ORIGINAL ARTICLE

Knowledge, attitudes, and qualification needs of primary health care professionals in the care of dementia

Conhecimento, atitudes e necessidades de qualificação de profissionais da atenção básica no atendimento às demências

Conocimiento, actitudes y necesidades de calificación de profesionales de la atención básica en la atención a las demencias

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ABSTRACT

Objective: To identify the knowledge and attitudes of doctors and nurses in tracking, diagnosing, treating, and monitoring dementias and their educational needs in this area. **Method:** Cross-sectional study, carried out among 195 doctors and 274 nurses working in teams of the Family Health Strategy (FHS) in the city of São Paulo. The instrument used was *Health Care for Dementia: the Primary Care perspective*. The data were submitted for descriptive statistics. **Results:** Among physicians, 64.1% reported routinely diagnosing dementia, but only 23.1% in the mild phase; 89.2% mentioned difficulties in identifying cases of the disease; 94.9%, difficulties in the treatment and monitoring of patients, including the needs to support the caregiver (28.2%); 84.6% of doctors and 79.2% of nurses reported difficulties in monitoring severe cases of the disease. **Conclusion:** Gaps in knowledge were identified regarding the tracking and diagnosis of dementia, patient monitoring, diagnostic information, and support for the caregiver.

Descriptors: Education, Public Health Professional; Primary Health Care; Physicians; Nurses; Dementia.

RESUMO

Objetivo: Identificar o conhecimento e as atitudes de médicos e enfermeiros no rastreamento, diagnóstico, tratamento e acompanhamento das demências e suas necessidades educacionais nesta temática. **Método:** Estudo transversal, realizado com 195 médicos e 274 enfermeiros atuantes nas equipes da Estratégia Saúde da Família, do município de São Paulo. Utilizou-se o instrumento *Atenção Sanitária às Demências: a visão da Atenção Básica*. Os dados foram submetidos à estatística descritiva. **Resultados:** Dentre os médicos, 64,1% referiram realizar o diagnóstico da demência de forma rotineira, mas apenas 23,1% na fase leve; 89,2% mencionaram dificuldades para identificar casos da doença; 94,9%, dificuldades para tratamento e acompanhamento dos pacientes, incluindo as necessidades de apoio ao cuidador (28,2%); 84,6% dos médicos e 79,2% dos enfermeiros referiram dificuldades no acompanhamento à forma grave da doença. **Conclusão:** Foram identificadas lacunas no conhecimento referentes ao rastreamento e diagnóstico das demências, acompanhamento dos pacientes, informação diagnóstica e suporte ao cuidador.

Descritores: Educação Profissional em Saúde Pública; Atenção Primária à Saúde; Médicos; Enfermeiras e Enfermeiros; Demência.

RESUMEN

Objetivo: Identificar el conocimiento y las actitudes de médicos y enfermeros en el rastreo, diagnóstico, tratamiento y acompañamiento de las demencias y sus necesidades educacionales. **Método:** Estudio transversal, realizado con 195 médicos y 274 enfermeros actuantes en la Estrategia Salud de la Familia, del municipio de São Paulo. Se utilizó el instrumento *Atenção Sanitária às Demências: a visão da Atenção Básica*. Los datos han sometidos a la estadística descriptiva. **Resultados:** Entre los médicos, 64,1% refirieron realizar el diagnóstico habitualmente, pero 23,1% en la fase leve; 89,2% mencionaran dificultades para identificar casos de la enfermedad; 94,9%, dificultades para tratamiento y acompañamiento de los pacientes (28,2%); 84,6% de los médicos y 79,2% de los enfermeros refirieron dificultades en el acompañamiento a la forma grave de la enfermedad. **Conclusión:** Identificaron lagunas en el conocimiento referentes al rastreo y diagnóstico de las demencias, acompañamiento de los pacientes, información diagnóstica y suporte al cuidador.

Descriptores: Educación Profesional en Salud Pública; Atención Primaria a la Salud; Médicos; Enfermeras y Enfermeros; Demencia.

INTRODUCTION

Aging is certainly an achievement of humanity. However, the increase in longevity may be accompanied by chronic-degenerative diseases, such as dementia, which are among the main causes of disability in old age. In 2016, it was estimated that there were a total of 43.8 million people living with this syndrome worldwide. Projections indicate that this number could reach 100 million in 2050[1].

Dementia can be defined as a brain dysfunction characterized by acquired and persistent intellectual deterioration, which gradually compromises functions in three spheres: cognition, function, and behavior. From the cognitive perspective, it alters the functions of memory, language, praxis and gnosia, in addition to visuospatial alterations. This compromised state can affect functions in two spheres: Daily Activities, such as bathing, dressing, feeding, cleanliness, transfer and continence; and Instrumental Activities of Daily Living, such as managing personal finances, professional activities and all those that involve the ability to perform tasks and that are modulated by the frontal lobe. Behavioral symptoms generally include agitation, dysphoria, apathy, irritability, aberrant motor behavior, delusions, hallucinations, disinhibition, among others, which tend to intensify as the disease progresses[1-3].

