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Capacitating community health workers to detect dementia at the mild stage

Capacitação de agentes comunitários de saúde para a detecção da demência na fase leve

Capacitación de agentes comunitarios de salud para detección de las demencias en la fase leve

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ABSTRACT

Objective: to evaluate the continuing professional development (CPD) process in capacitation of community health workers (CHWs) to detect early dementias. **Method**: this descriptive study compared the performance of eight CHWs from a Basic Health Unit in Santos, by applying semi-structured questionnaires before and after a CPD workshop held in 2018, after approval by the research ethics committee. The data were processed using thematic analysis. **Results**: the CHWs' lack of knowledge about dementia points to the need to invest in continuing professional development as an important tool to be used to detect early cases. **Conclusion**: continued professional development can contribute to identification of more cases in the early stages of dementia in primary care, so that necessary referrals and possible treatment are initiated early to benefit individuals and/or their families.

Descriptors: Community health agent; dementia; permanent education; health policy.

RESUMO

Objetivo: avaliar o processo de educação permanente na capacitação de agentes comunitários de saúde (ACS) para a detecção de pessoas com demência na fase leve. **Método:** descritivo, comparando o desempenho dos sujeitos antes e após a oficina de aprendizagem. Após a aprovação pelo Comitê de Ética em Pesquisa, foi realizada oficina de capacitação com oito ACS de uma unidade básica de saúde, da cidade de Santos, em 2018. Antes e após a oficina foram aplicados questionários semiestruturados. Os dados foram tratados a partir da análise temática. **Resultados**: a falta de conhecimento sobre a demência aponta para a necessidade de investimento em educação permanente dos ACS como uma importante ferramenta a ser utilizada na detecção de casos iniciais. **Conclusão:** a educação permanente pode contribuir para o maior número de casos identificados nas fases iniciais da demência na atenção básica de forma que os encaminhamentos necessários e tratamentos possíveis sejam iniciados precocemente de forma a beneficiar pessoas e/ou suas famílias.

Descritores: Agente comunitário de saúde; demência; educação permanente; política de saúde.

RESUMEN

Objetivo: evaluar el proceso de educación permanente en la capacitación de agentes comunitarios de salud (ACS) para detección de personas con demencia en la fase leve. **Método**: estudio descriptivo, comparado el desempeño de las personas antes y después del taller de aprendizaje. Tras la aprobación del Comité de Ética en Investigación, se realizó un taller de capacitación con ocho ACS de una Unidad Básica de Salud de la ciudad de Santos, en 2018. Antes y después del taller, se aplicaron cuestionarios semiestructurados. Los datos fueron procesados desde el análisis temático. **Resultados**: la falta de conocimiento sobre la demencia apunta hacia la necesidad de inversión en educación permanente, por parte de los ACS, como una importante herramienta a ser utilizada en la detección de casos iniciales. **Conclusión**: la educación permanente puede contribuir a la identificación en la atención básica de mayor número de casos en las fases iniciales de la demencia de forma a que las derivaciones aplicables y los posibles tratamientos se inicien precozmente para poder beneficiar a las personas y/o a sus familias.

Descriptores: Agente comunitario de salud; demencia; educación permanente; política de salud.

INTRODUCTION

With the demographic transition, by 2025 Latin America will have about 57 million people over 60 years old[1]. Estimates indicate that in 2010 there were 35.6 million people with some subtype of dementia worldwide. About 7.7 million new cases arise each year, which means a new case every four seconds somewhere in the world. The projections of prevalence and incidence indicate that this number will continue to grow, particularly among the elderly, as well as in countries in demographic transition, such as Brazil[2].

In the city of Santos, data published by the Municipal Government indicate the existence of approximately 85 thousand elderly in the city, representing about 20% of the total population[3].

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Thus, it is essential that community health workers (ACSs) have access to continuing health education (CHE) so that early detection of mild dementia can be improved, based on meaningful learning and the establishment of pedagogical environments to discuss practices, aiming at evaluating, reviewing and transforming the current work processes.[4]

This study aimed at analyzing the ACS training workshop for qualification and identification of cases of mild dementia.

