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Formal caregivers of older adults: reflection about their practice

Acompanhantes de idosos: reflexão sobre sua prática

ABSTRACT

OBJECTIVE: To understand the job function of caregivers of older adults and contribute to the debate on the consolidation of this professional practice.

METHODOLOGICAL PROCEDURES: This is a descriptive, qualitative, and exploratory study. Four focal group sessions were performed in 2011 with 11 elderly companions, formal caregivers of older adults in the *Programa Acompanhante de Idosos* (Program for Caregivers of Older Adults), Sao Paulo, SP, Southeastern Brazil. These sessions, guided by a semi-structured script, were audio-recorded and fully transcribed. Data were analyzed using the Content Analysis technique, Thematic Modality.

RESULTS: In view of considering the caregivers of older adults as a new category of workers, it was difficult to define their duties. The elderly companions themselves as well as the care receivers, their families, and the professionals that comprised the team were unclear about their duties. The professional practice of these formal caregivers has been built on the basis of constant discussions and negotiations among them and other team members in *Programa Acompanhante de Idosos* during daily work. This was achieved via a recognition process of their job functions and by setting apart other workers' exclusive responsibilities.

CONCLUSIONS: The delimitation of specific job functions for elderly companions is currently one of the greatest challenges faced by these workers to develop and consolidate their professional role as well as improve *Programa Acompanhante de Idosos*.

DESCRIPTORS: Caregivers. Professional Practice. Professional Role. Health Services for the Aged. Qualitative Research. Work.

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RESUMO

OBJETIVO: Compreender as funções dos acompanhantes de idosos e contribuir no debate acerca da consolidação dessa prática profissional.

PROCEDIMENTOS METODOLÓGICOS: Trata-se de estudo qualitativo, exploratório e descritivo. Foram realizadas quatro sessões de grupo focal com 11 acompanhantes de idosos das primeiras equipes do Programa Acompanhante de Idosos, em São Paulo, SP, em 2011. As sessões, orientadas por um roteiro semiestruturado, foram gravadas em áudio e transcritas integralmente. Os dados foram analisados por meio da técnica de Análise de Conteúdo, modalidade Temática.

RESULTADOS: Tendo em vista os acompanhantes de idosos como nova categoria de trabalhadores, havia dificuldade na compreensão de suas atribuições, tanto por eles mesmos como pelos idosos atendidos e seus familiares, incluindo os profissionais que compunham as equipes. A prática profissional dos acompanhantes tem sido construída a partir de discussões e negociações constantes entre eles e demais membros das equipes do Programa Acompanhante de Idosos no cotidiano de trabalho, por meio de um processo de reconhecimento de suas funções e diferenciação daquelas de responsabilidade exclusiva de outros trabalhadores.

CONCLUSÕES: A delimitação de funções específicas dos acompanhantes de idosos constitui-se atualmente como um dos grandes desafios enfrentados por esses trabalhadores para o desenvolvimento e consolidação de seu fazer profissional e do aprimoramento do próprio Programa Acompanhante de Idosos.

DESCRITORES: Cuidadores. Prática Profissional. Papel Profissional. Serviços de Saúde para Idosos. Pesquisa Qualitativa. Trabalho.

INTRODUCTION

In emerging countries, the phenomenon of population aging poses great challenges because it occurs in an accelerated and nongradual manner, in contrast to what happened in developed countries.[9] In Brazil, there 20,590,597 people aged 60 years or greater at present,[a] and 1,339,778 of them reside in Sao Paulo city, SP.[a] It is estimated that in 2025, Brazil will be the sixth country of the world with the highest number of older adults.[9]

The challenges include the accumulation of infectious and transmissible diseases as well as chronic degenerative diseases, which become one of the main causes of disability, morbidity and mortality with aging.[9]

This scenario, in addition to structural changes within families, led to the care of older adults via the informal system (voluntary support provided by family, friends, and neighbors)[b] to be insufficient.[4] Care provided by formal caregivers, i.e., workers hired to provide assistance to dependent older adults[b] became one of the complementary alternatives.[5]