Dementias can be caused by neurodegenerative disorders of various etiologies: vascular, traumatic, demyelinating, neoplastic, hydrocephalic, toxic, infectious, inflammatory, among others. They are classified as primary (resulting from damage to the brain structure) and secondary due to other underlying diseases — for example, high blood pressure and diabetes *mellitus*. They are further divided into two major groups: reversible, which include metabolic changes, intoxications, infections and nutritional deficiencies, and irreversible, such as Alzheimer's disease (AD), vascular dementia (VD), mixed (MD), by Lewy body (LBD), frontotemporal (FTD), and Parkinson's (PD), Huntington's (HD), and Creutzfeldt-Jakob disease (CJD)[1-2]. AD is the most common form of the syndrome worldwide, accounting for 60% to 70% of the cases. It is followed, in order of frequency, by VD, LBD, and FTD. Mixed forms are also common[1-3].

A systematic review that assessed the global prevalence of dementia among individuals aged 60 and over, which included 147 studies published between 1980 and 2009, identified rates between 5% and 7% in most regions of the world (North American countries, Latin America, Oceania, Asia and Europe). In the meta-analysis, it was found that the percentage increased with age and was higher in regions with a more vulnerable economy[3]. In Brazil, a review in literature that included studies published between 1995 and 2012 estimated a prevalence of 7.6% among people aged 65 and over. The rate was higher for AD, representing close to 54% of the cases; this rate increased with age and was higher among women[4].

Experiencing dementia is a painful experience for both the patient and the family. The act of caring of an elderly relative with dementia is an extremely complex task. The lack of understanding about dementia results in a stigmatization of the patient. The barriers range from diagnosis to health care, with negative impacts on the lives of caregivers and family members in physical, psychological, and emotional aspects, which is why caregivers do not only require information about the disease and its manifestations, but, above all, that their limitations and insecurities are known and valued by the health team[5].

For health professionals, knowing how to recognize the symptoms of the disease and to provide effective orientation to the caregivers can help reduce the tension between them. Most of the time, caregivers benefit from emotional and educational support from specialized professionals[5-7]. The general practitioner has a distinguished role in the prevention, diagnosis, and treatment of mental problems within the elderly. Nursing care, on the other hand, must be planned with the objective of preserving the patient's autonomy and independence, providing comfort, evaluating and advising on nutrition, evaluating health complications, if there is any anguish or changes in behavioral symptoms, as well as helping family members in ethical dilemmas and decision making. However, professionals are not always prepared for this[5,8].

Restricted knowledge affects people suffering with dementia, their caregivers, families, and support structures in various ways. It has a negative impact on the family unit and increases its vulnerability. In several countries, including those undergoing economic transition, members of large families no longer live close to their families and are no longer able to absorb the impact of care. This results in a greater need for professional care, something that tends to grow in the near future. Limited knowledge and poor infrastructure to provide adequate and timely support in cases of dementia increase the likelihood of higher costs, dependency, and morbidity[3,5,9].

Primary care services should provide complete health care for patients with dementia. However, the disease is underdiagnosed in primary health care institutions, with numbers between 25% and 80%. Variations in the severity and duration of symptoms have been highlighted as conditions that influence the detection of dementia in primary care services. In addition, not all the detected cases are referred to specialized services to carry out the etiological diagnosis. Among the reasons for the lack of referral, doubts by the health professionals and family members regarding the benefits that the etiological diagnosis can bring to the patient's quality of life[10] is predominant.

In Brazil, health care is linked to the Unified Health System (UHS). Currently, the Family Health Strategy (FHS) is considered the priority way for the reorganization of Primary Care (PC) in the country. Recently, the Ministry of Health launched a Manual of Technical Guidelines for the Implementation of the Care Line for Comprehensive Health Care for the Elderly in UHS, which recommends the use of the Multidimensional Assessment of the Elderly Person in Primary Care (MAEP-PC) instrument to identify the health needs of the elderly and stratify them into three major profiles (fragile, pre-fragile, and healthy), according to their levels of functionality, in order to establish the necessary care[11-12].

Faced with such a scenario, this study sought to answer the following question: What is the knowledge and attitudes of the FHS professionals regarding monitoring dementias? The answer to this question allows us to subsidize proposals for future training of teams in the scope of PC.

