

Ageing and dementia: what do community health workers know?

ENVELHECIMENTO E DEMÊNCIA:
O QUE SABEM OS AGENTES COMUNITÁRIOS DE SAÚDE?

ENVEJECIMIENTO Y DEMENCIA:
QUÉ SABEN LOS AGENTES COMUNITÁRIOS DE SALUD?

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ABSTRACT

The objective of this qualitative study was to assess the knowledge of community health workers (CHW) with respect to aging and dementia, with the purpose of assisting the implantation of caregiving services focused on dementia, in a city in the State of São Paulo. All ethical guidelines were followed. In all, 51 CHW were evaluated. Semi-structured interviews were conducted. The data analysis was based on content analysis. In response to the question, *What does elderly mean, for you?*, the majority of the workers associated old age with chronologically advanced age and with negative aspects of aging, such as physical and social dependence. With respect to the concept of dementia, the majority of those interviewed defined dementia as a biological problem that affects the brain, compromising memory functions and resulting in dependency. The results demonstrate the need for an educational program for CHW, in the area of gerontology.

KEY WORDS

Aged.
Aging.
Dementia.
Family Health Program.
Community Health Aides.

RESUMO

Trata-se de um estudo qualitativo cujo objetivo foi identificar o conhecimento que os Agentes Comunitários de Saúde (ACS) apresentam sobre envelhecimento e demência, com a finalidade de subsidiar a implantação de uma linha de cuidado à demência em um município paulista. Todos os cuidados éticos foram observados. Os sujeitos foram 51 ACS. O instrumento de coleta foi a entrevista semiestruturada. A análise foi fundamentada na técnica de conteúdo. Com relação à questão *o que é idoso para você*, a maioria dos agentes associam aspectos negativos do envelhecimento à idade cronológica, como dependência física e social. Com relação à concepção de demência, a maioria dos entrevistados a define como um problema biológico que afeta o cérebro, compromete a memória e causa dependência. Os resultados apontam para a necessidade de um programa de capacitação dos agentes em gerontologia.

DESCRIPTORIOS

Idoso.
Envelhecimento.
Demência.
Programa Saúde da Família.
Auxiliares de Saúde Comunitária.

RESUMEN

Se trata de un estudio cualitativo, cuyo objetivo fue identificar el conocimiento que los Agentes Comunitarios de Salud (ACS) presentan al respecto de envejecimiento y demencia, con la finalidad de impulsar la implantación de una línea de cuidado de la demencia en un municipio paulista. Todos los cuidados éticos fueron observados. Los sujetos fueron 51 ACS. El instrumento de recolección de datos fue la entrevista semiestructurada. El análisis se fundamentó en la técnica de contenido. En relación a la pregunta *¿qué es ser anciano para usted?*, la mayoría de los agentes asociaron su respuesta con la edad cronológica y aspectos negativos del envejecimiento, como dependencia física y social. Al respecto del concepto de demencia, la mayoría de los entrevistados la definió como un problema biológico que afecta al cerebro, compromete la memoria y causa dependencia. Los resultados indican la necesidad de un programa de capacitación de los agentes en gerontología.

DESCRIPTORIOS

Anciano.
Envejecimiento.
Demência.
Programa de Salud Familiar.
Auxiliares de Salud Comunitária.

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INTRODUCTION

The Family Healthcare Program (FHP), proposed by the Federal Government as a strategy for the implantation of the Single Healthcare System - Sistema Único de Saúde, has demonstrated the importance of the approximation between healthcare professionals and families⁽¹⁾. The lack of knowledge about topics related to aging may contribute for the provision of poor quality care⁽²⁾. If these healthcare workers are prepared to differentiate aspects of the aging process from pathological aspects, they will certainly be able to contribute with earlier detection of health problems in elderly patients.

Among the diseases affecting the elderly, dementia deserves a special mention since it interferes in their functional capacity. Estimates point that the number of cases of dementia in Latin America will increase 393% by 2040. In Brazil, the problem affects nearly one million people. More cases of dementia mean higher socioeconomic costs, which is a matter of concern for public institutions and governments. Studies focusing on healthcare policies and actions provided for this population are highly relevant⁽³⁾.