In Brazil, the foundation of the *Política Nacional de Saúde da Pessoa Idosa* aimed to qualify the assistance provided to this older adult population, prioritizing the longitudinal care of users, particularly in fragile conditions.[c] It is considered that a fragile older adult meets one of the following criteria: resides in a long-term care institution, has suffered from domestic violence or was recently hospitalized, has functional disability for daily life activities, is bedridden, or has a disability illness.[c]

In this context, healthcare interventions for the older adult population should focus on the maintenance or

[a] Instituto Brasileiro de Geografia e Estatística. Censo 2010. Brasília (DF); 2010 [cited 2012Mar 14]. Available from: http://censo2010.ibge.gov.br
[b] Ministério da Saúde. Portaria nº 1.395, de 9 de dezembro de 1999. Aprova a Política Nacional de Saúde do Idoso, cuja integra consta do anexo desta Portaria e dela é parte integrante. *Diario Oficial Uniao*. 13 Dez 1999;Seção1:20.
[c] Ministério da Saúde. Portaria nº 2.528 de 19 de outubro de 2006. Aprova a Política Nacional de Saúde da Pessoa Idosa.2006. *Diario Oficial Uniao*. 20 Out 2006 [cited 2012 Mar 25];Seção1:142. Available from: http://bvsms.saude.gov.br/bvs/saudelegis/gm/2006/prt2528_19_10_2006.html

improvement of the functional ability, perceived as the competence of sustaining skills for independence and autonomy to execute daily life activities.[b] The latter refers to crucial care, including basic aspects such as personal and instrumental care, e.g., financing and shopping management.[b]

Moreover, to overcome the fragility of older adults and avoid early institutionalization, it is necessary to support families and stimulate the construction and articulation of a social network to be a supporting point for the individual.[c] In Brazil, the assistance of older adults in long-term care institutions is only intended for those who cannot provide for their own living and care.[d] Notably, patients are moved to those institutions only after eliminating all other care possibilites.[4]

Therefore, it is essential to establish public policies to create alternatives for formal care, and support for families so that fragile older adults can stay longer within the community, maintaining their independence.[4,9,e] In terms of healthcare, home care is available as an assistance modality for dependent older adults or for those living alone.[f] However, although foreseen since 1994 in the *Política Nacional do Idoso* (National Policy for Older Adults),[d,f] the involvement of the state in the provision of this alternative is still insufficient and limited.[4]

The *Programa Acompanhante de Idosos* (PAI)[g] was developed in Sao Paulo, and it is a pioneering initiative in home care for fragile and socially vulnerable older adults. This program intends to provide support to daily life activities and other health and social needs of care receivers, favoring their autonomy, independence, and self-care; improving their health; decreasing social isolation; and avoiding or postponing their institutionalization.[3,h,i]

The PAI was founded in 2008 by hiring 14 teams, distributed throughout five regions of the city. In 2012, the program already included 22 teams,[i] which consisted of the technical team (a coordinator with social service training, a doctor, and a nurse), two nursing assistants, a driver, an administrative assistant, and 10 formal caregivers of older adults, named elderly companion.[h,i] The technical team is responsible for supervising the professional practice of the caregivers.[i]

The elderly companion is responsible for performing, at a greater frequency, activities at the house of care receivers that are followed-up by PAI.[h] Each elderly companion takes care of approximately 12 care receivers, and the actions of this caregiver have to comply with the care plan. This plan is included in a therapeutic plan for each older adult, developed by the team according to the assessment of the health and social needs.[h] This plan should also be in agreement with the guideline of PAI.[i]

Specific attributions of elderly companions include the following: provide home care assistance; prevent health hazards and promote healthy living; provide assistance with personal care and hygiene; provide support in healthcare activities, including a walk or trip to the pharmacy, bank, or church; stimulate the inclusion of the older adult in community services.[3,h,i]