OBJECTIVE

Identify the knowledge and attitudes of doctors and nurses in relation to the screening, diagnosis, treatment, and monitoring of dementia, as well as their educational needs on the subject.

METHODS

Ethical aspects

The project was approved by the Research Ethics Committees of the School of Nursing at University of São Paulo and the Municipal Health Secretariat of São Paulo. According to country wide legislation, the participants were informed about the objective, risks, and benefits of the study, as well as regarding their right to compensation if they felt harmed due to participation. All who agreed to participate in the study signed two copies of the Free and Informed Consent Term - FICT (one copy, by the subject; the other, by the researcher).

Study design, period, and location

Cross-sectional, prospective and quantitative study, guided by the STROBE[13] tool, developed in Basic Health Units along with FHS belonging to the West, Center, Southeast and North Regional Health Management Offices of the city of São Paulo, SP, Brazil, between February and July 2018. These regions were chosen because they concentrate the largest number of elderly people (over 60 years old), when compared to others.

Sample and inclusion/exclusion criteria

The population was composed of doctors and nurses who work in health units in FHS in the city of São Paulo, SP. The initial sample consisted of 508 doctors and 508 nurses. The inclusion criteria in the research were: being an acting nurse or doctor within the units included in the research and working in FHS for a period equal to or greater than 12 months. Subjects who were absent from the units for a period equal to or greater than 15 days were excluded.

All professionals who met the inclusion criteria for the study were included, constituting a sample for convenience. From the initial sample, 51 doctors and 15 nurses were excluded due to the absence of these professional on the team; 85 doctors and 46 nurses, for working in the FHS for less than 12 months; 86 doctors and 89 nurses, for refusing to participate in the study; and 91 doctors and 84 nurses, as they were absent from the unit for a period of 15 days or more. Thus, the final sample of the study was composed of 195 doctors and 274 nurses.

Study Protocol

Data collection was performed through a self-application by the professionals of the instrument *Health Care for Dementia: the Primary Care perspective*, in its versions for doctors (SCDPCP-D) and nurses (SCDPCP -N), translated and culturally adapted for Brazil[14], the original version being of Spanish origin[10].

SCDPCP-D contains 28 questions, including a case study; SCDPCP -N has 16 questions. Both versions contain open and closed questions (multiple choice, classification by ordering and dichotomous) regarding: professional profile and educational needs of professionals in dementia; diagnostic process of dementias; information provided to patients and their families; monitoring of patients and caregivers; main roles of the nurse in caring for patients with dementia and their families; and doctors' relationship with the specialized service. There are no incorrect answers: professionals are asked for their opinion regarding procedures related to their usual clinical practice to find out how they work in caring for patients with dementia and their families[14].

Results and statistical analysis

Responses were analyzed using descriptive statistics (number and percentage, mean, standard deviation, median, and minimum and maximum) and confidence interval. The data were stored in Excel® and analyzed by Software R 3.5.1®. The level of significance adopted was 5%; and the confidence intervals (CI) were established at 95%.

The results of the analysis of the application of the instrument were interpreted; and the knowledge gaps, identified by comparing the responses with the guidelines and publications in force for attending to dementia.

RESULTS

469 professionals met the inclusion criteria in the study and participated in the research, being 195 doctors and 274 nurses, with a representation of 38.4% and 53.9% of the initial sample, distributed as follows in the city of São Paulo: 263 (56.1%) are linked to the Regional Health Management Offices of the North; 148 (31.5%), to the Southeast; 37 (7.9%), to the Center; and 21 (4.5%), to the West.

The ages of the medical professionals ranged from 25 to 68 years, with an average of 43.9 and a median of 34 years; for nurses, between 26 and 65 years old, with an average of 39.2 and a median of 37.5 years. In both professional categories, females predominated (60% doctors and 90.1% nurses); in comparison with doctors, there was a predominance of nurses ($p \leq 0.001$).

The average time of work experience in PC was 7 years for doctors and 10 years for nurses (min/max: 1–40; 1–35; SD = 7, 5; 95% CI: 4.5–6.5; 9.0–10.0). The average time of work in the health unit was 4 years for doctors and 5 years for nurses (min/max: 0.8–22; 0.8–20; SD = 4.4; 95% CI: 2.0–3.0; 4.5–5.5). In both cases, the working time was longer among nurses ($p \leq 0.001$).

In the process of tracking and diagnosing dementias, 64.1% of physicians reported that they routinely diagnose the disease; and 56.9%, already in the moderate phase (95% CI: 49.9–63.7). Regarding the number of new cases seen and diagnosed, there was a predominance of 5 to 9 patients in the last 12 months (59.5% of doctors and 63.1% of nurses). Thirty-two (16.4%) physicians reported not making a diagnosis of dementia, preferring to refer the patient to a specialist (95% CI: 11.9–22.2).