The Community Healthcare Agent (CHA) is an important figure in the FHP. The CHA is the person responsible for linking families to the healthcare service, visiting each household at least once a month, mapping each area, registering families and encouraging the community⁽¹⁾. The CHA may either be members of a FHP team or the Community Healthcare Agents Program (CHAP), created in 1991 and considered part of the FHP in cities where only the CHAP is present. The basic attributions of the CHAs, detailed in 33 items, are established in Regulation GM/MS #1886, passed in December 18th, 1997. These include developing activities to prevent diseases and promote health by means of individual and collective educational actions with the families under their responsibility, addressing human rights and encouraging community participation in actions focused on improving quality of life⁽⁴⁾.

Inspiring trust in the community and having leadership characteristics are good prerequisites for the CHA. With such qualities, the agents become special workers, who know the reality of their community, the problems and priorities of the users. These qualifications, in principle, are more important than technical qualifications, acquired afterwards in training sessions⁽⁵⁾. *Belonging to the community*, as shown by the CHAs, makes it easier to bond with the community, which enables the construction of healthcare education processes⁽⁶⁾.

Opposed to the bond shared with the community and the prestige and power conferred by the population, the CHAs deal with the pressure of people dissatisfied with the healthcare service and with the efforts of community dwell-

ers that attempt to gain advantages in the access to the service⁽⁴⁾.

Studies about the conceptions of workers involved in the provision of healthcare for elderly people may contribute for the implementation of public policies. A study focused on analyzing the conceptions of the community healthcare agents show negative opinions about aging, and relations with elderly people marked by complaints about falling ill. When the agents were asked about what they would like to know about elderly people, the answer was *everything*. This shows that the community agents need information about aging and the pathologies that are associated with this process⁽⁷⁾.

Considering that healthcare education is one of the attributions of the CHA, we acknowledge the involvement of the agents in healthcare and education, which strengthens the importance of knowing their practices and conceptions of education and health - after all, *the conceptions about the health/disease process give meaning to the actions of the professionals*⁽⁶⁾. Therefore, the way in which the healthcare professional understands aging is reflected in the care provided⁽²⁾.

Studies about the conceptions of workers involved in the provision of healthcare for elderly people may contribute for the implementation of public policies.

One of the objectives of Permanent Healthcare Education, proposed by the Ministry of Health, is the possibility of transforming the professional practices and must consider people's prior knowledge and experiences⁽⁸⁾.

Therefore, identifying the knowledge of the CHAs about aging and dementia seems to aid in the comprehension of their actions and contribute with the creation of a healthcare education program that regards the CHAs' prior knowledge. Knowing their prior conceptions and knowledge, respecting their identity and autonomy is a fundamental step to create an adequate process of qualification, making the agents participate in the construction of knowledge.

OBJECTIVES

Identifying the knowledge held by Community Healthcare Agents (CHA) about aging and dementia, in order to implant a healthcare program focused on dementia in a city in the state of São Paulo.

METHOD

This is a qualitative, exploratory-descriptive, cross-section study.

Characteristics of the study site

The study was performed in a city in the state of São Paulo, in its central region, founded in 1857 and known as

the *capital of high technology*. When the study was performed, the city had eleven Family Healthcare Program units and twelve Family Healthcare Teams, with 4713 people over 60 years of age. Each unit had a team with a general practitioner, a nurse, a nursing assistant and six community agents. Some of the units also had a dentist.

Fifty-one community healthcare agents from ten units of the Family Healthcare Program of the city were interviewed, out of 60 CHAs in the city in 2006.

Ethical Procedures

All ethical procedures required for research on human beings were followed in this study. The Review Board (file 055/2006) approved the project.

Data collection occurred after the subjects provided written consent. Numbers replaced the agents' names in order to ensure their anonymity.

Data collection procedures

An instrument was elaborated for data collection. It underwent a pilot study meant to verify whether the questions were understandable. For the elaboration of the instrument and the analysis of its applicability, members of a gerontology research group registered in the CNPq Research Group Directory helped the authors.