The elderly companions are prohibited to do the following while providing care to care receivers: influence them about drug effects, inform them about the diagnosis, expose their family and personal life, receive or handle money, have possession of the residence key, and others.[i]

The required profile characteristics for hiring elderly companions include the following: have at least completed primary schooling; preferentially reside in the region where they work; are available and have necessary skills to perform daily activities (such as house cleaning, cooking, and participating in community activities); are affectionate; and are patient and available to interact with people in case of fragility or social vulnerability. In addition, these caregivers should take initiative and be creative apart from being able to calculate, read, and communicate in a written and verbal manner.[i]

There is no published study about the PAI program or the work process of elderly companions as a new category of workers who are part of the public policy scenario.

The present study aimed to understand the job functions of the elderly companions of older adults and contribute to the debate on the consolidation of this professional practice.

[d] Brasil. Lei nº 8.842, de 4 de janeiro de 1994. Dispõe sobre a Política Nacional do Idoso, cria o Conselho Nacional do Idoso e dá outras providências. *Diario Oficial Uniao*. 5 Jan 1994:77.

[e] Organização das Nações Unidas. Plano de ação internacional sobre o envelhecimento, 2002. Brasília (DF): Secretaria Especial dos Direitos Humanos; 2003. p. 86.

[f] Brasil. Decreto nº 1.948 de 3 de julho de 1996. Regulamenta a Lei n° 8.842, de 4 de janeiro de 1994, que dispõe sobre a Política Nacional do Idoso, e dá outras providências.1996. *Diario Oficial Uniao*. 4 Jul 1996 [cited 2014 Mar 25]: 12277. Available from: http://www.planalto.gov.br/ccivil_03/decreto/D1948.htm

[g] Batista MPP. Reflexões sobre o processo de trabalho do acompanhante de idosos do Programa Acompanhante de Idosos (PAI) no município de São Paulo, SP (Brasil) [dissertação de mestrado]. São Paulo: Faculdade de Medicina da USP; 2013.

[h] Secretaria Municipal de Saúde de São Paulo. Coordenação da Atenção Básica. Edital de credenciamento de instituições com conhecimento técnico e experiência em oferecer atividades de aprimoramento para profissionais da rede municipal de saúde. Processo: 2010-0.330.078-9. *Diario Oficial Cidade Sao Paulo*. 19 Fev 2011:71.

[i] Secretaria Municipal de Saúde de São Paulo. Documento norteador do programa acompanhante de idosos do município de São Paulo. São Paulo: Coordenação de Atenção Básica. Área Técnica de Saúde da Pessoa Idosa; 2012. p. 133.

PROCEDURES METHODOLOGICAL

This is a descriptive, qualitative, and exploratory study. Data were collected between the months of September and December 2011 after the focal group sessions[1,6] at the PAI headquarters, Sao Paulo, Southeastern Brazil, from 11 elderly companions who were part of the program since the beginning and remained in it, as the first teams of PAI.

A elderly companion from each of the first 12 teams, managed by a social organization, was invited in partnership with the municipality.[i] Twelve was an adequate number because an ideal focal group should consist of six to 15 people, favoring the participation of all caregivers involved.[10]

To invite participants, we initially held a meeting with the PAI management team to present this study. Following this, coordinators of different teams were contacted so that we could send all of them printer material containing a summary of the proposal. The goal of this action was to present this study to the teams, particularly to the elderly companions. Each team then decided whom to choose as a participant. In case more than one caregiver was interested in this study, researchers would provide all necessary clarifications. There were no participants from one PAI team, and researchers were not informed about the reason why they refused to participate in the study.

