factor to transform the individualized practice of family doctors into a more comprehensive, systematic and interprofessional practice, for greater recognition of programs and services available and referral and reinforcement of early dementia detection. The NASF team should include psychologists, physical educators, occupational therapists, physiotherapists, speech therapists, geria-

tricians, and psychiatrists⁸. The professionals were unable to explain the reason for not being able to count on these professionals for the demands accepted by this team.

Conceptual axis – the ESF and the demented older adult

Signifying Nuclei: perceptions about dementia, diagnosis, and care demand

Dementia is a public health issue²². Initially, it is characterized by intense psychological suffering in the face of the loss of self-awareness. Disease progression and the cognitive difficulties of memory, reasoning, and language hinder older adults' expression about their internal emotional state. Neuropsychiatric manifestations emerge as an aggravating factor²³ due to disease progression.

Doctor *Laura* highlights palliative care as some sort of dementia care. The palliative perspective ends up sentencing older adults from their diagnosis, as they no longer receive care and stimulation that delay the progress of the disease and contribute to improving emotional and relational aspects. Ballroom dancing, taekwondo, handicrafts, and a gym for seniors are activities developed in the ESF, but demented older adults are excluded.

Nurse *Daniela* explains that *the disease classification must not exceed the human being behind the disease*, and then says: *am I talking to the wind?* Translating the feeling of strangeness when dealing initially with the demented older adults, which ends up producing preconceived ideas about the potentialities and possibilities of older adults, who, even in moderate stages with caregivers' help, can participate and be stimulated in various activities.

ACS *Maurício* associates the cases of dementia with the difficulty of waiting and going to the health facility, which is a reality in advanced cases, emphasizing the relevance of home care in these cases. According to ACS *Letícia*, dementia is still understood as a concern of secondary and tertiary care: *they usually already take medications, have been to the neurologist, follow them up somewhere else, but as we are only part of general practice, they stay here*. The respondent has a history of working in hospitals. Her understanding affirms that the hospital-centric view persists, and dementia is restricted to the biological factor. This limited perception about the possibilities of ESF's work in these cases minimizes the service's potential in the face of the demented older adults and their families. Dementia is a disease that transcends the bio-

logical condition. It affects older adults emotionally, has a considerable impact on family dynamics and, especially, on the family caregivers providing care to older adults²³.

Doctor *Laura* points out that in the ESF: *there is no need to refer because the ESF has the NASF and the multidisciplinary matrix support*. However, nurse *Daniela* points out that *no NASF team is supporting the facility*. The facility's work dynamics in dementia cases seem conflicting. Let us see: ACS *Maurício* reports that referrals are made to specialties in dementia cases, while physician *Laura* supports her theoretical statements about NASF support and multidisciplinary matrix support in complex cases, and nurse *Daniela* brings up the practical issue of the facility's fragility due to the lack of NASF's service. She also recalls that if ESF, as primary care, aims to reduce the need for older adults to remain attended in high-complexity health services, NASF's presence could consider this objective and highlights the need for multidisciplinary in primary care, besides doctors, nurses, and community health workers.

Noteworthy is that no situations in which the psychosocial care network or other health support and care support networks were used to provide comprehensive care were reported throughout the professionals' discourse. The mentioned referrals were related to health specialties addressing the disease's physical demand, such as neurology.

In a diagnostic perspective, doctor *Laura* considers that *the symptoms can be perceived in three ways: complaint of the elderly user and the relative and perception of the health professional when following the family longitudinally, recognizing the changes and the typical statements of the onset of dementia*. Doctor *João* describes that the demand arises *in the complaint that the patient forgets something, sees changes in the patient, or thinks it is the patient making a scene*.

The interviewed doctors mentioned applying the Mini-Mental State Examination (MMSE) screening tests for diagnostic evaluation in case of suspected dementia. Doctor *João* says: *I like to refer the patient to neurology for evaluation in the diagnosis and during care*. Teipel et al.²⁴ showed the importance of using a test to assess symptoms in demented patients, such as neuropsychiatric inventory (NPI), MMSE for global cognition, QoL-AD for quality of life, the scale of Resource Utilization in Dementia (RUD) for dementia costs and a scale to assess caregiver stress.

ACS *Letícia's* statement exemplifies how walk-in user demands arise: *they look for me and say: look, my father went to the neurologist and asked for*

a tomography. Therefore, she refers to the demand for tests, including those who visit other outpatient supplementary health services or seek the medication that neurologists prescribed and are provided by the health facility.

The ESF is still perceived according to the classic model of care for diseases in their walk-in demands, corroborating the criticism of Sousa and Hammann²⁵ when they affirm that health actions are still sustained on the tripod doctor, equipment (tests and procedures) and medicines, and fail to change the organizational logic of health services and systems.

Conceptual Axis - Limitations of the ESF for the care of demented older adults

Signifying nuclei: Care barriers and proposed interventions

Concerning barriers to care for demented older adults and their families in the ESF, ACS *Letícia* reports that the team is reduced, mainly because few medical residents carry out home visits. In the same vein, doctor *João* emphasizes the doctor's full schedule [...] the number of patients with other diagnoses, unfortunately, ends up being more important than dementia. *João* reports that there is a need to cancel home visits to demented older adults in several situations due to more acute diseases, such as high-risk pregnant women.

Nurse *Daniela* understands the difficulties related to humanization as a barrier in the face of an intense work routine with indicators and monthly care goals to be met by professionals. She realizes that, on the one hand, it is good to have goals to guide each line of care. However, on the other hand, it is bad because of the pressure to meet goals and not lose the job. Given this condition, the work ends up focusing on patients' pressing demands: *So, you need a prescription? There you go. Take it.*

ACS *Maurício* highlights the problems older adults face when they are referred for treatment, such as physiotherapy in distant places due to the lack of a close care network, and not getting around by bus or long journeys, and often not having financial resources for commuting.