LITERATURE REVIEW

Caring for people with dementia is a primary care (PC) challenge[5]. Worldwide, dementia has been underdiagnosed and the diagnosis is usually made at an advanced stage of the disease in the specialist clinic. This fact has multifaceted causes and involves from the lack of education and training of health professionals inserted in the PC to the screening, diagnosis and pharmacological/non-pharmacological treatment of new cases[6]. Even in developed countries, only one fifth of the diagnoses are routinely recognized and documented in primary health care[7].

For this to become a reality, there must be a health policy, programs and health strategies that address the broad and complex impact of this disease on society.

The Municipal Health Secretariat (MHS) of the city of São Paulo (SP) implemented a technical area of health for the elderly, which has as one of its duties the creation and implementation of training courses in the area of aging and health of the elderly, from continuing education to higher, middle and basic levels[8].

The ACS as a family health strategy (FHS) professional is an important link with the community, as they are responsible for home visits, mapping areas, registering families and promoting the exchange of knowledge between people in the community and the other health care professionals[9,10]. The professional should be trained in the different aspects of the health-disease process, including biomedical knowledge and information on the interaction that they should have with families and their needs.

Thus, there must be a constant movement to guarantee these professionals the possibility of fully developing their potential, encouraging them to do participatory, reflective and transformative community work[11].

The importance of this professional's qualification and training for the detection of mild dementia can facilitate access to information, guidance and referral, support and care for people with possible dementias and their families[12].

METHODOLOGY

The descriptive method with intervention (workshops) was used, comparing the professional's performance before and after the workshop. An ACS training workshop was held in the city of Santos to provide care for people with dementia and their families. The project was submitted to and approved by the Coordinating Office of Continuing Health Education (COFORM) of the city of Santos and by the Ethics Committee for Research with Human Beings under Opinion No. 2,577,483.

Then, the coordination of the primary care unit (PCU) of Embaré was contacted to close dates and verify the ACS' availability. The inclusion criteria were the following: being an ACS from the Embaré PCU, having time available and interest in participating in the workshop, and signing the free and informed consent form (FICF). The exclusion criteria were the following: missing two and/or more meetings, not signing the FICF. Eight ACSs from the unit participated in the workshop after the explanation of the objectives and ethical principles, followed by the signing of the FICF. Four weekly meetings of five hours each were held, totaling 20 hours of training, from April to May 2018. Each meeting addressed central aspects of dementia that were divided into topics according to the purpose of each meeting.

Data was collected through two semi-structured questionnaires (before and after the workshop), with the participants' socio-demographic data, such as age and schooling level, as well as open-ended questions with information on the performance of the ACSs in the primary care unit (PCU), the number of elderly individuals treated in the region and the level of understanding about dementia syndromes.

All the meetings were recorded and transcribed. Thematic content analysis was used following these steps: pre-analysis – articulation of the initial objectives with the research process, to enhance the final result; investigation of the material – delimitation of the eminent contents and the order in which they will be addressed; analysis of the results obtained and interpretation – interrelationship between the results collected and theoretical materials

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previously selected and/or noted by the analysis[13].

The first workshop was attended by the nine ACSs from the Embaré PCU. They were informed about the purposes of the workshop and the ethical principles were specified. In this meeting, the presentation of the members and the explanation of the activities to be developed according to the schedule were set forth, as well as the rules for participation, such as the limit of one absence to receive the training certificate.

The participants were asked to complete the pre-workshop questionnaire. Then, central information regarding dementia syndromes was introduced, such as: definition, presentation of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) III/V, prevalence and incidence in the Brazilian scenario, risk factors, treatment possibilities and diagnosis/prognosis. For this, there was a presentation through a conversation circle. Thus, during the exchange of information, everyone was free to punctuate and/or question unclear aspects[14,15].

In the second meeting, the five participants present justified the absence of the others due to the shifts implemented during campaigns for organization of queues and distribution of passwords.

The topics addressed at this meeting were clinical diagnosis, evaluation, pharmacological and non-pharmacological treatment, prognosis, prevention, stages and classification of the main subtypes of dementia (Alzheimer Disease (AD) dementia, vascular dementia (VD), lewy body dementia (LBD) and frontotemporal dementia (FTD)[16]. Despite the small number, all members participated in the discussions, based on cases of elderly people seen in the facility.