As for the signs and symptoms most considered by professionals for the diagnosis of dementia, 52.3% of doctors mentioned cognitive impairment with memory disorders as priorities; and 34.4%, the psychological and behavioral symptoms of dementias (depression, delusions, agitation, personality changes, etc.). The nurses reported the same priorities, however in reverse order, with 44.9% and 50%, respectively (Table 1).

There was a predominance of the use of instruments to assess cognitive ability by doctors (doctors: 159, 81.5%; nurses: 201, 73.4%; $p = 0.039$), specifically the Mini Mental State Examination - MMSE ($p = 0.002$) and the clock drawing test ($p = 0.047$). Among nurses, there was a preponderance of the use of instruments to assess functional capacity (doctors: 71 or 37% and nurses 159 or 58%;

(p ≤ 0.001) (Table 1). Four (2.0%) doctors and 25 (9.1%) nurses reported using MAEP-PC for cognitive or functional assessment.

Difficulties faced in diagnosing dementias were mentioned by 174 (89.2%) doctors. The predominant difficulties were to differentiate the signs and symptoms of dementia from geriatric depression and the signs and symptoms of dementia of normal aging, respectively cited by 40% and 34.9% of doctors. Furthermore, 175 (89.0%) referred to hindering aspects while making the diagnosis, among which the lack of time to apply tests and perform analyzes (56.4%) and little confidence in issuing the diagnosis (19 %) (Table 1).

Among the complementary exams most requested by physicians to diagnose the dementia subtype, complete blood count (57.9%; 95% CI: 50.9–64.7), thyroid-stimulating hormone (57.4 ; 95% CI: 50.4–64.2), vitamin B12 (55.9%; 95% CI: 48.9–62.7), biochemical examination with glycemia (55.4%; 95% CI : 48.4–62.2), serology for syphilis (54.9%; 95% CI: 47.9–61.7) and cranial computed tomography (43.1%; 95% CI: 36, 3–50.1) (Table 1). Forty-five doctors (23.1%) reported not using complementary tests to diagnose the disease subtype, preferring the referral to a specialist (95% CI: 17.7–29.5).

Most doctors reported informing the families the diagnosis of patients sometimes and frequently (69%) and rarely or sometimes (62%). Of the total, 138 (70.8%) referred to intervening factors when informing the diagnosis to the patient, among which were the patient's lack of cognitive ability to understand the information about the diagnosis (34.4%) and the advanced stage of the disease (21.5%) (Table 2).

The monthly number of consultations ranged from 1 to 4 (65.6% of doctors and 63.1% of nurses). In addition, 79.5% of doctors and 82.9% of nurses reported that they regularly schedule home visits to monitor patients.

As for referral to medical services specialized in the diagnosis or control of dementias, most physicians cited their referral neurologist (64.6%), the Elderly Reference Center (63.6%) and the Specialty Medical Clinic - SMC (41.5%). Sixty-eight (34.9%) professionals reported referring more than 75% of suspected cases to confirm the diagnosis (95% CI: 28.5–41.8); and 50 (25.6%) reported directing patients for the control of behavioral disorders (95% CI: 20.0–32.2) (Table 3).

Among the functions of the nursing team in monitoring dementia, nurses classified as priorities the periodic assessment of cognitive impairment (42.3%), risk assessment at home (31%) and support for the needs of the caregiver or family (26.6%) (Table 3).

Almost all physicians reported difficulties in the treatment and monitoring of patients with dementia (185; 94.9%; 95% CI: 90.8–97.2), with emphasis on treatment with specific drugs such as anticholinesterase and memantine (32.3%), the large amount of time required for monitoring and treatment (31.3%), and the support needs of the caregiver and the family (28.2%) (Table 3).

In severe dementias, 84.6% of doctors and 79.2% of nurses reported difficulties in complex pharmacological treatment (45.6% of doctors), lack of support for specialized care (39.5% of doctors and 44.3 % of nurses), and unresolvable demands in PC (35.9% of doctors and 37% of nurses) (Table 3).

More than 70% of doctors reported that they always or almost always suggested memory exercises and cognitive stimulation and refer suspected cases to the specialist. As for admission to a Long-Term Care Facility for the Elderly (LTCFE), about 65% of doctors almost never or never recommend it (Table 4).