Data were collected in meetings with the community healthcare agents according to a previously elaborated script. The agents were oriented about filling out the instrument and the researchers remained with the agents during data collection in order to solve possible doubts.

Data such as age, gender, education and career length in their current position were included for the characterization of the workers. Regarding the knowledge they had about aging and dementia, the data collection instrument covered two discursive questions: 1.) What is an elderly person for you? 2.) What is dementia for you?

Data Analysis

Data were coded and sorted into categories, according to the Content Analysis - Thematic Analysis model⁽⁹⁾.

RESULTS AND DISCUSSION

Most of the 51 community healthcare agents (CHA) are female (84%); average age is 29 years, varying from 19 to 58; most agents have full high-school education (50%). The career length of the agents at the unit varied between 1 and 3 years (60%), and 32% have been working in the area for less than one year. Forty-four agents (88%) mentioned not having a course in the Gerontology area. Most of them (78%) reported having many contacts with elderly people, but little specific knowledge; only one agent mentioned having enough knowledge and plenty of contacts with elderly

people. These reports are extremely valuable for the Permanent Education process, as they show the importance of combining prior knowledge to the informative activities about the aging process, as well as values and habits, symbolic models that guide the specific practices of the agents towards the elderly.

Initially, the focus lied on the apprehension of the agents' existing conceptions about the concept of elderly. When answering the question *What is an elderly person for you?*, most interviewees described the elderly person according to a chronological perspective, people at an advanced age, over 60 years old, according to the World Health Organization (WHO) definitions.

Many elements are mixed with chronologic age to determine differences among the elderly, such as the socio-economic context, gender, health and personality (10). The aging process has particular characteristics for each individual, with some looking old at age 50 and others looking jovial at age 65. One of the agents' reports mentions chronologic age using a lower age range than the one defined by the WHO, as seen:

The person who reached old age, such as over 45 or 50 years old. (CHA 39).

Most reports showed negative opinions about aging, associating it to losses and presenting perceptions of old age as a synonym of helplessness, poverty and abandonment⁽¹¹⁾. Negative concepts were markedly present in this study, which corroborates with other findings in literature.

A study on the elderly people in a Social Center for Elderly People in Goiania-GO, whose focus was to study aging according to the perception of the elders themselves, found that, although positive and negative aspects were highlighted, the perspective of aging is highly influenced by society, which has a stereotyped view of aging. Often, the view of the elders themselves does not correspond to their state. There is a concept that says that old people cannot learn, wear fashionable clothes, dance, wear make-up, etc. The elders also mentioned decreased memory and the presence of diseases and pain as being typical of aging⁽¹²⁾.

A study with 189 children in elementary school with the purpose of building an Attitude Scale Regarding Aging for children asked them: *What is being an elderly person like?* Many answers were given, highlighting positive aspects such as being an exemplary person, being nice, good, caring, special, among others; but also negative aspects, such as being angry, moody, slow, unhappy, fragile, old-fashioned, rude. The infantilization of elderliness was also noted in the children's speeches, as they referred to elderly people with diminutive, patronizing adjectives⁽¹³⁾.

Infantilization of old age was also noted in interviews with employees of a long-term elderly care institution in a city of the state of São Paulo⁽¹⁴⁾. Most agents presented the association between aging and declining health. However, declining health could be associated to poor socio economic conditions.

[...] they start having some health problem that is typical of aging [...] (CHA 22).

[...] and have a lower life expectancy, often due to socio-economic causes (CHA 17).

With the Industrial Revolution and the arising of a capitalist society, the elderly had their role reduced as an economically active population, since this group has a lower capacity of producing goods. This context generated a view of the elderly as someone who is non-productive.

However, within a context of high unemployment in Brazil, the income received from the Social Security Service in Brazil is the main source of income for the family⁽¹⁵⁾, revealing a role of the elderly in the family which was not mentioned by any of the agents.

In some of the reports, the agents showed their perceptions about the emotional characteristics of the elderly:

[...] that person who starts to show signs of loneliness [...] (CHA18)

[...] they need attention much more than they need medication [...] (CHA 49).

Another conception shown by the agents was the association of elderliness and childhood, below:

[...] when a person starts presenting childlike characteristics (2nd infancy) (CHA 18).