We performed four monthly group sessions, with an average duration of 2h per session. The group was coordinated by two moderators, and they used a previously written semi-structured script. Each session was initiated with a guiding question, intended to direct the discussions to the subject under research.[1]

All sessions were recorded and transcribed. At the end of the process, the obtained data obtained were processed according to analysis of the thematic content.[2] After each session, the produced material was attentively read to continue with sequential analysis, which helped in the creation of provisory categories for supporting subsequent meetings.[1,6]

This research project was approved by the Ethics Committee of the *Secretaria Municipal de Saúde de São Paulo* (Municipal Department of Health) and of the *Faculdade de Medicina* of the *Universidade de São Paulo*, according to the following protocols: CAAE 0031.0.444.162-11, Opinion 128/11, with approval date 5/9/2011 and 133/11, with approval date 4/13/2011, respectively. All participants signed the Informed Consent Form.

RESULTS

Elderly companions of older adults from the PAI teams located in the following regions participated in this research: Barra Funda, Bela Vista, Cidade Ademar, Ipiranga, Itaim Bibi, Jaçanã, Lapa, Santa Cecília, Santana, Sao Miguel, and Vila Formosa.

With regard to the profile of participants, they were female, aged 32 to 56 years. Four of the elderly companions were single, three were divorced, and one was a widow. With regard to the education level, one had not completed high school, one had completed college education, and the rest had completed high school. None of the participants had received caregiver training before working for PAI. With regard to their motivation to work for PAI, participants had affinity for care receivers or they had previous experience as professional or informal caregivers or were unemployed.

During the development of focal groups, the most relevant questions reported by caregivers were related to the creation and contradictions of their duties as well as their professional role. They also raised questions about their relationship with the technical team they were part of as well as with the care receivers and their respective family members, who were co-responsible for the care process. There was lack of clarity among these workers with regard to role assignments.

Throughout the process, we found expressive differences among the actions of each elderly companion. For example, some of them cleaned the house and changed diapers of the care receivers, while some did not. This disparity in actions was explicit within each group and among teams when a given caregiver was replaced by another one because of a vacation or leave.

> "When I visit, the patient wants me to do the same chores as my colleague. (...) 'If she does it, why can't you?'" (AI6)

Because of the difficulty in understanding the specific duties of the elderly companions, the care receivers and their family members sometimes asked caregivers to perform tasks that were not part of the scope of their duties, according to the perception of elderly companions. As an example, one care receiver expressed his dissatisfaction with the technical team with regard to the work of the elderly companions. In this case, the care receiver and his private caregiver expected the elderly companion to clean the kitchen, and the elderly companion thought that this was not part of her duties.

According to participants, a possible reason for this situation is that this is a new job category that most people

[i] During data collection, two partner institutions were planning and executing the *Programa Acompanhante de Idosos* in Sao Paulo, SP, both coordinated by the Municipal Health Secretariat. One institution coordinated 12 teams from the program, and the other, two teams.

are not familiar with. In addition, most people have preconceptions about the duties of both private formal caregivers and domestic servants. Therefore, because it is a new type of job, care receivers and their families, the technical team, and even the teams of the PAI find it hard to understand the duties and responsibilities of the elderly companions. These caregivers collectively built this perception during group meetings.

> "Because this service is new, it is necessary to clarify the exact duties to all teams. If one team agrees to perform certain tasks and the other team refuses, it becomes confusing whether we are supposed to perform it or not." (AI11)

For elderly companions, the standardization of expected duties within the same team would lead to clarity among care receivers and their family members.

> "A team works toward the same goals, which means that, whatever one does, the other has to do in the same way." (AI11)

In contrast to other professional team members who have a specific deontological code, which guides them and lays the foundation of their professional practice, there is no specific professional training for caregivers.

> "Because it is a new service, we are not provided with training." (AI11)

> "There is no manual for the caregiver." (AI10)

Compared with other professional team members, the difficulty in defining the duties of the elderly companions among the teams sometimes leads to tense situations related to their professional role. For example, some elderly companions had the impression that nursing assistants were "detectives" who were present to inspect their work at the residences of the care receivers. They realized that that these assistants informed the technical team about care receivers' opinion and satisfaction with their work. Furthermore, assistants frequently invalidated the instructions that elderly companions provided to care receivers.