Table 1 – Process of tracking and diagnosing dementias by the Family Health Strategy teams (n = 469), São Paulo, São Paulo, Brazil, 2018

Tracking and diagnosing dementia	Doctor		Nurse	
	n	%	n	%
Main signs and symptoms that lead to suspected dementia				
Cognitive impairment with memory disorders	102	52.3	123	44.9
Psychological and behavioral symptoms of dementia (depression, delusions, agitation, personality changes)	67	34.4	137	50.0
Impaired ability to perform activities of daily living	41	21.0	85	31.0
Cognitive and functional assessment tests most used in clinical practice				
Cognitive Capacity				
Mini Mental State Examination	132	67.7	182	66.4
Global cognitive-functional assessment	13	6.7	16	5.8
Clock drawing test	13	6.7	14	5.1
Functional Capacity				
Katz Index	43	22.1	124	45.3
Pfeffer's test	17	8.7	13	4.7
Main difficulties in identifying a case of dementia				
Differentiating the signs and symptoms of dementia from geriatric depression	78	40.0	NA*	NA*
Differentiating the signs and symptoms of dementia from normal aging	68	34.9	NA*	NA*
Main aspects that make it difficult to identify a case of dementia				
Lack of time to carry out the diagnostic process (apply tests, analyzes)	110	56.4	NA*	NA*
Little confidence in the diagnosis (doubts around the patient having true dementia)	37	19.0	NA*	NA*
Most requested complementary tests for the diagnosis of the dementia subtype				
Complete blood count	113	57.9	NA*	NA*
Thyroid-stimulating hormone	112	57.4	NA*	NA*
Vitamin B12	109	55.9	NA*	NA*
Biochemical examination with glycemia	108	55.4	NA*	NA*
Serology for syphilis	107	54.9	NA*	NA*
Renal function	95	48.7	NA*	NA*
Liver enzymes	94	48.2	NA*	NA*
Serology for human immunodeficiency virus	89	45.6	NA*	NA*
Folic acid	68	34.7	NA*	NA*
Calcium	61	31.3	NA*	NA*
Magnetic resonance imaging of the skull	32	16.4	NA*	NA*

Note: *Not Applicable.

Table 2 – Diagnostic information of the dementia to patients and their families by the Family Health Strategy teams (n = 195), São Paulo, São Paulo, Brazil, 2018

Diagnostic information of the dementia	Doctor	
	n	%
Diagnostic information of the dementia		
To the patient		
Never	40	20.5
Rarely	63	32.4
Sometimes	58	29.7
Frequently	34	17.4
To Family members		
Never	13	6.7
Rarely	47	24.2
Sometimes	48	24.7
Frequently	86	44.3
Main causes that influence not informing the patient of the diagnosis of dementia		
Not having enough capacity to comprehend the information about the diagnosis	67	34.4
Being in an advanced stage of the disease	42	21.5
The family does not want the patient to know the diagnosis	15	7.7
Possibility of the diagnosis causing negative effects on the patient's daily life	12	6.2

Table 3 – Monitoring of patients with dementia by the Family Health Strategy teams (n = 469), São Paulo, São Paulo, Brazil, 2018

Monitoring of dementia	Doctor		Nurse	
	n	%	n	%
Medical services available in the coverage area for referral of dementia cases for diagnosis and/or control				
Reference neurologist	126	64.6	NA*	NA*
Elderly Reference Center	124	63.6	NA*	NA*
Ambulatory of Medical Specialties	81	41.5	NA*	NA*
Hospital neurology service	18	9.3	NA*	NA*
Ambulatory of Dementia Specialties	14	7.2	NA*	NA*
Main roles of the nursing team in monitoring patients with dementia in Primary Care				
Periodic assessment of cognitive impairment	NA*	NA*	116	42.3
Home risk assessment	NA*	NA*	85	31.0
Supporting caregiver and/or family needs	NA*	NA*	73	26.6
Control of patient's comorbidities	NA*	NA*	61	22.3
Periodic assessment of functional impairment	NA*	NA*	59	21.5
Pharmacological prescription and therapeutic follow-up control	NA*	NA*	46	16.8
Cognitive stimulation activities	NA*	NA*	38	13.9
Main difficulties for the treatment and monitoring of patients with dementia in Primary Care				
Treatment with specific drugs (anticholinesterase and/or memantine)	63	32.3	NA*	NA*
Monitoring and treating a patient with dementia requires a large amount of time, not available in Primary Care	61	31.3	NA*	NA*
The support needs of the caregiver and/or the family	55	28.2	NA*	NA*
Difficulties in monitoring patients with severe dementia				
Yes	165	84.6	217	79.2
No	30	15.4	57	20.8
Main reasons				
Pharmacological treatment is complex	89	45.6	NA*	NA*
No specialized service support	77	39.5	121	44.3
Patients are difficult	NA*	NA*	81	29.7
Their demands are not solvable in Primary Care	70	35.9	101	37.0
Require many home visits	48	24.6	43	15.8

Note: *Not Applicable.