For the third meeting, the Mini Mental State Examination (MMSE) was presented[17]. The eight participants were divided into two groups, with four each, and the examination took 2.5 hours so that everyone could actively participate in the workshop.

Initially, some questions were asked regarding the topics already addressed, in order to clarify doubts about the information previously discussed.

The last meeting was attended by eight ACSs who were again divided into two subgroups. As proposed in the methodology, each ACS answered the post-workshop evaluation questionnaire. Still as a workshop evaluation technique, throughout the meetings, trigger questions were asked to clarify the remaining doubts and enable a better understanding of some information. A space was opened for criticism regarding the workshop's methodology, schedule, times and numbers of meetings. At the closing there was the presentation of age care services and the assistance to their families/caregivers that are available in the Baixada Santista region.

RESULTS AND DISCUSSION

Initially nine ACSs from the Embaré PCU, in the city of Santos, participated in the workshops according to previous consultation of the schedule and available times. One of the participants did not meet the inclusion criteria as he missed two of the meetings due to the fact that he had to work in the influenza prevention campaign promoted by the facility. Of the remaining eight participants, there were seven women and one man.

Regarding the age group, three of the participants were between 40 and 50 years old, two were between 50 and 60 years old and three were over 60 years old. With respect to the length of experience, the eight participants had a mean of 16 years of career, but six of them started working at the PCU/Embaré less than 8 months before this study. That facility covers the regions of Embaré, Macuco and Estuário. Among the ACSs, five provided care to families in the territory of Embaré, two in Macuco and Estuário and one had no defined region.

From the content analysis of the statements regarding the open questions, three thematic categories emerged: the role of the ACS in the detection of mild dementia; the ACS' perception of dementia; and possibilities of articulation of the topic in primary care. The categories are discussed below.

The role of the ACS in the detection of mild dementia

Before the Workshop

The Ministry of Health (MoH) defines the role of the ACS as the employee who facilitates the bond between the families and the health service. Living in the territory makes this approach more feasible[18]. Initially, the ACS' reports corresponded to the importance of their role in the health service for listening and welcoming the citizens:

> *[...] that's why the PCU puts us on the front lines. (ACS 2)*

However, the fact of being in the same territory as the users was pointed as a negative aspect of the profession, as one interviewee reported:

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> *I don't like it. Sometimes people meet me at the market and say: 'look the doctor scheduled me for […]' they don't respect Saturdays, Sundays or holidays. (ACS 3)*

In this study, the workers reported being approached at off-hours as they are easily found by the community to answer questions regarding appointments and examinations. These results are confirmed in other studies[4,9,11].

Despite having their duties well defined by the MoH, a study conducted in Campinas confirmed these findings by pointing out that, in the practice, these professionals work more than previously established[18]. In the proposed workshop, the schedule was changed due to the reorganization of the ACSs for the influenza vaccination campaign.

When asked about the role of the ACSs with respect to diseases common to the aging process, such as dementia, none of the participants could identify any possibility of action in face of this specific demand.

The report made by the *World Alzheimer Report* identifies that lack of knowledge about dementia is part of the public stigma and results in late diagnosis and referrals to appropriate services and treatments[19]. This stigma is also highlighted in the literature on dementia[1,2,5-7,12,20].

After the Workshop

The ACSs understood the importance of their role regarding the issue of dementia by identifying the most common symptoms, cognitive screening and explicit behavioral changes. Seven demonstrated a better understanding of the dementia syndrome, highlighting the possibilities of screening and skills for recognizing potential cases.

> *It will depend on the outcome of the memory test, the observation of the elderly's behavior, the way they talk and what the family says. (ACS 3)*

The application of memory and cognitive screening instruments, as well as an interview with family members and/or caregivers, has been recommended in primary care in order to follow up positive non-dementia cases and referrals to the specialized clinic for those with clinical dementia[21].

With respect to the possibilities to contribute for the diagnosis of mild dementia, of the eight participants, only six answered. Of these, four believed to contribute only with family orientation; one with the screening evaluation, observation of the elderly's behavior and conversation with the family; and another emphasized screening evaluation, referral to the PCU, specialty outpatient clinic and family support. All suggested adding more hours to the workshop for a better use and appropriation of the contents related to the disease.