On the other hand, these issues were more frequent when the PAI was being implemented. Elderly companions said that as they gained experience, they begin to understand their professional role and respective duties in a better manner.

> "When I began working here, I did not know the difference between the roles of the professionals of my team, but it is getting clear now..." (AI9)

Hence, caregivers reported that their duties could be explained more regularly and with clarity to care receivers as well as their family members during the care giving process. Such clarification would help in their work with patients, avoiding conflicts in the elderly companion-patient relationship.

> "The coordinator should clarify our duties. Then, the patient will not end up asking for tasks he/she knows are not part of our duties and will not be mad at us for the same." (AI11)

In addition, regarding their duties, elderly companions acknowledge the existence of prohibited tasks in the guideline, which they still have to perform many times when facing an ethical dilemma. For example, they handle the money for patients when patients are not physically capable of doing grocery shopping. In this type of situation, caregivers feel compelled to overlook the rules. They do that out of compassion or as a "matter of humanity" so that they can "leave with peace of mind."

> "The patient was only feeding on wheat flour mixed with water and was still hungry. That is why I went to the grocery store and bought food for the patient." (AI6)

The elderly companions also understand that their job is quite dynamic and that they constantly face unexpected events and new challenges. Therefore, they say that the guideline is not detailed enough to help them deal with all the challenges they face.

During tasks that they consider being "difficult," such as handing patients with mental disorders or when they are confronted with domestic violence, elderly companions said that supervision provided good support when they felt "unsafe" and helped them in discussing with the team with regard to how to proceed. However, they also pointed out that there should be more open dialogs with the technical team and that elderly companions' opinion should be appreciated on the basis of their knowledge and experience, which did not happen in all teams.

DISCUSSION

Our results show the complexity of the elderly companions' work, which is evident when analyzing the ethical dilemma they face by providing assistance to multiple demands of older adults. Consequently, sometimes these caregivers act in contrast to the rules provided in the guideline. Therefore, there were contradictions with regard to the job function of the elderly companion, deriving from important issues they face during their professional practice. Such findings allow us to infer that instead of blaming the worker for services provided outside designated prescription, it is rather necessary to develop collective strategies for improving work organization[7] as well as the PAI.

We observed that the elderly companions' job is a new type of job that influences how older adults and their family members as well as elderly companions themselves and their team members understand their duties. Patients frequently asked elderly companions to perform tasks that, in their opinion, were not part of their duties. To overcome the difficulty in denying these requests and avoiding conflicts with the patient, elderly companions think that it would help if the technical team could continuously provide the patients with clear details about the elderly companions' duties and how they would be performed.

The perception of the caregivers regarding their duties matches the information provided in the guideline. The guideline acknowledges that the elderly companions' work requires them to have a closer approach to the patient's life, which means a personal and emotional involvement. Furthermore, the team should continuously reflect the limits and actions of elderly companions, aiming to establish appropriate parameters for allowing involvement in the patient's life and to detect when their actions are off-limits, as determined by the guideline.[i]

This approach would also help create agreements between elderly companions of the same team for standardizing their practice. That would favor the comprehension of the patient as well as of the elderly companion with regard to the duties. Thus, patients would understand that elderly companions' actions are not ruled by their own perception but rather by guidelines set out by the PAI.