Table 4 – Monitoring of patients with dementia by the Family Health Strategy teams - medical recommendation (n = 195), São Paulo, São Paulo, Brazil, 2018

Monitoring of dementia	Would not Recommend						Would Recommend					
	Never		Almost Never		Few times		Sometimes		Almost Always		Always	
	n	%	n	%	n	%	n	%	n	%	n	%
Medical recommendation												
Vitamins	18	9.2	23	11.8	25	12.8	38	19.5	45	23.1	23	11.8
Natural/herbal treatments	60	30.8	51	26.2	25	12.8	18	9.2	8	4.1	4	2.1
Anticholinesterase drugs	24	12.3	24	12.3	34	17.4	31	15.9	32	16.4	20	10.3
Memantine	22	11.3	21	10.8	28	14.4	43	22.1	30	15.4	26	13.3
Tricyclic antidepressants	28	14.4	34	17.4	27	13.8	45	23.1	25	12.8	5	2.6
Selective serotonin reuptake inhibitor antidepressants	21	10.8	24	12.3	30	15.4	54	27.7	29	14.9	5	2.6
Typical antipsychotics	32	16.4	43	22.1	33	16.9	37	19.0	19	9.7	2	1.0

Table 4 (concluded)

Monitoring of dementia	Would not Recommend						Would Recommend					
	Never		Almost Never		Few times		Sometimes		Almost Always		Always	
	n	%	n	%	n	%	n	%	n	%	n	%
Atypical antipsychotics	34	17.4	45	23.1	33	16.9	41	21.0	9	4.6	2	1.0
Memory exercises (in general)	5	2.6	5	2.6	8	4.1	6	3.1	43	22.1	120	61.5
Cognitive stimulation (specific)	6	3.1	2	1.0	11	5.6	12	6.2	40	20.5	109	55.9
Music therapy, aromatherapy	31	15.9	22	11.3	21	10.8	26	13.3	27	13.8	45	23.1
Assistance in a daycare center for the elderly	10	5.1	14	7.2	19	9.7	40	20.5	36	18.5	64	32.8
Admission to a long-term care facility for the elderly	75	38.5	58	29.7	22	11.3	5	2.6	1	0.5	5	2.6
Referral to a specialist	2	1.0	3	1.5	5	2.6	26	13.3	46	23.6	101	51.8
Visit from a social worker	11	5.6	23	11.8	31	15.9	40	20.5	32	16.4	40	20.5
Association of family members of Alzheimer's patients	31	15.9	23	11.8	17	8.7	28	14.4	23	11.8	50	25.6

Table 5 – Monitoring of the caregiver of the patient with dementia by the Family Health Strategy teams (n = 469), São Paulo, São Paulo, Brazil, 2018

Monitoring of the caregiver	Doctor		Nurse	
	n	%	n	%
Planning frequency for monitoring the caregiver of patients with dementia				
Never	27	13.8	15	5.5
Rarely	55	28.4	69	25.2
Sometimes	69	35.6	100	36.5
Frequently	43	22.2	90	32.8

There was a predominance of nurses in the planning and specific monitoring of the health needs of caregivers of patients with dementia (p = 0.003). The distribution of results in absolute and relative frequency can be seen in Table 5.

Physicians' satisfaction with referring patients with dementia to specialized services was considerably low. The greatest satisfaction was for the ability to solve the demands (5.7) (min./max.: 1–10; median: 5.0; SD = 2.4; 95% CI: 5.5–6.0) and the lowest, for returning information to the PC service (3.3) (min./max.: 1–10; median: 2; SD = 2.6; 95% CI: 3.0–3.5). In addition, patient follow-up by the specialized service had an average satisfaction rate of 5.5 (min/max: 1–10; median: 5; SD = 2.5; 95% CI: 5.0–6.0); the waiting time from requesting the visit to the patient until its completion was 4.0 (min/max: 1–10; median: 4.0; SD = 2.5; 95% CI: 3.5–4.5); and the accessibility to the emergency service, of 3.8 (min./max.: 1–10; median: 3.0; SD = 2.6; 95% CI: 3.0–4.0).

Finally, 98.1% (95% CI; 96.4–99.0) of the professionals considered it necessary to carry out specific training in dementia (99.5% of doctors and 97.1% of nurses). However, 122 (62.6%) doctors and 149 (54.4%) nurses reported never having participated in training for this purpose. Among those who reported participation in the last year, 18.5% (36) were doctors and 20.1% (55), nurses.

DISCUSSION

The results revealed in this study corroborate specialized literature, which highlights: the moderate phase as the one in which the diagnosis of dementia is most commonly made; doctors' low confidence in making the diagnosis, since most of them do not diagnose the dementia subtype, preferring to refer the patient to a specialist; the difficulty in differentiating the signs and symptoms of dementia from normal aging and from geriatric depression; the lack of time and little confidence when issuing the diagnosis[10,15-18].