[...] they become children again (CHA 49).

This association presented by the agents is usually determined by issues related to dependency, a perspective of the elderly person as someone who needs tutelage, like children⁽¹⁴⁾. The idea of dependent behavior was present in other reports, of agents who defined elderly as someone who needs to be taken care of.

For me, an elderly person is someone who needs special care [...] because they often cannot take care of themselves or make ends meet (CHA 44).

The agents also showed another necessity of aging, highlighting the importance of giving more attention to elderly people:

[...] they need care and dedication (CHA 29).

[...] and deserve more and better care from the CHAs (CHA 11).

The agents also associated the elderly people's necessity for care with the consequence of pathologic aging:

They are people with health problems who cannot provide for themselves. They always need someone to be with them or guide them [...] (CHA 08).

Dependency can be determined according to several variables, from functional incapacity due to disease to an inadequate social and economic environment.

In a study about dependence and autonomy, the authors explain the theory of learned dependency, with its

social microcontexts, with a plethora of attitudes that strengthen behaviors of dependency presented by the elderly. The authors demonstrate the importance of offering aid that will encompass the possibilities of the dependent elderly person, avoiding the creation of overprotective environments, where autonomy is not encouraged⁽¹⁴⁾.

The exaggerated conception of the elderly person as a dependent individual may either result in overprotective behaviors, which strengthen their condition of dependency, or result in situations of negligence and lack of attention towards them, ignoring the demands of the dependent elderly for adaptations to perform his or her activities.

Still on the care provided to the elderly person, the family is worth noting, which culturally and legally takes on an important role in the provision of care. Some agents mentioned the family and its role in healthcare in the following reports regarding the elderly:

[...] they feel like they're a burden for the family (CHA 03).

[...] most were abandoned, seen as burdens for the family (CHA 37).

Some of the interviewees showed positive conceptions for aging, with the positive reports predominantly associated to increased life expectancy, as in the following definitions:

Being elderly, for me, means having the knowledge of a whole life [...] it is the experience passed from generation to generation (CHA 47).

It is a person who has already undergone several experiences (CHA 46).

For the most part, they are sweet and caring [...] (CHA 49).

These definitions of an elderly person value and show respect towards aging. Regarding the conception of what dementia is, most interviewees described dementia according to the biological perspective of the disease, defining it as something that affects the brain and the nervous system:

For me, dementia is the weakening of the brain, an affliction of the nervous system [...] (CHA 38).

Every cell takes part in the process of aging, although neurons are worth of note. As they have no efficient restorative capacities, damage to these cells may result in *marked functional losses*, putting the nervous system at risk. As such, physiological and functional changes can be observed in the brains of patients with neurodegenerative diseases during the aging process⁽¹⁶⁾.

Dementia somehow *affects the nervous system*, as reported by the CHA, but, in some cases, the structure of the system is not affected⁽¹⁷⁾.

The term dementia comes from the latin *de* (deprivation) and *mens* (intelligence). Even without knowing the etymology of the word, some of the agents associated de-

mentia with something that hinders reasoning, as well as describing the disease as a mental condition.

The lack of critical reasoning, mental disorders (CHA 20).
It is a serious mental condition (AC 07).

Dementia is indeed a mental condition and a public healthcare problem. In 2004, the cerebro-vascular diseases, such as dementia, caused 11.7% of the deaths in people over 60 years of age⁽¹⁷⁾. One of the CHAs had the following definition for dementia:

People with any kind of mental condition (CHA 16).

There are several mental problems or disorders that have no relation with dementia. Dementia is a syndrome, i.e., a group of signs and symptoms, characterized by the development of multiple cognitive deficits (aphasia, apraxia, agnosia or disorders in executive functions), interference in social and professional activities and reduced memory⁽¹⁸⁾.

Some of the agents mentioned memory afflictions:

When the individual starts to present memory lapses [...] (CHA 37).

It is when people start to forget about situations [...] (CHA 10).

Many elderly people report problems associated with memory, but this does not mandatorily implies in objective memory loss⁽¹⁶⁾. Memory alterations may also be associated with difficulties to pay attention to something, or as a consequence of the use of medication such as benzodiazepines and neuroleptics. Authors mention that complains about memory problems among the elderly have caused a high amount of false positives, characterizing what they define as a *serious contemporary medical problem*⁽¹⁷⁾.