To better standardize the professional practice of elderly companions, it is necessary to strengthen and sustain the platforms for internal exchange of experiences among the teams. That will facilitate discussion of the different approaches toward patient services. This will also allow teams to create collective agreements for the development and improvement of their work.[7] The exchange platforms, such as those of supervision, were much appreciated by elderly companions for the development of their work; however, they highlighted that there was a need for a better balance between power relationships in the team management.[k]

The difficulty of elderly companions in understanding their own roles can be explained by the disparity among them when performing some tasks. According to the guideline, one of the characteristics of the worker's profile should be his/her availability and skills to perform basic tasks at a residence, e.g., house cleaning.[i] Therefore, the refusal to perform this task or any task of a similar nature can be related to elderly companions trying to create a hierarchy of their own activities. Consequently, caregivers may need to define their social status. Analyses of how professional groups organize themselves in terms of their occupational practices allow them to think about the type of power they intend to exert socially.[8]

It is possible that the difficulty in understanding the elderly companions' duties is also related to the fact that they did not undergo specific training before working for PAI. Reasons for the lack of training are as follows: they are part of a new category of workers; they do not have professional models to base their work on, or some frail related to their guideline. However, it is understandable that the elderly companion consider the guideline to be incomplete, as it is Known that it is impossible for any prescription to provide answers to the various situations people face in their job.[7]

The lack of institutionalization of this profession is also critical, given that in contrast to other professionals of the team, there is no deontological code with specific principles set out for the caregivers' job. Elderly companions also think that a manual related to their job would help them in defining their duties.

This perception of the participants can be understood from the concept of professionalism. This is a social process that allows certain jobs to master an expertise, which then achieve social legitimacy and gain a certain degree of monopoly of professional practices. This process is quite related to the delimitation of the professional boundaries in the work market and inherent corporatism of each profession.[8]

In this scenario, some elderly companions said that their duties were less defined in comparison with those of other team members, which adds up to the difficulty in understanding the professional place of the caregiver. This difficulty is also evident in the relationship of some participating caregivers and nursing assistants. Despite the fact that the guideline does not set out a hierarchy for these professionals, some teams end up having one. The construction of a professional place for the elderly companions in the team should be based on collaborations and not on competition among professionals. Corporative conflicts in the team management can possibly result in losing focus on patient's health, which is the most important part of their job.[k]

The difficulty in setting the caregivers apart from the other team members was more evident in the beginning of the PAI, which allows inferring that the work time had influenced the building of the professional practice of the elderly companions. Therefore, the need to answer the challenges faced by these workers and thoughts about their limitations and possibilities of confrontation can be used as a reference to define their duties in comparison with those of other workers.

[k] Ministério da Saúde. Secretaria de Atenção à Saúde. Núcleo Técnico da Política Nacional de Humanização. Clínica ampliada, equipe de referência e projeto terapêutico singular. 2ª ed. Brasília (DF); 2007. p. 60.

Consequently, it is considered that the definition of the role of a elderly companion was built throughout the planning and implementation process of PAI; in that sense, we identified a growing need of institutionalizing this type of professional activity.

However, the gradual differentiation of the elderly companion from other team members should not disregard the search for completeness of the actions performed with the patients. Acknowledging the heterogeneity of the older population, it is important for the care practices to be interdisciplinary.[c] Creation of intersection areas among the tasks performed by different team members is an ongoing debate in the healthcare field and should be encouraged within the teams.[k]

The public initiative of the Sao Paulo municipality in hiring formal caregivers to provide assistance to fragile older adults favors the quality of assistance provided to this population. This goal is ensured by PAI, which guarantees this service via different means such as supervision of the practice of elderly companions and interprofessional discussions in order to elaborate a care plan that matches the needs of patients.[i]

A limitation of this study is that in terms of the method used, the team itself chose the elderly companions who would participate in the focal group; therefore, researchers were not only unaware whether other caregivers were interested in this study but also did not know which internal criteria each team used.

Another limitation is that the target population of this research consisted of elderly companions of the PAI teams managed by one partner institution of the municipality. Therefore, it was not possible to analyze the influence of possible differences related to how other partners manage this program.

Nevertheless, as our study was qualitative, included focal groups and prioritized the inclusion of the elderly companions who represented different teams of the program, our research allowed observing the aspects that interfere with the development of their professional practice and the content of their work. It also allowed inferring a more comprehensive thought about this subject.

We suggest that other studies should be conducted in future on the work process of the elderly companions of teams that have recently been implemented into the PAI.

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