A small number of doctors and nurses referred to MAEP-PC, which its implantation in PC has enabled the instrumentalization of professionals for the evaluation of the elderly in the city of São Paulo, SP, Brazil. Recently, the instrument underwent reformulation so that, in addition to reducing application time, the questions became more objective, clear, and easier to answer.

Regarding the tests requested by FHS doctors for the diagnosis of the dementia subtype, those whose request is allowed at this level of health care were highlighted, among them the complete blood count, the vitamin B12 dosage, the biochemical examination with glycemia, the serology for syphilis and the cranial computed tomography. As for the screening tests for dementia, the most cited instruments were the MMSE and the Katz Index, however, there was a greater tendency for physicians to carry out cognitive assessment, whereas nurses preferably performed the functional assessment, which also occurred in the Spanish study[10].

It was found that information of the diagnosis is given more often to family members. Among the reasons for not disclosing the diagnosis to patients, the lack of cognitive ability to understand the information and the advanced stage of the disease were cited, like the Spanish study[10]. The opinion of family members is decisive for not communicating the diagnosis to the patient in at least one third of the cases. Training that covers ethical-legal aspects related to dementias can be useful for the decision to communicate the diagnosis of the disease to the patient[10,19-20].

The professionals listed difficulties in monitoring patients with dementia in PC, among them the lack of time for the consultation; the complicated supervision of these patients, especially with the prescription of specific drugs to treat dementias; the need for frequent visits and consultations; the lack of support for specialized assistance; the unresolvable demands at this level of care and the need for family and social support. A considerable percentage reported that they usually schedule visits to monitor these patients. Such results do not differ from those found by other similar studies[10,15].

A qualitative study conducted in Brazil with 22 nurses from inpatient units to verify their knowledge about AD and the demand for care of patients and family members revealed limited knowledge on the subject. The analysis of their statements showed that most of the time they recognized the characteristic signs and symptoms and possible complications of the disease but were unaware of the aspects related to their management[15].

A cross-sectional study carried out with 152 doctors from the first year of the residency program at the Federal University of São Paulo showed a low percentage of responses related to the aspects of prevalence, incidence, and symptoms of dementia. However, they had a good level of knowledge about etiology, risk factors and diagnostic evaluation of the disease[21].

In the present study, a considerable number of physicians reported always or almost always suggesting memory exercises and cognitive stimulation and referring suspected cases of dementia to the specialist. Among the referrals, the most cited professionals and services were the reference neurologist, the Elderly Reference Center, and the SMC. With the implementation of the Elderly Health Care Network, the municipality of São Paulo now has several options for services for referral, articulation, and monitoring of the elderly population[11].

Despite the efforts of recent years to increase the supply of vacancies and equipment for the assistance of the elderly in the UHS, the existing services are still insufficient to its demand. Research carried out in regions further away from large urban centers revealed worrying results regarding access to specialists and waiting times. In the state of Paraná, the lack of availability for five medical specialties was identified, including geriatrics and neurology. In Minas Gerais, the average waiting time for the first consultation, regardless of specialty, was of 244 days, ranging from 6 to 559 days[22-23].

The frequency of referral for admission to LTCFE by doctors was relatively low. Historically, in Brazil, such institutions are associated with negative images. They had their origins in the so-called homes linked to charity works, which provided community services to people of any age in a situation of social vulnerability, in need of shelter and health care, in the absence of specific public policies. In the majority, care was of low quality and its residents frequently showed feelings of loneliness and abandonment[24].

As for the nursing functions in monitoring patients with dementia in PC, nurses classified as priorities the periodic assessment of cognitive impairment, the assessment of risks at home and the support to the needs of the caregiver or family. However, they did not mention the control of the pharmacological prescription and the therapeutic follow-up, the control of the comorbidities presented by the patient or the cognitive stimulation. Experts in the area consider that these are essential activities of nurses in a specific protocol for managing dementias[10].

Despite the implementation of MAEP-PC in the city of São Paulo, the low confidence in the diagnosis, the difficulty in monitoring patients with dementia, and the limited availability of time for care continue to be important barriers to detect dementia in the early stages. Specific training on the subject can improve confidence in the diagnosis, reduce consultation time and decrease the rates of inter-consultation caused by uncertainty[25-27].

There was a predominance of the nurse's role in monitoring the caregivers of patients with dementia. A good portion mentioned that the follow-up occurs sometimes (36.5%) and frequently (32.8%), which differs from the results of the Spanish survey [14], in which it was found that about half of the doctors (46.2%) and nurses (47.6%) performed the usual monitoring of caregivers of patients with dementia.