It was observed that, even after the dynamics offered, in order to teach them, the professionals still did not feel safe to identify and approach users. Possibly, a workshop with 20 hours was insufficient for the complexity of the issues involved in dementia. Another negative factor pointed out was holding the workshop at the time and place of work, as they were constantly being asked to leave the room.

The ACS' perception of dementia

Before the Workshop

The lack of information and training about the disease can generate or reinforce, even in health professionals, false beliefs including that dementia is a common or *normal* disease of the aging process, according to the following report:

> *This is part of the nature of the human being. 90/80 years, it is normal. (ACS 3)*

It is worth mentioning that "the elderly person with suspected dementia, after evaluation at the PCU, should be referred to specialized care, respecting the reference flows"[20: 113]. However, the lack of investment in continuing education aimed at primary care professionals generates a greater search for specialized assistance and, consequently, long queues.

The fact that three of the participants were over 60 years old favored the awareness that dementia is a priority public health problem given the population aging. Here is another statement:

> *[…] then you ask yourself: who will take care of us if I ended up like this? (ACS 5)*

After the Workshop

During the dynamics, they identified situations of routine home visits in which they could use screening tests and family-directed listening for possible follow-ups.

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> *I think one citizen has Alzheimer. He can only remember things about the past. If it's not her [the wife] who tries to bathe him, he doesn't take a shower because he says 'I already showered' but he actually didn't […] (ACS 6)*

At the meetings, it was found that the ACSs commonly associated dementia with the clinical manifestations of other health conditions, such as the *delirium* of an infectious condition:

> *One day my mother was talking nonsense. I thought she had dementia when […] I saw she had a fever of almost 104 degrees. In the emergency room they identified by urine test that she had an infection. It was almost going up to the kidneys [...] after they gave her the medicine she was good again. (ACS 6)*

When asked about how to identify a possible case of dementia, only six answered, and only one showed consistency in the answer, based on the discussions.

The stigma around dementia was evident, as well as the difficulty in understanding the factors involving a *dementia* case and the perception of the family as a fundamental element in this process.

Possibilities of articulation of the topic in primary care

Before the Workshop

In answer to the question *What are the most common health problems of elderly people that you monitor?* the most common answers were hypertension and diabetes, followed by arthrosis/osteoporosis, cerebrovascular accident and, finally, dementia, being mentioned by only one of them.

Regarding the referral of dementia cases to the health network, the answers indicated the following: referring to the general practitioner of the PCU; referring directly to the neurologist; to the Psychosocial Care Center (*Centro de Atenção Psicossocial*, CAPS) and only one mentioned the head nurse as the most feasible possibility to think about actions in the specialized clinic.

> *We don't talk about "squeezing in" here, but they [nurses] have a way to ask this person to go to the clinic immediately. But forward it blocks who goes to the neurologist. (ACS 2)*

A research developed in England has suggested that investments in training primary care professionals can minimize the burden on care for people with impaired memory and cognition in specialized care[22].

After the Workshop

It was possible to identify the awareness of the ACSs regarding the need to articulate this public health problem in primary care. Two of them stated that investments in training workshops are essential; two suggested educational actions to families; and one considered it important to implement a continuing education program for detection of dementia in the primary care. A study identified other innovative practices that meet dementia-friendly communities, such as holding events to inform and raise awareness, and the creation of memory clinics, in which any of the professionals in the staff can be taught to apply cognitive screening instruments[22].

The growing world population ageing and its direct relationship with chronic degenerative diseases such as dementia, have evoked worldwide campaigns by the World Health Organization and the *Alzheimer Disease International* (ADI), to raise awareness among managers as to the implementation of global action plans that may culminate in the creation of public policies on the prevention and early treatment of dementias or be included in other policies already implemented[23].

CONCLUSION

ACS professionals are an important link between the primary health care team and the general population. The high number of elderly in the city of Santos provides estimates of high incidence and prevalence rates of dementias. The training of professionals for the detection of degenerative chronic diseases is essential based on the adoption of continuing education as a fundamental strategy for the re-establishment of training, attention and public policy formulation practices.

The training workshop proved to be a powerful resource in the training of the ACSs for screening and identification people with dementia in the primary care.

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