Doctor *João* finds it difficult to partner with the caregiver: *sometimes, you try to keep in touch with the family, and it takes a year.* He reports situations during home visits in which, in his conception, he does not consider it as negligence but realizes that many relatives view the care of older adults as a burden. The huge demand for care and the lack of a multidisciplinary team face health issues of

the older adult's family, which need psychosocial monitoring to be supported, oriented, and cared for, preventing violence against older adults. *Minyo*³ points out that intrafamily violence is difficult to diagnose. According to the complaints, older adults often deny it, and negligence, psychological, financial, and property abuse are the most common.

The ACS are present in the community and the home visit. They perceive the changes established in the family dynamics. According to *Maurício*, some older adults: *sometimes get aggressive because they don't want to bathe, and the relative has to get around that situation; it is challenging for the caregiver.* The difficulties in understanding dementia, often due to lack of education and the family's socioeconomic limitations, are described by doctor *Laura* as hurdles to providing adequate care.

The act of caring gradually becomes a complex activity. Challenging feelings emerge, causing deprivation and modifying the caregiver's lifestyle. The disease follows a path that transcends the biological event itself, showing psychological and socio-cultural constructions permeated by meanings and interpretations by those who experience and have care relationships with the older adults²⁶. The subjective constructions about care directly impact the quality of the relationship established between caregiver and care; associating care with a burden makes the experience difficult to bear.

In this sense, the respondents brought out in their statements the importance of the bond between health professionals and older adults and their family caregivers. Doctor *João* reports: *when a patient creates a bond with you, he adheres to the treatment much better; when he likes the professional, he feels bad even for not having the treatment [...] he believes in you. He knows that you are there to help him.* Concerning care, *Cecílio*²⁷ points to technical competence, professional ethical posture, and the ability to build bonds as the main elements in the health professional's work.

Nurse *Daniela* highlights the difficulty of building a bond with the demented older adults with cognitive changes preventing communication between professionals and patients. She perceives the strategy of maintaining the bond with the family caregivers, getting closer to the patient, since the relatives can interpret their behaviors and identify their needs: *You do see that he is productive. You speak, you see that no matter how much they forget, they have a reference of yours.*

Family caregivers' care is as paramount as that of the demented older adults in family health care.

ACS Leticia always highlights *'I offer a vacancy in care for the older adult's relatives. I call for a group of hypertensive and diabetic patients: I see the family as a whole'*. Some respondents perceived the caregiver's care as the support of awareness to motivate the treatment of the demented older adults, thus avoiding deterioration of the condition. Doctor Laura realizes that some caregivers have difficulties taking care of themselves and *trying to make the family aware that individual care is required, as is personal hygiene. This is back-breaking work because of those with an older adult in the family life for this*. The doctor reveals that *'my current perspective is very specialized, which is not what I used to think three years ago'*, a change in perspective from her entry into family health.

International surveys²⁸⁻³⁰ showed barriers for comprehensive care that coincided with the respondents' positions and others that seemed essential to mention: communication problems with mental health specialists, time constraints, unfamiliarity with community resources, and professionals' difficulty dealing with changes. Some authors^{29,32} also signaled the need for home care in cases of commuting difficulties. The articulation of a more holistic care model was presented by Apesoa-Varano et al.³³, and the emotional burden and legal issues involved in caring for demented older adults.

In the face of these barriers, some respondents proposed as solutions reducing the number of patients attended by each family health team to 1,500 users, as they could coordinate the reception and strengthen the bond better; the participation of other specialties, such as physiotherapy and psychology in the multidisciplinary team of the primary family health facility for home visits.

Final considerations

The study showed that representations of ESF professionals are directly related to the position held by professionals. Professionals described the ACS as the thermometer and eyes of the facility. Doctors perceive themselves as in great demand and are seen as biomedical knowledge holders and medication prescribers, while nursing is seen

as the mediating professionals between ACS and doctors.

The dementia process significations reflect the most advanced levels of the disease, and the care provided is seen as palliative. Regarding the diagnosis, the doctors interviewed mentioned the mini-mental screening test, the attention to the complaints of older adults, relatives, and health professionals' perception when monitoring the family. The doctors highlighted the importance of the neurology referral network.

The walk-in demands of older adults and their families are still sustained on the tripod doctor, equipment (tests and procedures), and medicines. The family caregiver's difficulties in understanding dementia, the perception of care as a burden, and socioeconomic limitations were aspects described as dementia intensifiers. The establishment of a bond between professionals, family caregivers, and older adults was perceived as a vital emotional health care device for monitoring dementia cases. Some professionals perceive that family caregivers abdicate themselves as they care for others, while others understand the care provided to the family caregivers to motivate them to keep caring for older adults.

The huge demand for care and the priority given to acute situations, the lack of support professionals, such as psychologists and physiotherapists, difficulties perceiving the singularity, and building the bond were perceived as barriers in dementia care. Another point was the failure to establish a care network with other public, private, or community services.

Theoretically, family health care is a public health device that can intervene and provide comprehensive care to the demented older adults and their relatives as it views the "individual in a relationship", as opposed to the "biological individual" mentioned by Merhy⁹. However, the service practice analyzed in this study shows that the hegemonic biomedical model still dictates the rules in the EFS work process. The huge care demand for team care and the focus on the tripod medication, tests, and doctor, the lack of NASF's support, psychosocial care network, and the possibility of establishing a community care network end up limiting care providing palliative care measures.

Collaborations

HG Nascimento and AEB Figueiredo participated in all stages of preparation of the article.

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