It is known that caring for a patient with dementia is a challenging task. A critical review of the literature showed that caregivers of patients with dementia have a higher risk of cardiovascular disease, especially hypertension, which is mediated by a chronic inflammatory response and sympathetic overactivation, depression, and anxiety. In addition, the caregiver's depressive symptoms lead to increased health care costs over an average of two years, including the costs of using over-the-counter medications. As the "dementia tsunami" approaches, the burden on the health and social care system will increase, unless family caregivers are properly supported, and their health needs are assisted[28].

Physicians' satisfaction with the specialized service fell short of expectations. The counter-reference of the information to the PC service, the accessibility of services in an emergency situation, and the waiting time from the request for a visit to its occurrence received the worst evaluations (3.3; 3.8 and 4.0, respectively). On the other hand, the ability to solve the problem and the follow-up of patients with dementia received the highest evaluations (5.7 and 5.5, respectively), although far from ideal. In the Spanish study [10], better evaluations related to the ability to solve the problem (6.3) and to the monitoring of patients with dementia (5.7) were also found. The worst assessment fell on the accessibility of the service in emergency situations (4.1).

A peculiar fact that occurred in this investigation and in the study carried out in Spain[10] was that doctors reported referring patients more to confirm the diagnosis of dementia than to control behavioral symptoms. Spanish authors attribute this finding to the long waiting time for the visit and the low accessibility of services in an emergency. They consider it necessary to establish a more efficient collaboration between primary health care and specialized services, with assistance protocols and multiple forms of communication, such as the use of telephone contact at agreed times, the use of applications, the availability of day hospitals or short stay units to solve the most complex cases.

Regarding the need for permanent education in dementia for professionals in PC, data from the Spanish survey[10] corroborate the results of this study, as 98.6% of its professionals considered it necessary to carry out specific training in dementia. Compared to this study, a lower percentage of doctors (49.1%) and a higher percentage of nurses (75.2%) reported never having participated in specific training in dementia. Another Brazilian study also found a lower percentage of doctors (48%) who reported never having participated in a training program in dementia[21].

In the FHS, nurses are considered the managers of the teams' care, as they direct the population's health needs, manage the assistance programs, and replicate the training in the health units. They work alongside doctors, teams from the Psychosocial Care Centers, and the Family Health Support Center, participate in clinical discussions and coordinate assistance regarding the health needs of individuals and their families. The permanent education of nurses is, therefore, essential for the improvement of care practices and the direction of teams.

International investigations that included medical professionals, nurses and nursing assistants in dementia education programs found an improvement in the approach, diagnosis, care, and monitoring of patients with dementia and their families[25-27].

A study carried out in the health units with the FSH of the North Coordination office of the city of São Paulo evaluated the impact of online training entitled *Identification of Dementia in the Elderly*. Their results revealed a significant improvement in knowledge after training. However, there was a slight decline in knowledge in late evaluation (180 days)[29]. Although training has shown immediate results in the knowledge of professionals in monitoring dementia, this knowledge has afterwards decreased,

and this suggests that, in addition to training from a distance, face-to-face meetings are necessary, with spaces for discussion between specialists and PC professionals. The training must be based on the epidemiological knowledge of dementias, on diagnostic sureness, and on the management of behavioral symptoms[25-27].

Study limitations

One of the limitations of this study is the composition of the sample, which may have contributed to the participation of health units and professionals with a greater interest in the subject, as well as to the subjectivity of responses, based on the perception of professionals.

Contributions to the field of nursing, health, and public policy

The knowledge gaps regarding the dementia evidenced in this research is a worldwide concern. First world countries have been organizing themselves for more than two decades to tackle the stigma and social exclusion associated with dementia, overcome the limited knowledge on the subject, and to reduce the costs related to care.

In Brazil, a country in demographic and epidemiological transition, and with a small number of health professionals specialized in assisting the elderly, this investigation provides information to support proposals for training in dementia to FSH professionals and, also, for Permanent Education in Elderly Health. In addition, it provides data so that management in health can plan the FHS teams' agendas considering the care for the elderly population by age group, and not by more prevalent diseases among the elderly, such as high blood pressure and diabetes mellitus, for example.

This work can also contribute for higher education institutions to promote changes in their professional training curricula, expanding and sustaining healthcare practice, so that they consider the needs and demands of the Brazilian demographic transition process.

CONCLUSION

The results of the present study showed gaps in the knowledge of PC's medical professionals and nurses related to the process of tracking and diagnosing dementia; monitoring of patients, especially in the most severe form of the disease; handling of specific drugs; diagnostic information to the patient and families; and caregiver support.

A proposal for training in dementia should be developed considering such knowledge gaps in favor of improving care practices, in addition to reducing the costs associated with the lack of knowledge of professionals and caregivers on the subject.

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