However, the diagnosis of dementia does not happen only according to memory analysis. The diagnosis of dementia is eminently clinical, following diagnostic criteria (DSM-IV). The cause of dementia depends on complementary investigations - laboratory exams and neuroimaging⁽¹⁷⁾.

In the clinical diagnosis, the presence of functional alterations is usually investigated. The community agents associated these alterations with dementia, matching functional incapacity with the condition of dependence:

[...] they depend on others to keep on living, that is, they aren't fully capable anymore. (CHA 48).

A disease that makes people unable to perform usual things, and thus they become dependent on others [...] (CHA 50).

Other agents associated functional decline directly with dementia:

It is a disease that interferes in the functional capacity of the elderly (CHA 28). [...] lose their movements (CHA 42).

Functional capacity is the ability of maintaining mental and physical skills to lead a life without dependency and with autonomy. This maintenance of abilities is affected by dementia.

The syndrome affects both the Instrumental Activities of Daily Life (IADLs), such as taking a bus, money management, shopping, and the Basic Activities of Daily Life (BADLs), such as bathing, dressing, eating, toileting, walk short distances and sphincter control (continence). Elderly people diagnosed with dementia first tend to lose the IADLs, as most of these activities require more skills than the BADLs, usually performed at the elder's own home⁽¹⁸⁾.

Changes in behavior, an important aspect of the syndrome, was reported by the CHAs:

[...] inadequate behaviors, out of what is considered normal (CHA 06).

Some agents reinforce this opinion, although the focus is on changes in social behavior:

[...] interference in the ability to socialize with the environment they live in (CHA 27).

They are those who have difficulties in everyday relationships (CHA 11).

The behavioral and psychological symptoms of dementia (BPSD) include restlessness, perambulation, aggressiveness, sleep disorders, repeatedly asking questions, among others. They cause much distress on the caregivers, resulting on emotional overload⁽¹⁹⁾. With the purpose of understanding the process of experiencing the provision of care for demented elderly people, family caregivers of elderly people diagnosed with Alzheimer's disease registered in a Family Healthcare Unit in a city of the state of São Paulo were interviewed. The respondents report that the elder's behavioral alterations cause great emotional impact on the caregivers⁽²⁰⁾.

Still, regarding the symptomatology of dementia, some agents showed a perception about the affection of the demented patient:

[...] they lose self-esteem [...] need attention [...] (CHA 50).

Alterations related to affection, added to behavioral alterations, often lead to difficulties in establishing the diagnosis between dementia and depression, especially since depression in elderly patients may cause loss of attention, reduction in mental capacity and memory deficits, symptoms that are common in dementia. It is worth noting that altered cognitive behaviors may result from depression instead of dementia, as well as depressive symptoms may stem from a cognitive deficit⁽²¹⁾.

Finally, it is interesting to analyze the report of some agents about the age range afflicted by dementia:

This disease is more common on elderly people [...] (CHA 31).

I know it is a disease of elderly people (CHA 34).

Understanding aging only as a pathologic phenomenon may cause less-than-adequate comprehension about important symptoms presented by the elderly person, with the erroneous impression that this is typical of the age⁽²²⁾.

The concerning aspects of the perception between elderly people and dementia is the acceptance of the symptoms of the disease as common and typical of age, which may delay visits to a healthcare professional and mask the disease.

CONCLUSION

It is possible to identify the weak and strong aspects of the knowledge of the CHAs about certain subjects, and as such think about strategies to better qualify them in their work at the FHP.

In this study, we observed that the conceptions of aging presented were mostly chronological and negative. This negativity was expressed with reports associating from aging, declining health and dependency to reports characterizing the elder as a "burden for the family".

The construction of a positive image about aging is still a challenge, since the CHAs have daily dealings with elders that are predominantly characterized by complains about the disease. The work of the CHAs must encourage the social insertion of elderly people, and, as such, the government needs to invest in the education of subjects that are capable of dealing with aspects related to aging.

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